






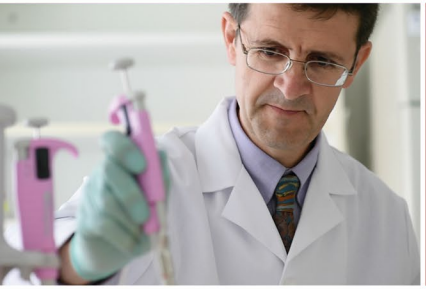


Diversity, Equity and Inclusion Research Across the ADRD Continuum: A Call to Action for the ADRC Network

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Fall ADRC Meeting Theme and Goals

Overarching Meeting theme:

Diversity, Equity and Inclusion

NIA's Goal in Health Disparities Research

"***NIA seeks to understand the environmental, sociocultural, behavioral, and biological drivers of health inequities and disparities related to aging and diseases such as Alzheimer's disease and related dementias***"

- DEI theme permeates through nearly all the sessions during this 2-day meeting
- Collectively, the ADRC network has conducted breakthrough research in ADRD
- Goal of this meeting is to build upon the scientific advances in ADRD and identify new areas for innovative health disparities research

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DEI Research: Why is it Important for ADRD Disparities?

- Ensure research studies are **more representative** of the US population and results more generalizable
- Enhance the understanding of **ethnoracial differences** across the full spectrum of ADRD research– neurobiology, clinical phenotype, biomarkers, diagnosis, and treatment and prevention
- Gain the **trust and commitment** of minoritized communities, thereby improving recruitment and retention in ADRD studies and clinical trials
- Reduce **health disparities and health care discrimination**, and improve access to high quality care

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Discrimination in Health Care

Dr. Martin Luther King Jr. Statement, March 1966

“Of all forms of discrimination and inequalities, injustice in health is the most shocking and inhuman”

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Health Disparities & ADRD Research: Nomenclature & Definition

- **Race** refers to the concept of dividing people into groups based on sets of physical characteristics.
  - It has no biological basis
  - Is the result of systemic and structural racism
  - Racial inequities lead to adverse socioeconomic and health consequences
  - The term “racialization” reflects categorizing or marginalizing a group of people; it has no inherent biological basis

The OMB defined racial categories include:

- American Indian or Alaska Native
- Asian
- Black or African American
- Native Hawaiian or Other Pacific Islander
- White

- **Ethnicity** relates to shared cultural characteristics such as language, ancestry, religion, beliefs, diet, etc. The OMB defined ethnic categories include
  - Hispanic, or non-Hispanic
  - Ethnic categories apply to all races

