

Ethical Issues in Genetic and Molecular Epidemiology

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Abstract

There is a robust literature on the ethical issues in genetic and molecular epidemiology. The literature addresses issues of participant recruitment, assurance of privacy and confidentiality, interpretation, and communication of results in terms of ethical principles of autonomy, beneficence, nonmaleficence, respect for persons, and justice. Aspects of these issues need to be revisited as new technologies and considerations raise additional questions. For example, in recruiting participants into studies involving genetic factors, should consent be obtained from family members? A growing literature suggests that third parties, such as family members, may need to be involved in the consent process in some types of studies. They may also need to be considered in the test and study notifications. Similarly, concern exists that various groups, such as racial or ethnic groups, have a stake in the outcome of populations genomics research and should have input in research participation decisions. However, less support exists for such groups having standing compared with family members.

The problems of interpreting genetic biomarker epidemiologic studies merit consideration. Researchers will have to guard against over or under interpretations. Over interpretation involves reductionist tendencies to identify complex risk patterns with extensive environmental and behavioral components as merely genetic. Under interpretation is failure to identify clinically relevant findings or findings that represent an early warning of hazard or risk that should be communicated to population groups.

Two related overarching issues also need consideration. One is the tension between a person's ability to control genetic information versus the societal expectation to benefit from genetic advances. The other is that if investigators and research agencies over invest in searches for genetic underpinnings of every discrete health outcome and ignore environmental exposures and attributable risks, they may misuse societal resources and miss opportunities to prevent disease. Much valuable information is yet to be discovered concerning the genetic components of complex diseases and such research should be supported. However, the public health and medical relevance of such research and the opportunity costs of using public funds should be continually considered. Ultimately, only when both genetic and environmental factors are known will the full range of preventive strategies be able to be applied to cancer. However, the steps in reaching that ultimate capability contain choices that have ethical, social, and scientific implications. Many known ethical issues involving genetic biomarkers will be exacerbated by technologies of genomics, toxicogenomics, or proteomics that have multiple outputs. Investigators will face much uncertainty about the meaning of these outputs and when outcomes are identified that are clinically relevant to participants. High outcome technologies will be likely to raise questions of what constitutes "ab-normalcy" and the attendant issues of stigmatization, labeling, and other societal reactions.

References

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Schulte P, Lomax GP, Ward EM, Colligan MJ. Ethical issues in the use of genetic markers in occupational epidemiologic research. *J Occup Environ Med* 1999;41:639-46.

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December 30, 2002–January 24, 2003—Report No. 160

PUBLICATIONS

Publication Distribution for December 30, 2002–January 24, 2003 (28,371 publications; 4,203 orders). Of these orders, 263 (6.26%) were for more than 10 copies resulting in 23,778 copies being distributed in bulk. Breakdown by mode of request:

Phone	2,188	Website	802	Email	336
Mailboxes	405	Letters	355	Faxes	90
Exhibits	1	800# transfers	16	Visitor	10

MEETINGS AND PRESENTATIONS

NIOSH Construction Steering Committee. Marie Haring Sweeney and other members of the NIOSH Construction Steering Committee met with John Howard, Director of NIOSH, John Henshaw, Assistant Secretary of Labor, Bruce Swanson, Stewart Burkhammer, Michael Buchet, and Richard Rinehardt, OSHA Directorate of Construction, and William Perry and Loretta Schuman, OSHA Directorate of Standards and Guidance. Areas of mutual interest and future collaboration were identified and discussed. [January 7, Washington, DC]

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International Conference on Molecular and Genetic Epidemiology of Cancer. On January 22, Paul Schulte gave an invited presentation entitled “Ethical issues in genetic and molecular epidemiology.” The conference was co-sponsored by the American Association for Cancer Research (AACR) and the Society of Toxicologists (SOT). [January 18–23, Waikoloa, HI]

SIGNIFICANT EVENTS

School Safety CD-ROM Beta-Testing. On December 23, the NIOSH/EID Web Team uploaded the contents of the beta-test version of the CD-ROM entitled *Safety Checklist Program for Schools*. The CD-ROM also contains about 10 pages of contents that include resources for schools, small businesses, graduate schools, young workers, and hundreds of links to related safety information. The beta-test version will be active for a 2-month period at the following NIOSH Web site: <http://www2.cdc.gov/ffhhs/-DRAFT-chkfst>