

# Genetic Diversity: A Key to Health Equity

## **Neila Kalipersad**

University of Pennsylvania, Class of 2025  
Wharton Dean's SUMR Scholar 2023

## **Amol Jhala**

University of Pennsylvania, Class of 2025  
Wharton Dean's SUMR Scholar 2023

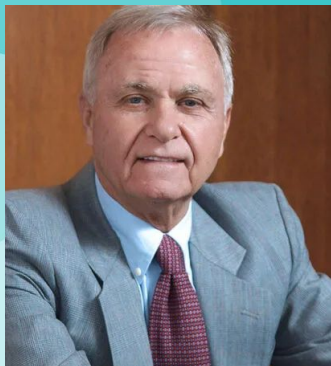
## **Mentors**

Arnold "Skip" Rosoff, JD; Robert I. Field, PhD, JD; Anthony W. Orlando, PhD

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# Our Team



**Arnold J. Rosoff, JD**

Professor Emeritus of  
Legal Studies and  
Business Ethics at the  
Wharton School of  
Business



**Robert I. Field, PhD, JD**

Professor of Health  
Management and Policy  
at the School of Public  
Health and Drexel  
University Professor,  
Kline School of Law

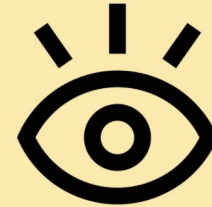


**Anthony W. Orlando, PhD**

Associate Professor in  
the Finance, Real Estate,  
& Law Department at  
California State  
Polytechnic University,  
Pomona

# Project Overview

- Precision Medicine (PM) tailors drugs and treatments based on genetic makeup, but equitable effectiveness requires sharing genetic data.
- Some population subgroups, particularly non-European communities, are underrepresented in genetic databases.
- Overall question: why is this the case and how can we solve this problem?



## Project overview

# Significance

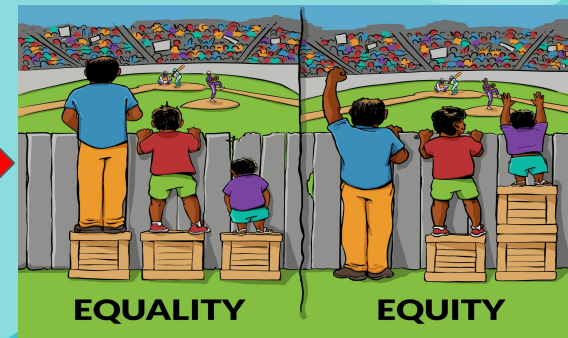
Unequal Representation in Genetic Databases



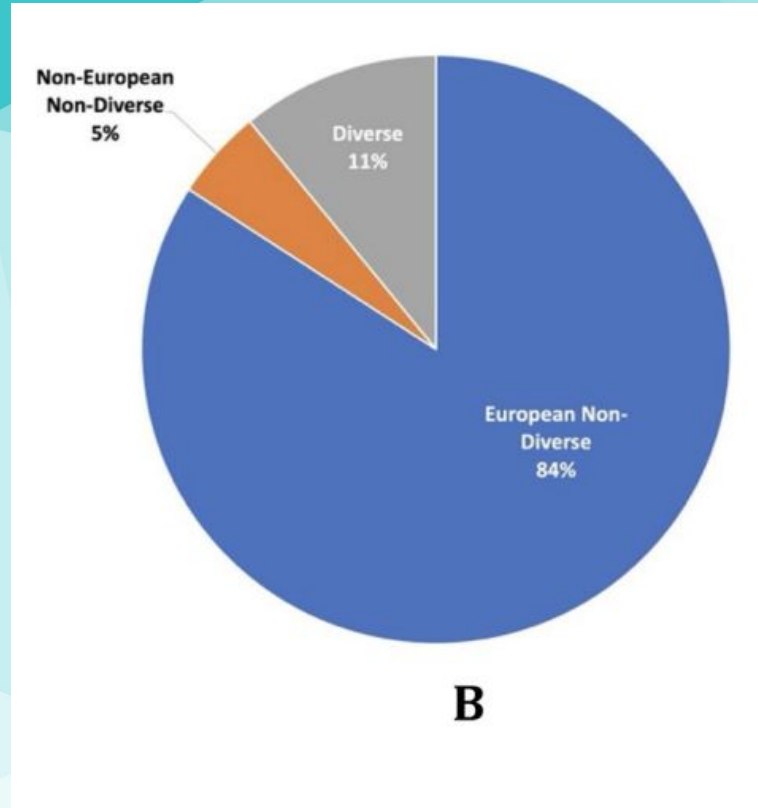
Consequences of Efficacy in PM and Health Equity



Potential for transformation:  
Equitable Healthcare Outcomes for All



# Significance Visualized



# GOAL: Improving Database Representativeness to Promote Health Equity

## Aim 1

Measure the scope of genetic data disparities in databases



## Aim 2

Unearth the effects of these disparities on PM's effectiveness



## Aim 3

Propose potential steps to address disparities in database composition with the goal of improving health equity



# INTRODUCTION TO METHODS

- Approach: Literature Review and Interview Based
  - IRB approval underway
- Participants:
  - Key Stakeholders
  - Journal editors
  - Genetics researchers
  - Genetic database managers





# Identifying Key Stakeholders

- Researchers
- Regulators
- Funders
- Database Managers
- Journal Editors



## **OBJECTIVE OF THE INTERVIEWS**

- Understand diverse perspectives
- Address the issue of underrepresentation
- Inform future policies and practices



## **NEXT STEPS**

- Begin interviewing researchers, editors, and database managers
  - Continue finding relevant literature and gaps in literature
  - Gather all information to find solution to increase equity in genetic databases

## OUR ROLE IN THE PROJECT

- Curating the Interviewee List
- Analyzing and reviewing relevant literature
  - Academic articles
  - News articles



## LESSONS LEARNED

- IRB Significance and Coordination
- Effective Communication/Networking
- Analyzing Research Literature
- Long-Form Writing
- Preparation for the Future

LESSONS  
LEARNED



# THANKS!

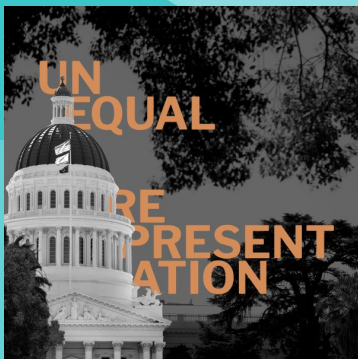
Thank you to:

- Skip Rosoff, Anthony Orlando, and Robert Field
- Joanne Levy
- The SUMR 2023 Cohort

# Some Examples

## Unequal Representation Causes

- Lack of trust in healthcare system, specifically BIPOC Communities
  - Tuskegee Syphilis Study
- Genetic testing is expensive
- Informed Consent



## Treatment for Disease and Health

- CRISPR and Vaccines
- Cancer Treatment
- Obesity Treatment

