

Unforgettable: The Power of Partnership in the Pursuit of Health Equity in Alzheimer's and all other Dementia

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Chief Diversity, Equity and Inclusion Officer

alzheimer's  association®



**Morehouse School of Medicine
Master of Public Health
Inaugural Class 1995**

alzheimer's  association®

OUR WORK IS ABOUT COMMUNITY AND SCIENCE



The Alzheimer's Association is a global organization working to advance care, support and research across the world

DIVERSITY, EQUITY & INCLUSION

DEVELOPING OUR UNDERSTANDING

DIVERSITY

- **Numerical** representation of differences
- Different **perspectives, characteristics & beliefs**

EQUITY

- **Everyone gets what they need** to survive, access to opportunity, resources and support

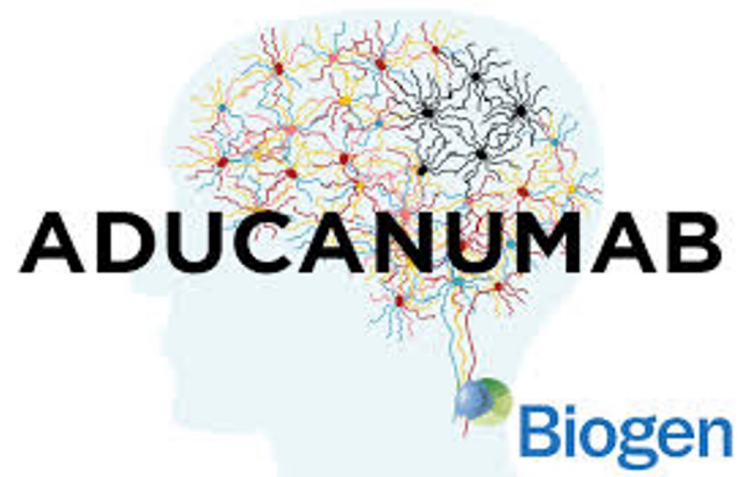
INCLUSION

- Achieving an authentic & empowered participation and **true sense of belonging**

Stanford Social Innovation Review. (2016, September 15). What the Heck Does 'Equity' Mean? https://ssir.org/articles/entry/what_the_heck_does_equity_mean

ANNOUNCEMENT SURPRISES THE FIELD

- *March 2019:* Trials halted due to futility analysis conducted on partial data set
- *October 2019:* Announcement expanded data set shows promise
- *December 2019:* Results reported at CTAD
- *March 2020:* Launch of re-dosing studies to provide drug access to trial participants
- *Mid 2020:* Submitting to FDA for regulatory review
- *August 7:* FDA reviewed aducanumab, **an anti-amyloid antibody for treatment of dementia and mild cognitive impairment (MCI) due to Alzheimer's disease**. This begins the FDA's review process under priority review.
- *June 2021:* FDA provides **conditional approval** for *aducanumab*, which will be known as *aduhelm*
- *November 2022:* Eisai/Biogen announce results from Clarity-AD – Lencanumab, now known as Leqembi (FDA Approval) waiting for CMS coverage (July)





