Overview of ELSI Research Opportunities

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Working Group Sponsors

• Minority Health Research Center
  – Mona Fouad, Director

• Heflin Center for Genomic Science
  – Bruce Korf, Director

• Center for Social Medicine
  – Jeffrey Clair, Director
Agenda

• NIH ELSI Research Program: Background, Priorities, and Funding Opportunities
• UAB ELSI Working Group activities
• Opportunities for Collaboration
• Discussion
ELSI Research Program

• Established in 1990 by National Human Genome Research Institute (NHGRI)
• Part of the Human Genome Project
• Goal is to foster basic and applied research on the ethical, legal, and social implications of genetic and genomic research for individuals, families, and communities
ELSI Priorities

• Genomic research
• Genomic health care
• Broader societal issues
• Legal, regulatory, and public policy issues
ELSI Priorities: Genomic Research

- Recruitment issues (including diversity in research participation)
- Perceptions of risks and benefits by the public, research participants, researchers, and IRBs
- Fair distribution of benefits from research
- Third-party benefits and risks of genomic research (including effects on family members and broader communities)
- Role of community consultation and engagement
ELSI Priorities: Genomic Health Care

- Fairness in the distribution of genomic and genetic services
- Assessment and evaluation of personalized genomic-based health care in terms of general effectiveness and comparative cost-effectiveness
- Communication of genomic information and test results in clinical settings
- Issues surrounding the use of pharmacogenomics and other genomics-based therapies, including reimbursement
- Understanding the contribution of genomic, psychosocial and cultural factors that may have a role in health disparities
ELSI Priorities: Broader Societal Issues

• Ethical issues relevant to genomic research and genomic health care involving special populations (e.g., newborns and children, people with disabilities, pregnant women, deceased individuals)
• Implications of increasing genomic knowledge for how health and disease are conceptualized by individuals, health care providers and the health care industry
• Implications of genomic variation research (and of genetic ancestry testing) for understanding identity, race and ethnicity, and relationships within and among human populations
• Implications of manifestations of genetic determinism, reductionism, essentialism, and exceptionalism in public attitudes and in public policy
• Implications of genomic information for understandings of free will and individual responsibility
ELSI Priorities: Legal, Regulatory, and Public Policy Issues

• Appropriate regulation of genetic testing (including direct-to-consumer genetic test marketing), pharmacogenomics and genomics-based therapies

• Ownership and liability issues surrounding the secondary use of biobanked samples

• Genetic discrimination and stigmatization (including the impact of GINA)

• Non-medical uses of genomics in non-health care settings (e.g., criminal and civil courts; employment; schools; the military)
ELSI Funding Opportunities

• Program Announcements (PA)
  – R01, R21, R03

• Requests for Applications (RFA)
  – RFA-HG-12-005: Specialized Centers of Excellence in ELSI Research (CEER) (P50)
  – RFA-HG-12-012: Exploratory Centers of Excellence in ELSI Research (CEER) (P20)

• Other research funding opportunities
  – PA-10-071: NIH Support for Conferences and Scientific Meetings (R13/U13)
UAB ELSI Working Group

• Planning meeting held in January 2012
• Preparing to apply for P20 grant to fund Exploratory Center for Excellence in ELSI research
  – Due July 19
  – Provides support to expand or modify existing resources at an institution for the purpose of developing a Specialized Center (P50) CEER application
  – Need to identify a well-defined, highly significant current research topic that will serve as the focus or organizing theme of activities
• Organizing a small conference for next fall