

# The Burden of Alzheimer's Disease and Related Diseases in Vulnerable Populations

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# What is Alzheimer's disease (AD?)

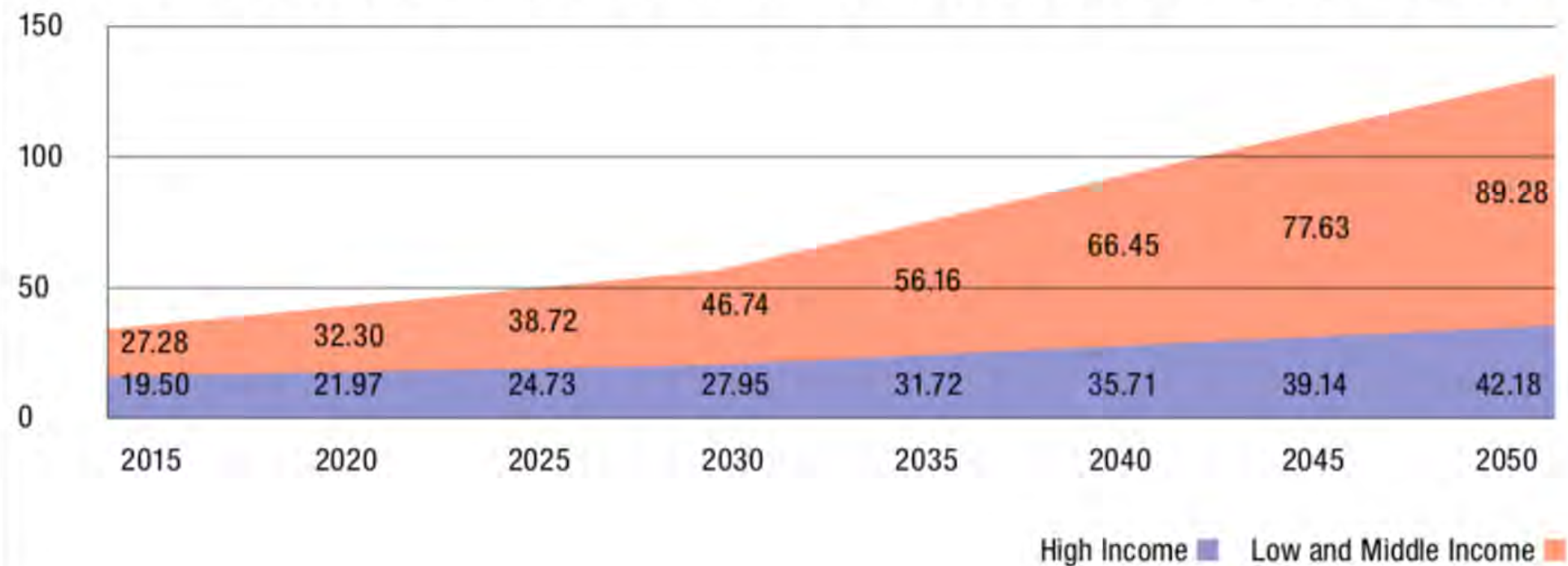
- AD is a degenerative brain disease and the most common cause of dementia, accounting for approximately 70% of patients.
- Dementia is not a specific disease but rather an overall term that describes a group of symptoms.

# World Health Organization projections

- In 2025, about 3/4 of the estimated 1.2 billion people over 60 years old will reside in developing countries.
- By 2040, if there are no changes in mortality or burden-reduction in dementia, 71% of 81.1 million people with dementia will be living in the developing world.

Figure 2.4

The growth in numbers of people with dementia (millions) in high income (HIC) and low and middle income countries (LMIC)



Source: Alzheimer's Disease International

"If we aren't intersectional,  
some of us, the most  
vulnerable, are going to fall  
through the cracks."

- Kimberle Williams Crenshaw  
(civil rights advocate)

**What is the prevalence of dementia in vulnerable populations?**



Photo: Alex Kornhuber

# Important disclaimer:

- It is estimated that 5 to 7% of people throughout the world live with dementia;
- However, the lack of standardized diagnostic procedures throughout the world is a major limitation in the estimation of the true burden of dementia.

# Dementia in indigenous populations

- There is no universally-accepted definition of what constitutes an "indigenous population".
- Self - identity
- It is estimated that 370 million people worldwide - 5% of the world population - consider themselves indigenous.
- There are only 15 studies looking at the impact of dementia in indigenous populations.



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- There are only 15 studies looking at the impact of dementia in indigenous populations.
  - These studies suggest that the prevalence of dementia doubles with every 5.5-year increase in age after age 60.
  - Estimates of prevalence dementia in indigenous populations ranged widely, from 0.5%- 20%.