2021 Special Report: Race, Ethnicity and Alzheimer's in America

www.alz.org/facts

What We Did

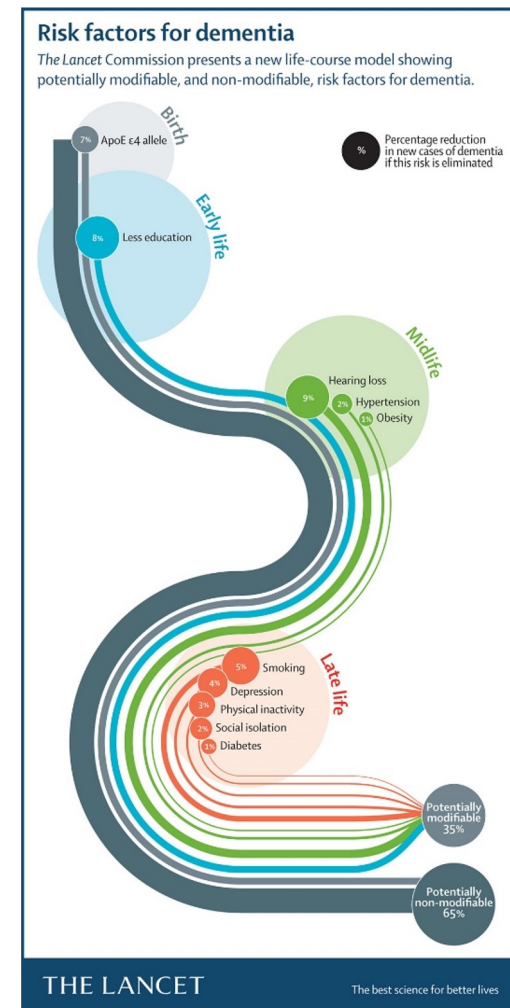
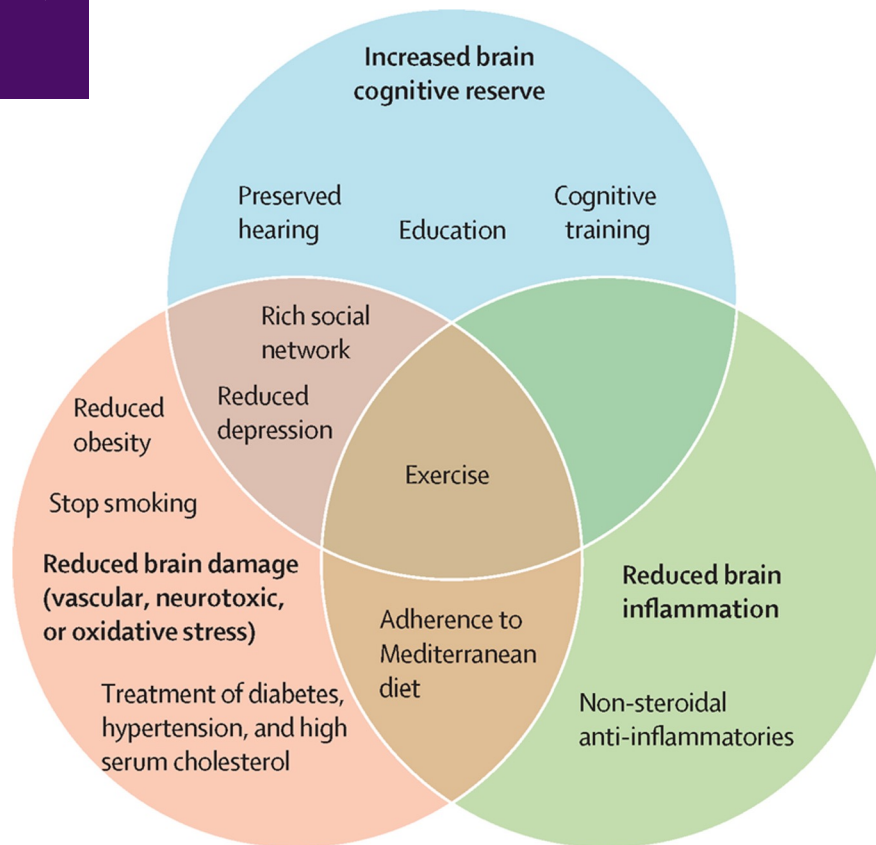
- Conducted two nationwide surveys of U.S. adults (n=2,491) and Alzheimer's caregivers (1,392).
- For the first time ever — surveys included responses from: Asian, Black, Hispanic, Native and White Americans.
- Surveys examined attitudes and experiences of both groups in regard to:
 - ✓ Knowledge and understanding of the disease
 - ✓ Access to care and support services
 - ✓ Trust in health care, providers and disease research
 - ✓ Interest in clinical trials
 - ✓ Existence of discrimination and how that impacts care

Gender, Racial and Ethnic Disparities in Alzheimer's Prevalence

- Almost two-thirds of Americans with Alzheimer's are Women.
- Older Black and Hispanic Americans are more likely than older Whites to have Alzheimer's or other dementias.
- **Constellation: Fundamental and Unique**



FOCUS ON RISK REDUCTION 2017 & 2020



***Air Pollution
Traumatic Brain Injury
Excessive Alcohol Use**

CONSTELLATION: GENETICS AND ALZHEIMER'S

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AAIC20

We need to better understand how **genes impact Alzheimer's risk in different peoples**

HISPANICS ARE

1.5

times more likely to develop dementia than non-Hispanic whites

The **ApoE-e4** gene is the strongest known predictor of Alzheimer's risk for White, European-descended populations.



ACCORDING TO NEW RESEARCH REPORTED AT #AAIC20, this gene seems to be a less accurate predictor of risk for some Latin American populations.

