Diversity, Disparities and Community Engagement in Healthcare

Jorge Gomez, MD, PhD

Assistant Vice President for Research

Assistant Professor, Dept of Translational Medical Sciences

School of Medicine

Health Sciences Center

Texas A&M University

September 13, 2022

Health Equity, Inequity, and Disparities

Definitions

- **Health Equity:** Attainment of the highest level of health for all people. Health Equity means efforts to ensure that all people have full and equal access to opportunities that enable them to lead healthy lives.

- **Health Inequities:** Differences in health that are avoidable, unfair, and unjust. Health inequities are affected by social, economic, and environmental conditions.

- **Health Disparities:** unequal burden of disease in a population due to race, ethnicity, gender, education, socioeconomic status, disability, geographic location, sexual orientation, cultural or religious believes (DHHS)
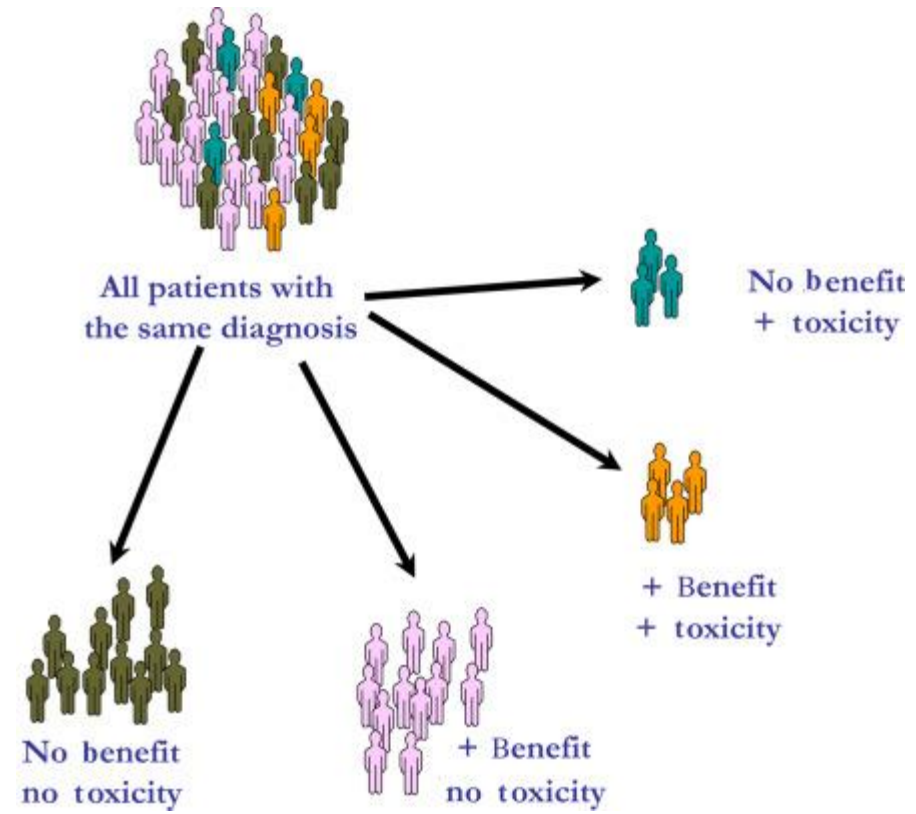
Diversity, Disparities and Community Engagement in Healthcare

