

Genomics and Society Working Group

ANNUAL REPORT TO COUNCIL - 2018

JEFFREY R. BOTKIN, MD, MPH

GSWG Membership



Jeffrey R. Botkin, M.D. (Chair)
Patricia Deverka, M.D.
Gail Henderson, Ph.D.
Steven Joffe, M.D., M.P.H
Sandra Soo-Jin Lee, Ph.D.
Maxwell J. Mehlman, J.D.
Melanie F. Myers, Ph.D.
Vardit Ravitsky, Ph.D.
David Veenstra, Pharm. D, Ph.D.
Consuelo H. Wilkins, M.D.,
M.S.C.I.

GSWG Charge

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- Provides input about the ELSI Research Program, including input about its relative research priorities, the appropriate balance between investigator-initiated and program-initiated research, and the best use of limited budgetary and staff resources.
 - Provides input about the activities of the Division of Genomics and Society in light of changes in genomics, genomic medicine, and the policy landscape, aiming to identify emerging issues or gaps.
 - Identifies areas of potential synergy or collaboration among the different Genomics and Society research and policy components of NHGRI
 - Identifies areas of potential synergy or collaboration between NHGRI and other NIH Institutes and national and international organizations.
 - Identifies Genomics and Society issues and activities that are more appropriately addressed by other NIH Institutes or other agencies or organizations.

Recent Publication

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SPECIAL ARTICLE | **Genetics
inMedicine**

Normative and conceptual ELSI research: what it is, and why it's important

Lisa S. Parker, PhD¹, Pamela L. Sankar, PhD², Joy Boyer³, JD Jean McEwen, PhD³ and
David Kaufman, PhD³

May 2018 Meeting

ELSI budget and portfolio overview

- ELSI 2018 budget – \$20.6 million with \$6.5 million available for new grants (5% of NHGRI)

Discussion of outreach to scholars in non-traditional ELSI domains

- Push at academic institutions to pursue NIH funding from across campuses
- Many scholars may not be familiar or experienced with NIH funding
- Health disparities research, implementation science, communication scholars, legal scholars, etc

May 2018 Meeting

Discussion of race, genetics and ancestry

- A complex set of issues and a continuing source of misunderstanding and risk
- Fostering ELSI engagement in genome science in this domain
- Possibility of new programs to address some of the challenges

Presentation about the *All of Us* Program

- Encouraging an expanding role for ELSI research and scholarship

Topics of Interest

- International perspectives: Canadian approach to ELSI research from Dr. Vardit Ravitsky (upcoming)
- ELSI issues emerging from strategic planning meetings
- ELSI issues in clinical gene editing research – a transition from information-based issues to interventional issues
- Forensic uses of genomic and genealogical databases – review what ELSI has done in this domain

Topics of Interest

- Evidentiary standards for the use of genomics in clinical medicine and public health
- ELSI issues from polygenic risk scores from large datasets (cardiovascular risk, intelligence, etc)
- Use of genomic technologies (e.g., gene editing) by non-traditional researchers (“gene hacking”)

Strategic Planning

GSWG providing high-level guidance for the Society, Engagement and Education Focus Group

- Feedback has included:
 - Strategies to solicit community input
 - Need to be innovative, creative and forward-looking
 - Need to be clear in terms of goals

NHGRI Strategic Planning Session at the American Society for Bioethics and Humanities: ELSI Affinity Group, October 19, 12:45-1:45 pm