

Useful Resources and Tools Related to Human Specimen and Data Repositories

- **Clinical Research Policy Analysis and Coordination Program (CRpac) website**
 - http://oba.od.nih.gov/policy/policy_key_policy.html#CRP_004
 - Includes links to pertinent resources, policies and regulations

- **Report of the Public Responsibility in Medicine and Research (PRIM&R) Human Tissue/Specimen Banking Working Group**
 - <http://www.primr.org/PublicPolicy.aspx?id=68>
 - This report, written by a group representing the full range of stakeholders in specimen research, is organized into two parts. The first part includes a discussion of current challenges in the area of human specimen banking and recommendations to the federal regulatory and funding agencies. The second part provides tools for IRBs, repository managers, and researchers in the form of educational materials, discussions of relevant issues, and points to consider.

- **National Conference of State Legislatures, Information on Genetic Privacy Laws**
 - <http://www.ncsl.org/IssuesResearch/Health/GeneticPrivacyLaws/tabid/14287/Default.aspx>
 - This page contains links to information on state genetic privacy laws, including the Congressional Research Service, March 2008 report, “Genetic Information: Legal Issues Relating to Discrimination and Privacy” as well as the texts of individual state laws.

- **National Human Genome Research Institute webpage on Informed Consent for Genomic Research**
 - <http://www.genome.gov/27026588>
 - This webpage provide the research community with information to assist the development of informed consent materials for genomics-related research projects such as genome-wide association (GWA) and genome sequencing studies.

- **Department of Health and Human Services (HHS), “GINA”, The Genetic Information Nondiscrimination Act of 2008, Information for Researchers and Health Care Professionals”**
 - <http://www.genome.gov/Pages/PolicyEthics/GeneticDiscrimination/GINAInfoDoc.pdf>
 - This fact sheet provides an explanation of the statute to assist those involved in clinical research to understand the law and its prohibitions related to discrimination in health coverage and employment based on genetic information.