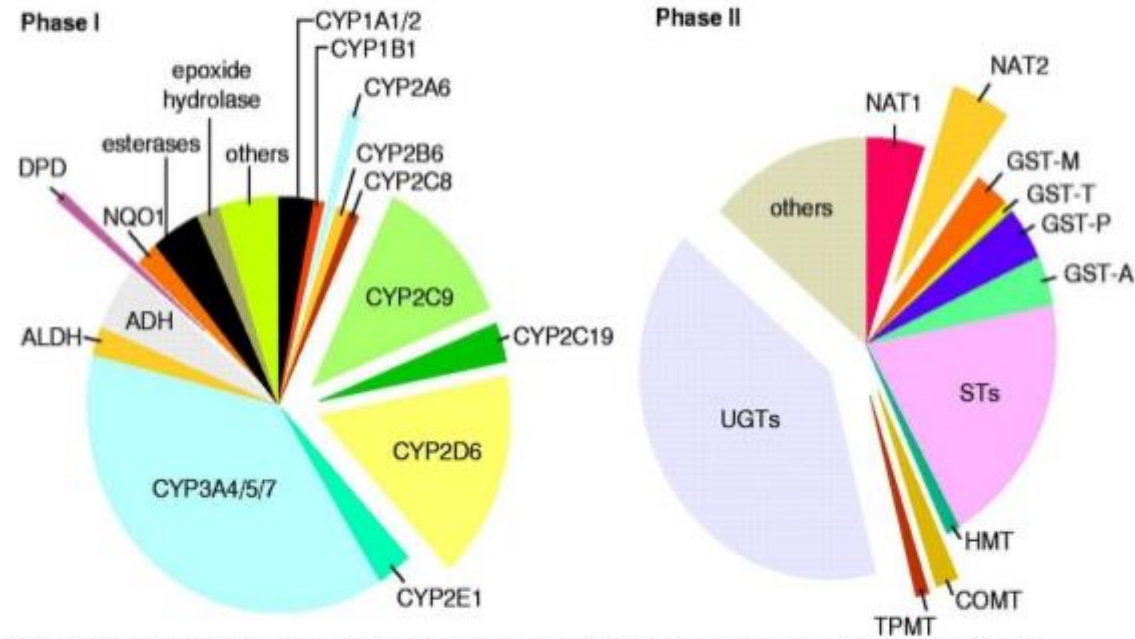**History and Ethics: Ethnic Minority Engagement in Research**

Hispanic in the US

Background

- Hispanic/Latinx population in the US: >60M (USCB, 2020)
- Heterogenous group:
  - Diverse national origin
  - Racial makeup
  - Genetic ancestry
  - Modifiable risk factors
  - Environmental exposures
  - Lower SES, acculturation
  - Higher burden of disease: Diabetes, Cancer, Infectious, among others
  - Higher uninsured, underinsured, limited access to health care
  - Lower survival rates
  - Leading cause of death in childhood and adolescence
  - Low participation in clinical trials

All patients with
the same diagnosis

No benefit
+ toxicity

+ Benefit
+ toxicity

No benefit
no toxicity

+ Benefit
no toxicity

TEXAS A&M
UNIVERSITY.

DRUG METABOLIZING ENZYMES

Phase I: biotransformation reactions: oxidation, hydroxylation, reduction, hydrolysis
Phase II: conjugation reactions—to increase their water solubility and elimination from the body. The reactions are glucuronidation, sulation, acetylation, glutathione conjugation

MUTANT ALLELES OF PHASE I ENZYMES

CYP 450 gene	Mutant Alleles	Substrates
CYP2C9*1	*2, *3, *4, *5, *6	Warfarin, losartan phenytoin, tolbutamide
CYP2C19*1	*2, *3, *4, *5, *6, *7, *8	Proguanil, Imipramine, Ritonavir, nelfinavir, cyclophosphamide
CYP2D6*1	*1XN, *2XN, *3,*4,*5, *6 *9,*10,*17	Clonidine, codeine, promethazine, propranolol, clozapine, fluoxetine, haloperidol, amitriptyline

