



Genomics and Society Working Group

National Advisory Council for Human Genome Research
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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



Stephanie Russo Carroll
DrPH, MPH



Marsha Michie, Ph.D.



Gabriel Lázaro-Muñoz,
Ph.D., J.D.



Lisa Parker, Ph.D.



Holly Landrum Peay,
Ph.D., M.S.



Beth Tarini, M.D., M.S.



Genevieve Wojcik, Ph.D.

Reminder: May 2021 GSWG Report

- > *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*



Steven Joffe, M.D., MPH

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**

ELSI Priority: Social Determinants of Health

- > **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

ELSI Priority: Genomics Beyond Health

- > **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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