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Biobanking: Honoring Donors' Rights

Biobank Basics

- Collection of biological material and data
- Information available for research
- Have existed since the 1800s
- Registries and surveys prompted recent attention

Questions of Morality

- Consent procedures
- Confidentiality
- Research results
- Incidental findings

Consent Procedures

- Blanket consent
  - No restrictions on researchers
  - European preference and emerging trend
- Tailored consent
  - Choices about research types
  - American preference

Consent Procedures

- Blanket consent disadvantages
  - The more general, the less informed
  - Only broad descriptions about the purpose are available

Consent Procedures & Confidentiality

- Tailored consent advantages
  - Types of research
  - Uses of data
  - International sharing
  - Commercial partners
  - Link data to personal and medical information
  - Can re-contact donors

Research Results

- Normally published long after the study began
- Published in science journals
- Not always published
  - No value
  - Misleading information

Incidental Findings

- Individual research participant
- Potential health or reproductive importance
- Discovered in the course of conducting research
- Beyond the aims of study

My Position

Reduced level of social benefit in return for honoring rights of donors

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Questions and Conversation