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LEADING AMERICA TO HEALTHIER LIVES

DIVERSITY AND INCLUSION IN CLINICAL RESEARCH: HOW DO WE GET THERE?

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Disclosure Statement

I have no financial disclosures that would be a potential conflict of interest with this presentation



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Objectives

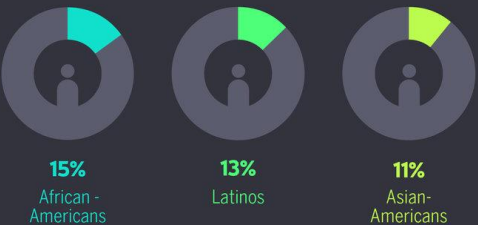
- Examine barriers to participation in clinical research
- Strategies to research and engage vulnerable populations for research
- Recommendations to improve access to research for poor and underserved communities



Historical Context to Research in Vulnerable Populations

Racial Disparities in Mental Health Treatment

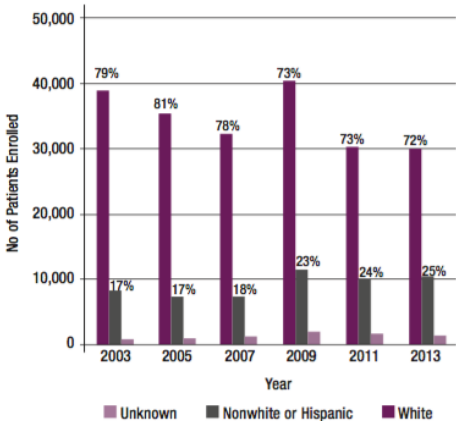
Groups report feeling that they would have received better mental health care if they were a different race or ethnicity.



SOCIALWORK@SIMMONS
Source: National Alliance on Mental Illness

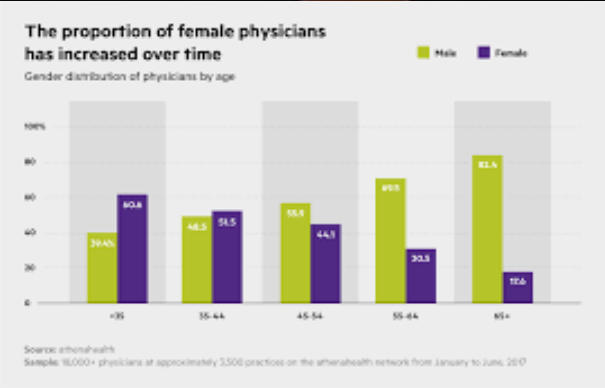
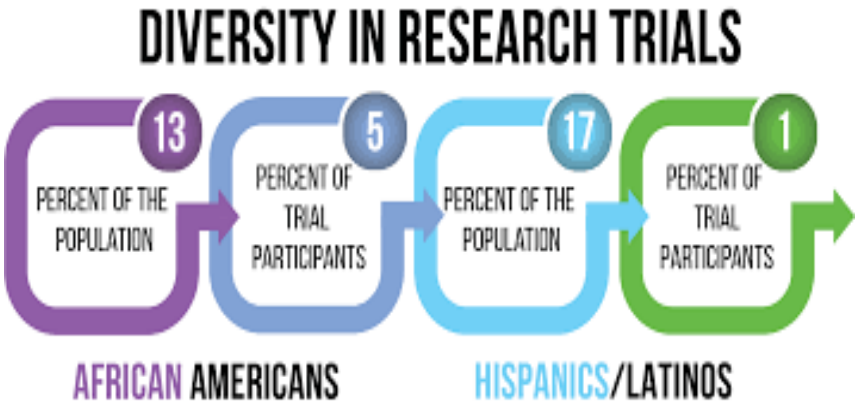


Figure Minority Enrollment in National Cancer Institute–Funded Trials from 2003 to 2013³



Minority indicates nonwhite race or Hispanic ethnicity; majority indicates white race and non-Hispanic ethnicity.