# Worldwide, 50 million people live with dementia; 152 million in 2050.


41 million Latin Americans are 60 years or older, and 7.1% of them live with dementia. The prevalence of dementia in those 65+ is higher than those living in developed countries.

A study of a low-income, rural, isiXhosa-speaking community of S. Africa found that 11% of those older than 65 had dementia.

In India, 76 million people are over 60 years old. Anywhere from 1% to 3.4% of people aged 60 to 65 in urban and rural areas have dementia, according to studies.

A study of rural Bangladesh found that 11.5% of people over 60 years old had questionable dementia, and 3.6% had definite dementia.

Aboriginal Australians have one of the worst life expectancies and health outcomes. Approximately 13.4% of those older than 60 years live with dementia (3 times higher than rest of population).



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Table 1

## AD and VaD prevalence and key risk factors in developing countries

	Year	Criteria	Sample size (n)	Age (years)	Prevalence (95% CI)			Causes of other dementias
					All dementia	AD	VaD	
<b>Asia</b>								
China <sup>30*</sup>	2007	DSM-III, ICD-10	87 761	>65	3.1% (2.8–3.5)	2.0% (1.5–3.1)	0.9% (0.7–1.1)	Mixed, PDD, DLB, FTD
China (Beijing, Xian, Shanghai, Chengdu) <sup>31</sup>	2005	DSM-IV	34 807	>65	5.0%	3.5% (3.0–3.9)	1.1% (0.9–1.1)	Mixed, PDD, DLB
Taiwan <sup>40,43†</sup>	1995-1998	DSM-III-R, DSM-IV	7149	>65	3.2% (1.5–4.9)	1.9% (1.2–2.5)	0.7% (0.1–1.3)	Mixed
South Korea <sup>3,32,44‡</sup>	1994-2005	DSM-III, DSM-IV	7096	>65	10.1% (7.3–12.9)	5.2% (3.5–6.8)	2.1% (1.2–2.9)	Mixed
Thailand <sup>45</sup>	2001	DSM-III	4048	>60	3.4% (2.8–4.0)	..	..	..
India <sup>33,34,46-48§</sup>	1996-2006	DSM-III, DSM-IV	14 767	>65	2.7% (1.4–4.0)	1.3% (0.8–1.8)	1.1% (0.2–1.9)	Mixed, PDD, DLB, PSD
Sri Lanka <sup>49</sup>	2003	DSM-IV	703	>65	3.98% (2.6–5.7)	2.85%	0.6%	Mixed
Israel (Wadi Ara) <sup>50¶</sup>	2002	DSM-IV	823	>65	21.1%	20.5%	6.0%	Mixed
<b>Africa</b>								
Egypt <sup>51</sup>	1998	DSM-IV	1366	>65	5.93%	2.86%	1.25%	Mixed
Nigeria <sup>52#</sup>	1995	DSM-III, ICD-10	2494	>65	2.3% (1.2–3.4)	1.4% (0.62–2.2)	0.72%	Mixed, DLB
<b>Latin America **</b>								
Cuba <sup>53</sup>	1999	DSM-IV	799	>60	8.2% (6.3–10.4)	5.1% (3.6–6.6)	1.9% (1.0–3.0)	Mixed, alcohol dementia
Argentina <sup>54</sup>	1999	DSM-IV	1900	>65	11.5%	..	..	Age
Brazil <sup>35–37,55††</sup>	2002-2008	DSM-III-R, DSM-IV	7513	>65	5.3% (1.5–8.9)	2.7% (0.1–5.2)	0.9% (0.06–1.78)	Mixed, PDD
Chile <sup>56</sup>	1997	DSM-III-R	2213	>65	4.3% (3.5–5.3)	..	..	..
Colombia <sup>57,58</sup>	2000	DSM-IV	1611	>65 and >75	1.8% (1.2–2.7) and 3.4% (1.2–5.6)	..	..	..
Peru <sup>38</sup>	2007	DSM-IV	1532	>65	6.7% (5.5–8.0)	..	..	..
Venezuela <sup>39</sup>	2002	DSM-IV	2438	>55 and >65	8.0% (7.0–9.2) and 10.3% (8.3–13.0)	4.0% (3.3–4.8)	2.1% (1.6–2.7)	Mixed

# Black vs. White Americans

## The Chicago Health and Aging Project:

- Blacks performed worse than whites on cognitive tests.
- Blacks were more likely to have prevalent Alzheimer's disease at baseline.
- Blacks had higher risk of incident Alzheimer's disease.
  - Rate of cognitive decline among blacks differed little from whites.
- Persistent differences in cognitive level between races underlie higher risk of



- Rate of cognitive decline among blacks differed little from whites.
- Persistent differences in cognitive level between races underlie higher risk of incident Alzheimer's disease.
- These observed differences are caused by racial disparities over the lifespan:
  - Access to high quality education
  - Access to material and social resources
  - Exposure to discrimination
  - Exposure to neurotoxins
  - Access to healthcare

“I gave three years of my life to take care of my dying mother who had Alzheimer’s disease. Being there for her every need for three years might have looked co-dependent but it wasn’t because it was what I wanted to do.”