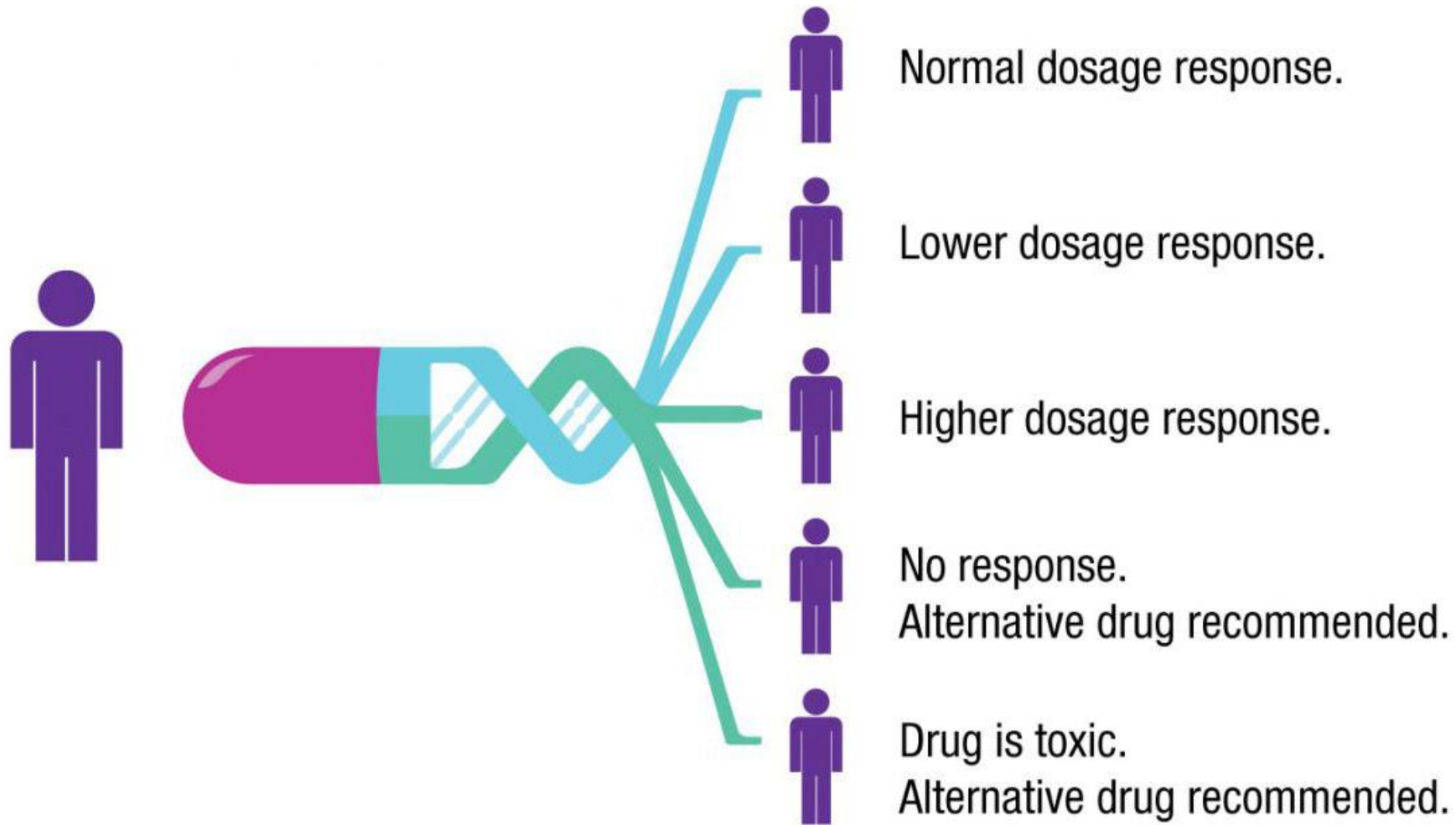Red: Absent; Blue: Reduced; Green: Increased activity

Accurate prescribing through genetics.

Normal dosage response.

Lower dosage response.

Higher dosage response.

No response.
Alternative drug recommended.

Drug is toxic.
Alternative drug recommended.

