Genomics and Society Working Group

National Advisory Council for Human Genome Research
September 19th, 2022

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GSWG Mission

> Provide NACHGR advice on short- and long-term planning and priority setting for genomics and society activities at NHGRI, particularly the ELSI Research Program

> Provide input about:
  - ELSI research priorities
  - Appropriate balance between investigator-initiated and program-initiated research
  - Best use of limited budgetary and staff resources
Current GSWG Members

Chair: Malia Fullerton, DPhil
Kyle Brothers, M.D., Ph.D.
Shawneequa Callier, J.D., M.A
Gabriel Lázaro-Muñoz, Ph.D., J.D.
Lisa Parker, Ph.D.
Holly Landrum Peay, Ph.D., M.S.
Stephanie Russo Carroll, DrPH, MPH
Beth Tarini, M.D., M.S.
Marsha Michie, Ph.D.
Genevieve Wojcik, Ph.D.
Challenges at the intersection of science and society

Genomics community has more work to do in reckoning with the legacy of race & racism

ELSI community is well-positioned to identify and address these challenges as they touch on genomics
Today: Emerging ELSI Research Priorities

- Social Determinants of Health (SDOH)
- Health equity
- Structural factors and social justice
- Gene and environment interaction research
- Genomics beyond healthcare
Inclusion of SDOH in genomics research is a scientific issue first and foremost, with related ethical, legal and social implications.

Improving work on SDOH must involve:
- Understanding how and why studies of complex traits might avoid genomic determinism
- Ongoing extensive community interaction and engagement, and
- Developing sustained partnerships with SDOH researchers

Forthcoming NASEM report on population descriptors will identify related methods and challenges to be considered.
ELSI Priority: Health Equity

- Questions asked today are similar to those asked decades ago
  - Action is needed now to ensure that genomic studies generate knowledge that will benefit diverse patients and communities

- While enhanced workforce diversity is important, genomics cannot rely solely on people from underrepresented groups to break down research and translational barriers

- Review criteria that address health disparities and health equity as explicit outcomes of genomic research will be critical
ELSI Priority: Structural Factors and Social Justice

- Structural factors and structural racism continue to be important challenges for both ELSI and genomics.

- ELSI Research Program areas have been reorganized to highlight research areas related to Sociocultural Values and Genomics at the Institutional and System Level.

- To better address these areas, ELSI must attract more scholars and fields with expertise in structural inequities and justice theory.
ELSI Priority: Gene and Environment Research

> Genomic ELSI often focuses on individual’s risks and benefits while environmental sciences focus on community level
  
  – As genomics moves into population health, we need to think about population-level ELSI, and learn from environmental studies
  
  – Groups that have been previously harmed, minoritized, and/or abused in research are as concerned about harms to groups as to individuals

> ELSI can help guide the robust inclusion of community members as researchers
  
  – This may require new funding models ensuring community members are involved in all aspects of research, including study design, implementation, dissemination
Genomics research has expanded beyond traditional (health-focused) applications, e.g., sociogenomics, forensic uses
  – Appropriate, indeed essential, for ELSI research community to engage with non-health applications
  – Simultaneously, care should be taken to not let ‘easy villains’ distract us from broader structural concerns

ELSI can work with and support the rest of the genomics community in combating misinformation
Conclusions

- ELSI research has an important role to play in guiding efforts to address ongoing structural inequities in genomics research
- Priority should be given to population-level analyses, including responsible incorporation of SDOH, sustained community involvement in research, and consideration of health equity
- Broadening ELSI expertise to include new perspectives will be key
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