Additionally, genes that determine Alzheimer's risk

MAY DIFFER AMONG HISPANICS OF VARIOUS ORIGINS

This suggests **testing positive for ApoE-e4**



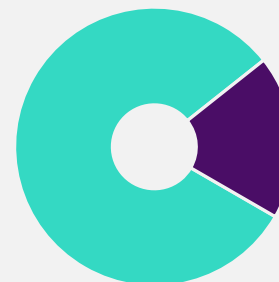
MAY NOT MEAN THE SAME FOR ALZHEIMER'S RISK ACROSS RACIAL/ETHNIC GROUPS

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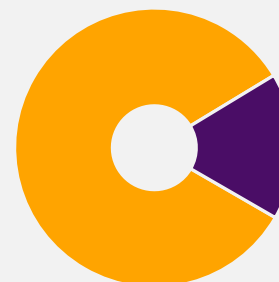
THE SPRINT-MIND STUDY

First Study (2019) to Demonstrate Reduction of New Cases of Cognitive Impairment

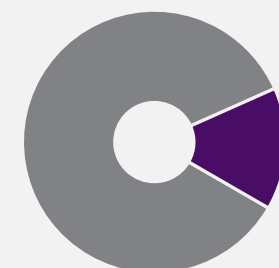
- 9,000+ people, Over age 50, All-cause dementia risk
- Standard vs. Intensive Blood Pressure Intervention
- Intensive treatment 120 systolic vs. 140 systolic
- Dramatic reduction of small vessel disease on **MRI**



19% REDUCED
risk for **MCI**



17% REDUCED
risk for **Dementia**



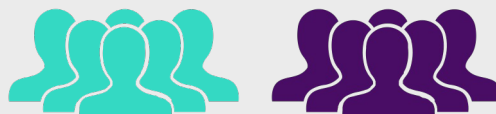
15% REDUCED
combined risk for
MCI and Dementia



U.S. Study to Protect Brain Health through Lifestyle Intervention to Reduce Risk



Two year multi-center randomized clinical trial



Self-Guided and Structured Lifestyle Groups (age 60-79)



