

# Building Better Brain Health for All People

GCBH Recommendations on  
Removing Barriers and Improving  
Opportunities Around the World



A Report from the  
**GLOBAL COUNCIL ON BRAIN HEALTH**

# Background: About GCBH and Its Work

Global Council on  
**Brain Health**<sup>SM</sup>  
A COLLABORATIVE FROM **AARP**

The Global Council on Brain Health (GCBH) is an independent collaborative of scientists, health professionals, scholars, and policy experts from around the world working in areas of brain health related to human cognition. The GCBH focuses on brain health relating to people's ability to think and reason as they age, including aspects of memory, perception, and judgment. The GCBH is convened by AARP to offer the best possible advice about what older adults can do to maintain and improve their brain health. GCBH members come together to discuss specific lifestyle factors that may impact people's brain health as they age, with the goal of providing evidence-based recommendations for people to consider incorporating into their lives.

As a global body of experts, we aim to highlight issues of relevance to people everywhere that impact brain health. We know that many people across the globe are interested in learning what they can do to maintain their brain health as they age. To serve that need, the council provides trustworthy information and recommendations, based on scientific evidence supplemented by a consensus of experts from a broad array of disciplines and perspectives. GCBH resources continue to grow with an emphasis on practical advice to the public, health care providers, and policymakers seeking to make informed choices about brain health.

## Acknowledgments

Appendix 1 lists many significant participants in the creation of this report. But particular appreciation goes to the teams within AARP that made the creation possible: Policy, Research and International Affairs; Integrated Communications and Marketing; Office of Diversity, Equity and Inclusion, and Community, State and National Affairs.

We gratefully acknowledge the insights shared by people living with dementia and some of their caregivers with AARP staff. When we shared the personal stories of the lived experience experts within this report, we only used their names if we were given their permission to do so. There were numerous anonymous contributions that significantly added to the depth of our understanding.

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# Introduction

**Y**our brain lives in a world affected nonstop by the people and environment around it. These ongoing interactions, which begin before birth and continue throughout your lifespan, help shape your “mind,” which is defined as “the part of a person that thinks, reasons, feels, and remembers.” (Merriam-Webster, n.d.) The GCBH seeks to create a world that fosters the best possible brain health so that everyone’s minds can flourish, and people can have the best quality of life. Whatever a person’s individual circumstance, all people should have the opportunity to develop and sustain high-functioning minds with the greatest possible resilience from health challenges.

In considering the meaning of brain health, the GCBH has chosen a broad framework for this discussion that incorporates a range of conditions including cognitive decline, dementia, stroke, and traumatic injury. Our discussion applies not only to the health of the brain as an organ in the body but to mental health or people’s “emotional, psychological, and social well-being,” which can affect brain health as people age (Centers for Disease Control and Prevention, 2021b).

We encourage individuals to embrace healthy lifestyles when that is possible, thereby empowering themselves to develop and sustain the best possible brain health, regardless of their background or the societal challenges they may face. Data that highlight group-level differences in brain health should not obscure this important message or the fact that individuals from any background have the potential to thrive. There are of course many examples of people whose minds have flourished into ripe old age despite facing significant obstacles across their lifespan.

At the same time, powerful forces and social conditions often stand in the way of wholesome choices, negatively influencing people’s health and their opportunities to sustain it. The GCBH believes that an array of strategies is needed to enhance equity in brain health for all of the global population.



The **World Health Organization (WHO)** has pointed out that physical health, the environment, safety, learning, social connection, and access to services all influence brain health across the life span. Yet we know that these and other influential factors such as wealth and culture vary markedly in different locations. Urban residents typically have greater access to health care and other services than rural residents, although resources vary widely even within metropolitan areas. Underserved communities – those that lack sufficient access to resources and supportive services – face worse health outcomes than the affluent. Family support varies among individuals and cultures. Much of the public lacks a basic understanding of brain-health issues and the risks posed to them by unhealthy behaviors, inhospitable environments, and harmful social policies, or the health benefits they may receive if these factors are changed.

The social systems theoretically designed to help people promote better brain health often fail people who need their services to thrive. We can do better. People from racially or ethnically diverse communities who receive discriminatory treatment from providers of health care and other services suffer harmful inequities that undermine the community's trust. In the United States, one in two African Americans report that they have experienced discrimination when seeking dementia care (Alzheimer's Association, 2022). We also know that Black Americans and Hispanic Americans in the United States face significantly higher risks of dementia than non-Hispanic whites (Mayeda et al. 2016). Women around the world experience two-thirds of all the dementia and shoulder two thirds of the caregiving duties associated with the diseases causing dementia (Mielke et al., 2022; Lock et al., 2020; Nebel et al., 2018). Beyond systemic discrimination, care may be delivered in a manner that is insensitive to cultural factors, reducing its quality and causing stress (Ketchum et al., 2023; Dilworth-Anderson et al., 2012). Language barriers can prevent effective communication between patients and health care providers (Schouten et al., 2020).

Inequities in the conditions and opportunities that affect health, including brain health, are not unique to the United States, however. Alzheimer's disease, for example, is projected to continue growing in low- and middle-income countries (Nandi A. et al. 2022), many of which are lacking in resources to address their health-related needs. Discrimination according to age, gender and gender identity/roles, sexual orientation, national origin, ethnicity, caste, disabilities (visible as well as invisible), and genetic forms of neurological diseases contribute to poor physical and mental health around the world.

While there is no single global solution, scientific evidence points to an array of approaches that can serve as building blocks to strengthen cognitive resilience around the world. Policy, research, technology, community engagement, infrastructure, environmental design, and family supports are all part of the answer. Progress can be achieved through a multifaceted approach to address barriers that are rooted in government policy, health care, institutional values, professional practice, and culture itself.

Neighborhoods and community institutions can be designed in ways that sustain the healthy habits that promote better brain health among the diverse residents of those communities. Technology can enable better access to linguistically and culturally appropriate education, treatment, and support for individuals, even those in remote locations. Support for struggling family caregivers can benefit people at all levels of education and wealth. Initiatives that engage the communities themselves to address the barriers to better brain health can unlock untapped strengths, such as the existing social infrastructure. Employers can implement practices that support employees' healthy aging and which drive engagement, retention, and productivity leading to economic prosperity.

For all these reasons, the GCBH believes the approach to building better brain health for all must be holistic and coordinated, with contributions from the public and private sectors, faith-based institutions, and non-profit advocacy groups. Working with and guided by the communities themselves, strategic relationships to promote brain health can be leveraged and expanded to achieve more productive collaboration across sectors.

To address structural equity barriers, this report makes recommendations to the public that are grounded in the latest scientific findings and informed by the lived experience of individuals with varied degrees of cognitive loss. The GCBH acknowledges that structural barriers vary widely by country and community. While this report is written primarily from a United States' perspective because the majority of GCBH participants live there, we have incorporated globally relevant information from international experts and sources when possible and practical to do so. Further, we understand that eliminating disparities is a difficult, long-term task that requires new and more inclusive ways of thinking. Achieving equity requires, in the words of Thomas Kuhn, “shifting the paradigm” – transforming the existing scientific approach through innovative thinking to ensure that people are treated as individuals rather than members of population groups (Anand et al., 2020).

Much still needs to be learned about the cognitive and mental health risks in varied communities, along with the interventions and supports that would make a difference. Populations are aging on every continent. The changing demographics increase risks for significant brain-health crises in every community. Human suffering and the cost of care will rise sharply if we don't change the status quo, making it even more urgent to ensure that all people have opportunities to sustain healthy brains and minds.

This report provides a roadmap for innovations and strategies that can yield meaningful progress. We urge policymakers in different nations to take steps that enhance equity. We believe that countries can learn valuable lessons from each other. Wherever you live, brain health and mental well-being are foundations for independence, dignity, and quality of life. For all our societies, brain health across populations is essential to economic and social flourishing.

## Living with Dementia and Societal Disadvantage

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According to the **Centers for Disease Control and Prevention**, “Cognitive impairment is when a person has trouble remembering, learning new things, concentrating, or making decisions that affect their everyday life.” In developing this report, the GCBH sought to consider the real-world experience of individuals who live with such cognitive loss.

To gain perspective, we convened a diverse group of more than a dozen adults of different ages, races, ethnicities, genders, and levels of education to discuss their personal experiences. Our participants came from varied geographical areas, urban and rural, and were living with different levels of cognitive health. Almost all were able to express themselves effectively, some with the help of caregivers and translators.

A few of the women recalled that health care providers had blamed their symptoms on menopause and resisted looking further. Non-English speakers felt isolated and vulnerable to discrimination from society because of language barriers. A Black member of the LGBTQ+ community in the early stages of dementia spoke of historic mistreatment of minorities in the health care system, which has left a legacy of mistrust.

At the same time, the group shared an array of similar frustrations. Several participants said they had trouble getting useful information on their conditions. Men and women both reported difficulties in being taken seriously by doctors when they reported their symptoms. Some also lamented the obstacles to care, a particular issue in rural areas.

In different ways, participants described the life-changing stress of undergoing cognitive changes while attempting to remain independent.

“I felt scared when I noticed that I was gradually losing my memory,” said a Chinese American man who has mild cognitive impairment and lives alone [name withheld on request]. “Asking people to repeat their names or things they said is not easy, and sometimes people get annoyed by that, and they would become impatient with me, but I didn’t do anything wrong. I didn’t choose to forget things so fast. Sometimes, I also hate myself for being like that. I am also afraid of being discriminated against as a person living with cognitive decline who cannot speak good English.”

A former neurologist, Dr. Sara Langer, said it took her years to persuade doctors that she had a serious cognitive issue. “There’s a fundamental sexist barrier – women are not taken seriously enough,” said the 64-year-old woman, who was diagnosed with Lewy body dementia after years of frustration in the medical system. She added: “There are huge implicit biases against all sorts of groups of people. If the doctors cannot relate to the experience, the diagnosis is delayed.”

Participants also described the obstacles they encountered in getting crucial health care. “In rural communities, medical choices can be slim to none,” said Bonnie Erickson, a woman in the Western United States who has vascular dementia yet has had difficulty getting coverage to see a neurologist.


“Doctors don’t know what they don’t know, but both they and their patients *assume* the doctors know,” said Chris Tann, a resident of Georgia who has been diagnosed with Frontal-temporal dementia. “This is a basic problem. We trust if we go to the doctor that the doctor will know my medical history and have understanding of dementia.”



**I am also afraid of being discriminated against as a person living with cognitive decline who cannot speak good English.**



**There’s a fundamental sexist barrier – women are not taken seriously enough.**

A black and white photograph of three men standing in a room, engaged in conversation. The man on the left is Black, the man in the middle is White, and the man on the right is White with glasses. They are all smiling and appear to be in a relaxed, collaborative setting. The man on the left is gesturing with his hands as he speaks.

## Starting Point: Barriers to Brain Health Vary by Social and Environmental Conditions

**W**hen it comes to supporting brain health, conditions vary widely. Life experience for some may be more supportive to cognitive well-being than it is for others. Social policies, professional practices, and the environment where people live and work – both built and natural – can create barriers to brain health that are especially harmful to some communities. Structural racism and systemic discrimination can make brain-healthy choices more difficult. Too often, a lack of cultural understanding and socio-environmental context makes health care less effective for multicultural populations. Barriers to better brain health are rooted in history and continue to affect people through their lives.

The life experiences that precede dementia differ among cultures and within them, and those that protect public health need a better understanding of what this means for prevention, interventions, and treatment. Whatever the race or ethnicity, low-income communities often lack the services, resources, and supports that promote better health, forcing individuals and their family caregivers to cope in various ways and struggle unnecessarily.

Despite some recent attempts at improvement, existing medical research data is not representative of racial diversity, a serious deficiency that must be remedied to achieve equity. (See Appendix 5). This shortage of data on the broad population, reflects the historic and ongoing lack of diversity and inclusiveness in clinical trials and scientific inquiry. Equity requires that this deficit be addressed through greater and more culturally responsive recruitment efforts of communities that have been neglected, participation of population groups in planning these studies, culturally appropriate design of research studies, and the secure sharing of that data to maximize its use. Importantly, more meaningful data can lead to insights and lessons that improve policy decisions affecting health.

Research on incidence/prevalence of dementia and information on disparities among different populations and countries is shown in Appendix 4 and 5.



## Our Vision

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A world in which peoples' minds can flourish in environments that supports optimal cognitive health and resilience. Barriers to better brain health are eliminated in all communities. A world free of discrimination, stigma, and misinformation. A world in which healthy minds act with intention to experience wholesome lives, and where all people live in secure and health-promoting environments. Health care is person-centered, addressing people's needs with dignity, cultural awareness, and sensitivity.

## Definition of Brain-Health Equity

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GCBH defines Brain-Health Equity as the fair and just opportunity to have a healthy mind through the course of life. All people should have this opportunity, which should not be undermined by systemic policies and practices, including population-wide factors that confer unfair disadvantages or advantages to some.

This is consistent with the World Health Organization definition of “health equity” as “the absence of unfair and avoidable or remediable differences in health among population groups defined socially, economically, demographically or geographically.” (World Health Organization, n.d.)

In seeking brain-health equity, we recognize that no group is a monolith and individual experiences and needs vary significantly. Failings in the health care system are a major factor in brain health disparities, but there are many other societal forces at play including the “physical, built, and policy environments” that shape people's lives and choices (Centers for Disease Control and Prevention, 2021a). Indeed, the state of a person's brain health in late life may be the product of many years of lived experience. The GCBH recognizes that such lived experience may differ among cultures and population groups, and that inequities are a result.

## Consensus Statements on Brain-Health Equity

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The GCBH met and identified the major reasons behind the existing disparities in brain health. The discussion section following the recommendations for key stakeholders provides greater explanation of these factors.

- 1. A lack of quality data on brain health among different groups hinders understanding and decision-making among policymakers, health care providers, and individuals themselves.** This dearth of information remains an obstacle to achieving equity and limits our understanding of effective interventions.
- 2. Structural barriers have created, promoted, sustained, and rewarded inequities leading to disparities by socioeconomic status, race, and ethnicity.** The factors include:
  - a. Historic and ongoing mistreatment and demonstrated untrustworthiness in existing systems.
  - b. Education – lack of quality as well as quantity.
  - c. Health care – lack of access, quality and cost.
  - d. Health care systems lack of cultural humility and agility.
  - e. Housing and neighborhood resources including culturally appropriate wholesome food, safe recreation, and convenient services.

- f. Environmental quality and climate challenges.
- g. Occupational and economic opportunity, including for generational wealth.
- h. Violence/safety and the criminal justice system which often serves as a de facto mental health system.
- i. Urban or rural built environments that reduce access to health, wealth, social engagement, and happiness.
- j. Stresses of being a caregiver. Cultural values and community supports and services matter greatly and vary widely.
- k. Social and family support systems. Family structures and existing friend groups are diverse and crucial, yet many people lack access to such supports.
- l. Lack of diverse representation in the workforce at all levels, including but not limited to academic, scientific, and health care industries.
- m. Lack of retirement income/Financial Insecurity.
- n. Language barriers and health history and literacy before immigration.

**3. Policies and widespread practices that have created barriers to brain health.** Examples include:

- a. Residential segregation often leads to neighborhood disparities, which results in lack of resources in many communities. Too often, land-use policies prevent equitable access to health-promoting resources.
- b. Not prioritizing mental health issues as equal to physical health issues, reducing access to mental-health care.
- c. Legislative, judicial and political norms which have historically and currently led to established disparities (like discrimination in voting rights, for example).
- d. Immigration policies have created stress and fear, lack of access to services, and loss of family supports, leading to social isolation, which is a late-life risk factor for cognitive problems.
- e. Mass incarcerations of certain groups of people.
- f. Lack of affordable insurance coverage hinders health care access and quality.