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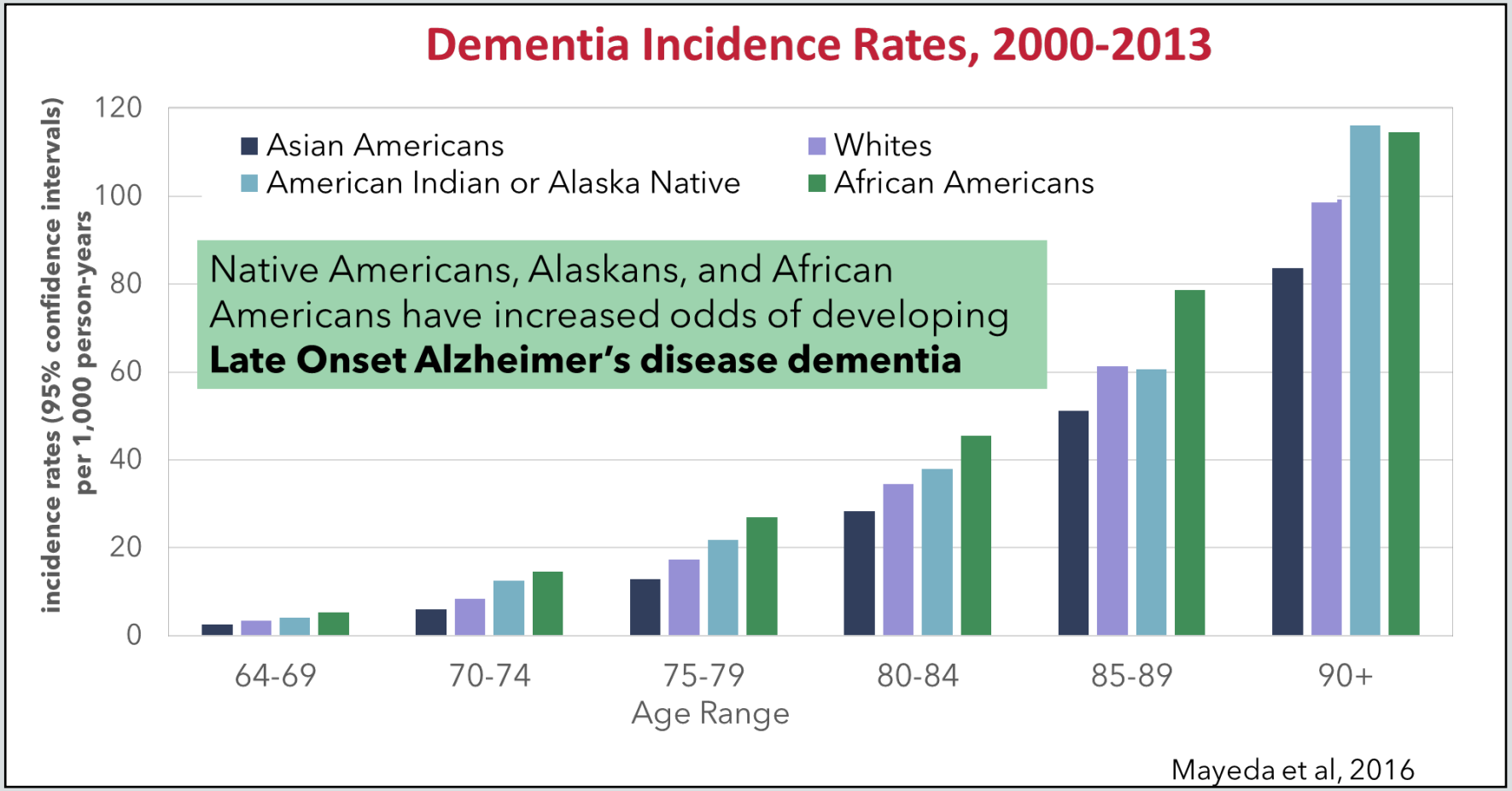
Health Disparities and ADRD Research: Incidence & Prevalence



Mayeda et al, 12(3);216-224, March 2016

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AD and MCI Prevalence in Racialized Groups

	Clinical AD prevalence, cases per 100 (95% CI)	MCI prevalence, cases per 100 (95% CI)
All participants		
Non-Hispanic White	10.0 (9.6–10.4)	21.1 (20.8–21.5)
Hispanic	14.0 (12.0–16.1)	25.9 (24.5–27.3)
Black	18.6 (18.0–19.1)	32.0 (31.7–32.4)
Overall prevalence	11.3 (10.7–11.9)	22.7 (22.3–23.2)

1.5-1.8 x higher prevalence for Black individuals compared to whites

TABLE 2 2020 US Census–adjusted prevalence, cases per 100 persons, (95% CI) of clinical AD and MCI, by age and race/ethnicity using 10,342 participants from the Chicago Health and Aging Population Sample

RAJAN ET AL. *Alzheimer's Dement*. 2021;17:1966–1975.

