Concept: Investigator-Initiated Research in Genomics and Health Equity

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National Advisory Council for Human Genome Research
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Maximize the usability of genomics for all members of the public, including the ability to access genomics in healthcare — engagement, inclusion, and understanding the needs of diverse and medically underserved groups are required to ensure that all members of society benefit equitably from genomic advances, with particular attention given to the equitable use of genomics in healthcare that avoids exacerbating and strives towards reducing health disparities.
Health equity

• When every person has the opportunity to attain their full health potential and no one is disadvantaged from achieving this potential because of social position or other socially determined circumstances

https://www.cdc.gov/chronicdisease/healthequity/index.htm

• Health disparities/health equity through a genomics lens:
  • Access to high-quality and comprehensive genomic information
  • Development of accessible technology and methods
  • Access to genomic testing
  • Quality of treatment and management of genomic findings
  • Acceptability of genomic approaches and interventions
Future Directions in Genomics and Health Equity Research Virtual Workshop

- Workshop Goal: Identify research gaps and opportunities that will help address health disparities and improve health equity in genomics
- April 6-7, 2022
- Over 300 participants
- Co-chairs: Judy Cho, Icahn School of Medicine at Mount Sinai; Sandra Soo-Jin Lee, Columbia University

Workshop-identified research areas and opportunities

- Understand how lack of diversity in populations and communities comprising genomic research cohorts impacts health disparities
- Distinguish race and other social descriptors from genomic information in determining lab and clinical algorithms
- Nurture long standing relationships with diverse communities to build trust and conduct research equitably
- Develop metrics of health equity, such as measures of access to genomic testing, and apply them across genomic studies
- Diversify the genomic workforce and landscape
- Address the lack of diverse genomic data
Purpose

• Support investigator-initiated research in genomics and health equity
  • Developing approaches, generating and disseminating data, and implementing metrics or interventions
  • Advance the equitable use of genomics to improve health in all U.S. populations

• Research spanning across NHGRI’s scientific areas
Selected research topics

• Improving prediction of molecular variation from genetic variation in admixed populations, accounting for biological and social determinants of health
• Maximizing the utility of genomic, social, and environmental data in underrepresented populations
• Addressing challenges to genomic data sharing or data science that impact health equity
• Developing and applying metrics of health equity in genomic research that are acceptable and useful to communities, participants, and researchers
Robust strategies for including diverse perspectives

• Advance the scientific and technical merit of the proposed project through inclusivity
• Integrated with a specific research objective or objectives
• Integrated into review criteria
• Examples of possible strategies
  • Enhancing engagement of diverse communities as a central component of the research
  • Enhancing workforce diversity and career development in research teams
  • Developing trans-disciplinary collaborations requiring unique expertise or perspectives
  • Strengthening team science to promote equitable contributions to research and publication
Program organization

• 4 RFAs
  • R01 and R21 activity codes
  • General and NI/ESI investigators from diverse backgrounds
  • Commitment to building independent research careers for investigators from diverse backgrounds
• Annual meeting to convene grantees
## Budget

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$ in 1,000s

- Per-award limits (direct costs): <$500K per year for R01; <$250K for R21
- 1 receipt date/year for 3 years
- Up to 4 R01 applications, 2 R21 applications funded each year
- Half of awards to NI/ESI investigators from diverse backgrounds
Acknowledgments

WORKSHOP

• Co-chairs: Judy Cho, Sandra Lee
• >300 speakers, panelists, moderators, breakout group leaders, participants
• NHGRI Planning Committee: Vence Bonham, Amber Jackson, Nicole Lockhart, Ebony Madden, Lorjetta Schools, Jennifer Troyer

CONCEPT

• Training, Diversity and Health Equity (TiDHE) office
• Extramural Research Program (ERP) staff
• Office of Communications
The Forefront of Genomics®