**4. Sociocultural factors may inhibit seeking help for brain health.**

- a. Willingness to seek help for cognitive and mental health issues varies among different cultures, a factor that may be influenced by unsatisfactory experiences in the health care system.
- b. Caregivers' honor of elders may lead them to resist help if they view their role as protecting elders from harm; they may fear involving outsiders because "no one loves my family or friend like I do."
- c. Some cultures stretch self-help to the limit, due to beliefs in personal control or low comfort in navigating the health system, resulting in late diagnosis and advanced disease.
- d. Suspicion of health care providers who are strangers or seen as profit-driven, superstition, and other beliefs may reduce willingness to get services.
- e. Across cultures, the stigma around mental, behavioral, and cognitive health and ageist attitudes often prevents people from addressing brain-health issues.
- f. Treating older adults as vulnerable and weak (i.e., ageism) can take away their opportunity to be gainfully engaged in the workforce or community.

**5. Professional and learned practices have led to bias, which fuels discrimination in its many forms.**

- a. Entrenched ways of thinking and behavioral norms within health professions and other services may undermine care and harm outcomes, while failing to engage those who need support.
- b. Individuals have been taught to discriminate and behave in ways that perpetuate barriers; when attitudes are entrenched, people may lack awareness that their actions are discriminatory.



## Recommendations for Key Stakeholders

### For Policymakers and Thought Leaders



- a. Shift the paradigm. Treat people as individuals. Recognize cultural differences. Cognitive screening and diagnostics should be culturally-appropriate.
- b. Make a greater priority of prevention through the course of life, and be proactive for brain health, including fostering neighborhood-level interventions that facilitate healthy lifestyles.
- c. Increase uptake and use of culturally-appropriate cognitive screenings for older adults.
- d. Establish public policies and practices to promote greater awareness and early identification of cognitive and mental health issues.
- e. Develop standard health equity and quality measures, and fund more research to study brain-health equity including evaluation of policies' disparate impacts. Track these measures to identify progress and ongoing needs. Policy, program, population, and clinical research require a lens for differentiated impact on disparities. Health metrics need to include diversity targets.
- f. Eliminate stigmatizing language entrenched in laws, policies, and systems that perpetuate and codify inequitable treatment. Language has the power to harm and to heal. Examples of stigmatizing laws that can exacerbate behavioral health disparities include nuisance laws restricting where recovery centers can be located.
- g. Establish mental health parity. Improvements in mental health equity can lead to benefits in the economy and across other sectors; explore cross-sectoral outcomes within policy evaluations. Holistic care requires that providers treat brain, mental and physical health equally.
- h. Recognize the built/social environmental context of individuals, which may determine whether they can follow healthy recommendations (e.g., if healthy lifestyle changes are recommended, are there safe and accessible parks and recreational facilities to exercise? Nutritious and affordable food options? Welcoming community gathering spaces to socialize and connect?)



- i. Make governing of policymaking processes more equitable and inclusive of diverse voices, recognizing community members' expertise, especially those who will be impacted by the policy. Community involvement starts at the beginning of any program or initiative and grants equitable authority to make decisions.
- j. Leaders should respect individual choice and identity (such as gender expression and chosen family) and honor individuals as participants in their own journeys.
- k. Measures are needed to improve people's access to hearing aids, which are expensive and generally not covered by insurance. The approval of the sale of a new category of over-the-counter hearing aids in the United States is a positive step, but more people need to get their hearing corrected.
- l. Adopt preventive measures to reduce risk factors for Alzheimer's and related dementias by promoting evidence-based brain-health strategies (e.g., encouraging physical exercise, healthy diet, sleep, managing stress).
- m. Land-use policies and neighborhood/building design guidelines should be put in place to support intergenerational physical, mental and social health.



## Recommendations for Community Groups

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- a. Improve data collection on brain health of different population groups. In order to develop meaningful data for specific groups, communities should be properly represented in clinical trials and other population studies. Measures used should be culturally sensitive. Community groups should consider working together to develop and share data and inform constituents about opportunities to participate in research.
- b. Community leaders from diverse organizations can collaborate among themselves, with health care providers, government officials, and researchers on initiatives to raise public awareness and understanding of brain-health concerns.
- c. Employers can reduce the financial and emotional stress on family caregivers for people living with brain health conditions by offering caregiving leave, flexible working arrangements, and allowing workers to use paid sick leave for family caregiving. Employers also can offer wellness programs and employee incentives to encourage healthy behavior.
- d. Community leaders should step up their advocacy for brain health and promote public awareness. Leaders should strive for effective community engagement to represent people's needs and support the goal of "nothing about us without us."
- e. Activists should push for higher-quality long-term services and supports in their community to support independence and ease the burden on family caregivers.
- f. Services should be provided in a person- and community-centered manner that is culturally sensitive and language appropriate.
- g. Community groups should be engaged in local planning and design initiatives to advocate for places to heal, play, and learn across all ages.

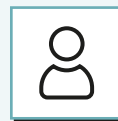


## Recommendations for Health Care Providers

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- a. Shift the paradigm: Avoid race-norming in medical assessments and treat people as individuals.
- b. Address language barriers, which can cause incorrect assessment of impairment.
- c. Focus on the individual, not the average. Within-person longitudinal assessment is better. Monitor individual change.

- d. Prioritize prevention and establish brain health screening as an important element in check-ups of aging adults and others at risk.
- e. Learn what community-based resources are available to consumers so you can make referrals to social care and/or social workers as needed to reduce social vulnerabilities like isolation, hunger, inadequate housing and lack of transportation or engagement. (For example, there are technology-based tools that are available to help providers identify social services for their patients).
- f. Empower your patients by ensuring they have access to their medical records. Encourage questions (including written questions) and meaningful discussion. Persons living with dementia should be included in the conversation as much as possible.
- g. Recognize the importance of family caregivers, include them in consultations as appropriate, and make sure they have the information and support they need.
- h. Pay attention to address the broad social factors that influence health in general and brain health in particular.
- i. Strive to deliver care in a culturally sensitive manner and avoid language that connotes stigma.



## Recommendations for Individuals

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**Note:** The GCBH emphasizes that individuals are not responsible for unfair and inequitable aspects of society that drive disparities in health. Life choices are not made in a vacuum, and some people have vastly greater advantages than others. It is nonetheless empowering to take what actions we can on behalf of our own health and well-being. A common theme running through all the GCBH reports is that it is never too late to benefit from instituting healthy habits no matter your age.

- a. Seek health care providers you can trust. When in doubt, get guidance and recommendations for health care providers from someone trusted in the community.
- b. Be an active participant in your health care, asking questions and expressing concerns. Individuals can download the app “**QuestionBuilder**,” which is a tool to help patients and caregivers prepare for medical appointments.
- c. If you have been diagnosed with dementia, AARP has a guide on questions to ask your health care providers: <https://www.aarp.org/health/brain-health/info-2021/dementia-diagnosis-questions.html>
- d. Recognize that your lifestyle affects your brain health, and make healthy choices whenever you can. The GCBH has issued **13 comprehensive reports** on various modifiable lifestyle habits and the evidence behind what works and what doesn’t to reduce risks to your brain health as you age. Reduce or eliminate unhealthy habits, and seek professional help if needed.
- e. Learn the **Six Pillars of Brain Health** and try to practice them regularly: being social, using your brain, getting exercise, eating right, getting sufficient sleep, and managing stress. For an online platform to help you think about ways to incorporate these healthy habits into your daily lifestyle, consider AARP® Staying Sharp®, an AARP member benefit. See: <https://stayingsharp.aarp.org>. Those who are not AARP members can find a great deal of information about the Six Pillars of Brain Health online from the Global Council on Brain Health. See: <https://www.aarp.org/health/brain-health/global-council-on-brain-health>.
- f. Recognize that your environment affects your brain health and prioritize neighborhoods, homes, and workplaces that are designed to support the Six Pillars of Brain Health (e.g. access to nature, parks, healthy grocery stores, walkable neighborhoods, etc).

## Recommendations for Advocates



- a. Understand the unmet needs of your community, including for basic information on brain health, provide materials that are language accessible, and steer people toward resources they need.
- b. Create innovative communications that are culturally appropriate for your audience and bring them into the conversation.
- c. Set an aspirational target to get more people from all communities screened for baseline brain health and cognitive function. Everyone should have equal potential to be screened, evaluated, diagnosed, and treated with a plan of care.
- d. Reach out to diverse stakeholders including policymakers, and make specific asks for supports or policy changes.

### Empowering Families Around the Globe

Throughout the world, from rural villages to big cities, from the wealthiest neighborhoods to the most underserved, families (either of origin or choice) stand out as a vital – and often underutilized – resource to promote brain health, no matter the social or economic context.

With proper support, family members can educate loved ones about healthy choices, engage with health care providers and community services, establish a healthy environment within the home, reduce social isolation and give valuable care. This GCBH report documents many of the structural barriers that often stand in the way and must be addressed. Yet an effective strategy for progress in brain health also must find ways to optimize the positive role that families can play.

An August 2022 [report by the World Health Organization](#) maintains that more countries should have “family friendly policy protections in place to safeguard child brain development.” Examples include tuition-free pre-primary education, maternity and paternity leave, and paid time off for breast feeding.

“Importantly,” the report notes, “the impacts of both neighborhood disadvantage and exposure to violence in early life can be mitigated by positive family functioning and parenting.”

While issues vary among cultures and many strategies are needed, efforts to promote brain health often seek to raise people’s awareness of steps they can take for themselves and loved ones. Family and intergenerational support make enormous contributions to individual brain health not only for children but older adults as well. [The National Academies of Sciences, Engineering, and Medicine](#) found that social isolation was associated with a 50% increase in the risk of dementia, and loneliness in older adults was associated with higher rates of depression, anxiety heart disease, stroke, and suicide. Addressing social isolation which often occurs in aging adults can have a tremendously beneficial effect on promoting brain health. See [Global Council on Brain Health’s report, The Brain and Social Connectedness](#).



**More countries should have ‘family friendly policy protections in place to safeguard child brain development.’**





# Discussion

## Structural Barriers to Healthy Minds

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Our health is influenced by much that is beyond our control. In many ways, our well-being, including brain health, is the product of a wide set of social, economic, environmental, and political forces that shape our daily surroundings and personal options. Within every country, public policies, political systems, economic conditions, social norms, and environmental factors influence people's ability to live well or poorly through the course of life.

Individuals with certain traits and backgrounds may face barriers based on layers of prejudice. There is no doubt that in the United States race and ethnicity plays a significant role in the personal lives of individuals. For example, **in 2019, the Pew Research Center** examined which people of different backgrounds reported experiencing discrimination. Pew found that “three-quarters of Black Americans and Asian Americans (76% of each) say they have experienced discrimination or have been treated unfairly because of their race or ethnicity at least from time to time; 58% of Hispanic Americans say the same. Most white Americans (67%) say they have never experienced this.” Yet racism is not the only form of discrimination resulting in prejudice or disparate treatment. Many individuals have multiple characteristics that create barriers to fair and just opportunities to develop and sustain healthy minds through the course of their lives. An elderly, Black woman with disabilities in the United States, for example, faces increased risks of inequitable treatment based on societal discrimination on at least four levels due to ageism, racism, gender bias, and ableism (discrimination against people with disabilities). Without even knowing anything about this person or her life story, and before considerations of social status, nationality, religious affiliation, sexual orientation, class, education, and economic level are taken into account, imagine the barriers she has faced over her lifetime and how her options have been affected simply by her personal characteristics. Multiple “-isms” can create a series of barriers making it more difficult for a person to adopt and/or sustain healthy behaviors. No wonder then, that opportunities for better brain health of people are shaped by the environment and circumstances of their lives.

Income and financial security, education, early childhood development, working conditions, housing, environment, diet, and recreation are among the factors that influence health for better or worse. They can provide essential support to human development, or they can contribute to vulnerability and illness. The WHO estimates that such “**social determinants of health**” drive 30%-55% of health outcomes globally (World Health Organization, n.d.-b). It further projects that 43% of young children in low-and middle-income countries under the age of 5 “**are at risk of not reaching their development potential.**”

This troubling reality sends an unmistakable message: If we want to improve people’s brain health, we have to pay more attention to the needs of those at greatest risk of poor health and address social conditions that stand in the way. To improve brain health for all, we must foster not only equitable access to health care but the many nonmedical forces in society that influence well-being. Research suggests that even something as fundamental as our ability to achieve healthy sleep is more difficult for people who are from racially or ethnically diverse communities and for those who are socioeconomically disadvantaged (Grandner et al., 2016).

Consider differences in education. Research has suggested that higher levels of education can reduce an older person’s risk of dementia and may improve an adult’s ability to cope with or resist cognitive decline. Low levels of education in early life appear to be a risk factor for dementia. Both quality and quantity in education matter (Soh Y. et al. 2023). The brain’s capacity to adapt how it operates to compensate for cognitive challenges, including dementia, is known as cognitive reserve – a critically important capacity that appears linked to education and occupational attainment (Farfel et al., 2013). Research further suggests that a sufficient cognitive reserve may help delay the onset of symptoms. Even when people start to develop signs of dementia, those with higher education tend to master more strategies and tools to slow down the progression of symptoms. In the GCBH’s **cognitively stimulating activities report** we said, “while it’s never too late, the sooner you start [engaging your mind in learning] the better because education and learning are known to enhance cognitive reserve, making you less susceptible to the effects of age or disease-related brain changes.”

Income and financial security are other influential factors that may have an uneven impact on brain health across and within societies. There is no dispute that in countries around the world, the lower the socioeconomic position of a person or group, the worse the health outcomes in general. We also know that socioeconomic conditions also help determine people’s brain health over their lifetimes.

A lack of sufficient income, for example, is linked to reduced health care access and greater personal stress, which undermines health over time (American Psychological Association, 2018). Research has shown that dementia is most common in low-income neighborhoods with fewer resources and has tied lower levels of brain health to lower socioeconomic status (National Academies, 2021). A Danish study, for example, found that higher-income people in Denmark were less likely to be diagnosed with dementia than those with low incomes, and when diagnosed, tended to have milder symptoms (Petersen et al. 2021).

Financial status may determine where we live, and that also shapes our cognitive health. People with financial resources can afford to live in more affluent neighborhoods that are well-resourced (Solari 2021). Further, we know that the built environment can promote or hinder people’s ability to safely engage in their communities, learn new things and obtain essential goods and services (Finlay et al., 2021a, b). Where we live affects our access to nutritious food, personal safety, and the quality of the air we breathe (Finlay et al., 2021c; Yu et al., 2023). Experts also found architectural design plays an important role in fostering social and environmental input which is required to maintain cognitive stability throughout a lifetime (Nanda & Warner, 2021).

Housing and communities should be “safe and affordable; facilitate multigenerational interaction; meet sensory, emotional, physical, social, behavioral, and health needs across the lifespan. . .enabling

every resident to thrive,” according to a statement of principles approved by AARP, the Agile Ageing Alliance, and the German Marshall Fund (Edkins et al., 2019). While aging in place is important, housing, workplace design and neighborhood design should also support aging with purpose and allow for active cognitive engagement that supports brain health.