NIH National Institutes of Health All of Us Research Program ABOUT FUNDING NEWS, EVENTS



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Problem Statement

- Diverse patient populations in the United States are regularly underrepresented in clinical trials
- Less than 10% of patients with cancer participate in US cancer clinical trials participation of racial and ethnic minority groups is disproportionately low
- When racial ethnic minorities are not adequately represented in clinical trials they are not being included in the populations assessed for safety and efficacy of innovative therapies
- Clinical trial participants are disproportionately non-Hispanic white men with higher education levels and household incomes



Challenges in Reaching Vulnerable Populations for Research

Patient/Community Barriers

- Medical mistrust
- Limited access to healthcare services
- Lack of understanding of research
- Fear
- Communication

Provider Barriers

- Knowledge gap in how to engage community
- Lack of tools support communication with underserved communities
- Lack of awareness of community perspectives



Diversity Defined

- The differences in racial and ethnic, socioeconomic, geographic, and academic/professional backgrounds
- People with different views, opinions, religious beliefs, political beliefs, sexual orientations, heritage, and life experience



Inclusion Defined

- Bringing individuals together in a way that differences can be respected and serve as a catalyst for collaboration
- Inclusion promotes an environment of involvement, respect, and connection
- Shared ideas, backgrounds, and perspectives create mutual benefit



Relevance to Healthcare Environment

- Randomized controlled trials (RCTs) – gold standard
- Provide the highest level of evidence for clinical practice
- It has been suggested that RCTs often do not enroll subjects who are representative of patients seen in the community
- Infrequent enrollment of older patients, women, and minorities
- Raises questions about the generalizability of medical evidence to important patient groups
- Historical context – fear, distrust, stigma, and social justice
- Translation of research – moving from the bench to the bedside



Our Nation is Changing

Demographics

- The US is changing – it is becoming more diverse
- Increase in different cultures in the US
- Baby Boomers are the fastest growing segment of the US population
- Millennials are the largest generation in the US labor force
- One in five Americans live in a multigenerational household



US Demographics

The US is becoming a more multicultural society

- According the US Census Bureau, by 2040 no race will make up a majority
- By 2050:
 - US African American population is estimated to increase from 13 percent to 14 percent
 - Hispanic population is estimated to increase from 14 percent to 25 percent
 - Caucasian population is estimated to decrease from 74 percent to 50 percent
 - Asian population is estimated to increase from 3 percent to 8 percent



