

# Ethical Issues in Genetic Research

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# Topics

- ✓ Genetic testing
- ✓ Informed consent
- ✓ Feedback to research participants
- ✓ Risks of participation

# Genetic testing

- ✓ Prenatal testing
- ✓ Carrier testing  
see Lerman et al., 2002 JCCP
- ✓ Population Screening  
see Khoury et al., 2003 NEJM

# Genetic testing

- ✓ Predictive testing  
e.g., Huntington's Disease
- ✓ Susceptibility testing  
e.g., Cancer, Alzheimer's disease

See Lerman et al., 2002 JCCP

# Informed Consent

- ✓ Inform participants that their biological samples will be used for **genetic research**
- ✓ Describe procedures for collecting biological data
- ✓ Length of storage of samples

# Informed Consent

- ✓ Include family members?
- ✓ Will the biological samples be made available to secondary investigators or external entities?

# Informed Consent

- ✓ Will participants be recontacted in the future?
- ✓ Will the biological data be used to test (future) hypotheses not described in the consent form?

# Feedback to research

## participants

- ✓ Not clinically relevant

- ✓ Lab needs CLIA

certification

- ✓ Genetic counseling

- ✓ Risk

- ✓ Research publications

e.g., pedigrees

# Risks of participation

## Breach of confidentiality:

- ✓ Insurance
- ✓ Employability
- ✓ Reproduction plans
- ✓ Negative impact on relationships
- ✓ Stigmatization

# Ethical, Legal, and Social Issues (ELSI)

[http://www.ornl.gov/sci/techresources/Human\\_Genome/elsi/elsi.shtml](http://www.ornl.gov/sci/techresources/Human_Genome/elsi/elsi.shtml)