A stimulating environment with opportunities for creative, complex, and educational activities (Finlay et al., 2021d) may even help individuals resist cognitive decline and promote neurogenesis – the formation of neurons, which enable the brain to transmit information – and neuroplasticity, the brain’s ability to create new neural connections. This is true for people of all ages.

Significantly, health differences documented in studies between Black and white Americans have been shown to decrease when the influence of location is properly taken into account. For example, racial disparities in national data on hypertension, diabetes, obesity in women, and use of health services all declined when researchers focused on data from an integrated neighborhood in Baltimore (LaVeist et al., 2011). To reduce disparities, policies “must address the differing resources of neighborhoods and must aim to improve the underlying conditions of health for all,” the scholars concluded. Our policies, our cultural norms, and the very places/ environments we live and work in are set up for inequity, and until this inequity is addressed, achieving equity in brain health will remain a challenge.

## Health Care Inequities

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The evidence makes clear that health status and outcomes vary both within countries and among global regions. Access to health care is very uneven, as are outcomes, with resources concentrated in urban and more affluent regions. Low-income areas, including many rural communities, are less likely to have an adequate supply of primary care doctors, further reducing access. As a result, their residents have less opportunity for vaccines and other preventive care.

In Latin America, which has a high degree of income inequality, health varies markedly between the rich and poor. A study in the United Kingdom found that dementia incidence was higher in Black people than in whites or South Asians; it also found that Black people with dementia died at a younger age than whites with dementia (Mukadam et al., 2022).

The prevalence of dementia in Latin America and the Caribbean countries is higher than that in Europe or the United States and is expected to increase by 100% to 250% by 2050. These countries urgently require the development of harmonized, innovative, multisectoral, educational, and regional centers focused on brain health and dementia research. Regional hubs devoted to research, capacity building, implementation science, and education are critically needed (Duran-Aniotz et al., 2022).

In the United States, evidence that Black Americans and other underserved groups receive lower quality health care than white Americans has been building for years (Smedley et al., 2003). Lower quality comes in the form of fewer preventive services and worse outcomes. Death rates are often higher for underserved groups. “While Black, Hispanic and American Indian, and Alaska Native communities have experienced substantial improvements in healthcare quality, significant disparities in all domains of healthcare quality persist,” the U.S. Agency for Healthcare Research and Quality reported in 2021 (Agency for Healthcare Research and Quality, 2022).

Low-income individuals, racially and ethnically diverse communities, women, people with disabilities, LGBTQ+ populations, immigrants, and others may all face barriers to proper care. About half of the U.S. population who do not have health care insurance are from ethnically and racially diverse



communities, with Black Americans, Hispanic Americans, Native Americans, and Pacific Islanders all less likely to have insurance coverage than whites (Young, 2020). Disadvantaged racial and ethnic groups often suffer from a weak local infrastructure of social services and long-term care (Ahuja & Levy, 2021). When it comes to dementia care, “racial and ethnic minorities, persons with lower socioeconomic status, sexual and gender minorities, and rural populations experience greater challenges accessing and receiving quality services” (Aranda et al., 2021).

When individuals receive care, their providers may lack sufficient cultural competence and sensitivity, leading to poor communication and substandard treatment. In the United States, non-English speakers are highly vulnerable to cultural misunderstandings when they visit the doctor. Racism, ageism, and homophobia (Al Shamsi et al., 2020) are biases that can undermine treatment and cause doctors to overlook or misdiagnose symptoms [see next section below]. Researchers have found that African Americans often receive substandard care even when they are fully insured (Bridges, n.d.).

The unequal and inferior treatment of individuals and communities has caused deep distrust, which can lead people to avoid care or cause doctors to misunderstand their patients and wrongly view them as noncompliant. This dynamic can be extremely harmful for individuals with disabilities or chronic health conditions who would best be served by frequent interactions with the health care system. Distrust is common among African Americans in the United States, reflecting a history of unequal treatment in the health care system.

Holistic care, which should be accessible to all, requires that providers treat brain, mental and physical health equally. Yet insurance coverage for mental health – and enforcement of existing requirements – remains uneven in the United States. A 2018 study at the Morehouse School of Medicine highlighted the geographic disparities and gave failing grades to 32 states when it comes to ensuring sufficient access to mental health services (Morehouse School of Medicine, 2018).

Health care providers can do much more to promote equity. Inequalities in the health care system must be addressed to achieve the best brain health and mental well-being for all people across the lifespan.

## **Institutional Racism and Bias Impacts Health Outcomes Including Brain Health**

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Racism remains an overarching barrier to health, both as it shapes broad policies and institutions in society that influence people’s well-being, and as it affects the behavior of health care providers who may not even be aware of their own prejudices.

“Racial and ethnic minorities tend to receive lower-quality health care than whites do, even when insurance status, income, age, and severity of conditions are comparable,” the National Academies’ Institute of Medicine reported 20 years ago. (Institute of Medicine, 2002).

“A growing body of research shows that centuries of racism in this country has had a profound and negative impact on communities of color,” according to the CDC, which defines racism as a system “of structures, policies, practices, and norms – that assigns value and determines opportunity based on the way people look or the color of their skin.” Racism leads to inequities that increase the risk of illness and death for a range of conditions such as hypertension, diabetes, obesity, asthma, and heart disease, the CDC points out (Centers for Disease Control and Prevention, 2021c).

In various ways, racism can negatively impact overall health including brain health and mental well-being. Discrimination in housing and economic opportunity limits people's choices to live in neighborhoods that have access to wholesome food, clean air, and safe recreation. Research by GCBH member Lisa L. Barnes and others has linked cognitive impairment in older Black Americans to experiencing the effects of discrimination in their lives (Barnes et al., 2012). More recent research found that lifetime racial discrimination was associated with lower hippocampal volume and everyday racial discrimination was associated with fast accumulation of white matter hyperintensity in non Hispanic Black Americans (Zahodne et al. 2023).

Health care providers who view patients through stereotypes or a racial lens may exhibit bias in their choice of treatments to the detriment of patients, even when providers are unaware. It has been well-documented, for example, that physicians are more likely to amputate the legs of older Black Americans than older white Americans. A recent study of Medicare patients found that when patients experienced pain, white Americans received 36% more pain medication than Black Americans. "Such bias could reflect mistaken beliefs that Black patients experience less pain and are more likely to misuse prescription opioids than White patients," the researchers suggested (Morden et al., 2021). Bias also exists in studies of brain health as Black Americans and Latinos are less likely to receive anti-dementia medications than their White American counterparts (Zhu et al. 2022).

In survey data reported last year by the Alzheimer's Association, 36% of Black Americans, 19% of Asian Americans, and 18% of Hispanic Americans said they thought that discrimination would hinder their ability to receive care for Alzheimer's disease (Alzheimer's Association, 2022). In addition, at least half of caregivers of color said they had encountered discrimination while helping a loved one get health care.

The traditionally white-centric approach of scientific research has led to a paltry base of evidence on brain health for other populations, even though dementia rates vary among racial and ethnic groups. At the same time, there is a need to ensure that cognitive testing avoids racial and cultural bias. Black Americans who have experienced racism, for example, report higher rates of depression and other conditions that may potentially affect measures of cognition and lead to inaccurate conclusions (RUSH, 2022).

## Brain-Health Disparities Among Different Cultures

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In discussing cultural considerations of equity, the GCBH recognizes the danger of generalizing. Much needs to be learned about the forces that influence personal health including the effects of culture. Differences among individuals and within larger groups can affect health outcomes. Yet it is clear that certain communities experience disparities in health care.

Here are just a few examples out of many:

- **Lower rates of retention in treatment.** Such reduced engagement in care has been documented for Black and Hispanic Americans (Acevedo et al., 2020).
- **Misdiagnosis of racial and ethnic groups.** Underserved groups have historically been misdiagnosed, as exhibited by rates of diagnosis of attention deficit disorder and schizophrenia (Gara et al., 2018).
- **Language barriers.** Individuals with limited English proficiency in the United States have greater difficulty accessing care and preventive services (Masland et al., 2010).
- **Lack of rural hospitals.** More than 120 hospitals in rural America have closed in the last decade. More than two-thirds of rural counties had no psychiatrists and almost half of rural counties had no psychologists (Han et al., 2021).

Cultural attitudes may at times stand in the way of diagnosis and care. Stigma and cultural views on mental illness and psychiatric issues can discourage individuals from seeking care. Some fear the health care system and believe that doctors may harm their loved one. Some may view it as their own duty to handle a relative's health issue or go it alone when it would be better to call in a professional.

Superstition may discourage some individuals from seeking care. If dementia starts to emerge, some people may blame themselves. Some may assume it is impossible to treat a cognitive problem when that may not be the case.

Differences among cultures make it crucial for health care providers to possess “cultural agility” – the ability to take helpful and constructive action for patients of varied backgrounds (Watson & Hunter, 2015). In a diverse society, doctors and nurses need such agility to engage all their patients and offer effective guidance and treatment.

**American Indian/Alaska Native** people experience less financial security and lower behavioral health outcomes when compared with all other Americans. For these groups in particular, historical trauma and a range of social, policy, and economic disadvantages undermine wellness. Poverty, under-employment, lack of access to health care, lower educational attainment, housing problems, and violence are among the factors that undermine health. Native communities face service delivery issues that are complicated by personnel shortages, limited health care resources, and long distances to cover. Of the 514 tribal mental health facilities, only 39% provide 24-hour services.

The high status of elders, along with the cultural obligation to take care of them, makes it difficult to seek health care that may result in a diagnosis of dementia. Stigma surrounding cognitive decline creates further barriers to treatment (Bird et al., 2017).

For reasons such as these, disparities in care exist in varying degrees around the world, and are pronounced in the United States.

**African Americans** by various measures of social and health well-being, including income, education, and certain chronic conditions, face challenges to health that may be reflected in higher rates of brain-related illness. Older African Americans have double the rate of Alzheimer's disease and other dementias as white Americans of the same age (Alzheimer's Association, 2019). Research is needed to understand the reasons why, although high rates of cardiovascular disease appear to be a factor. Despite the higher risk, Black Americans are significantly less likely to be diagnosed with dementia than white Americans, a sign of inequitable care that appears to reflect racism in the health care system. Racism through life may further undermine mental wellness.

For a variety of historic and ongoing reasons, many Black Americans lack trust in the health care system. Only 48% said they were confident they can receive care that is culturally competent, and just 53% believed that a cure for Alzheimer's disease would be allocated fairly across the population (Lennon et al., 2022).

**Latino and Hispanic Americans** face a range of health, economic, and cultural obstacles to sustaining optimal brain health. Latino Americans have limited access to quality care and are severely underrepresented in dementia research. Yet Latino Americans are projected to have the steepest increase in Alzheimer's disease in the next 40 years compared to other ethnic groups (Quiroz et al., 2022). Another study found that, compared to other major racial and ethnic groups, Hispanic Americans had the highest numbers of full families in poor health (followed by Black/African-American low-income families) (Braveman & Barclay, 2009).

Language also creates challenges. Less than 6% of U.S.-based physicians identify as Spanish-speaking, yet Spanish is the second most common language spoken in the United States. Spanish speakers also may face delays when they call 911 in health emergencies, depending on a dispatcher's ability to understand them (Fernandez et al., 2011).

**Asian Americans** historically have had lower rates of health coverage than white Americans, but that gap has essentially vanished with the implementation of the Affordable Care Act (Park et al., 2019). Experiences vary widely among Asian Americans, however, and not all communities have enjoyed the same advances in coverage. As recently as 2017–2018, Korean Americans and Vietnamese Americans were substantially less likely to be insured than Indian, Chinese, and Filipino Americans. As a cultural factor, many Asian Americans wait until they are sick before seeking health care. And clinical trials often do not include enough Asian Americans in samples to provide complete information on equity (Obra et al., 2021). Studies also identified the need of public health education to enhance dementia knowledge and rectify the biased attitudes toward dementia in some group of this ethnic population (Sun et al., 2021). Researchers should not treat Asian Americans as a monolithic group. More than 30 different nationalities and ethnic communities may be classified as Asian American, with significant implications for their health and wellness (Ty et al., 2023).

## Mental Well-Being of LGBTQ+ Community

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Lesbian, gay, bisexual, and transgender individuals may face stigma, discrimination, and denial of rights that undermine mental well-being and **create disparities in health outcomes**. Discrimination, social rejection and a lack of cultural competency within the health care system can lead to stress, anxiety, and illness including cancer. LGBTQ+ individuals are more likely to smoke, use drugs, and drink alcohol (McCabe et al., 2009). One study found that LGBTQ+ individuals are twice as likely as others to experience a mental health problem. Another suggested that mood and anxiety disorders are even more prevalent among transgender individuals (Wanta et al., 2019).

There also is evidence that people in the LGBTQ+ community who are also members of multicultural populations face the most severe disparities in health (Krehely, 2009) overall, including brain health. LGBTQ+ individuals who are Black American or Hispanic American face many added challenges regarding exposure to disease, susceptibility, and access to providers and treatment. Acquiring insurance and finding affordable care that is culturally sensitive and gender-affirming are among the obstacles to maintaining optimal brain health and mental well-being (Crissman et al., 2019).

## Living with Dementia

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Supports are needed to help people live as well as they can with dementia and maintain the best health and mental outlook possible. Individuals wish to live their lives with purpose, social ties and independence. Yet for those living with dementia, help in attaining these goals is often lacking, which leads to stress, anxiety, and other health challenges.

According to the **National Academies of Sciences, Engineering, and Medicine**, supports may include “help with medication use, paying bills, avoiding falls, and managing daily personal care needs, as well as support in activities that are socially, physically, and cognitively stimulating. . . . To live well with dementia – at all stages of the disease – people need care, services, and supports that reflect their



values and preferences, build on their strengths and abilities, and promote well-being.” (National Academies, 2021).

More than 40% of older adults who needed help with activities of daily living to remain in the community experienced “adverse consequences” due to lack of sufficient support, a review of studies by the Commonwealth Fund concluded (Sands et al., 2006). And of this group, older adults with dementia, those with low incomes, and those with the greatest needs for help experienced the worst consequences. These findings suggest that underserved, low-income communities find it harder and more dangerous to live with dementia, and are more likely to have unmet needs if they remain in the community. By one projection, the number of Black Americans with dementia will increase by about 200% between 2020 and 2060, while the number of Hispanic Americans with dementia will soar by 440%. By contrast, the number of those who identify as non-Hispanic whites with dementia is projected to go up by 69% (Ahuja & Levy, 2021).

Family resources and access to local services vary widely, making it much more challenging from some individuals and communities to live with dementia than others. For example, adults aging with downs syndrome frequently develop dementia and they are **often living with aging parents** who face their own age-related physical and cognitive challenges. Bridging the gap between aging and disability services to ensure family supports in these situations is critical.

## Your Job can Affect Your Brain Health

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Your work life can be a big influence on your health. Employer policies on health care and wellness matter. Physical danger, environmental hazards, adequacy of sleep, access to health care, and the amount of leisure time in your life may all be influenced by your workplace.

Long hours in demanding jobs can undermine health in various ways. To give just one example, consider how a noisy workplace may affect hearing. More than 30 million U.S. workers risk hearing loss due to noise and chemicals, and this poses a risk of cognitive decline, according to CDC (Centers for Disease Control and Prevention, 2021d). [Of this group, one in five already has a hearing impairment.] The **2020 Lancet Commission on Dementia prevention, intervention and care** reported that dementia prevalence could be reduced by 8% if hearing loss in mid-life was eliminated. Or consider an employer’s policy on paid leave. If a worker needs personal time for important responsibilities, such as family caregiving, but time off means financial sacrifice, the result can be great stress.