TEXAS A&M
UNIVERSITY

A Race-combined approach

VKORC1
+
CYP2C9*2
+
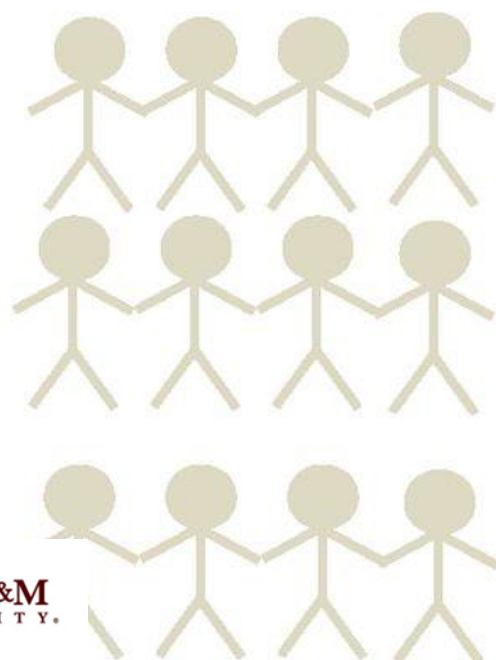CYP2C9*3
- - - - - - - - - - - - -
Warfarin dose for all
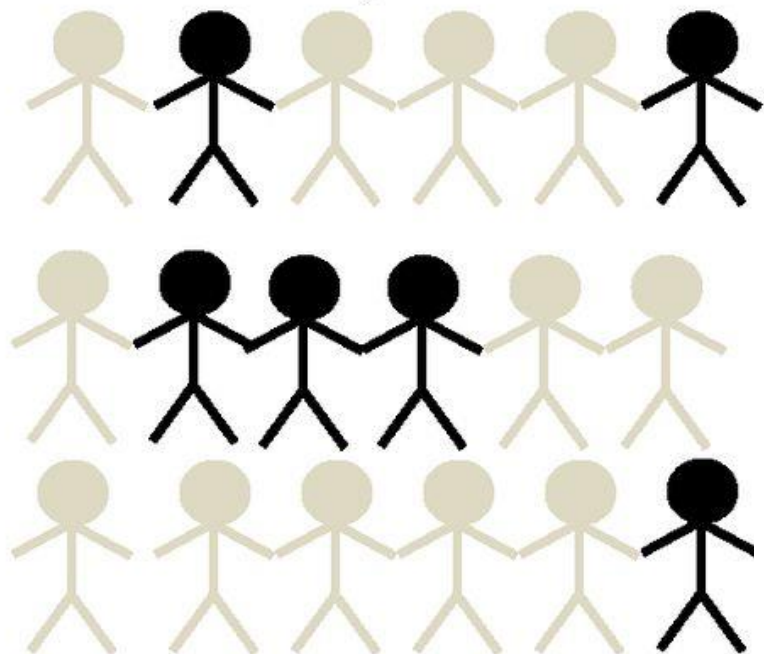
B Race-stratified approach

VKORC1
+
CYP2C9*2
+
CYP2C9*3
- - - - - - -
Warfarin dose European
Americans

VKORC1
+
CYP2C9*3
+
CYP2C rs12777823
- - - - - - -
Warfarin dose African
Americans

ĀM | TEXAS A&M UNIVERSITY.
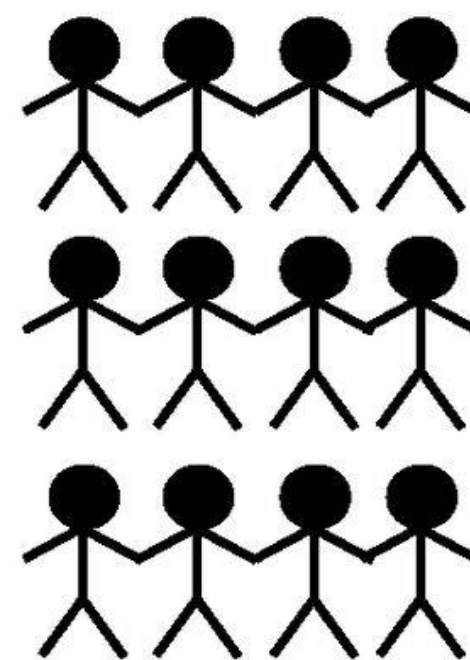
History and Ethics: Ethnic Minority Engagement in Research