2,000 Participants at five U.S. sites

A LANDMARK STUDY: TWO LIFESTYLE INTERVENTIONS

Self-Guided
Lifestyle
Intervention

*Differ in format,
expectations, and
accountability*

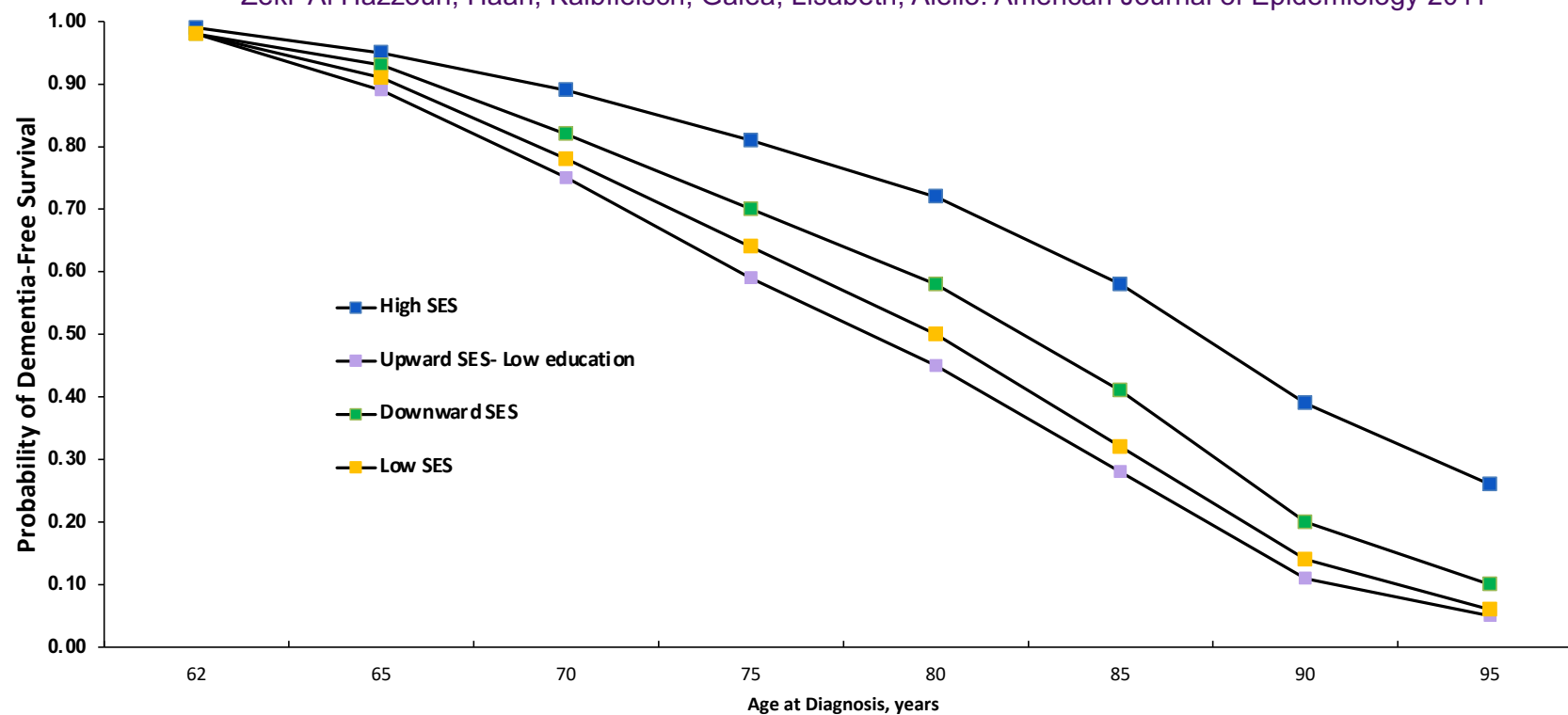
Structured
Lifestyle
Intervention

Physical Activity | Nutrition | Cognitive Stimulation | Health Coaching



Constellation: Social Class

Zeki Al Hazzouri, Haan, Kalbfleisch, Galea, Lisabeth, Aiello. American Journal of Epidemiology 2011

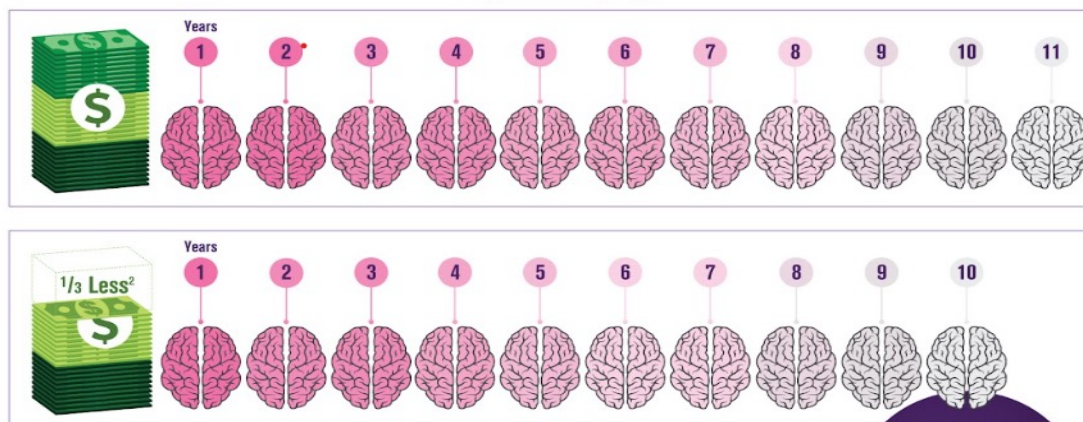




Constellation: Social Class

Sustained low wages in midlife are associated with faster cognitive decline.¹

Cognitive Aging



New research presented at the Alzheimer's Association International Conference® (AAIC®) 2022

1. Katrina Kezios, PhD, et al. Low Hourly Wages in Middle-Age are Associated with Faster Memory Decline in Older Age: Evidence from the Health and Retirement Study.
2. "Low wage" defined as hourly wage lower than two-thirds of the federal median wage for the corresponding year. Earnings based on wages earned from 1992 to 2004 among 3,803 individuals born 1936-1941.

Cognitive decline typically seen over 11 years in higher earners occurs faster – within just 10 years – in lower earners.