Women often pay the greatest price in personal stress and health for caregiving while also working outside the home. If you are constantly scrambling to keep up with multiple jobs, it may seem impossible to add exercise or find the time to prepare healthy meals. A person who works a night shift while caring for their kids or an adult relative during the day may not be able get the recommended 7–8 hours of sleep per night (Mosconi, n.d.).

Low-income multicultural populations that face discrimination in the workplace are more likely to work in dangerous jobs than affluent, highly educated population groups. Native Americans, Hispanic Americans, and Black Americans are less likely to possess employer-sponsored health benefits than white workers, which makes it harder for them to maintain good health and manage chronic conditions as they get older (Artiga et al., 2021). Immigrants and migrant workers have less employment-based protections and experience higher rates of long-term disability. Between 2019 and 2020, for example, the rate of fatal injuries in the workplace rose for Hispanic Americans (4.5 deaths/100,000 workers) while falling for other population groups (Bureau of Labor Statistics, 2022).

But employers can play an instrumental role in creating workplaces that can support the brain health of their employees. For example, the Center for Brain Health in Dallas, Texas started a program around the brain healthy workplace and piloted it with a large Texas design corporation. They provided brain health training to employees to improve three main factors: clarity of thinking, emotional balance, and connectedness to people and purpose. (see Chapman et al. 2021 for the factor analysis). They found that a combination of brain health training, workplace characteristics and workplace habits could increase employees' Brain Health Index (measures of physical changes in brain metrics such as brain blood flow, neural connectivity and white matter integrity) by up to 32 points (Nanda et al. 2023). While this study focused on knowledge workers, it shows that the investment of employers in active training to support brain health can be impactful.

## Global Survey: The Public Seeks Guidance on Brain Health

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No matter where you live, behavior change is hard. Clear-cut, useful information, along with ongoing professional support, would make it easier, **according to a survey** of 27,590 adults in 81 countries.

“There already exists lots of information on beneficial diet or lifestyle changes, but it is not always easy to know what works or how necessary they are,” said a Norwegian respondent to the **Global Brain Health Survey**, conducted in 2019 and 2020 by the Lifebrain Consortium at the University of Oslo. “If there was an online database with evidence-based suggestions, advice, apps, etc., I would use it.”

The findings are outlined in a **Lifebrain report** on how to promote brain health. Among the highlights:

- **People seek useful information.** More than nine out of 10 respondents (95%) said public health officials should provide “clear, evidence-based information” on brain health.
- **Health care providers have a role to play.** Almost nine out of ten (87%) said they would need professional support from a health care provider.
- **Habits should be monitored.** Four out of five (80%) called for monitoring to assess the impact of changes in their lifestyles.
- **More supports are needed.** About three out of four favored such measures as subsidies for healthy food (72%), and adding “relaxation activities” to schools and workplaces (76%).

## Knowledge Gaps: Where More Research is Needed

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Much more research is needed to understand the challenges to brain health faced by particular populations and solutions that would ensure greater equity for all. GCBH members agree that critical questions will not be addressed until research about brain health becomes much more inclusive. Studies must be planned and carried out in a manner that reflects the diversity of the population.

Among the questions that call out for answers:

- What kind of interventions would be most effective for populations that experience disparities in brain health?
- Are there unique cultural differences that should be taken into account when studying the brain health of different groups?

- How do inequities in social determinants of health, including education, income, and the environment, drive differences in brain health and to what extent can we make up for early life deficits like poor education?
- In what ways do institutional racism among health care providers contribute to disparities in brain health?
- What are the best ways for employers to foster healthier work environments?

While these and other questions require much greater scientific exploration, they will not be adequately answered until there is fundamental change in the way brain research has historically been conducted. From start to finish, the entire research enterprise must become more inclusive. Organizers of clinical trials must do more to recruit and retain members of different population groups so that all communities are adequately represented. Greater diversity is also needed among researchers and the questions they study. Funders should recognize this need in the opportunities they offer and projects they support.

Progress toward equity can further be achieved by establishing standard health equity and quality measures – and tracking them over time. In 2021, the National Academies of Sciences, Engineering, and Medicine reported that “The current body of evidence on dementia care does not reflect the experiences of diverse populations, including people of different races, ethnicities, ages, genders, sexual orientations, and abilities.” **The report** urged more research on interventions “at the community level (care protocols, dementia villages), policy level (paid family leave policies, payment policies, and transportation policies), and societal level (public awareness campaigns).”

All these steps are needed to increase understanding about brain health and enhance equity.

## A Healthier Path for All

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Achieving equity in brain health calls for new strategies across a range of sectors. Individuals should be encouraged to make healthy choices, but strategies must recognize the influence of larger societal factors.

Scientific research must adapt in a way that recognizes population diversity. Technology should be applied in a way that gives all communities access to information and care. Rather than acting alone in silos, professionals should forge strategic partnerships that leverage their insights.

Planners should recognize the importance of the local environment, both built and unbuilt, as an under-appreciated factor in promoting brain health. Architects, local officials, and community leaders all have roles to play. University of Michigan researchers use the term “**Cognability**” to assess how neighborhoods support brain health, notably through features that encourage exercise, social connections, and intellectual stimulation. Schools, recreational facilities, community gathering sites, and places of work are examples of environments that can be designed in ways that influence our cognitive vitality.

Technology is another underutilized solution to enhance brain health for all, including underserved and isolated communities. Consider all the people in the world who possess smartphones. At the tips of their fingers, they have access to platforms like YouTube and TikTok that could provide content that raises awareness in a manner that is educational and entertaining. AARP developed Staying Sharp, a program that offers content about general wellness with a focus on brain health. Staying Sharp is available online and via a mobile app.

Greater community engagement is another part of the answer. Public understanding of basic brain health needs to be enhanced and widely held misconceptions eliminated. Community leaders can

step up their advocacy for brain health and play a larger role in raising awareness of brain health within their constituencies –in effect serving as ambassadors for brain health, providing information and informing individuals where to find local services.

To be effective, however, initiatives in education, outreach, and communications must be crafted and delivered in a manner that resonates with the target audience. Messages should be simple and straightforward, eschewing language that may sound like gobbledygook to much of the public. Further, communications should recognize important local values, such as how a community wants to treat its elders, how it views the responsibilities of family members, and whether care may seem undignified or disrespectful to those receiving it.

Within the health care system, providers should prioritize prevention and establish brain-health screening as a routine part of check-ups for aging adults and others at risk. Health care providers should be aware of community-based resources so they can make referrals as needed. People who require long-term care supports should be able to find them more easily.

Families of all income levels can play a critical role in supporting brain health. Optimizing this resource requires greater awareness and guidance, an effort that can be promoted by policymakers, community organizations and health care providers. Empowering family caregivers is an underutilized strategy to strengthen brain health – both for those who need care and the family members who provide it. In many cultures, stigma and shame may inhibit families from seeking outside help. However, community leaders and influencers can do a great service by trying to counteract these harmful attitudes that are embedded in many societies.

When family caregivers do connect with the health care system, providers should treat them as vital members of the health care team. Employers can further support family caregivers through leave policies and flexible work arrangements that enable them to help at home while keeping up with their job duties.

Employers can adopt policies that promote better brain health by encouraging and modeling healthy behaviors such as physical movement, adequate sleep, and healthy eating. Flexible work arrangements, reasonable workloads, prioritizing safety and mental health, and providing paid leave for time off, all serve to create environments where employees are more likely to adopt and sustain healthy lifestyles. Employers who provide health and wellness benefits will directly promote the cognitive and mental well-being of their employees.

Governments can take varied steps to advance brain health for all. Policymakers in different societies have launched initiatives that engage multiple sectors and feature an array of strategies. Selected examples:

- Uruguay, which has been a **pioneer in brain health initiatives**, has added basic, self-help guidelines on the subject to school curricula recognizing that behavioral choices can affect brain health through the course of life.
- Poland’s **Healthy Brain Plan** contains recommendations for many sectors of society, while emphasizing the need for “Increased public awareness, in particular concerning social, fiscal, and personal consequences posed by brain diseases.”
- Norway’s national **“Brain Health Strategy”** seeks to build common understanding of the issues across different sectors and create an alliance between researchers and organizations for patients and consumers.
- The U.S. **“Road Map for Indian Country,”** designed by the Centers for Disease Control, urges more messaging for tribal communities on the role of caregivers and the benefits of early diagnosis of dementia to “help establish a care team of family, community members, and healthcare and social service providers.”



# Conclusion: The New Paradigm

**A**s people live longer lives, all societies have an economic stake in embracing a new paradigm that optimizes the cognitive resilience of their populations. Failing to do so will bring increasing economic and social costs. Achieving this, however, requires change in entrenched policies and cultural values.

The process of making policy and monitoring its impact should become more equitable and inclusive, with a high priority on seeking out community members' expertise. Laws and policies that perpetuate inequities should be eliminated, as should stigmatizing language that is embedded in those laws and policies.

Gaining actionable knowledge from diverse communities should be a priority in research funding opportunities, scientific questions to explore, and participation in clinical trials. Data should not only be collected but interpreted to reveal trends and point to solutions that benefit those who have been neglected historically.

It is time to consider the environment, built and natural, in a fresh way that recognizes the importance of our daily surroundings in sustaining cognitive well-being. And it is necessary to recognize how broad social forces may influence our brain health through the course of life.

In conclusion, a successful approach to enhancing brain health must integrate many elements, nonmedical as well as medical, prevention, and remediation. It will require a long-term commitment to counter practices that are deeply ingrained in society. But such work is essential. Better brain health would enable people's minds to flourish so they can live more rewarding lives. Everyone deserves this opportunity, and communities around the world will reap the benefits.

# Appendices

1. Participants, Liaisons and List of Additional Resources
2. Process Used to Produce the Report
3. Glossary
4. Dementia disparities around the world
5. Dementia disparities in the United States
6. Discussion Questions Framing the Deliberations
7. Disclosure Statement of Potential Conflicts of Interest
8. Funding
9. Bibliography
10. List and Links to Other GCBH Reports

## 1. Participants, Liaisons and List of Additional Resources

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Members of the Global Council on Brain Health are independent health care professionals and experts coming from a variety of disciplines. The issue specialists and Governance Committee members formulated these recommendations, and the Governance Committee approved them.

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Other experts from relevant public agencies and non-profit associations reviewed the paper and provided guidance and feedback to help shape the document. Grateful acknowledgment goes to:

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- **Sherrill Wayland, MSW**, SAGE
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## List of Additional Resources from Experts and Liaisons

### 1. Addressing language barriers. Below are dementia screening tools for people speaking Asian languages.

The Singapore Ministry of Health has evaluated the efficacy of both screening tests developed in Asian populations, as well as those translated into Asian languages, and thus, is a good general resource (see Dementia Singapore [Cognitive Assessments and Screening Tests](#) and Ministry of Health [3.2 Assessment of dementia](#)). Below are some screening tools that were specifically designed within Asian populations:

Name of Screening Tool	Languages or countries	Brief summary	Source
Korean Dementia Screening Questionnaire (KDSQ)	South Korea	Used in periodic general health check up program that screens for cognitive dysfunction	<a href="#">Kim 2020</a>
Picture-based Memory Intelligence Scale (PMIS)	NA	Uses images to help transcend language barriers	<a href="#">Verghese 2012</a>
Hasegawa Dementia Screen (HDS-R)	Originally developed in Japanese, then translated to Korean, Chinese, and English	First described in 1974 and revised in 1991, has subsequently been translated to other languages	Kato 1991 – NA
Visual Cognitive Assessment Test (VCAT)	Singapore, Malaysia, Indonesia and the Philippines, Brazil, Canada, India and South Korea	Developed by the National Neuroscience Institute addresses the challenges of dementia screening in multi-lingual countries	<a href="#">Lim 2018</a>

There are also multiple screening tools that have been translated into Asian languages (28 tools in 7 Asian languages) ([Rosli 2015](#)). The Singapore version of the 10-item Abbreviated Mental Test (AMT) – has been validated for use in elderly Chinese subjects and can correctly identify 80% – 97% of people with dementia. Other widely used tests that have been translated are:

1. Mini-Mental State Examination (MMSE): 28-item Chinese Mini Mental State Examination (CMMSE) has been validated
2. Montreal Cognitive Assessment (MoCA)
3. Clock Drawing Test (CDT)

AARP has advocated for better language access in the United States so people with limited English proficiency can meaningfully engage in shared decision-making about their health care. See a recent article about Asian languages: <https://blog.aarp.org/thinking-policy/high-rates-of-limited-english-proficiency-in-chinese-american-community-highlights-necessity-of-language-access-in-health-care>

### 2. People with intellectual disabilities have unique needs in assessing cognitive impairments.

The National Task Group (NTG) on Intellectual Disabilities and Dementia developed a screening tool to develop a baseline in adults with intellectual disabilities or developmental disabilities that tracks changes in function that could indicate the onset of dementia. For more information about NTG’s Early Detection and Screen for Dementia, see: <https://www.the-ntg.org/ntg-edsd>



### **3. Example of Dallas, Texas advocates and health care providers working together on building better brain health focused in a primarily Hispanic American community.**

The Center for BrainHealth® (a cognitive neuroscience research center of The University of Texas at Dallas) has partnered with local public health non-profit *Community Does It* to pioneer the first-ever BrainHealthy Community in Pleasant Grove, one of the most under-resourced and underserved communities in Dallas.

This initiative features community-centric programs and multigenerational engagement to give every individual the opportunity to thrive in their lives with better brain health, whatever their starting level. A BrainHealthy Community Liaison – a former educator with roots in Pleasant Grove – is actively working within the community to create and deliver content and tools that are culturally sensitive, useful, easily accessible, and free of language barriers. The initiative is funded in part by the Addy Foundation.

The goal is to establish the societal and economic gain when people of all sectors of life have access to individualized, proactive brain health protocols. According to Dallas Mayor Eric Johnson, “A focus on better brain health can empower people and improve their quality of life. And for our communities, it can be transformative.” For more information, contact Lori Cook, PhD, CCC-SLP, Director of Clinical Research Center for BrainHealth, [lori.cook@utdallas.edu](mailto:lori.cook@utdallas.edu)

### **4. Example of Valdosta, Georgia advocates and community groups working together on better brain health focused in a primarily African American community:**

Reminiscent and Bright Focus Foundation are working together on a pilot program in Valdosta, Georgia to improve brain health equity. The project seeks to educate people about dementia and brain health, partnering with the local community to increase awareness about risk reduction and to encourage participation in clinical trials. See the video link here: [Valdosta Video](#). This short film describes the historical challenges posed and new solutions that advocates and community groups are implementing in Valdosta. For more information, contact Nancy Lynn of the BrightFocus Foundation, [NLynn@BrightFocus.org](mailto:NLynn@BrightFocus.org).

### **5. Example of Maryland advocates and community leaders working together with health care researchers to share health care information through the Health Advocates In-Reach and Research (HAIR) Network.**

This is an example of how focusing on hyperlocal engagement in African American communities is being used to shape better outcomes with COVID-19 and diabetes in Maryland. Similar models, working together with barber shops and hairstylists in local communities, could be tried for brain health.

