Online Ethics Center
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Annotated Bibliography: Conducting Human Genetic Research

Author(s)

Anonymous

Year

2000

Description

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

Body

1. Research with Stored Tissue Samples
    1. Clayton-Wright, Ellen, et. al., "Informed Consent for Genetic Research on Stored Tissue Samples," *JAMA* 274(1995): 1786-1792.

       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.

    2. Korn, David. "Dangerous Intersections: New Proposals to Protect Genetic Privacy May Collide with Public Interest in Fostering Medical Research," *Issues in Science and Technology* (Fall, 1996): 55-62.

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

    3. Weir, Robert. "DNA Banking and Informed Consent," *IRB: A Review of Human Subjects Research* 17(Sept.-Dec., 1995): 1-8.

       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
    1. Glass, Kathleen, Weijer, Charles, Palmour, Roberta, et. al. "Structuring the Review of Human Genetics Protocols: Gene Localization and Identification Studies," *IRB: A Review of Human Subjects Research.* 18(4), 1996: 1-9.
    2. Glass, Kathleen, Weijer, Charles, Palmour, Roberta, et. al. "Structuring the Review of Human Genetics Protocols Part II: Diagnostic and Screening Studies," *IRB: A Review of Human Subjects Research.* 19(3), 1997: 1-13.

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

    3. Hanning, Vickie, Clayton, Ellen, and Edwards, Kathryn. "Whose DNA is it Anyway? Relationships between Families and Researchers." *American Journal of Medical Genetics.* 47(1993): 257-260.

       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.

    4. Jeungst, Eric. "Respecting Human Subjects in Genome Research: A Preliminary Policy Agenda." In H. Vanderpool, ed., *The Ethics of Research Involving Human Subjects: Facing the 21st Century* (Frederick, Maryland: University Publishing Group, 1996): 401-429.

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

    5. Powers, Madison. "Publication-Related Risks to Privacy: Ethical Implications of Pedigree Studies." *IRB: A Review of Human Subjects Research.*

    15(1993): 17-22.

    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
    1. Foster, M., Eisenbaum, A. J., Carter, T. H. "Communal Discourse as a Supplement to Informed Consent for Genetic Research." *Nature Genetics.* 17(1997): 227.

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

    2. Greely, Henry T., "The Control of Genetic Research Involving the 'Groups Between.'" *Houston Law Review.* 33(1997): 1431-1473.

        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.

    3. Sosklne, C.L., "Ethical, Social, and Legal Issues Surrounding Studies of Susceptible Populations and Individuals." *Environmental Health Perspectives.* 105(1997): 837-841.

        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.

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 Scenarios for Ethics Modules in the Responsible Conduct of Research.

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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Bibliography

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Topics

Human Subjects Research

Discipline(s)

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