The Varying Value of Education

Heart Disease Death Rates, United States, 1993 - 2001

Age-Standardized, for Blacks and Whites Aged 25-64, per 100,000 (Jemal, 2008)

| Education | Women | | | Men | | |
|------------------|--------------|-------------|-------------|--------------|--------------|-------------|
| | Blacks | Whites | B/W Ratio | Blacks | Whites | B/W Ratio |
| All | 106.1 | 37.9 | 2.80 | 194.9 | 100.7 | 1.94 |
| <12 years | 132.9 | 97.8 | 1.36 | 262.9 | 214.9 | 1.22 |
| 12 years | 142.1 | 50.1 | 2.84 | 258.2 | 145.2 | 1.78 |
| 13-15 years | 73 | 25.1 | 2.91 | 120 | 73.1 | 1.64 |
| 16+ years | 62.8 | 16.9 | 3.72 | 99.2 | 51.1 | 1.94 |
| Low/High Ratio | 2.12 | 5.79 | | 2.65 | 4.20 | |

Health Disparities Research Theory (SOC)



The appearance of crime among the southern Blacks is a symptom of wrong social conditions – of a **stress of life**... To be a poor man is hard, but to be a poor... in a land of dollars is the very bottom of hardships”

- W.E.B. DuBois



2021 Special Report: Race, Ethnicity and Alzheimer's in America

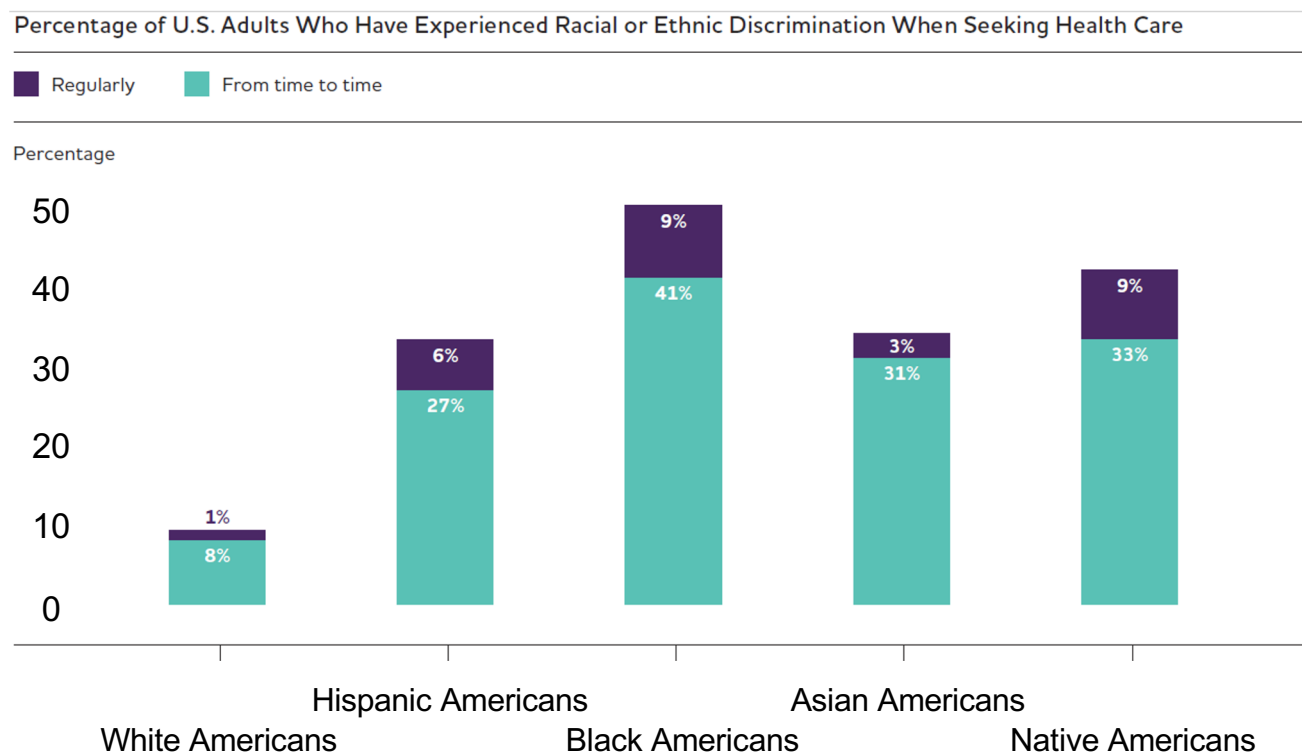
www.alz.org/facts

More than one-third of Black Americans, and nearly one-fifth of Hispanic and Asian Americans believe discrimination would be a barrier to receiving Alzheimer's care