- [Barber Shops’ critical role in Covid-19 vaccination strategy](#)
- [Bringing Health Care to the Barber’s Chair | Enterprise Research Stories](#)
- [HAIR Wellness Warrior Workshop: A Love Letter to our COVID-19 Clinical Partners](#)
- [HAIR Wellness Warriors Sing: Health is Wealth \(original song\)](#)
- [The History of Black Healthcare | The Cutting Edge | May 4th, 2023](#)
- [ProChange, Maryland Center for Health Equity Awarded \\$1M CDC Contract to Reduce Health Disparities in Diabetes Prevention](#) – Barbershop, salon and text messaging programs designed to keep African Americans from getting type 2 diabetes

Barbers/stylists from Baltimore City, Montgomery County and Prince George’s Counties, Maryland in the United States have completed 17 hours of Centers for Disease Control training over 4 weeks to become Certified Lifestyle Coaches for the Diabetes Prevention Program. This is the first time a cohort (N=26) of barbers/stylists have been trained. In June 2023 these “HAIR Wellness Warriors” will recruit 600–750 of their clients into the program for 12 months in Hyattsville, MD

## 2. Process Used to Produce the Report

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On June 15–16, 2022, members of the GCBH met at the AARP State office in Miami, Florida to discuss the impact of disparities among different groups of people on brain health for adults 50 and older. A list of participants and GCBH members is included in Appendix 1. The purpose was to examine the experience of people due to the larger social context in which they live and how that might influence people’s brain health across their life span.

This meeting built on our past reports recognizing that not all individuals start from the same foundation of the social determinants of health. Nor do they have the same opportunities or environments that make it easy to sustain healthy behaviors. After describing the issues that create barriers affecting people’s access to resources that facilitate better brain health, the GCBH worked over the next year to discuss and suggest actionable recommendations to increase brain-health equity.

Over the course of 2022, four convenings were held to discuss issues of brain-health equity across the globe and the cultural reactions and beliefs about brain health and the diseases that cause dementia. Twelve people living with dementia were invited to respond to four core questions outlined in Appendix 6c about their lived experiences, review the draft report, and provide comments.

The scholars brought in as issue experts to advise the council, and who represent a range of perspectives, backgrounds and disciplines, were selected because they have conducted research that has significantly contributed to the understanding of brain health among older adults of different backgrounds and cultures. The diverse areas of their expertise include gerontology, neurology, neuropsychology, psychology, public health, epidemiology, and medical anthropology.

The issue specialists considered numerous different questions as a framework to guide their deliberations (see Appendix 6). The major questions focused on the barriers to equity, policies that reinforce them, and practical recommendations to make brain health more attainable for all. The Council recognized the many disparities and barriers which make it very challenging to adopt and sustain brain healthy behaviors, particularly for women and members of ethnically and racially diverse communities around the world. Council members also discussed how to define the concept of brain-health equity and how cultural differences should be taken into account when we consider solutions.

After in-depth moderated discussions, several follow-up conference calls, and an exchange and refinement of drafts, the issue specialists and Governance members arrived at consensus statements identifying the major reasons behind the existing disparities in brain health and provided recommendations for policymakers, thought leaders, community groups, health care providers, individuals, and advocates.

The Governance Committee reviewed and finalized the document during subsequent conference calls and emails. The Governance Committee issuing the recommendations are also independent health professionals representing diverse expertise in epidemiology, psychology, public health, neurology, psychiatry, geriatrics, cognitive neuroscience, neuropsychology, and health policy. In addition, liaisons from civic and non-profit organizations with relevant expertise in brain health were invited to provide input and technical feedback during the Issue Experts’ and Governance Committee’s refinement of the draft recommendations. Following a final review, the GCBH Governance Committee approved the document on June 21, 2023.

This paper summarizes the consensus reached by the experts and describes the major points of discussion that led to the recommendations. It also identifies gaps in our knowledge about these

activities and cognition, provides a glossary defining terms used in the document, and lists resources for further information. This paper was not intended to be a systematic, exhaustive review of all pertinent scientific literature on the topic. Rather the selected references provided at the end of the document give helpful background material and present the current evidence base underpinning the GCBH consensus in this area.

### 3. Glossary

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#### **The glossary highlights how the GCBH used these terms within the context of their discussions and in this document.**

**Anxiety disorder.** A condition of excessive worry about everyday issues and situations that interferes with regular activities

**Anxiety.** Apprehensive uneasiness or nervousness. In severe cases can result in a mood disorder where the person experiences extreme worry or nervousness about people, challenges, or events when there is little or no reason for that level of concern.

**Brain health.** A state of having good underlying neural mechanisms to support high functioning mental processes of cognition that support well-being.

**Cognition.** All forms of knowing and awareness, such as perceiving, conceiving, remembering, reasoning, judging, imagining, and problem solving.

**Cognitive decline.** The loss of cognitive abilities over time as people age, absent a specific disease or condition.

**Cognitive impairment.** The stage between the expected cognitive decline of normal aging and the more serious decline of dementia. It can involve problems with memory, language, thinking, and judgment that are greater than normal age-related changes.

**Cognitive reserve.** Individual differences in the resilience or adaptability of cognitive processes, such as memory, reasoning and attention, that together help explain why some people are more susceptible than others to age- or disease-related brain changes.

**Cognitive screening.** A routine evaluation for problems with certain brain functions called “cognition.” Cognition includes thinking, learning, remembering, and using judgment and language.

**Confounder.** A situation in which the effect or association between an exposure and outcome is distorted by the presence of another variable.

**Connected.** To experience a sense of belonging and welcome in a group.

**Cultural sensitivity.** An awareness and acceptance of cultural nuances and differences in such a way that it withholds judgment of cross-cultural practices.

**Culturally responsive.** Being culturally responsive requires having the ability to understand cultural differences, recognize potential biases, and look beyond differences to work productively with children, families, and communities whose cultural contexts are different from one’s own.

**Dementia.** Dementia isn't a specific disease. Instead, dementia describes a group of symptoms related to memory, thinking and social abilities and affecting them severely enough to interfere with independent daily functioning. Though dementia generally involves memory loss, memory loss has many different causes. Alzheimer's disease is the most common cause of a dementia in older adults, but there are a number of types of dementia. Depending on the cause and type of dementia, some dementia symptoms can be reversed.

**Demographics.** Statistical differences relating to the population and particular groups within in. or, Statistical approach of describing characteristics of human populations such as age, gender, race, income, etc.

**Health disparities.** Differences (usually unfair) between population groups, and, in the context of health, as it relates to access to health care and insurance coverage.

**Depression.** A common but serious mood disorder where one feels severe sadness and dejection.

**Efficacy.** The degree to which an intervention accomplishes the desired or projected outcomes.

**Empathy.** Empathy involves an understanding of another person's world by listening to allow a better understanding of the other person's situation, and by responding with verbal and non-verbal messages that communicate affective understanding of that person's situation. Cognitive empathy refers to the ability to recognize and interpret the other person's situation while affective empathy refers to an accurate emotional expression of that person's situation.

**Happiness.** A range of positive emotions, including joy, pride, contentment, and gratitude.

**Incidence.** In epidemiology, incidence is a measure of the probability of occurrence of a given medical condition in a population within a specified period of time. Sometimes loosely expressed simply as the number of new cases during some time period.

**Intervention.** Any measure whose purpose is to improve health or alter the course of disease.

**Language.** A formal system of communication which involves the combination of words and/or symbols, whether written or spoken, as well as some rules that govern them. Countries have been grouped as high-income, upper middle income, lower middle income and low-income. The threshold levels of gross national income per capita are those established by the World Bank.

**Mass incarceration.** A term that describes the exceptionally high rate of incarceration in the United States, which imprisons more people than any nation in the world.

**Mental.** Relating to the mind, including reasoning, thinking, mood, attention, feelings, emotion and interest in activities.

**Mental health.** A state of mind characterized by emotional well-being, good behavioral adjustment, relative freedom from anxiety and disabling symptoms, and a capacity to establish constructive relationships and cope with the ordinary demands and stresses of life. (APA Dictionary of Psychology)

**Mental well-being.** People's experiences of feeling good, functioning well and coping adequately with life circumstances and challenges.

**Observational studies.** In observational research, scientists observe groups of people to identify characteristics, such as traits and choices, that are associated with disease or health.



**Prevalence.** In epidemiology, prevalence is the proportion of a particular population found to be affected by a medical condition at a specific time.

**Randomized controlled trial (RCT).** In a typical randomized controlled trial, people are randomly selected to receive either the intervention or a control condition. In a double-blind trial, both the participants and the researchers are unaware of (or “blinded” to) which person received the intervention until after the results are analyzed.

**Residential segregation.** The physical separation of two or more groups into different neighborhoods or, spatial separation of different population groups within a given geographical area. The groups are either minority or dominant groups in the region and live in different areas of that region.

**Risk.** Risk is the chance or probability of a particular event happening in a group of people with similar characteristics or traits, compared with those not having that characteristic or trait. Making up an individual’s overall risk of having a condition is the cumulative effects of factors that increase the chance of developing the condition (risk factors) as well as factors that decrease the chance of developing the same condition (protective factors).

**Risk reduction.** Reducing risks for cognitive decline or impairment in the abilities to think, reason, and remember means lowering your chances of experiencing loss in those abilities. A person’s overall risk may also be reduced by increasing factors that protect against cognitive decline or dementia. Dementia (due to Alzheimer’s disease or another related disorder) is one condition, and cognitive decline (the slowing of thinking and memory in the absence of a major brain disease) is another condition. When scientists study risk reduction strategies for cognitive decline, they are looking for factors that can reduce the risk of impairment to cognitive functions in the population in general. Therefore, some activity or intervention that reduces risk for a particular condition or disease means that a smaller proportion of people who engage in that activity are likely to have the condition or disease. However, risk reduction strategies are not the same as preventing any one individual from getting the condition or suffering from disease. For example, research has long shown that wearing a seatbelt reduces – but does not eliminate – the chance of injuries among people who are involved in automobile accidents, and we nevertheless now recommend people wear seatbelts while they are driving.

**Social cohesion.** The perceived degree of connection among neighbors, and people’s willingness to intervene for the common good.

**Social determinants.** Nonmedical factors that influence health outcomes. They are conditions in which people are born, grow, work, live, and age, and the wider set of forces and systems shaping conditions of daily life.

**Stress.** The physiological or psychological response to internal or external stressors. Stress involves changes affecting nearly every system of the body, influencing how people feel and behave. For example, it may be manifested by palpitations, sweating, dry mouth, shortness of breath, fidgeting, accelerated speech, augmentation of negative emotions (if already being experienced), and longer duration of stress fatigue. (APA Dictionary of Psychology) Well-being. Self-evaluation of life satisfaction often described as the state of being comfortable, healthy, or happy.

**Stroke.** A stroke occurs when a blood vessel that carries oxygen and nutrients to the brain is either blocked or ruptured.

**Well-being.** Self-evaluation of life satisfaction often described as the state of being comfortable, healthy, or happy.

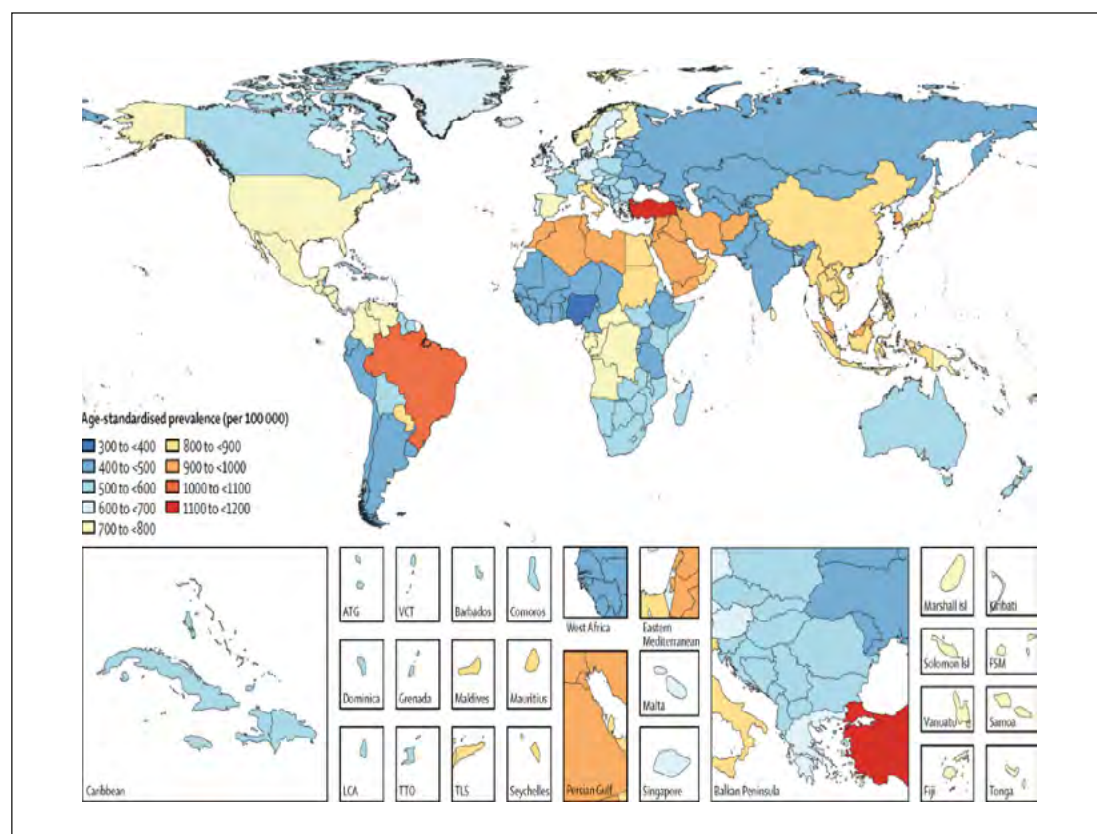
## 4. Dementia Disparities Around the World

According to the WHO, more than 55 million people are currently living with dementia worldwide, and at least 60% of them come from low-and middle-income countries (World Health Organization [WHO], 2023).

There is a major limitation in collecting data on dementia from many regions of the world. According to the Global Dementia Observatory (GDO) only 19 countries routinely monitor people with dementia. Most of them are high-income countries, according to the World Bank income group classification. As of 2017, over 38% of the countries around the globe have not compiled any recent dementia data (WHO, 2018).

Despite these limitations, there are several ongoing noteworthy efforts that use advanced mathematical modeling techniques to estimate current prevalence rates and future projections of the number of people living with dementia to help advocates and policymakers around the world prepare for the future. In 2016, the Global Burden of Disease study produced global estimates of dementia prevalence. The Middle East, North Africa and some parts of Latin America had the highest prevalence of dementia, followed by the East Asia and Pacific regions, and then North America (Figure 1).

