

ITPB Research and Education Data Management Group

Details on IRB Policies affecting research and education data management.

Assembled by Libbie Stephenson 01/15/2008 (Libbie@ucla.edu)

IRB Policy 39 <http://www.oprs.ucla.edu/human/documents/pdf/39.pdf>
Research Involving Use of Human Specimens, and Specimen Banking

Focus is on genetic and human tissue repositories. Contains details on how to manage this "data" in terms of how it may or may not be shared, used again, or stored. Provides some standard operating procedures.

IRB Policy 40 <http://www.oprs.ucla.edu/human/documents/pdf/40.pdf>
Data Repositories

Contains details on how investigators should establish and manage repositories containing personally identifiable human subject data. A repository is defined as "a storage site or mechanism by which identifiable data are stored or archived for research by multiple investigators or multiple research projects." This policy provides details on how to establish a data repository, and provides some details on standard operating procedures at <http://www.oprs.ucla.edu/human/documents/pdf/Data%20banking%20SOPs%202005>

IRB Policy 41 <http://www.oprs.ucla.edu/human/documents/pdf/41.pdf>
Secondary Use of Existing Data

Contains reference to data enclaves defined as "secure environments where investigators can conduct analyses on "unexpurgated" data; these environments are referred to as "data enclaves" or "secure data enclaves". Investigators have to file a research plan and meet strict criteria for what can be printed, saved, and removed from the site. Example of a data enclave at UCLA: The California Center for Population Research Secure Data Enclave. www.ccpr.ucla.edu/asp/sde.asp

IRB Policy 42 <http://www.oprs.ucla.edu/human/documents/pdf/42.pdf>
Research Involving Public Use Data Files

Contains details on pre-approved public data sets/repositories will not require UCLA IRB approval or certification of exemption from UCLA IRB review prior to access to the data. ICPSR is an example of a pre-approved public data repository.

IRB Policy 43 <http://www.oprs.ucla.edu/human/documents/pdf/43.pdf>
Data Security Guidelines

Provides guidelines on how to keep data secure.