Health Disparities and ADRD

- **Global population is ethnically and racially diverse**, thus need for more inclusive research worldwide
- **Developing countries** will experience significant increase in the number of people with ADRD and related disparities
- Limited information on the **impact of race and ethnicity** on the neurobiology, biomarkers, clinical phenotype, and treatment and prevention of ADRD
- Genetics **plays a smaller role** in ethnoracial differences in ADRD prevalence
- **Social and environmental disparities** are major reasons for racial and ethnic differences in ADRD incidence and prevalence

Beydoun et al, Alz Dementia;2022

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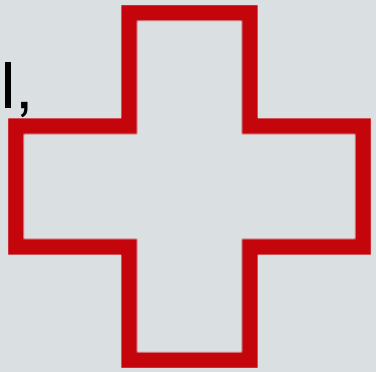
Health Disparities and ADRD

- Lack of longitudinal studies evaluating the effects of **lifelong** social, environmental, & behavioral exposures in racialized groups



- **Poor quality health care and related discrimination** are major contributors to ADRD-related morbidity and mortality in marginalized populations

- Diagnosis and treatment of ADRD is **delayed in minoritized populations** due to limited access to health care, lack of insurance, and poor health literacy

Bryant et al, Alz Dementia, 2022:1-8
Alz Dementia,15(2);292-312, Feb 2019

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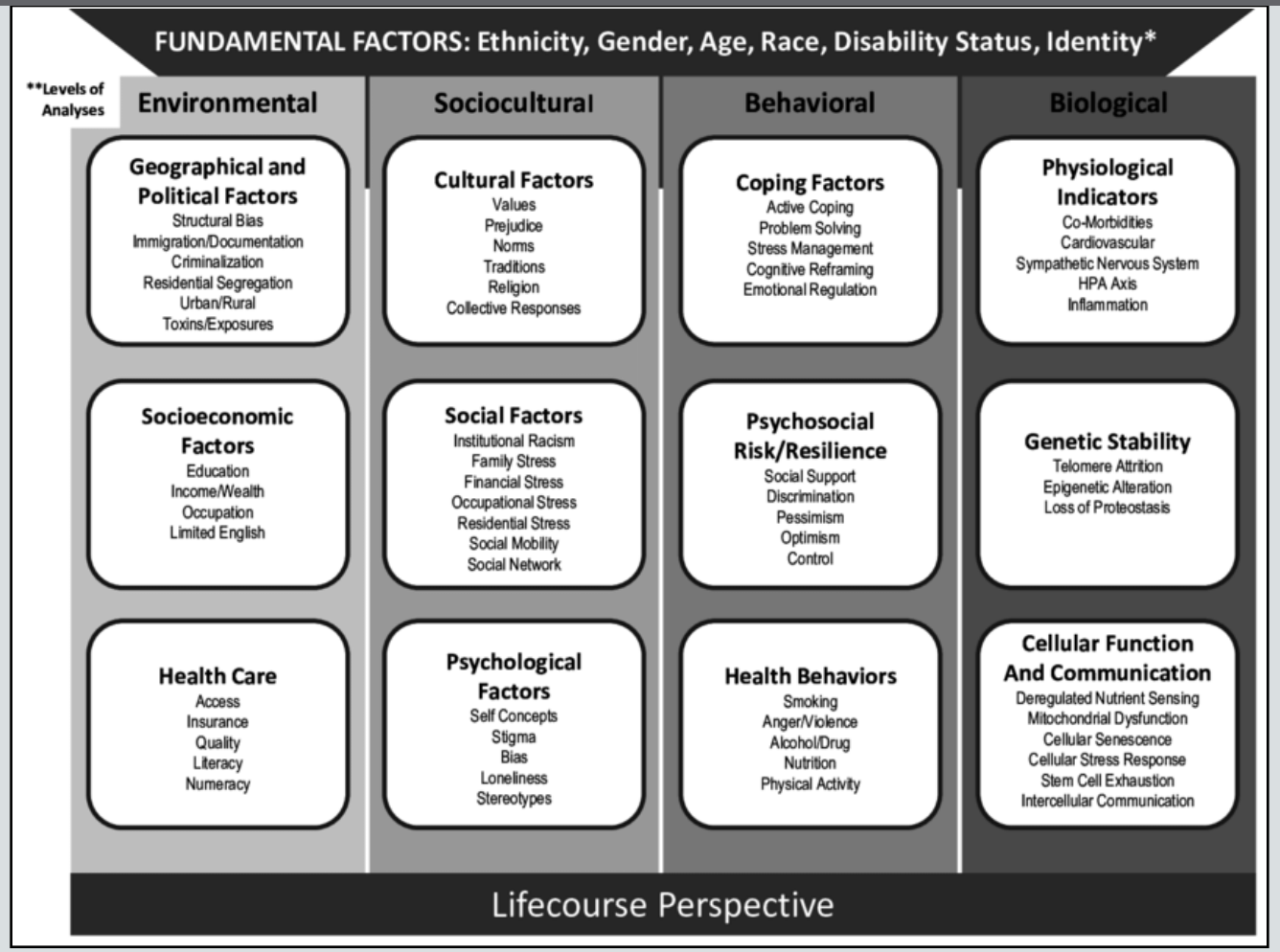
NIA Health Disparities Research Framework