**Figure 1: Age-standardized prevalence for Alzheimer’s disease and other dementias per 100,000 population by location for both sexes, 2016 (Nichols et al., 2019)**

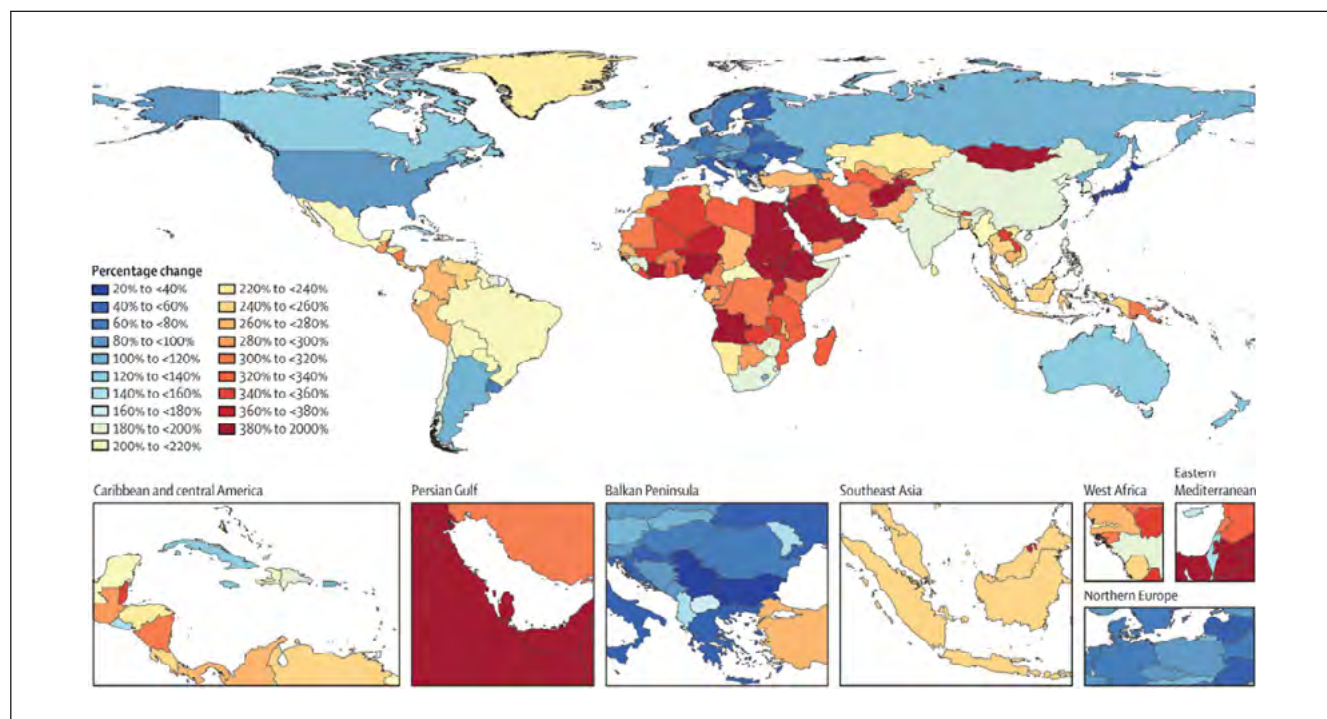


ATG=Antigua and Barbuda. FSM=Federated States of Micronesia. Isl=Islands. LCA=Saint Lucia. TLS=Timor-Leste. TTO=Trinidad and Tobago. VCT=Saint Vincent and the Grenadines.

**Source:** Nichols, E., Szoeke, C. E., Vollset, S. E., Abbasi, N., Abd-Allah, F., Abdela, J., ... & Murray, C. J. (2019). Global, regional, and national burden of Alzheimer's disease and other dementias, 1990–2016: a systematic analysis for the Global Burden of Disease Study 2016. *The Lancet Neurology*, 18(1), 88–106. Used with permission.

In a study forecasting dementia prevalence, it was found that the smallest increase in prevalence over the years (2019–2025) will happen in the high-income countries of the Asia Pacific and Western Europe regions. Whereas the highest increase in the number of cases will take place in the low- and middle-income countries in North Africa, the Middle East and eastern sub-Saharan Africa (figure 2).

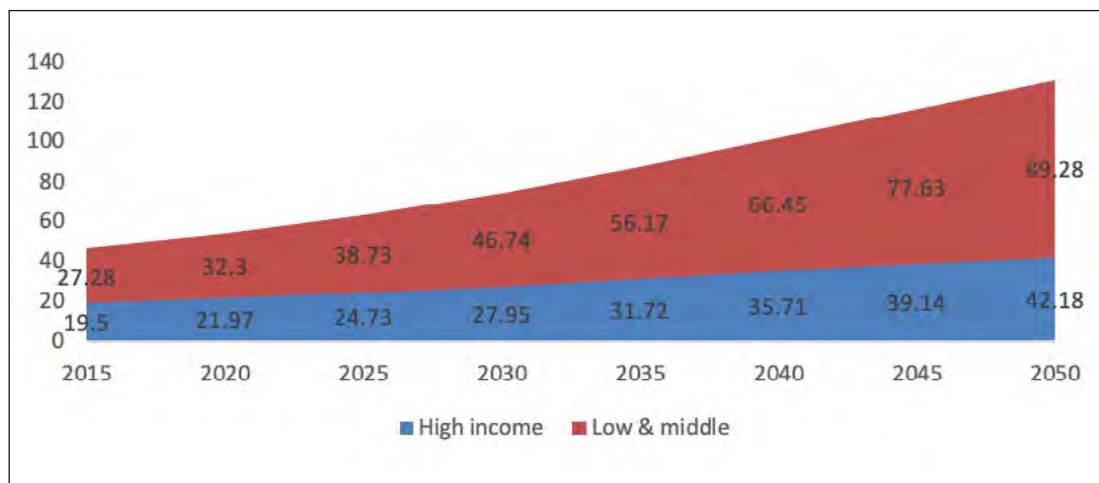
**Figure 2: Percentage change between 2019 and 2050 in all-age number of individuals with dementia by country (Nichols et al., 2022)**



**Source:** Nichols, E., Steinmetz, J. D., Vollset, S. E., Fukutaki, K., Chalek, J., Abd-Allah, F., ... & Liu, X. (2022). Estimation of the global prevalence of dementia in 2019 and forecasted prevalence in 2050: an analysis for the Global Burden of Disease Study 2019. *The Lancet Public Health*, 7(2), e105-e125. Used with permission.

The findings are reinforced by the World Alzheimer’s Report 2015 that found the number of people living with dementia worldwide is likely to double every 20 years, reaching 74.7 million in 2030 and 131.5 million in 2050. The larger part of the projected increase will come from the low- and middle-income countries of the world (Figure 3).

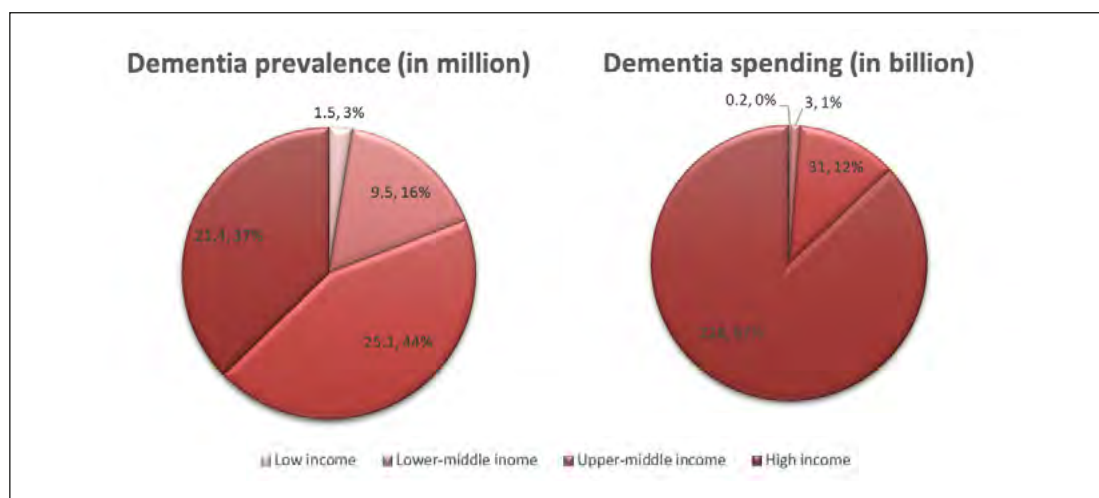
**Figure 3: The growth in numbers of people with dementia (millions) in high income vs low- and middle-income countries (Prince M. et al, 2015)**



**Source:** Prince, M., Wimo, A., Guerchet, M., Ali, G.-C., Wu, Y.-T., & Prina, M. (2015, August). World Alzheimer report 2015 – Alzint.org. <https://www.alzint.org/u/WorldAlzheimerReport2015.pdf>. Used with permission.

The costs of dementia care are also distributed disproportionately worldwide, but mostly in the reverse direction as prevalence. While high-income countries only account for 37% of the world’s dementia prevalence, the greatest share of the global direct costs of dementia (87%) is spent in these countries (Pedroza et al., 2022).

**Figure 4: Dementia prevalence and spending by World Bank income group, 2019**

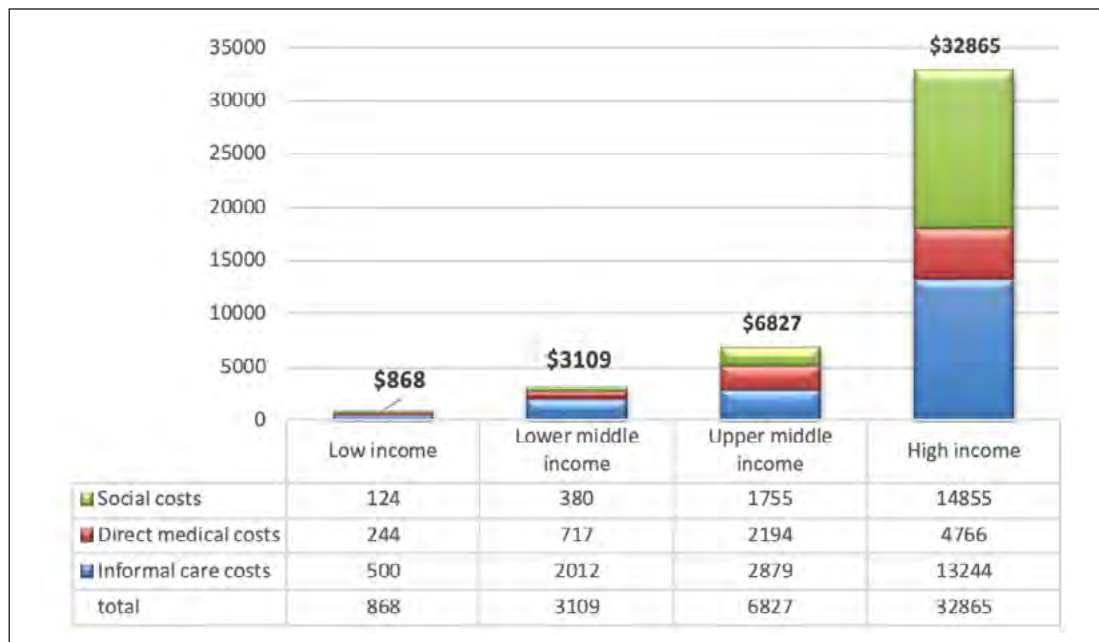


**Source:** Pedroza, P., Miller-Petrie, M. K., & Chen, C. (2022). Global and regional spending on dementia care from 2000–2019 and expected future health spending scenarios from 2020–2050: An economic modelling exercise. *eClinicalMedicine*. 2022; 45. Used with permission.

However, medical costs (e.g., hospital care, medications, clinic visits) account for less than 20% of this amount. The main costs related to dementia care hail from social and informal care (Wimo et al., 2013). Social care costs comprise formal services provided outside of the medical care system, including community services such as home care, food supply, and transport, and residential or nursing home care. The costs of informal care reflect the time family caregivers spend caring because many people who care for a relative lose their jobs or reduce their working hours. The economic spending on

informal care is also disproportionately distributed according to the income level of the countries. Low- and middle-income countries aggregate larger chunks of the dementia care costs from the informal settings than the high-income countries (Figure 5).

**Figure 5: Categories of per person dementia care costs (USD) in different World Bank income groups**



**Source:** Wimo, A., & Prince, M. (2011, June). *World alzheimer report 2010* – [alzint.org](https://www.alzint.org/u/WorldAlzheimerReport2010.pdf). *Alzheimer’s Disease International*. <https://www.alzint.org/u/WorldAlzheimerReport2010.pdf> Used with permission.

In addition to disparities in dementia prevalence and spending around the world, there is growing evidence on inequities within different countries based on gender, race/ ethnicity, and geographic location.

## United Kingdom

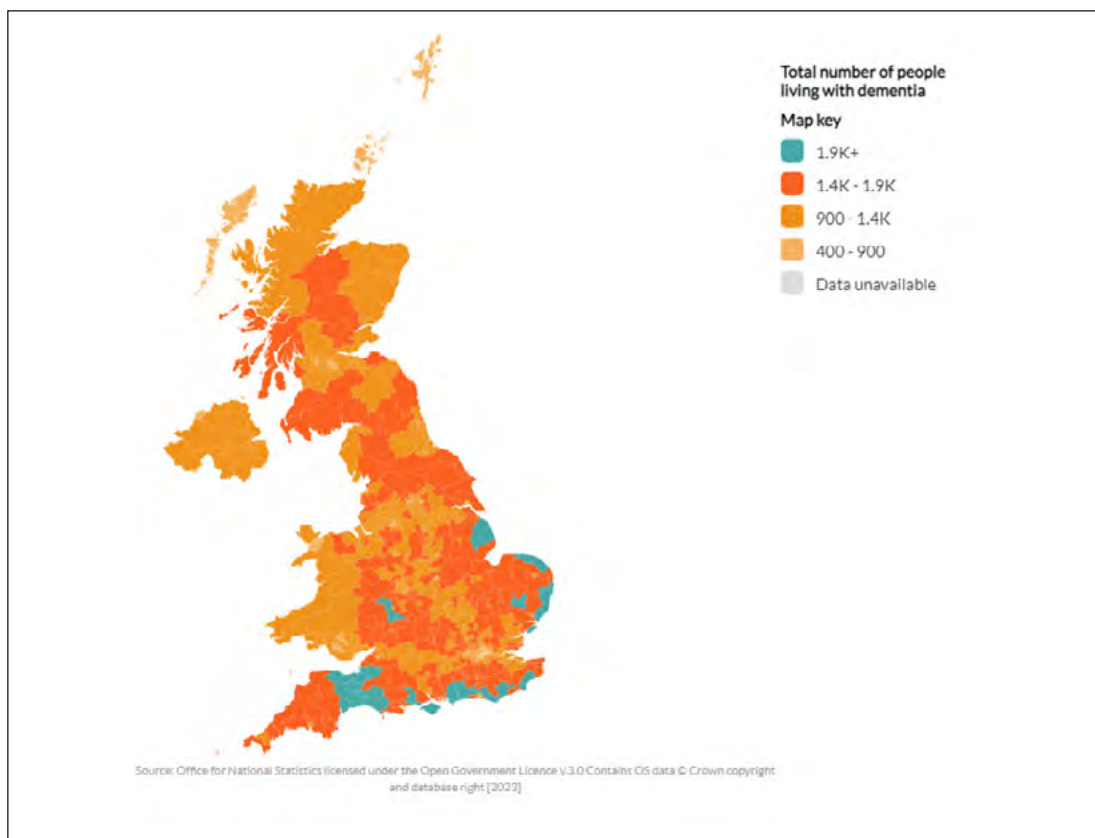
The United Kingdom (UK) has a minority ethnic population making up more than 10% of the whole population (Office for National Statistics (ONS), 2022). An estimated 25,000 people in the UK living with dementia are from racially and ethnically diverse backgrounds. Figure 5 shows what percentage of each constituency’s population is living with dementia, highlighting the relative impact of the condition in each area (Alzheimer’s Research UK, 2023).

