Ethical issues in genetic research

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Genetic research raises ethical issues that differ in many ways from those that arise in other kinds of human subject research.

Aside from the generally low likelihood of injury from drawing blood, the harms that might result to subjects once the genetic data is obtained range from minor to major, from physiological to psychosocial and even economic.

Disclosure of results may cause loss or increased cost of health and/or life insurance, discrimination and stigmatization.

In this presentation, I am going to discuss the issue through the followings:

1. Privacy and confidentiality
   • Unlike other kinds of health data, genetic information applies to or is about more than one person. (parents, siblings, children, and perhaps others).
   • Research that includes follow-up studies requires that a subject's unique information be linked to the genetic information.
   • For this and other reasons, many investigators seek to unlink personal identifiers from genetic data or biological specimens.
   • Successful unlinking reduces or eliminates some threats to privacy and confidentiality.

2. Informed consent
   • The participant should be adequately informed.
   • Consent should be free from coercion or undue influence.
   • The participant should be fully competent.

3. Risks of harm
   • The idea of testing can cause pre- and post-test anxiety.
   • Disclosure of results may result in employment and social bias, discrimination and stigmatization.
   • Family members of the index subject may face similar risks of harm.

The presentation also tackles the subject of research on stored biological samples and the ethical issues, with discussion of the laws and regulations applicable.