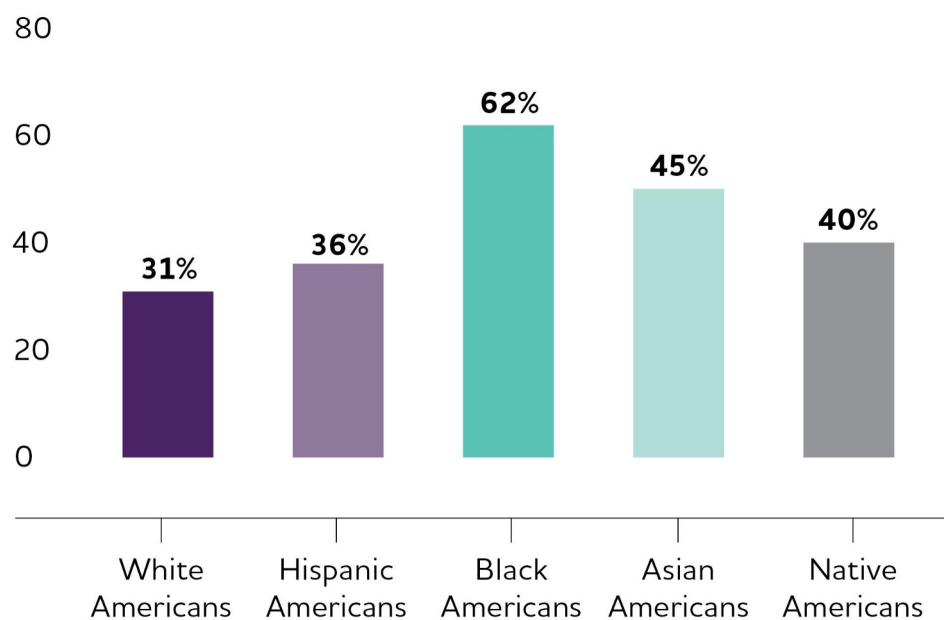
Perceived Barriers to Getting Excellent Health Care and Support for Alzheimer's or Another Dementia Among U.S. Adults

| | White Americans | Hispanic Americans | Black Americans | Asian Americans | Native Americans |
|---|-----------------|--------------------|-----------------|-----------------|------------------|
| Affordability of care | 61% | 55% | 52% | 70% | 61% |
| Lack of good health care insurance coverage | 31% | 41% | 31% | 39% | 36% |
| Lack of good health care services in my community | 20% | 24% | 27% | 27% | 24% |
| Lack of family and social support to help me | 20% | 21% | 20% | 25% | 20% |
| Being treated differently because of my race, color or ethnicity | 1% | 18% | 36% | 19% | 12% |
| Not being able to communicate easily in English | 4% | 9% | 9% | 8% | 5% |
| Other barriers | 2% | 1% | 1% | 1% | 2% |
| There would be no barriers | 21% | 17% | 20% | 12% | 14% |

Half of Black Americans report experiencing health care discrimination; At least one-third of Native, Asian and Hispanic Americans as well



Nearly two-thirds of Black Americans believe medical research is biased against people of color — a view shared by substantial numbers of Asian, Native, and Hispanic Americans



FUNDAMENTAL: INCLUSION IN DEMENTIA RESEARCH

- < 5% of trial participants are
 - Black/African American
 - Latino/Hispanic
 - Asian American/Pacific Islander
 - American Indian/Alaskan Native
- Less likely to be recruited for clinical trials
- Higher Drop out rates in AD trials
- Awareness/Education/Bioethics



CALL TO ACTION: PURSUING EQUITY IN ALZHEIMER'S and ALL OTHER DEMENTIA

- Conduct, Promote and Support Multi-Level Health Disparities Research Focused on All Dementia
- Increase Diversity in Health Systems and Health-Related Institutions
- Enhancing Cultural Competence in Dementia Research and Care
- **Participatory Engagement with Local and National Orgs others to Build Trust and Agency**

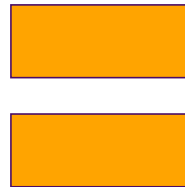
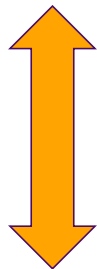
Community-Based Participatory Research

CBPR is a partnership approach that equitably involves community members, organizational representatives, researchers and others in all aspects of the process, with all partners in the process contributing expertise and sharing in the decision-making.

The aim of CBPR is to increase knowledge and understanding of a given phenomenon (Israel et al, 1998).

