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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
• 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
Reduced level of social benefit in return for honoring rights of donors
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Questions and Conversation