

Contents

- [1 Bioethics](#)
- [2 Genetic Information Nondiscrimination Act \(GINA\)](#)
- [3 Personal Health History](#)
- [4 Privacy and the States](#)
- [5 Research Involving Children](#)

Bioethics

- The Hastings Center has written a bioethics briefing book that seeks to inform debate surrounding thirty-six of the most controversial bioethics topics in the media today.
 - ◆ Available at: [From Birth to Death and Bench to Clinic: The Hastings Center Bioethics Briefing Book for Journalists, Policymakers, and Campaigns](#)

Genetic Information Nondiscrimination Act (GINA)

- The Coalition for Genetic Fairness has developed a web-based tool regarding GINA and what it means.
 - ◆ Available at: [A Guide to the Genetic Information Nondiscrimination Act](#)

Personal Health History

"[My Family Health Portrait](#)", provided by the Surgeon General, is an internet-based tool that makes it easy to record family health history. The tool is easy to access on the web and simple to fill out. It assembles the information and makes a "pedigree" family tree that can be downloaded.

Privacy and the States

(Please note that the Knowledge Center has not reviewed the complete content of these sites.)

- The Health Privacy Project has a summary of privacy laws by State.
 - ◆ Available at: [The State of Health Privacy](#)
- The National Conference of State Legislatures maintains several resources associated with health privacy including a summary of State genetic privacy laws.
 - ◆ Available at: [State Genetic Privacy Laws](#)

Research Involving Children

- Julie Samuël, et al., *Biobanks and Longitudinal Studies: Where Are the Children?*, 6:3 GenEdit, 1-8 (2008)
 - ◆ An article analyzing the "ethical frameworks concerning participation in biobanks and suggests that such frameworks, developed in the context of competent adults as research subjects, are not adapted for research involving children.
 - ◆ Available at: [link](#)
- OHRP FAQ on Research Involving Children: [link](#)