The Power of Collaborative Partnerships

Each community has its own needs and assets, as well as its own culture and social structure -- a unique web of relationships, history, strengths, and conflicts that defines it.



Include community members from the very beginning of the building process. Encourages both trust in the process and community buy-in and support.

Community-based Participatory Research Principles (CBPR)



Our National Partners

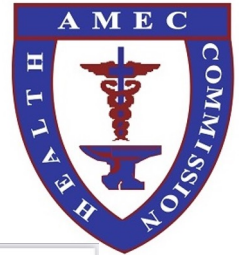


African Methodist Episcopal Church



- **Overview of partnership and goals**
 - To create greater awareness of Alzheimer's Association resources, programs, care and support services for families impacted by Alzheimer's and other dementias in communities served by the AME Church.
 - Engage church members in the Association's volunteer, diversity outreach, advocacy, research and fundraising initiatives.
 - The potential reach of the AME Church is significant. The global membership is 2.5 million. With about 2 million members in the US. There are 7000 locations across the US with a presence in all 50 states.

AME Connectional Purple Sunday



- Annual partner event designed to educate about Alzheimer's and other dementias.
- 400 attendees attended in 2021. 4K attendees in 2022.
- **Purple Sunday 2023, 8K attendees**
- Call to action from AME Bishop inviting all AME churches to partner with their local ALZ chapter to plan a Purple Sunday event.
- Opportunities for extensive local engagement and increased reach.

A flyer for the Alzheimer's Association Purple Sunday event. It features the Alzheimer's Association logo and the AMEC Health Commission logo. The text includes the event title, date and time options, dial-in information, and a list of guest speakers.

alzheimer's association

JOIN US FOR PURPLE SUNDAY

March 21 at 4 p.m. EDT | 3 p.m. CDT | 1 p.m. PDT

Dial-in: 1-312-626-6799
Meeting ID: 895 1270 9446
Passcode: 089255

The African Methodist Episcopal Church and the Alzheimer's Association® invite you to attend a virtual connectional Purple Sunday, designed to educate AME members about Alzheimer's and other dementia. Attendees will learn:

- » The impact of Alzheimer's in our community.
- » How to recognize warning signs of the disease.
- » The importance of early detection.
- » How to access the Association's care and support resources.

GUEST SPEAKERS INCLUDE:

- » Bishop Harry L. Seawright, Presiding Prelate, 9th Episcopal District and Chairman, International Health Commission.
- » Mrs. Christy Davis Jackson, Esq., Supervisor, 6th Episcopal District.
- » Mr. Antjuan Seawright, MBA, 7th Episcopal District.
- » Presiding Elder Charles H. Lett, Sr. and Mrs. Sylvia Lett, 1st Episcopal District.

The AME Church Virtual Mass Choir, under the direction of Reverend Maurice Wright, 9th Episcopal District, will provide musical selections.

Learn more at amechealth.org/alz

Bishop Harry L. Seawright

Supervisor Christy Davis Jackson, Esq.

Mr. Antjuan Seawright

Presiding Elder Charles H. Lett, Sr. and Mrs. Sylvia Lett

Time for equality.

Increasing representation of Black men in scientific research.

Save the Date:
2023 BMBH Conference
Feb 8-9th, Tempe, AZ

[Black Men's Brain Health Conference >](#)

Understanding why Black men are more prone to Alzheimer's, dementia, and other brain disorders is critical.



alzheimer's
association



Berkeley
Social Welfare



ASU Walter Cronkite
School of Journalism
and Mass Communication
Arizona State University

ASU Barrett
The Honors College
Arizona State University

www.unforgettableplay.com

"This heartfelt stage play will show the impact of caring for a loved one living with Alzheimer's disease"



GARRETT DAVIS'

Unforgettable



Presented by



SATURDAY | JUNE 10TH | @ 11AM & 3PM

All Performances are FREE but you MUST register to attend for more information call 833-443-7388

**The DuSable Black History Museum and Education Center
740 E 56th Place | Chicago, Illinois 60637**

Executive Producer: Dr. Carl V. Hill and Alzheimer's Association Producer: Gdavis Productions & Films Written By: Garrett Davis Script Supervisor: Beverly Berry and Yarissa Reyes Directed By: Robert Dartez Wright Wardrobe: Tiffany Penn

ALZHEIMER'S  ASSOCIATION®

CHANGING THE TRAJECTORY OF ALZHEIMER'S DISEASE:

Delayed Onset

If we develop a treatment by 2025 that delays the onset of Alzheimer's by just 5 years...