Hill et al, Ethnicity & Disease:25(3);245-254, Summer 2015

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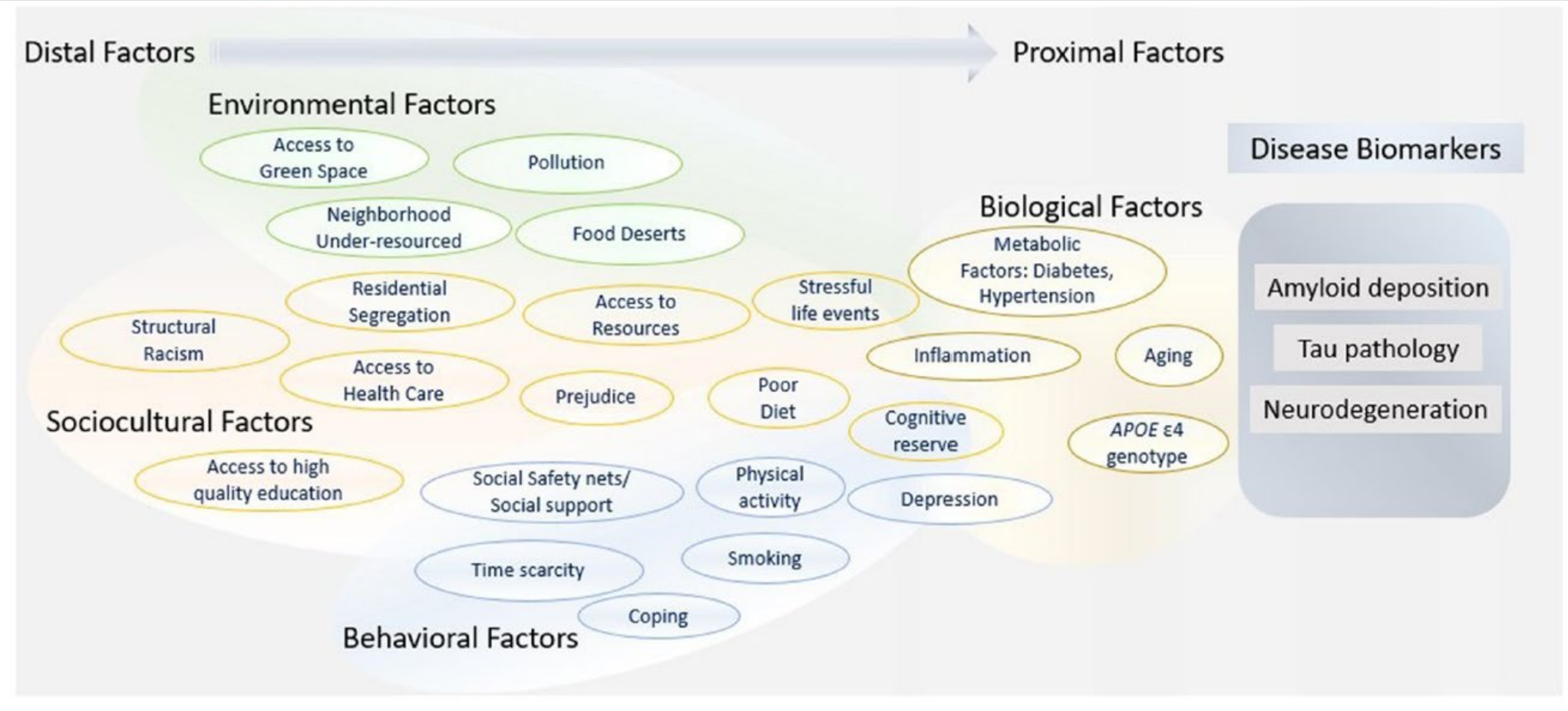
Integrating NIA and AT(N) Research Framework



