

# Use of SSNs and PII in Human Subject Research

## ROWAN UNIVERSITY POLICY

**Title:** *Use of Social Security Numbers and Personal Identifying Information in Human Subject Research*

**Subject:** *Research and Scholarly Activities*

**Policy No:** *Res: 2017: 01*

**Applies:** *University-Wide*

**Issuing Authority:** *President*

**Responsible official:** *Vice President for Research*

**Adopted:** *08/29/2016*

**Last Revision:**

**Last Reviewed:**

### I. PURPOSE

The purpose of this policy is to protect the use of social security numbers and personal identifying information collected for research purposes.

### II. ACCOUNTABILITY

Under the direction of the President, the Vice President for Research shall implement and ensure compliance with this policy.

### III. APPLICABILITY

This policy applies to all faculty, employees and students, post-doctoral fellows, visiting scientists or visiting scholars who may request the Institutional Review Board to use social security numbers or personal identifying information in the course of their research and scholarly activities.

### IV. DEFINITIONS

1. *Clinical Research:* Clinical research is a branch of healthcare science that determines the safety and effectiveness (efficacy) of medications, devices, diagnostic products and treatment regimens intended for human use. These may be used for prevention, treatment, diagnosis or for relieving symptoms of a disease. Clinical research is different from clinical practice.
2. *Clinical Trial* – Means to evaluate the effectiveness and safety of medications or medical devices by monitoring their effects on large groups of people.
3. *Coded Information:* Means identifying information (such as name or social security number) that would enable the investigator to readily ascertain the identity of the individual to whom the private information or specimens pertain has been replaced with a number, letter, symbol, and/or combination thereof (i.e., the code); and a key to decipher the code exists, enabling linkage of the identifying information to the private information or specimens.
4. *Investigator* - Principal Investigator, co-principal investigator, co-investigators and any other University personnel (including faculty, non-faculty employees, residents, postdoctoral trainees and students), visiting scientists, visiting scholars who, in the course of their association with the University are or will be responsible for the design, conduct, administration, collaboration, analysis and/or generating data and materials, funded by external sponsors or university's internal funds or proposed for funding by any sponsor, or of unsponsored research or training activities.
5. *Personal Identifying Information (PII):* PII is information about a person that is readily identifiable to that specific individual. Personal information includes such things as, but not limited to: (1) Social security or employer taxpayer identification numbers (EIN); (2) Drivers license (unless appearing in a law enforcement record State identification card, or passport numbers); (3) Checking account numbers; (4)

Savings account numbers; (5) Credit card numbers; (6) Debit card numbers; (7) Personal Identification (PIN) codes, which are numeric and/or alphabetical codes assigned to the cardholder of a financial transaction card (FTC) by the issuer to permit authorized electronic use of that FTC; (8) Digital signatures; (9) Any other numbers or information that can be used to access a person's financial resources; (10) Biometric data; (11) Fingerprints and (12) Passwords.

6. *Social Security Number (SSN)*: In the United States, a Social Security number (SSN) is a nine-digit number issued to U.S. citizens, permanent residents, and temporary (working) residents under section 205(c)(2) of the Social Security Act, codified as 42 U.S.C. § 405(c)(2). The number is issued to an individual by the Social Security Administration, an independent agency of the United States government. Although the primary purpose is to track individuals for Social Security purposes the Social Security number has become a de facto national identification number for taxation and other purposes.

## V. REFERENCES

1. [42 U.S.C. 405 - Evidence, Procedure, and Certification for Payments](#)
2. [Rowan University Committee for the Protection of Human Subjects Institutional Review Board \(IRB\) Guidelines for Biomedical and Behavioral Research Involving Human Subjects May 26, 2015](#)
3. [Rowan University Policy - Acceptable Use](#)
4. [Rowan University Policy - Information Classification](#)
5. [Rowan University Policy - Transmission of Sensitive Information](#)
6. [The New Jersey "Identify Theft Prevention Act" C.56:11-45 "g" and "h"](#)

## VI. POLICY

1. Rowan University does not permit the use of a SSN as an identifier or match research data sets for any person or entity in any system, except where the SSN is required or permitted by law. The intent of this policy is to protect the personal information of research participants/subjects and provide guidance on the proper handling of Social Security Number (SSN) and Personally Identifying Information maintained by or on behalf of Rowan University.
  - a. Coded tissue samples/data sent to collaborators and data received from collaborators or tissue banks should not be labeled with names, birth dates, or medical record number or SSN.
  - b. Research participants are not required to provide their SSN except to receive payment as required by Rowan University Accounting Office.
2. The Accounts Payable office may require the researchers to obtain specific information including the SSN payment purposes and to meet its obligation to the Internal Revenue Service (IRS).
  - a. In order to receive payment, participants/subjects will be asked to provide their SSN and home address on a Payment Verification Form (PVF).
  - b. PVF is separate from research consent form. It cannot be linked to research protocol or research data or any other research information gathered during the course of research.
3. When there is use of SSN for payment purposes, all records containing SSN should be stored in a secure place which may include locked file rooms, desks or cabinets or stored in network drives with access limited to those individuals or entities that require access to perform a legitimate university job function.
  - a. SSN will be released to entities outside the institution only where permitted or required by law or with the expressed written permission from the individual or where approved by the Office of General Counsel.
  - b. Individuals permitted access to SSN will be instructed on the appropriate handling and protection of this data by their management or designated representative.
  - c. Subject to applicable document retention policies or unless required by law, when no longer required, paper documents and electronic media containing SSNs must be destroyed or disposed of using methods designed to prevent subsequent use or recovery of information.
  - d. Individuals permitted access to personal identifying information (PII) must safeguard the information and destroy the information.
4. In addition to this policy, Rowan University researchers, faculty, students and staff are required to adhere to:
  - a. Rowan University's "Acceptable Use Policy" No: ISO:2013:06;

- b. Rowan University's "Information Classification Policy": Information Security Policy No:ISO:2013:07; and,
  - c. Rowan University's "Transmission of Sensitive Information Policy": Information Security Policy No. ISO:2013:05.
  - d. The State of New Jersey "Identity Theft Prevention Act" requires reporting identity theft to local law enforcement agency.
5. If there is reason to believe that Identify theft or loss has occurred, the responsible custodian of PII must immediately report the incidence to the Office of Privacy and Compliance.
  6. The Institutional Review Board has the ultimate authority on how PII could be used for research purposes.
  7. Any exception to the policy should be submitted to the Office of General Counsel.

## **VII. ATTACHMENTS**

### **ATTACHMENT 1 PAYMENT VERIFICATION FORMS**

Rowan University's Accounts Payable Department requires that researchers obtain the following information from research participants/subjects to meet its obligation to Internal Revenue Service. The attached forms will be submitted to the University Accounts Payable Department. This form cannot be connected to any information collected as part of a research including but not limited to payment for interviews, surveys, questionnaires or participation in a clinical research study or clinical trial.

W-9s are required by the purchasing department to set up an individual in the Banner system. Payments in excess of \$600 made to individuals through Accounts Payable are reported annually to the IRS on Form 1099-MISC, Miscellaneous Income.

- [Accounts Payable - Miscellaneous Disbursement Voucher - General](#)
- [IRS Form W-9 - Request for Taxpayer Identification Number and Certification](#)
- [Independent Contractor Agreement](#)