- Melody Beattie  
(American author)



**What is the  
social and  
economic cost  
of dementia  
around the  
world?**

Photo: Alex Kornhuber



A proper understanding of the societal costs of dementia and how they affect families, health and social services, and governments is fundamental to raising awareness, achieving proper prioritization, and focusing efforts to improve the lives of people with dementia and their caregivers.

# The global impact of dementia

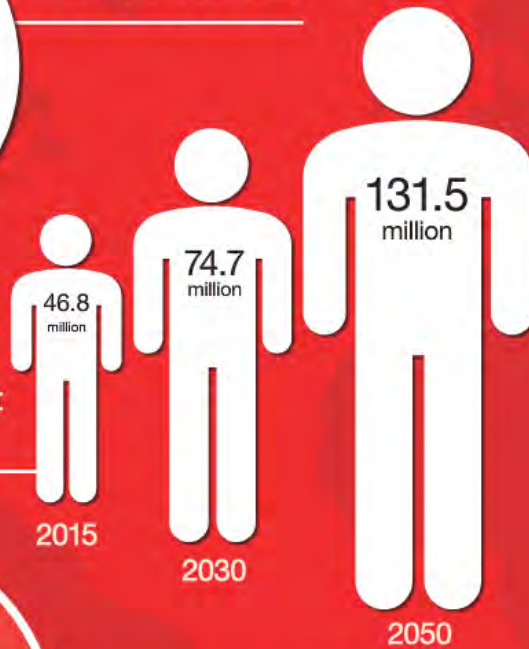


Around the world, there will be 9.9 million new cases of dementia in 2015,

**one every 3 seconds**

46.8 million people worldwide are living with dementia in 2015.

This number will almost double every 20 years.



Much of the increase will take place in low and middle income countries (LMICs): in 2015, 58% of all people with dementia live in LMICs, rising to 63% in 2030 and 68% in 2050.



The total estimated worldwide cost of dementia in 2015 is US\$ 818 billion.

By 2018, dementia will become a trillion dollar disease, rising to

**US\$ 2 trillion by 2030**

If global dementia care were a country, it would be the

**18th largest economy**

in the world exceeding the market values of companies such as Apple and Google



(source: Forbee 2015 ranking).



This map shows the estimated number of people living with dementia in each world region in 2015.

We must now involve more countries and regions in the global action on dementia.

