Consent Issues Related to Databases for Whole-Genome Association Studies

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Controlled-Access Database

- All genotype/sequence data, linked to
- Phenotype data
- Access granted by NIH committee
- IRB approval (generally) not required
- Users agree not to identify subjects, redistribute data, or submit papers for 9 (?) months

Open-Access Database

- Protocols, questionnaires
- Summaries of data
- Associations found - SNPs and traits
- All data if subjects provided consent

OR

Gene / xx Kb / Haplotype block only

- What did subjects expect?
- What is potentially identifiable?

Consent Requirements

Standard elements of consent.

Sharing of data with researchers.

Broad release of data.

Not require IRB approval.

Prefer not disease-specific only.