An annotated bibliography of resources on the ethics of human genetics research.

Body

1. Research with Stored Tissue Samples

   This report from an NIH consensus workshop sets the framework for subsequent policy positions by distinguishing "anonymous" from "linked" samples and arguing for formal consent requirements for research with both categories.


   This essay attempts to rebut proposals for more stringent protections on stored tissue samples, making the case for their utility as biomedical research resources.

This paper reports the results of a survey of consent forms for genetic research, documenting the current practices of genetic researchers with respect to the key issues discussed in this module.

2. Research with Families

   These two articles provide guidelines for the human subjects review of genetic research that have proven useful to institutional review boards.


   This article provides a case study analysis of the issues of ownership and control raised by the collection and use of genetic samples from families.


   This paper reviews ten issues that human genetics researchers commonly face in conducting genetic family studies, with examples of existing approaches to their resolution.


   This paper provides an overview of confidentiality issues involved in
genetic research, with a special focus on the questions raised by potentially identifying pedigree charts.

3. Research with Populations

This article uses case studies to illustrate the utility of community consultations in attempting to design and implement population genetic studies with specific social groups.


This article provides an argument in favor of expanding traditional human subjects' protections such as informed consent and rights to withdraw to the level of communities involved in genetic research.


This article describes some of the issues that have arisen for investigators attempting to study the genetic bases of disease susceptibilities at the population level, including risks of social stigmatization, inappropriate medical intervention, and genetic discrimination.

From [Research Ethics Module Supporting Pages](http://www.onlineethics.org/Resources/TeachingTools/Modules/19237.aspx)

**Notes**

Caroline Whitbeck introduced methods and modules for discussing numerous issues in responsible conduct of research at a Sigma Xi Forum in 2000. Partial funding for the development of this material came from an NIH grant. You can find the entire sequence on the OEC at http://www.onlineethics.org/Resources/TeachingTools/Modules/19237.aspx. Some information in these historical modules may be out-of-date; for instance, there may be a new edition of the professional society’s code that is referred to in an item.
If you have suggestions for updates, please contact the OEC.

**Contributor(s)**

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Use of Materials on the OEC

**Resource Type**

Bibliography

**Parent Collection**

Scenarios for Ethics Modules in the Responsible Conduct of Research

**Topics**

Human Subjects Research

**Discipline(s)**

Life and Environmental Sciences
Genetics and Genomics