

# **Prioritizing Health Equity in Genomics Research and Practice: Considerations for Next-Generation Newborn Screening Efforts**

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National Academies Roundtable on Genomics and Precision Health

June 7, 2023

# Disclosure Statement

- I have no disclosures or conflicts to report.

# Presentation Overview

- Highlight the importance of prioritizing health equity to promote just access in the context of next-generation newborn screening efforts
- Discuss strategies to respectfully engage groups that have been mistreated, underrepresented, and underserved in research and healthcare
- Identify key ethical considerations related to engaging traditionally marginalized populations in newborn screening efforts



# Current Funding

- Developing Evidence-Based Guidance for Engaging Rural Residents in the Deep South in Genomics Research: A Stakeholder-Driven Perspective (K01HG011495-01)
  - Examine and characterize rural stakeholder views related to genomics to inform evidence-based strategies tailored to promote the ethical inclusion of underserved rural residents in genomics research.
- Advancing Maternal Health Equity among Black Women in the United States: Considerations for Bioethicists
  - This project seeks to inform a broader and bolder bioethics framework to help bioethicists systematically and deliberately respond to long-standing health inequities, including the rise in maternal deaths among Black women.



National Institutes  
of Health



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Foundation**

*The content does not necessarily represent the official views of the funding agencies.*

# *Moving Us Forward: Fostering a Culture of Trustworthiness, Equity and Respect in Genomics Research and Practice*

- Bioethicists and ELSI researchers have an important role and responsibility to lead critical reflection, courageous dialogue, and truthful documentation regarding institutional untrustworthiness.
- Bioethicists should lead efforts to advance genomics equity among those that have been *mistreated, underrepresented, and underserved* in genomics research and healthcare.




THE AMERICAN JOURNAL OF BIOETHICS  
2023, VOL. 23, NO. 7, 106-108  
<https://doi.org/10.1080/15265161.2023.2207519>

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**Ethical, Legal, and Social Implications of Genomics Research: Implications for Building a More Racially Diverse Bioethics Workforce**

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Recent national calls for ethical, legal, and social implications (ELSI) research to “assess and address how ethical, historical, social, economic, legal, regulatory, socio-cultural, and contextual factors surrounding genomics serve as barriers or facilitators to the uptake of genomic science in mistreated, underrepresented, and underserved communities” (Department of Health and Human Services, 2023) have particular salience for research communities in the Deep South. Certain individuals and groups, including those in the Deep South region of the United States, are especially vulnerable to poor health outcomes due to overlapping social, economic, structural, and environmental factors that also influence access to and perceptions of

research. As such, ELSI research provides a critical avenue for bioethics scholars interested in engaging these emerging issues. As a bioethicist funded through NHGRI to conduct ELSI-related work with medically underserved communities in the Deep South, I am aware of efforts by ELSI leaders to build a more racially diverse workforce to advance genomic equity and discovery (National Advisory Council for Human Genome Research 2023). In fact, the “Building a Diverse Genomics Workforce: An NHGRI Action Agenda” (National Human Genome Research Institute, 2023) highlights the institute’s long-term commitment and strategic plan to diversify the scientific workforce, including the ELSI workforce.

# Key Health Equity Considerations: Engaging Populations with Intersectional Vulnerabilities

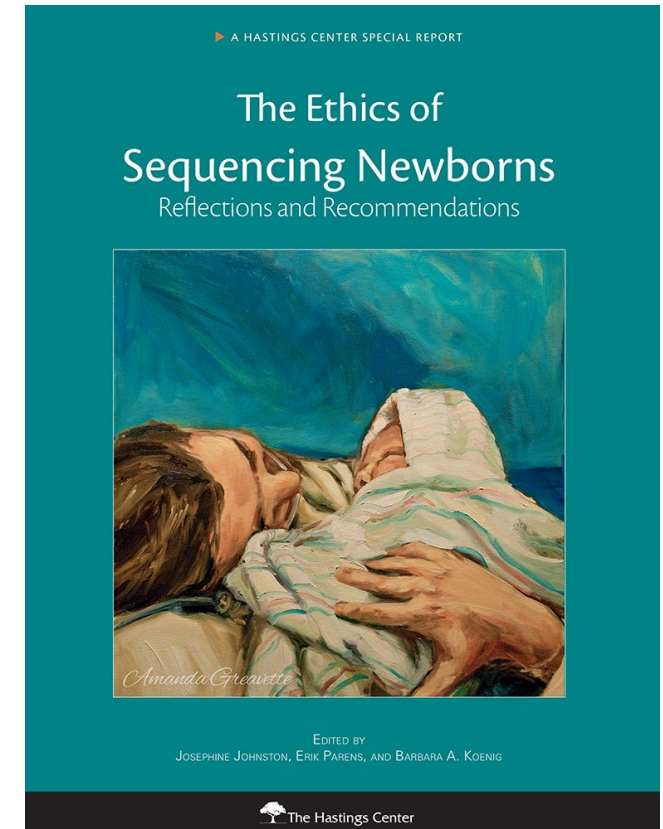
- **Racism, discrimination, and stigma are threats to health and healthcare equity.**
  - Intersectional identities, vulnerabilities, and resiliencies must be understood and considered in research and healthcare access and engagement.
- Evaluate and trust participants' perceptions of benefits, harms, and justice in genomics research.
  - Examine the ethical, social, and cultural contexts and environments relevant to the lived experiences of minoritized and diverse groups
  - Identify and mitigate risks
  - Adapt study procedures to reflect community norms, practices, and *preferences*
  - Respect the moral agency and expertise of participants

**Bioethicists are uniquely positioned to engage in normative and empirical analyses to deepen conversations around genomics equity.**

What are the key ethical issues in the context of newborn screening efforts?

# Ethics of Sequencing Newborns: Reflections and Recommendations

- *If used carefully, genomic sequencing may help improve the health and well-being of newborns and their families. If used indiscriminately, it may disrupt family dynamics, waste medical resources, and undermine public trust (Johnston et al. and members of the NSIGHT Ethics and Policy Advisory Board).*
- Education and communication strategies to manage greater access to genomic information (Lewis M, Bonhomme N, Bloss C)
- Integration of sequencing in state newborn screening programs (Powell C )
- Family-centered approaches to promote informed decision-making (Brosco JP)





# Advancing Genomics Health Equity

- **Model** meaningful partnerships and engagement efforts to “move us forward”.
- **Prioritize and Respect** the perspectives and local knowledge of socially marginalized groups through authentic engagement.
- **Engage** in cross-disciplinary collaboration (public health, ELSI, bioethics, medicine, medical humanities), critical reflection, and courageous conversations.
- **Generate** scholarship and **Develop** guidelines to offer guidance on complex issues.
- **Advocate** for specific funding opportunities that strengthen community-driven agendas for genomics and precision medicine in underserved communities.
- **Create** opportunities to train the next generation of structurally competent health equity scholars, researchers, and practitioners.

# Next Generation of Health Equity-Focused Bioethics Scholars



**Givanta Tribit, MS, CH**

**University of Alabama  
at Birmingham  
School of Public Health  
PhD Student**



**Folasade Lapite, MBE**

**Tulane School  
of Medicine  
MD Student**



**Wendy Jiang, MPH**

**University of Alabama at  
Birmingham School  
of Medicine  
MD Student**



**Alice Story, PhD**

**Baylor College  
of Medicine  
Post-Doctoral  
Trainee**



**Sophie Schott, BA**

**Baylor College  
of Medicine  
Post-Baccalaureate  
Trainee**

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# Thank you for listening!

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