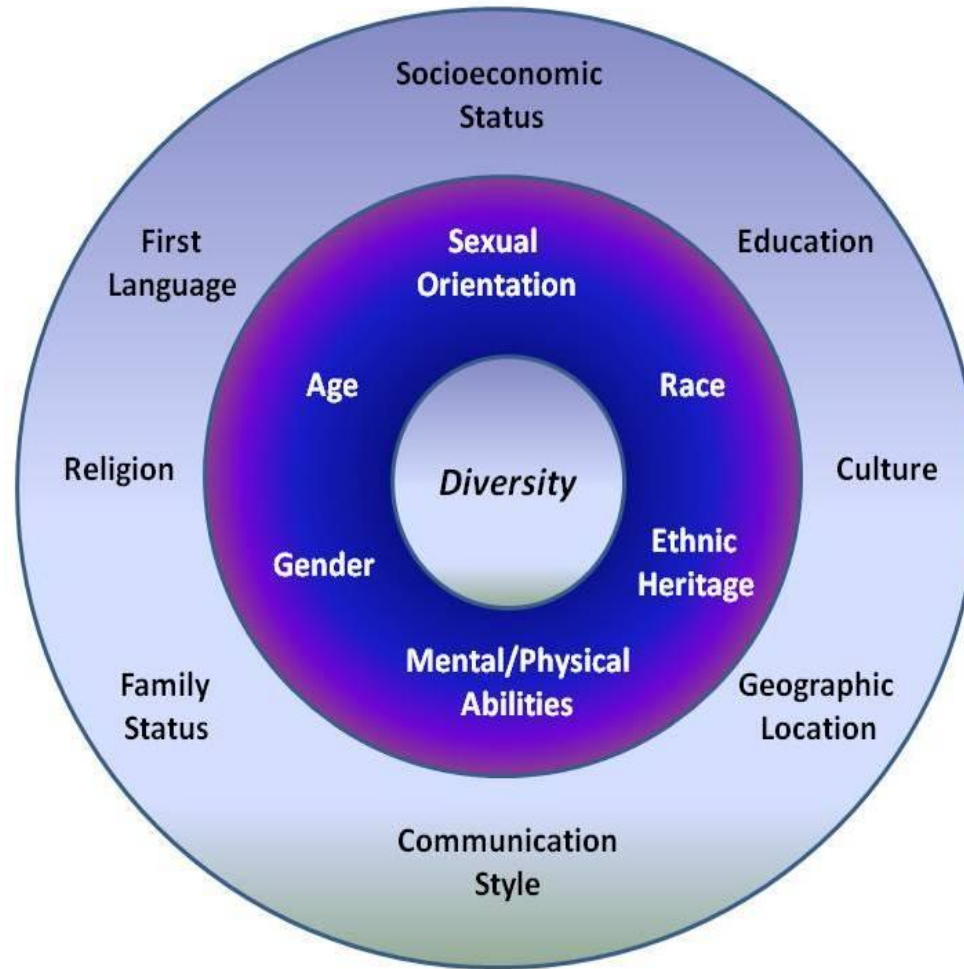


Linguistic Diversity

- Fourteen percent (14%) of the total US population speak a language other than English at home
- Fifty-four percent (54%) of those speak Spanish



Cultural Diversity



Cultural Diversity in Healthcare

- Differences based on cultural, ethnic and racial factors --- drivers of health beliefs and practices
- Culture must be considered in health care delivery
- Healthcare providers must recognize the diverse characteristics of their patients



Cultural Diversity in Healthcare

- Persons with physical and mental health challenges make up the largest minority in the US – approximately 50 million individuals (almost 20 percent of the population)
- An estimated 25 million Americans identify as gay, lesbian, or transgendered
- According to the 2016 National Study on Drug Use and Health, roughly 1 in 10 people in the US struggle with some level of substance use, including addiction to prescription drugs
- Seven out of ten youth between 17-25 years of age cannot qualify for military services (obesity, mental health, or criminal history)



Cultural Diversity in Healthcare

The patient experience:

- Family definition
- Language
- Personal space
- Body language – gestures
- Eye contact
- Health care beliefs
- Religion and spirituality
- Food and dietary practices
- View of birth, death, illness, and health



Social Determinants of Health

- The complex, integrated, and overlapping social structures and economic systems that are responsible for most health inequities.
- These social structures and economic systems include the social environment, physical environment, health services, and structural and societal factors.
- Addressing social determinants of health is important for improving health and reducing longstanding disparities in health and health care.



Social Determinants of Health

- Key Social Determinants
 - Poverty
 - Economic inequality
 - Social status
 - Stress
 - Education and care in early life
 - Social exclusion
 - Employment and job security
 - Social support
 - Food security
 - Cardiovascular disease
 - Diabetes

WHO, 1986. Ottawa charter for health promotion, Geneva: Author.



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Demographics of Clinical Research

- Historical
 - Where is research conducted?
 - Who has access?
 - How is research recruitment conducted?
 - When is research available?
- Trends
 - New therapies
 - Advances in precision medicine
 - Genomics
- Where we go in the future



Nursing in clinical research

- Why nursing is important?
- What do we do?
- Why is the clinical research nurse important?
- How do we take research to the patient?

