



**Improving Racial and Ethnic
Diversity in Genetic Research:
2024 Update on a Multi-Year Project**

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Our team (click on names for more detail):

- [Robert I. Field](#), Professor, Drexel University Schools of Law and Public Health
- [Anthony W. Orlando](#), Associate Professor, Cal-Poly-Pomona College of Business Administration
- [Arnold J. Rosoff](#), Professor Emeritus, Univ. of Pennsylvania
- ***Our research assistants, Camellia Bui & Nymisha Desai, are 2024 “SUMR Scholars” in the Student Undergraduate Mentored Research Program of Penn’s Leonard Davis Institute of Health Economics (LDI).***

The Problem and Our Goals

- **The Problem:** Minority population subgroups are commonly underrepresented in genetic databases used for biomedical research.
 - This problem has been recognized for 25+ years.
 - Little progress has been made in correcting the underrepresentation.
 - Underrepresentation denies minority populations the benefits of “Precision Medicine”, continuing and exacerbating inequalities and inequities in our healthcare system.
- **Our Goals:**
 - Understand better why the problem remains so persistent
 - Develop and propose solutions to the underrepresentation
 - Find and/or create allies who will join with us to address, and hopefully remedy, the problem

Our Research Steps to Date

- Literature search regarding the diversity and representativeness of genetic databases used for biomedical research
- Identification and analysis of genetically-based research on Alzheimer's Disease from 1997 to 2022
 - 168 published research studies were reviewed to ascertain the racial & ethnic diversity of the genetic material on which they were based.
 - We're satisfied our observations re Alzheimer's are generalizable to biomedical research more broadly.
- **Conclusion:** We found no appreciable progress toward genetic diversity & representativeness in 25+ years of work, although lack of these elements was widely recognized in the research community throughout this period.
 - See our work published in **HUMAN GENETICS, May 2023: *Demographic diversity of genetic databases used in Alzheimer's disease research***, <https://doi.org/10.1007/s00439-023-02551-3>

Our research plan for SUMR 2024

- We will conduct an extensive set of semi-structured interviews of parties who can potentially affect the genetic representativeness of work in this area, including:
 - Academic researchers working on genetically-based studies
 - Journal editors & others who control publication & dissemination of this work
 - Managers of genetic databases created and maintained by academic institutions, gov't agencies, and other types of entities, including DTC (Direct-To-Consumer) genetic testing organizations, such as **23andMe** and **Ancestry**
 - Research regulatory entities (e.g., the FDA)
 - Research funders (e.g., the NIH & other sponsors, including "Big Pharma")



What we seek to learn from the interviews

- How concerned is your organization about underrepresentation of minority populations in genetic databases & genetically-based research?
- Reasons/factors you and/or your organization see as underlying, causing, and/or perpetuating this problem?
- Steps your organization (a) has taken to date, (b) is now taking, or (c) is considering or planning to take to address this issue?
- Other organizations or people that could help us pursue our inquiry?
- Other thoughts, ideas, or suggestions you'd offer in support of our mission – i.e., to elevate the level of minority representation in genetic databases and research to address systemic inequity in our healthcare system?



What we'd like from our HLP colleagues

- Info about others working on this and related topics
- Suggestions of people & organizations to contact/interview
- Suggestions regarding questions to ask and insights into the general issue
- Ideas for solutions to the problem of lack of diversity and equitable representation in genetic databases used for biomedical research
- **Solutions we are considering:**
 - Promoting greater awareness of the problem in the research community
 - Identifying actions, incentives, and disincentives that journal editors and reviewers, research regulators (e.g., FDA), and funding entities (e.g., NIH) could use to promote or require greater efforts to rectify the problem



Please get in touch with us if you have ideas or insights to share

- Contact Arnold J. Rosoff (SUMR project principal contact) at rosoffa@wharton.upenn.edu or any of the following team:
 - Robert I. Field: robert.field@drexel.edu
 - Anthony W. Orlando: anthony.w.orlando@gmail.com

Suggested background sources

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