

# Ethical, Legal, and Social Issues (ELSI) of the Human Genome Project

The U.S. Department of Energy (DOE) and the National Institutes of Health (NIH) have devoted 3% to 5% of their annual Human Genome Program budgets toward studying the ethical, legal, and social issues (ELSI) surrounding availability of genetic information. This represents the world's biggest bioethics program, which has become a model for ELSI programs around the world.

## ELSI Issues

Some ethical, legal, and social issues (ELSI) raised by the increased availability of genetic information:

- Fairness in the use of genetic information by insurers, employers, courts, schools, adoption agencies, law enforcement, and the military, among others.

*Who should have access and how will it be used?*

- Privacy and confidentiality of genetic information

*Who owns and controls it?*

- Psychological impact and stigmatization due to an individual's genetic differences

*How does the information affect an individual and society's perceptions of that individual?*

- Genetic testing of an individual for a specific condition due to family history (prenatal, carrier, and presymptomatic testing); population screening (newborn, premarital, and occupational)

*Should testing be performed when no treatment is available?*

*Should parents have the right to have their minor children tested for adult-onset diseases?*

*Are genetic tests reliable and interpretable by the medical community?*

- Reproductive issues including informed consent for procedures, use of genetic information in decision making, and reproductive rights.

*Do healthcare personnel properly counsel parents about the risks and limitations of genetic technology?*

*How reliable and useful is fetal genetic testing?*

- Gene therapy which may someday be used to treat, cure, or prevent genetic disorders

*What is normal and what is a disability or disorder, and who decides?  
Are disabilities diseases? Do they need to be cured or prevented?  
Does searching for a cure demean the lives of individuals presently affected by disabilities?*

- Genetic enhancement includes using gene therapy to supply a characteristic such as height, that a parent might want in a child but which does not involve the treatment or prevention of a disease

*What safety and ethical questions does this raise?  
If this became common practice, how would it affect the diversity of the gene pool?*

- Fairness in the use of genetic technologies

*Who will have access to these expensive technologies?  
Who will pay for their use?*

- Clinical issues including education of health service providers, patients, and the general public; and implementation of standards and quality-control measures in testing procedures

*How will genetic tests be evaluated and regulated for accuracy, reliability and utility? Currently, there is little regulation at the federal level*

- Commercialization of products: Issues include property rights (patents, copyrights, and trade secrets) and accessibility of data and materials.

*Who owns genes and other pieces of DNA?*

- Conceptual and philosophical implications regarding human responsibility, free will versus genetic determinism, and concepts of disease and health.

*Do someone's genes make them behave in a particular way? Can people always control their behavior?  
What is considered acceptable diversity?*

A perspective about the Human Genome Project's possible impact on individuals with mental retardation and their families is presented [here](http://www.ornl.gov/hgmis/resource/elsi.html).

<http://www.ornl.gov/hgmis/resource/elsi.html>