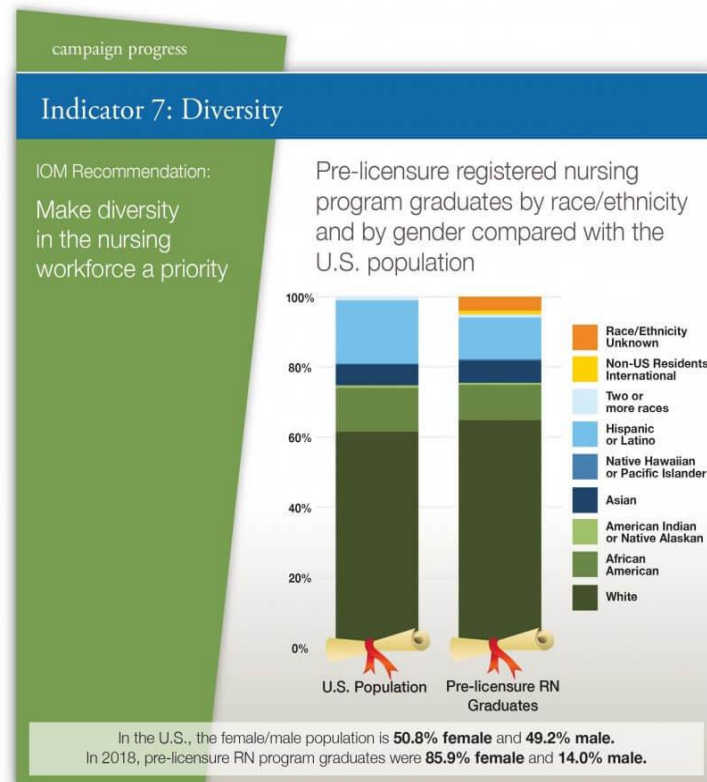


Strategies to Improve Access to Research for Underserved Communities

- Increase diversity of clinical researchers and providers
- Cultural competence training for staff
- Community advisory boards that include diverse stakeholders to guide the development, feasibility, and implementation of research studies
- Community representatives—to develop community talent and tap into their expertise and networks to reach potential research participants
- Transparency in sharing research findings – findings presented in appropriate language and at the appropriate reading level to allow participants to understand their contributions to science and their community
- Provide financial support/incentives for research participants from underserved communities



Strategies for Success: Workforce Diversity



The Campaign is working to promote diversity in the nursing workforce so that the profession reflects America's changing population.

Sources: American Association of Colleges of Nursing, Enrollment & Graduations in Baccalaureate and Graduate Programs in Nursing (series); Integrated Postsecondary Education Data System (IPEDS), Completions Survey (series); US Census Bureau, Population Division

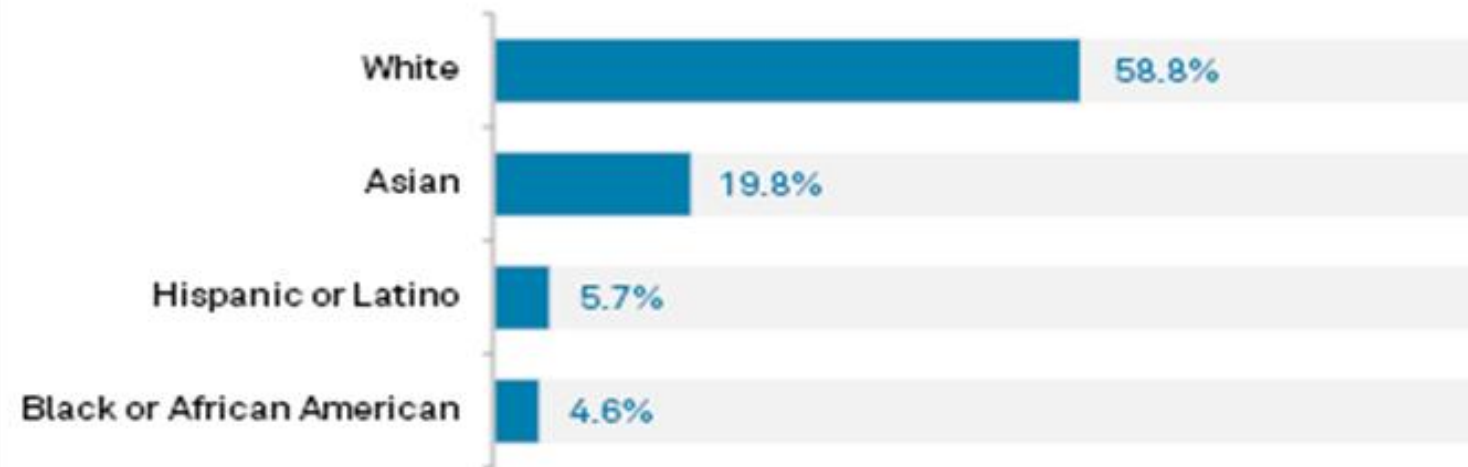
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Strategies for Success: Workforce Diversity

Medical school graduation rates, by race/ethnicity, 2015



Data accessed July 22, 2019.

Source: Association of American Medical Colleges



Take Home Messages

- Research is critical to advance improvements in health and health care
- Nurses are key in the development of a robust, agile clinical research agenda
- Diversity in clinical research is central in developing treatments effective for the general population
- Underrepresentation of impacted populations in clinical research can increase gaps in effective therapies for underserved populations and sub-populations
- Clinical research in the community can improve engagement, recruitment, and retention
- We all have a role in improving access to clinical research for everyone, but especially the underserved



“If you change the way you look at things, the things you look at change.”

Wayne Dyer



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Travis AFB



“In Officio Salutis”

In the Service of Health