In addition to the variation in geographic distribution of dementia cases in the UK, recent research has also found inequities in dementia incidence and mortality in terms of race and ethnicity. In a large sample of participants age 55 and older in the UK Biobank with a long follow-up, researchers found that Black participants were more likely to develop dementia than whites, but South Asian individuals were not (Mukadam, N. et al, 2022). In a large nationally representative sample, Asian UK ethnic groups were less likely to receive a dementia diagnosis compared with the white majority population, while the Black ethnic groups were more likely to receive a diagnosis compared to the same counterpart (Pham et al., 2018). However, several other studies reported mortality risk of dementia was lower in Black and Asian ethnic groups compared to the white British population, even after adjusting for age, gender, neighborhood-level deprivation, indicators of mental and physical comorbidities (Co et al., 2023). Researchers are currently looking for further explanations of such findings.



In England and Wales there is a national guideline regarding dementia assessment and management which recommends consideration of cultural and linguistic diversity when assessing people with cognitive complaints. It is evident that at least some of the current services reflect national policy for the assessment and management of memory problems in patients from racially and ethnically diverse backgrounds by using cognitive assessment tools that are culturally sensitive and appropriate and/or providing translated resources or interpreters (Brown et al., 2021).

**Figure 6: Dementia prevalence by UK constituency (percentage of population living with dementia), 2020**



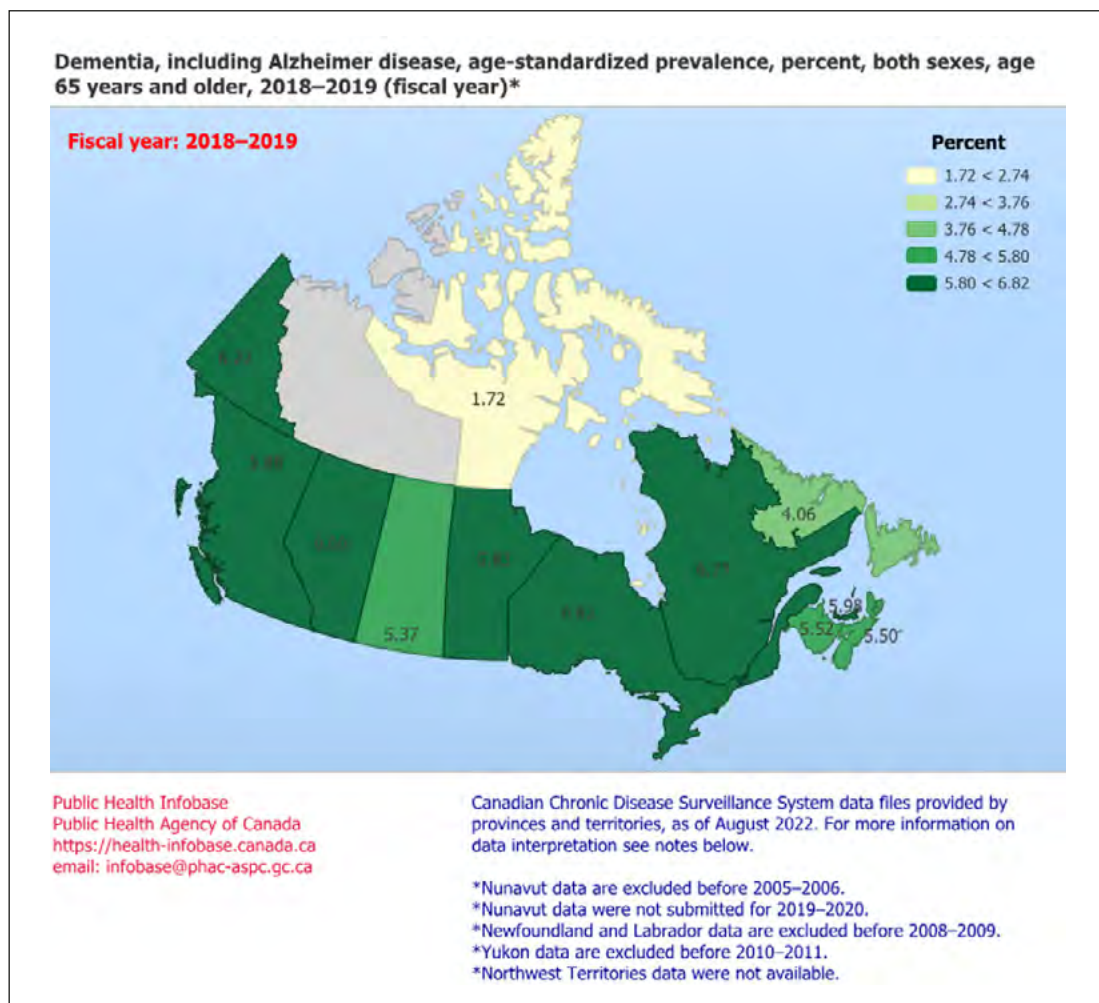
**Source:** Alzheimer's Research UK. (2023). *Dementia Prevalence by UK Constituency*. Retrieved May 21, 2023, from <https://visualisation.polimapper.co.uk/?dataSetKey=dementia-prevalence-by-uk-constituency-2023&client=alzheimersresearch> Used with permission.

## Canada

In Canada between April 2017 and March 2018 almost 452,000 people over age 65 were living with diagnosed dementia. The variation seen in dementia prevalence among the provinces can mostly be attributed to the population density of the area (Figure 6) (Public Health Infobase, 2023).

However, cognitive functioning among older adults has been found to vary by race and ethnicity, which can be explained by socioeconomic inequalities (in income and food security) and socially patterned behaviors (i.e., drinking, physical activity levels). Immigration status has also been found to be significantly associated with dementia prevalence, probably due to the healthy migrant effect playing a role in reduced rate of dementia among recent immigrants (Wong et al., 2021).

**Figure 7: Dementia prevalence (population percentage living with dementia) by provinces in Canada, 2018–2019**



**Source:** Public Health Infobase. (2023). *Canadian Chronic Disease Surveillance System (CCDSS)*. Public Health Agency of Canada (PHAC). Retrieved from <https://health-infobase.canada.ca/ccdss/data-tool/Comp?G=00&V=16&M=1> Used with permission.

## Israel

Israel, a multiethnic country, has the largest ethnic group of Israeli Jews, followed by Arab citizens, mostly Arab Muslims, with smaller numbers of Arab Christians in addition to Druze, Circassians, and others. Recent studies found clear evidence that the prevalence of dementia among members of the Arab population in Israel is relatively high and even higher than in societies with a similar profile of education and literacy such as India, Taiwan, Egypt, and other countries (Werner et al., 2015). This is consistent with other studies suggesting that compared to Israeli Jews, Arabs living in Israel are more likely to experience an onset and worsening progression of overall functional limitations (Osman & Walsemann, 2017).

## Latin America

Latin American countries are facing huge social, economic, and environmental challenges with a faster demographic shift but much less preparedness than the high-income countries. Due to demographic

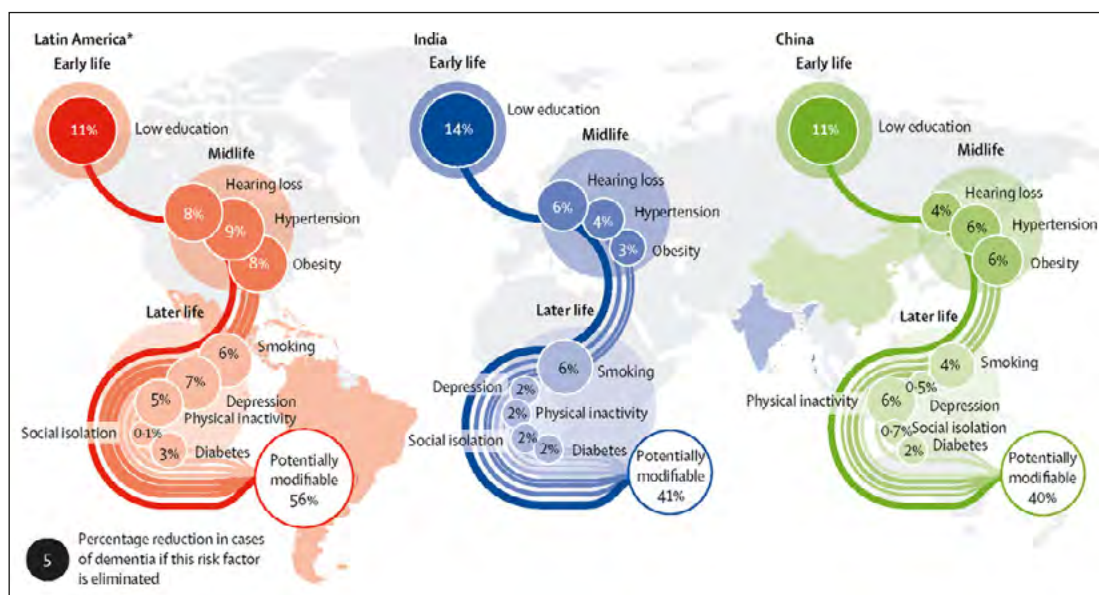
and health transitions, the number of people with dementia in Latin American countries is projected to rise from 7.8 million in 2013 to over 27 million by 2050 (Custodio et al., 2017). According to Argentine neuropsychologist Dr. Lucia Crivelli, “Latin America constitutes a large region united by a common culture and a shared history while at the same time evidencing significant differences in terms of demographic and geographical singularities. Uneven distribution of income and unequal access to resources may help explain the uniqueness of each community.”

To shed light on the current challenges in dealing with dementia Dr. Facundo Manes says, “Although National Plans for dementia are being developed in some Latin American countries, substantial challenges remain to provide an accurate diagnosis of dementia and achieve effective care.” In his opinion, inadequate knowledge, and insufficient awareness of timely detection of dementia among providers; low education and limited literacy skills of people in some region; and stigma towards mental health issues in general make it difficult for many people to obtain appropriate medical help. The costly services and infrastructures necessary for dementia diagnoses and subsequent care are often available only in some affluent urban areas of the countries (Manes, 2016).

### Dementia prevention efforts around the world

Around 35% of the worldwide dementia burden can be potentially prevented by addressing modifiable risk factors. The dementia prevention potential in China and low- and middle-income countries like India and Latin American countries is large, and if instituted by these countries, may have great potential for benefit of those populations (Figure 8) (Mukadam et al., 2019).

**Figure 8: Population attributable fractions for potentially modifiable risk factors in low-income and middle-income countries**



**Source:** Mukadam, N., Sommerlad, A., Huntley, J., & Livingston, G. (2019). Population attributable fractions for risk factors for dementia in low-income and middle-income countries: an analysis using cross-sectional survey data. *The Lancet Global Health*, 7(5), e596-e603. Used with permission.

**\*Data for Latin America include the data for Cuba, Dominican Republic, Mexico, Peru, Puerto Rico, and Venezuela.**

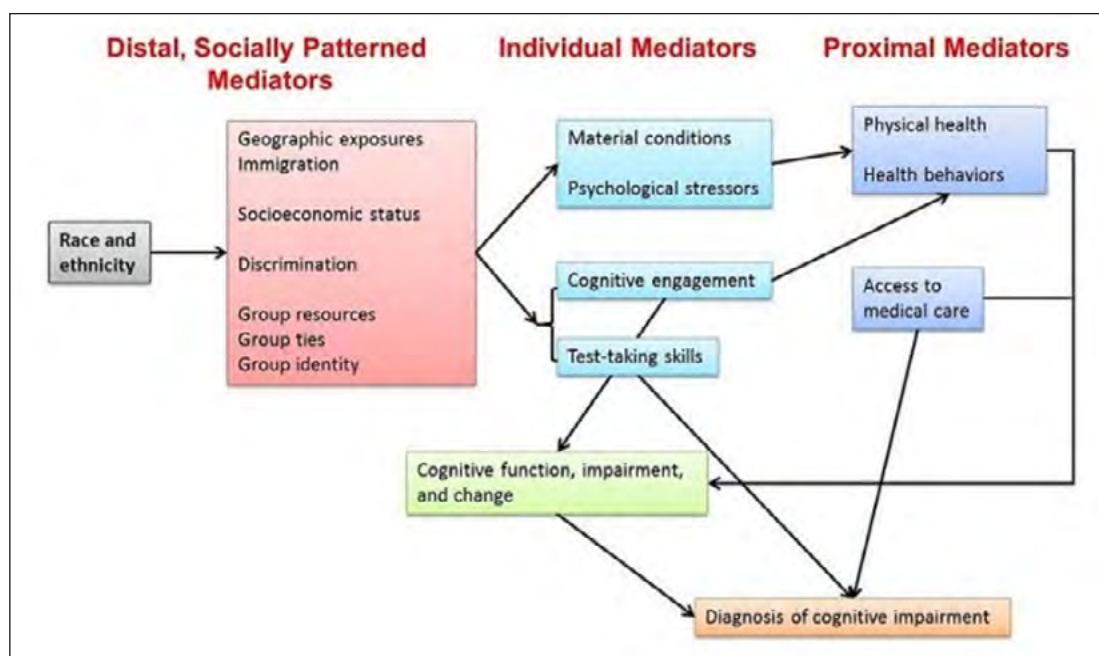
However, dementia prevention efforts require a comprehensive and coordinated approach involving multiple stakeholders at the local, national, and global level. In 2017, the WHO published a global action plan on dementia with an aim that by 2025 at least 75% of the countries around the world will have a national plan or strategy to deal with dementia. In addition, WHO makes a special recommendation that all public health responses to dementia must consider minority and vulnerable population.

As of 2022, only 44 out of 196 countries around the world have national guidelines for dementia, and only 37 of them include at least one equity-focused recommendation considering age, disability, race, religion, gender, and sexual orientation (James et al., 2022). According to WHO’s global target, the number falls short both in terms of having specific dementia guidelines and addressing equity issues.

## 5. Dementia Disparities in the United States

An estimated 6.5 million people aged 65 and older are currently living with dementia in the United States, which is equivalent to 1 in every 9 people over age 65. However, the risk and burden of dementia is not distributed uniformly among people of different racial/ ethnic backgrounds living in the United States. There are many social and individual factors that mediate the association between one’s race/ ethnicity and being diagnosed with cognitive impairment. Figure 1 shows a range of pathways that have been suggested as linking race and ethnicity with cognitive impairment, some of which have implications for disparities.