Gleason & Zuelssdorf et al, Alz and Dementia; 18:1545-1564, 2022

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NIA Health Disparities Research Framework

Key Observations for ADRD Research:

- Older US racialized populations suffer from **premature illnesses over life course**. These illnesses affect environmental-biological interactions and activate molecular mechanisms underlying ADRD
- Sociocultural and environmental factors likely act more **upstream of molecular processes** mediating ADRD
- Health disparities research should **prioritize mechanistic research** that could provide biological underpinnings for health disparities

Hill et al, Ethnicity & Disease:25(3);245-254, Summer 2015

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Health Disparities and ADRD Research

Effects of Race and Ethnicity on ADRD:

- Race and ethnic differences in education quality, health behavior, and sociocultural factors could reduce **cognitive resilience** and increase ADRD prevalence
- African Americans (AA) have lower levels of cognitive test performance, likely due to **testing bias,** but progress slowly
- **Lack of reliable cognitive testing norms** may over diagnose ADRD in underrepresented groups
- **Distinct risk factors** for ADRD in underrepresented groups include midlife obesity, physical inactivity and low education

Alz dementia, 15(2):292-312; February 2019
Nianogo et al, JAMA Neurol, 79(6);584-591, 2022
LL Barnes, Nature;18:56-62, Jan 2022
JJ Manly et al, J Geriatric Psychiatry & Neurol;18(4):213-217, 2005

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Health Disparities and ADRD Research

Effects of Race and Ethnicity on ADRD Biomarkers:

- **Absolute cut off points** for fluid AD biomarkers are not available for minoritized populations
- Cut off points in non-Hispanic Whites **may not be relevant** for racialized groups
- CSF levels of t-tau, p-tau 181 are **reportedly lower** in AA compared to non-Hispanic Whites
- Plasma AD biomarkers vary significantly in association with **medical comorbidities** and ethnicities

Alz Dementia, 15(2);292-312, Feb 2019
Gleason et al, Alz Dementia;18:1545-1564, 2022
O'Bryant et al, Alz Dementia;1-8, 2022

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Health Disparities and ADRD Research

Race, Ethnicity, and Treatment Trials – An NIA Priority:

- **Less than 5%** of clinical trial participants are from URGs
- Treatment trial outcomes are rarely **reported by racial/ethnic group** and often covaried by race
- Attrition rates for URGs are generally not reported in treatment trials; thereby preventing assessment of **"attrition bias"**
- Treatment trial results are **not generalizable** due to **"selection bias"** - clinic versus community-based recruitment

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Advancing ADRD Disparities Research: Select Alzheimer's Association ISAART Recommendations

- Identify strategies to **increase enrollment and retention** of diverse populations in ADRD studies
- Examine the potential effects of **lifelong exposure to social, environmental, and behavioral factors** on ADRD disparities in diverse populations
- Develop and validate **norms for cognitive tests** and cut off points for imaging and fluid biomarkers for minoritized populations
- Utilize the **existing NIA-funded longitudinal cohorts** with diverse populations to address gaps in ADRD disparities research
- Develop and validate **models of risk and protective factors** for racial/ethnic subgroups
- Employ **precision medicine approaches** to translate findings from ADRD disparities research

