Ethical Issues in Genetic Research

Janine D. Flory

American Psychosomatic Society

Genetic Epidemiology in Psychosomatic Disorders

March 3, 2004
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)