- Clinical Trials (CT): an important tool to provide novel treatments, diagnoses, and supportive interventions to patients

- Patients that participate in CT receive benefits of closed monitoring of disease and better patient outcomes

- Through CT, researchers and patients might gain a better understanding of individualized treatments and disease management

- Patient heterogeneity factors can be taken into account when participating in CT and contribute to a better understanding of therapy responses and disease management

TEXAS A&M UNIVERSITY

History and Ethics: Ethnic Minority Engagement in Research

Hispanic Participation in Clinical Trials: **Race and Ethnicity**

- Hispanics account for 2-3% of participation in CT

- Race and Ethnicity contribute to underreporting of Hispanics in CT

- Classifying Hispanics as one ethnic group is a problem by itself

- Hispanics vs Latinos means different things for different people in terms of heritage, ancestry, and place of origin, and does not differentiate from others in the Caribbean and other regions in Central and South America

The use of Hispanic/Latino term underestimates the diversity and heterogeneity of the population and its impact on disease risk, health behaviors, and outcomes

History and Ethics: Ethnic Minority Engagement in Research

Hispanic Participation in Clinical Trials: **Federal Government**

Federal Act of 2017 (FDAAA81):

- Requires reporting of racial/ethnic demographic data in all federally-sponsored CTs.
- It does not address self-reporting
- It does not address subgroups
- It does not provide guidance for methodologies of data gathering and enrollment

History and Ethics: Ethnic Minority Engagement in Research

Barriers to Enrollment of Hispanics in CTs

Hispanic Patients

- Lack of awareness
- Fear of being a "guinea pig", side-effects, placebo effect
- Underinsured, unsinured
- Low SES, education, knowledge
- Lack of access to academic clinical centers, transportation
- Communication barriers, language (English proficiency, low literacy)
- Complexity of protocol design
- New immigrants

Health care providers

- Physician preference, unconscious bias
- Fear of losing patients
- Lack of CT awareness, interest in contributing to CTs
- Lack of culturally competent staff, bilingual
- Source of funding (pharma vs academic)

TEXAS A&M UNIVERSITY

History and Ethics: Ethnic Minority Engagement in Research

Barriers to Enrollment of Hispanics in CTs: Addressing the Problem

- Implement culturally appropriate outreach and education programs at the local level
- Improve informed consent process, including appropriate translation
- Use of the patient navigator program
- Build community partnerships
- Learn to know your community's origin
- Establish trust with the community leaders
- Educate the health care staff and increase their cultural competence

Business as usual neglects or minimizes the social conditions in which the research is being conducted

TEXAS A&M UNIVERSITY

History and Ethics: Ethnic Minority Engagement in Research

Barriers to Enrollment of Hispanics in CTs: **Ethical Responsibility**

- In general, minority communities are vulnerable populations

- Evidence-based research must be derived from the population at large, not from subgroups

- Understanding community-based knowledge is of paramount importance to promoting CT in minority communities, including the Hispanic community

To promote population health, researchers must step out of their comfort zone of a protected and privileged class (educated, knowledgeable, resourceful, usually white population) and involve all sectors of society.

Clinical research should incorporate the upstream factors causing health disparities and adapt novel interventions in real-life settings taking into account the community knowledge they serve.

These strategies will help researchers to initiate trust, strengthen human dignity, and ensure mutual benefits for researchers and the community they serve.