PEL HIPAA and RESEARCH PROJECT 2007-2008

Project Overview
Data security and management in an era of de-centralized data-systems and cheap storage has long term implications if the data is not secured or created in a meaningful manner for preservation and/or sharing. Creating and designing trustworthy systems / training that protects the researcher, subject, or university from avoidable risk is an important project to undertake.

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Goals and Deliverables
• Peer institution data security practice review
• Appendix to the IRB approval form to assess data security measures of research proposal
• Web-board / knowledge base to for research to post and search answers based on data security practices
• Report on themes from interviews
• Education and communication plan for data security web-board (post-cards, top-ten things to know about HIPAA, training, emails notification...)

TOP TEN THEMES FROM INTERVIEWS
(1) There needs to be information on HOW to comply, and not just what to comply on.

(2) The behavior of individuals and/or human error poses significant risks.

(3) Some ‘centralization’ of IT/security would be good, but it’s important for a PI to be able to opt out.

(4) It is not the role of the IRB to assess security issues.

(5) PI’s often do not have expertise in technology or security.

(6) There should be more assistance in advising on, or reviewing, security plans.

(7) There should be specific risk assessments made as to the level of security actually needed.

(8) The future of research involves an increasing level of sharing and collaboration.

(9) Most grants do not pay for computer equipment, upgrades, or IT personnel.

(10) Demonstrate policy changes to the researcher in terms of how it will make their work easier