2010-03

PubPol 580 - Values, Ethics, and Public Policy, Fall 2009

Chamberlin, John

http://hdl.handle.net/2027.42/78190
Author(s): Anonymous MPP Student

License: Unless otherwise noted, this material is made available under the terms of the Creative Commons Attribution Share Alike 3.0 License: http://creativecommons.org/licenses/by-sa/3.0/

We have reviewed this material in accordance with U.S. Copyright Law and have tried to maximize your ability to use, share, and adapt it.

Copyright holders of content included in this material should contact open.michigan@umich.edu with any questions, corrections, or clarification regarding the use of content.

For more information about how to cite these materials visit http://open.umich.edu/education/about/terms-of-use.
Biobanking: Honoring Donors’ Rights
• 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
Biobanking: Honoring Donors’ Rights

Questions and Conversation