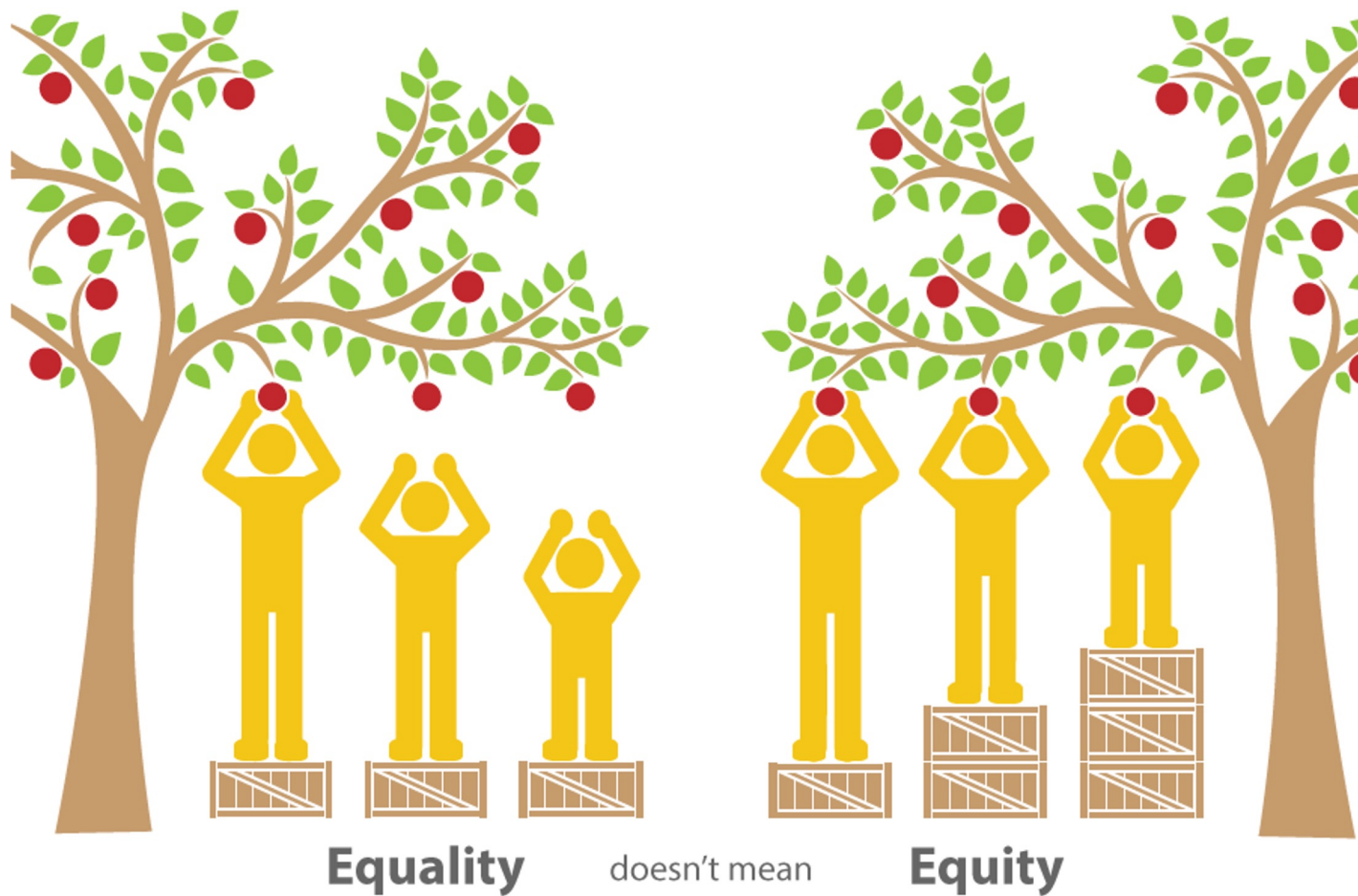
2015

2025

2050

5.7
million people

expected to develop Alzheimer's in 2050 would not.



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- **Conduct, Promote and Support Multi-Level Health Disparities Research Focused on All Dementia**
- **Increase Diversity in Health Systems and Health-Related Institutions**
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HALLMARKS OF ALZHEIMER'S DISEASE