Alz dementia, 15(2);292-312, February 2019

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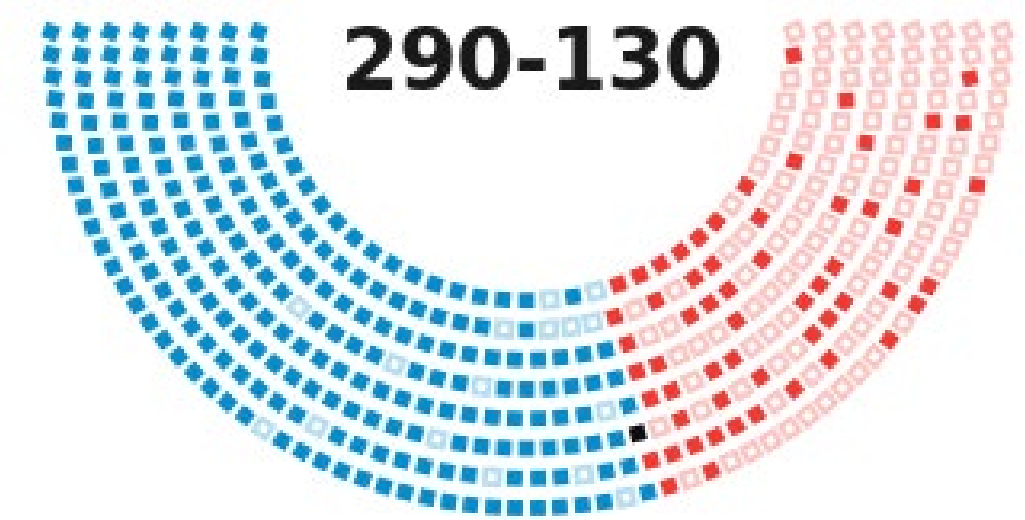
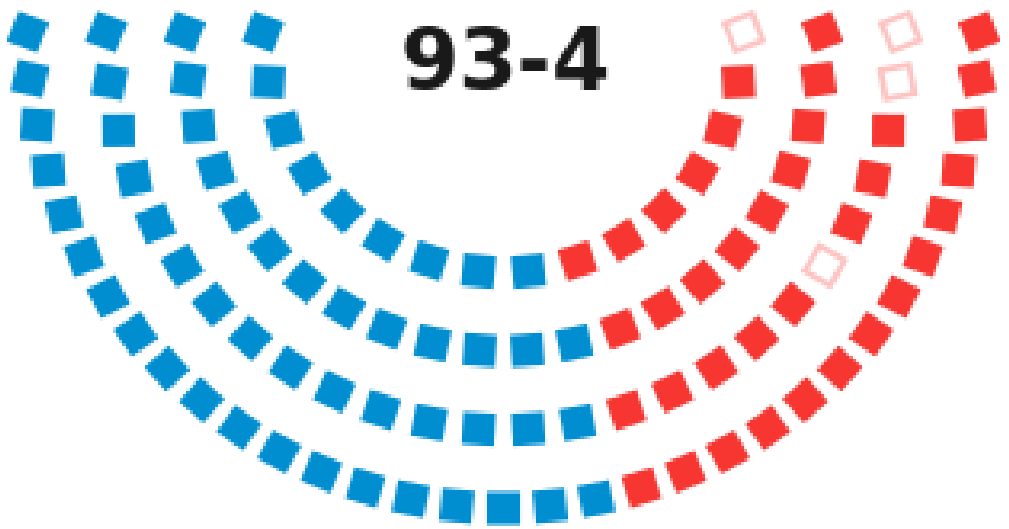


House Vote



Senate Vote

Call to action

1993 NIH Revitalization Act

- Federal legislative mandate that NIH-funded research would allow for "valid analysis of whether the variables being studied in the trial affect…members of minority groups."
- NIH established policies
  - Women and minoritized individuals must be included in all NIH-funded clinical research
  - Must address the inclusion of groups in proposal