Multi-IC Symposium on Application of Genomic Technologies to Population-Based Studies
June 5-6, 2006
Bethesda Marriott

ISSUES FOR CONSIDERATION

Panel 3: Requirements for informed consent and institutional approvals

a. Desirable common elements for consent for genome-wide studies, sequencing, and data sharing

b. Challenges encountered in working with IRBs for genomic applications to population studies

c. Protection of subjects beyond the sample collection phase

d. Description of privacy risks associated with public data-sharing to study participants

e. Informing subjects of future performance of genetic analysis and its implications

f. Informing subjects of how resulting data will be shared

g. Pros and cons of offering participants the choice to make their data publicly available

h. Sample consent language or guidance for PIs seeking to do Population Genomics studies from various ICs

i. Circumstances under which genetic information should/can be disclosed back to a community, or to individual subjects

j. Ensuring participant privacy when individual genetic profiles are placed into public databases that may be matched against personally identified DNA samples

k. Designing population studies of genomic variation to avoid stigmatizing the participating communities

l. Applying the "right to withdraw from research" to DNA banking and repository studies

m. Addressing cultural risks and benefits from research studies