Sensitive Data Sharing Policy

Institutional Policy

Title:	Sensitive Data Sharing Policy
Responsible Officer:	Director, Research Informatics and Director, IRB
Original Effective Date:	3/5/2014
Revised Date:	2/8/2019
Renewal Date:	On or before 2024
Approved By:	*Kathryn Tasker*

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1   Purpose

The purpose of this policy is to clearly define the rules regarding sharing sensitive data with research staff and collaborators in order to protect the privacy of research participants.

2 Scope

This policy applies to all employees including research faculty and staff as well as all named persons on an Agreement (e.g. Data Sharing or Data Use Agreements) to use sensitive data (SD) including subordinates or subcontractors working under the direction of an individual on an Agreement to use SD.

3 Definitions

Term: Sensitive Data

Any data which contains Social Security Numbers or other personal identification numbers, confidential personal or financial information, protected health information, student educational records, proprietary customer data or information that is otherwise deemed to be protected by HSL corporate policy, state, federal, or international laws, statutes, or regulations or explicitly identified in a contract.

4 Policy Statement

Employees will never share sensitive existing data with individuals or parties not specifically named on the personnel roster of the approved SD research protocol.

Aggregate data (e.g., tables, figures) may be shared so long as the data comply with the institution's Sensitive Data Suppression Policy, HSL IRB policies, and HSL HIPAA policies.

5 Procedures

For questions pertaining to use and sharing of research data, please contact the IRB Office, the Director of Research Informatics, or the Manager of Grants and Contracts.

5.1 General Rules

1. Employees of HSL may never share SD or allow any person to come into contact with the electronic or physical media in which the data are stored.
2. Data may only be shared with persons if they meet any of the following criteria:
    - Named on the personnel roster of an IRB-approved research project
    - Have a sub-contract or a contract for use of the data and are on the protocol of an IRB-approved research project
    - Have IRB approval for use of the data (either at HSL or the IRB at the reviewing institution)
    - Have a fully executed data use or data sharing agreement for use of the data.

5.2   Data Use Agreement Provisions

Formal Data Use and Data Sharing Agreements (e.g. CMS) may stipulate specific requirements regarding data sharing. In these cases, specific Data Use Agreements/Data Sharing Agreement requirements supersede those explicitly listed in policy.

> Note: CMS data may not be shared with internal or external investigators (including staff) without express written permission from CMS.

6   Related Policies

The document author(s) have attempted to identify policies that may be applicable or related to this policy. This is not an exhaustive list. All HSL employees are expected to abide by all active policies of the organization at all times. As such, employees are encouraged to review any and all potentially applicable policies regardless of whether they are identified below. HSL reserves the right to modify, cancel, or enact new policies at anytime, without notice.

- Limited Data Sets and Data Use Agreements
- HSL IRB Policies and Procedures (see Sections 3 - Investigator and Research Personnel Requirements, Section 11 – HIPAA, and Section 14 – Record Management)
- HSL Privacy Policies and Practices , Including Notice of Privacy Act (all sections)

7   Reference Materials

NA

8   Appendix

NA

9   Document Properties

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