**Figure 1: Pathways linking race/ ethnicity and cognitive impairment**



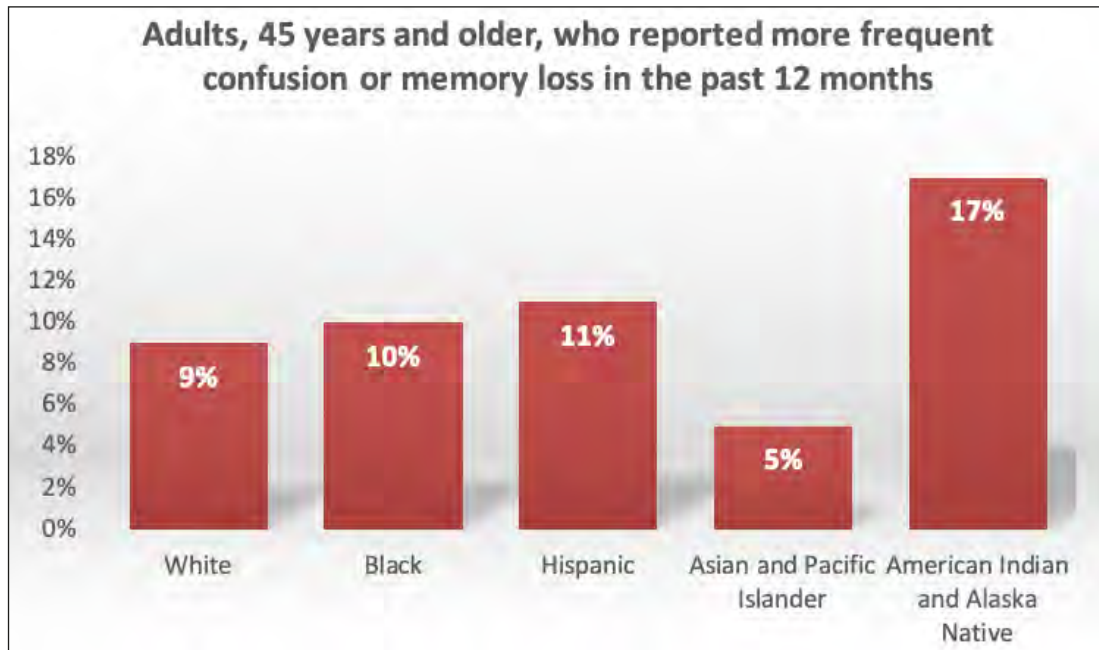
**Source:** Lines, L. M., & Wiener, J. M. (2014). *Racial and ethnic disparities in Alzheimer’s disease: a literature review*. U.S. Department of Health and Human Services | Office of Disability, Aging and Long-Term Care Policy. [http://aspe.hhs.gov/office\\_specific/daltcp.cfm](http://aspe.hhs.gov/office_specific/daltcp.cfm) Used with permission.

Racially and ethnically diverse populations, especially Black Americans and Hispanic Americans, are found to have a higher risk of dementia compared to white Americans in the United States across many studies irrespective of designs, sampling methods, and definitions of dementia. According to the Alzheimer’s Association, Black Americans are about twice as likely to develop dementia than white

Americans and Hispanic Americans are about one and one-half times more likely to develop dementia than white Americans. (Alzheimer’s Association 2020).

In a CDC report published in 2023, prevalence of subjective cognitive decline (SCD), which is an important symptom of early-stage dementia is found to be strikingly high among American Indian or Alaska Native adults (16.7%) compared to other racial/ ethnic groups (figure 2) (Wooten et al., 2023).

**Figure 2: Age-adjusted prevalence of SCD during 2015–2020 stratified by race/ ethnicity**

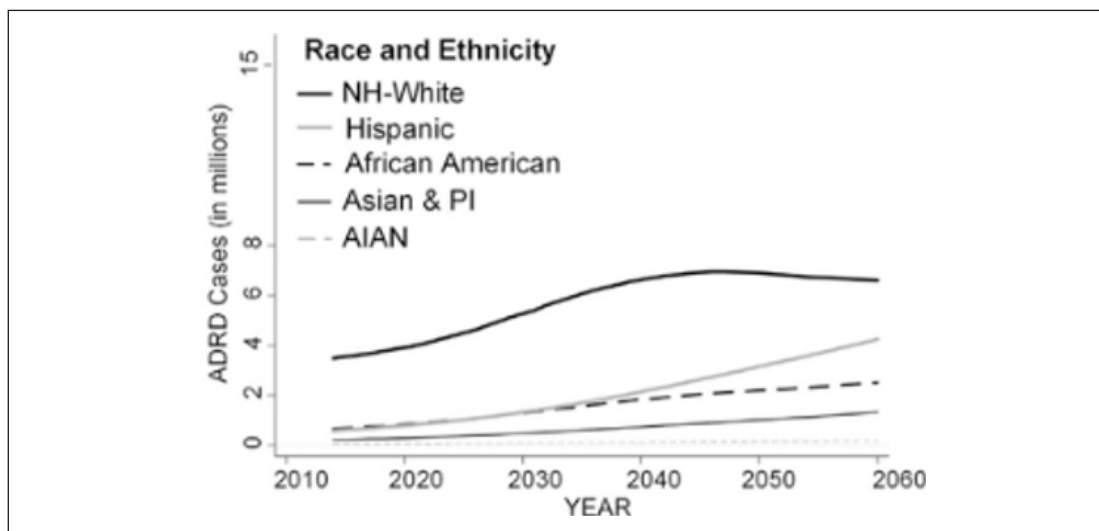


**Source:** Wooten, K. G., McGuire, L. C., Olivari, B. S., Jackson, E. M. J., & Croft, J. B. (2023). Racial and Ethnic Differences in Subjective Cognitive Decline -- United States, 2015 -2020. *MMWR. Morbidity and Mortality Weekly Report*, 72(10), 249 -255. <https://doi.org/10.15585/MMWR.MM7210A1> Used with permission.

CDC researchers have also predicted that by 2060, Hispanic Americans will have the largest projected increase in dementia cases due to population growth. Although because of the relative size of the population, non-Hispanic whites will still have the largest total number of dementia cases (Figure 3) (Matthews et al., 2019).



**Figure 3: Projected number of adults aged ≥65 years with ADRD by racial and ethnic groups 2015 to 2060**



**Source:** Matthews, K. A., Xu, W., Gaglioti, A. H., Holt, J. B., Croft, J. B., Mack, D., & McGuire, L. C. (2019). *Racial and ethnic estimates of Alzheimer's disease and related dementias in the United States (2015–2060) in adults aged ≥ 65 years. Alzheimer's & Dementia, 15(1), 17–24.* Used with permission.

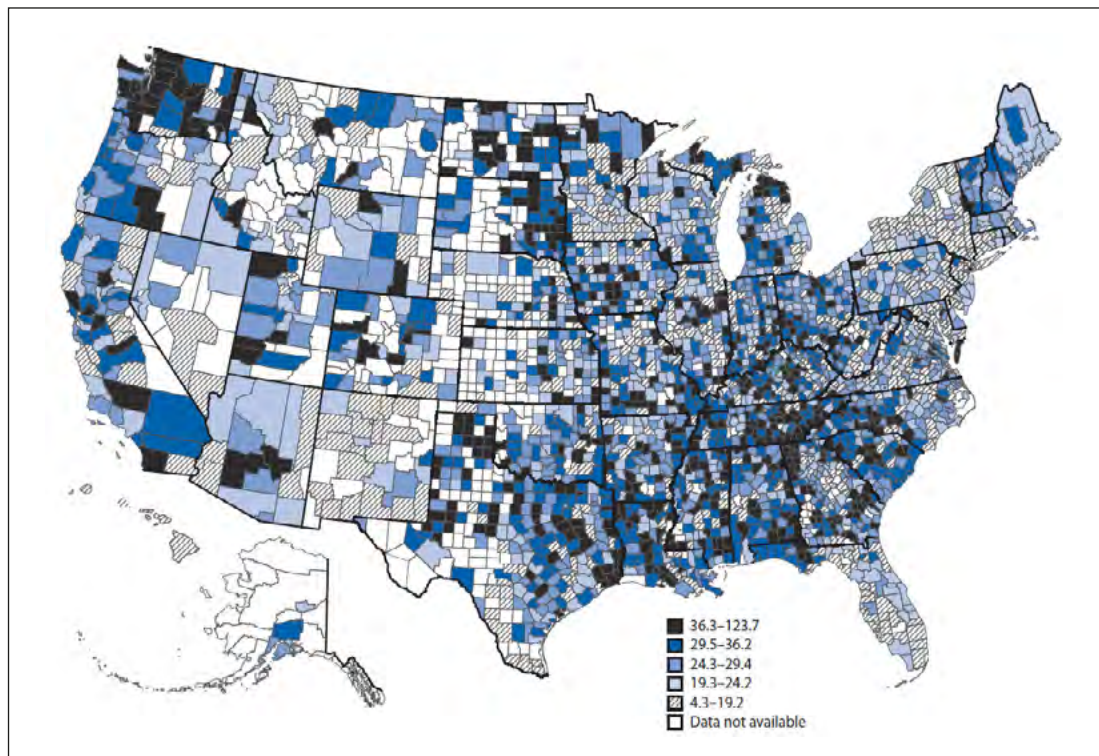
There is a state level variation in dementia prevalence across the U.S. which suggests that the number of diagnosed dementia cases does not fall evenly across all states. Figure 4 shows that some geographic regions in the US have states with higher dementia diagnosis whereas some regions have relatively lower prevalence (Koller & Bynum, 2015). Similarly, a variation in the death rates from the most common cause of dementia, Alzheimer's disease (AD), has also been noticed. Figure 5 below shows that AD mortality has significantly increased all over the country between the years 2005 and 2014 but primarily in the Southeast regions, plus some additional areas in the Midwest and West (Taylor et al., 2019).

**Figure 4: Standardized state prevalence (in %) of dementia in Medicare FFS population, 2008 by US region**

West		Southwest		Midwest		Southeast		Northeast	
State	Prevalence	State	Prevalence	State	Prevalence	State	Prevalence	State	Prevalence
WA	7.11	AZ	6.01	ND	6.52	AR	9.06	ME	7.71
OR	6.68	NM	6.94	SD	5.96	LA	9.33	VT	7.37
ID	6.19	TX	9.55	NE	6.57	MS	9.51	NY	8.67
MT	7.09	OK	8.28	KS	7.45	AL	9.30	PA	8.29
CA	7.61			MN	6.11	GA	8.94	NH	8.30
NV	6.70			IA	6.90	FL	8.19	MA	8.38
UT	6.83			MO	8.43	TN	9.30	CT	9.20
WY	7.71			WI	7.49	KY	8.69	RI	8.26
CO	7.49			IL	8.04	WV	8.68	NJ	8.22
				MI	8.50	NC	8.58	DE	7.72
				IN	7.92	SC	8.89	MD	7.90
				OH	8.93	VA	8.49		
						DC	8.10		

**Source:** Koller, D., & Bynum, J. P. (2015). *Dementia in the USA: state variation in prevalence. Journal of Public Health, 37(4), 597–604.*

**Figure 5: Average annual age-adjusted death rates from Alzheimer’s disease per 100,000 population, by county — United States, 2005–2014**



**Source:** Taylor CA, Greenlund SF, McGuire LC, Lu H, Croft JB. Deaths from Alzheimer’s Disease — United States, 1999–2014. *MMWR Morb Mortal Wkly Rep* 2017;66:521–526. DOI: <http://dx.doi.org/10.15585/mmwr.mm6620a1external icon> Used with permission.

However, since there is no dementia surveillance system in the United States at present, it is often challenging to have local level estimates of the risk and burden of dementia. Researchers often use projection methodology based on existing data to come up with dementia estimates at various levels stratified by race and ethnicity. In a large systematic review researchers have reviewed more than 1,200 studies to find out such reported dementia prevalence and incidence rates for racial/ethnic groups in the United States. The results show a wide variation in the estimates even within a race/ethnic group that highlights the fact of within-population heterogeneity in each group and drastically underrepresents the actual diversity (Mehta & Yeo, 2017). This underscores the importance of future studies to consider further disaggregation of large race/ethnic groups by ensuring adequate participation of minority populations in the research.

A very stark problem is the underrepresentation of minority populations in clinical trials and other population-based studies that could inform clinical trials. Studies have shown that only 1% of National Institutes of Health (NIH) clinical trials in the United States include Latino Americans as participants, but Latino Americans are 17% of the population (Wu et al. 2016). African Americans are similarly underrepresented in clinical trials (Vidoni, et al. 2020). Another study also showed that only 0.17% of the overall NIH budget was allocated to Asian American, Native Hawaiian and Pacific Islander -related clinical research projects over two decades (Doan et al., 2019). A major initiative is now underway at the NIH to be more inclusive in research (National Institute on Aging, 2023).

## 6. Discussion Questions Framing the Deliberations

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### a. Questions related to U.S. equity issues:

- How does the GCBH define “brain-health equity”?
- What policies exist that create barriers to better brain health?
- What are the important structural disparities/inequities that we should include in a discussion of brain health?
- How do social determinants of health impact brain health? Cite specific examples.
- What recommendations can we make to solve for these inequitable policies, disparities and social determinants of health?
  - Policymakers
  - Communities
  - Clinical environment
  - Individuals/families
- How do we promote better collection of data on disparities?
- Are there unique cultural differences that need to be taken into account for:
  - African Americans
  - Hispanic/Latino Americans
  - Asian Americans
  - Native Americans
  - Individuals in the LGBTQ+ community
  - Individuals living with dementia
  - Individuals living with early onset dementia
- What recommendations can we make to families to prepare for clinical encounters? (practical tips and tools)
- What are knowledge gaps in the field that would advance research into brain-health equity?
- How can we most effectively involve stakeholders to drive change with regard to brain-health equity?

### b. Questions related to international equity issues:

- Are there any brain-health equity issues in your country or the population you work with (consider the sociodemographic factors i.e. gender, race and ethnicity, geographic distribution, education and socioeconomic status)?
- What are the structural and cultural factors (i.e. health care system, built environment, policy, etc.) that are causing these inequities, and what recommendations do you make to overcome such inequities?
- Is “dementia care” a priority in your country or the population you work with?
  - Having a roadmap for improving public’s brain health with a focus on building equity
  - Providing any social support (monetary/ non-monetary/ residential support etc.) for the people with neurological disorder
- Does your country or the population you work with have a data gathering system on the incidence and outcome of neurological disorder?
- Is the data representative of the general population or include enough information on the racially or ethnically diverse communities?
- How do we promote better collection and sharing of brain-health data across the world?

### **c. Questions related to lived experience of equity issues:**

- 1.** What barriers or problems do people living with dementia experience that you'd like us to know about? *For example, are there barriers to people receiving information about dementia and brain health? Barriers to receiving a medical diagnosis? Difficulties finding care or services you need? Problems with the quality of care? Are there other barriers we should know about?*
- 2.** Are there specific problems or barriers to access to information, care, or services that you have experienced due to your demographic characteristics or because you are a member of a particular community? *In other words, are there specific barriers or problems you have faced because you are Black, LGBTQ+, Hispanic/Latino, a rural resident, etc.?*
- 3.** What has been helpful to you, or what would be helpful? *Such as, is there an example of a community-based or faith-based organization that provided guidance or services that you found helpful? Tools that have been helpful? Something you've found to be empowering?*
- 4.** What else would you like us to know about being \_\_\_\_\_ and a person living with dementia? *For this question, please fill in the blank with one or more ways that you would describe yourself: you race, ethnicity, gender identity, sexual orientation, religion, where you live, or another characteristic that you use to describe yourself.*

## **7. Disclosure Statement of Potential Conflicts of Interest**

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Thirty-three of the GCBH experts – all of the eighteen issue specialists and fifteen governance committee members – participating in the formulation of this report were asked to disclose potential conflicts of interest. Thirty-one attested they had no conflicts of interest. Dr. Petersen disclosed consulting with several pharmaceutical companies. Dr. Yaffe disclosed serving on a data and safety monitoring board for a pharmaceutical company. The authors are unaware of any affiliation of the experts that affected the objectivity of this paper and its recommendations. These disclosures are available upon request by contacting staff of the Global Council on Brain Health.

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## 10. List and Links to Other GCBH Reports

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All reports are available for download at [GlobalCouncilonBrainHealth.org](https://www.globalcouncilonbrainhealth.org).

- [The Brain-Body Connection: GCBH Recommendations on Physical Activity and Brain Health](#)
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- [Brain Food: GCBH Recommendations on Nourishing Your Brain Health](#)
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