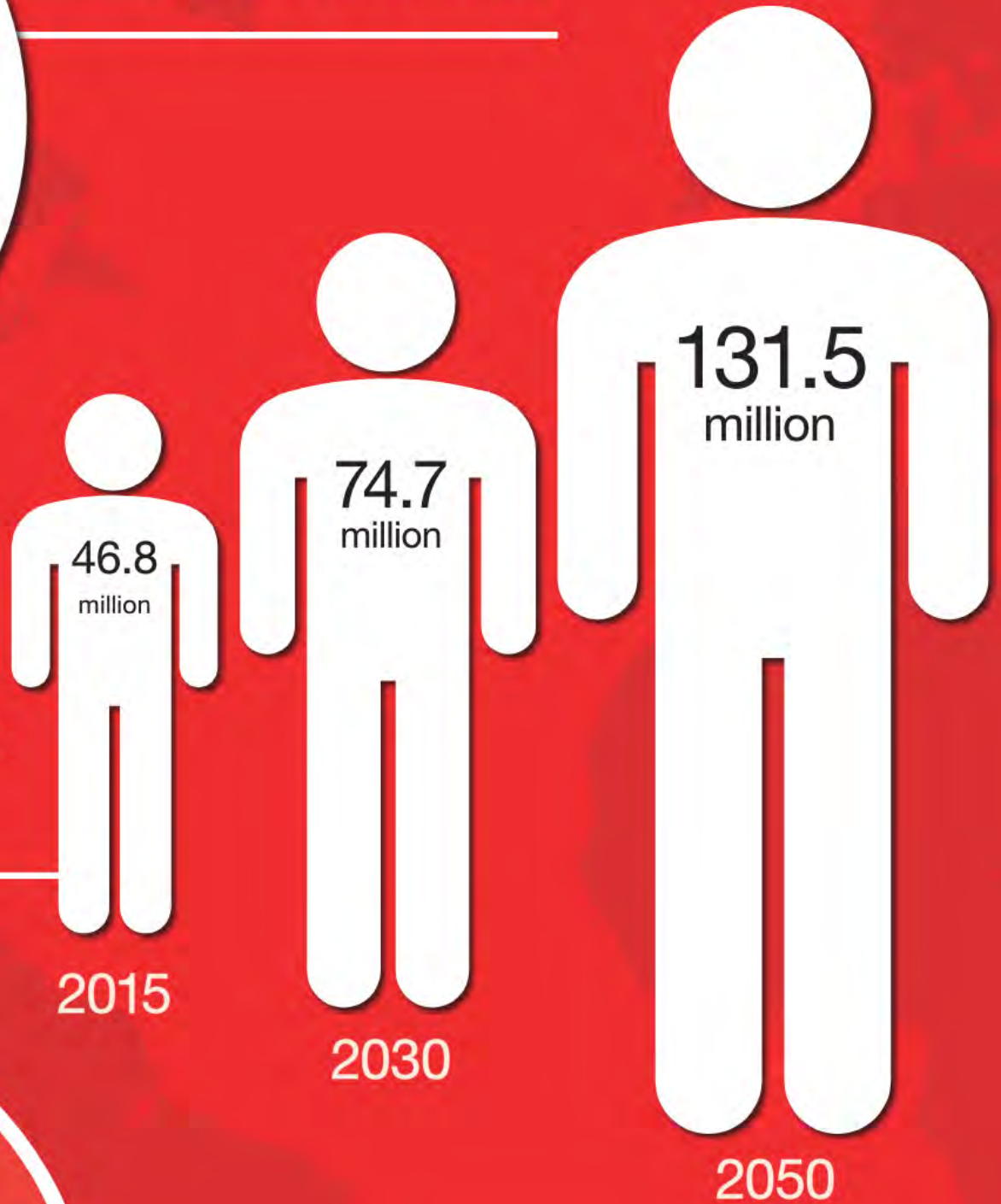


**Alzheimer's Disease International**

*The global voice on dementia*

The World Alzheimer Report 2015 was independently researched by King's College London and supported by Bupa.

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810  
BILLION

TRILLION

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(source: Forbes 2015 ranking).





**What is the  
social cost of  
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Photo: Alex Kornhuber

# Social Cost of Dementia

- In developing countries, the state does not provide long-term care.
- Traditional kinship structures are under threat from the demographic, social, and economic changes that accompany economic development.
- Worldwide costs of dementia used an average of 1.6 hours of informal care/day.

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- Worldwide costs of dementia used an average of 1.6 hours of informal care/day.
- Living with children is the norm, and three-generation households are common.
- Around 37% of people with dementia live alone or with a spouse only.

# Caregiver Burden

- Caregiver burden refers to the overall pressure of caregiving, encompassing physical, psychological, social, and financial factors.
- Studies show that caregivers tend to experience:
  - Physical and psychological stress
  - Higher risk of clinical depression
  - Higher risk of clinical anxiety
  - Higher risk of chronic medical conditions
- The lower the patient's daily functioning, the

- Higher risk of clinical depression
  - Higher risk of clinical anxiety
  - Higher risk of chronic medical conditions
- The lower the patient's daily functioning, the higher the caregiver's burden.
  - The more frequent and severe the patient's behavioral symptoms, the higher the caregiver burden.
  - The higher the sense of obligation a caregiver has, the higher the caregiver burden.

# Does Caregiver Burden Vary According to the Cause of Dementia?

One study showed that, in early stages, patients with dementia caused by cerebrovascular disease (vascular dementia) imposed a greater burden on caregivers than did patients with dementia due to Alzheimer's disease (AD).

The authors highlight that this observation may be related to the fact that patients with vascular dementia tend to need care for other conditions:

- hypertension
- heart disease
- stroke
- diabetes

- heart disease
- stroke
- diabetes

In late stages of disease, relatives of AD patients experienced more caregiver burden than those of vascular dementia patients.

Anecdotally, caregiver burden varies according to dementia type during early stages of disease (frontotemporal dementia vs. AD), but caregiver burden tends to homogenize in late stages of illness.



**What is the  
economic cost  
of dementia  
around the  
world?**



# Unpaid, "Informal" Care

- Translating the contribution of informal care into financial costs is not straightforward.
- The inputs most commonly assessed are:
  - assistance with basic activities of daily living (eating, dressing, etc.)
  - assistance with instrumental activities of daily living (finances, shopping, etc.)
  - supervision and management of behavioral symptoms
  - harm prevention
- Direct medical costs: hospital care

- supervision and management of behavioral symptoms
- harm prevention

- Direct medical costs: hospital care, medications, and visits to clinics.
- Direct social care costs: community services (such as home care), food supply, transportation, and residential or nursing home care.

World Bank income region	Informal care (all ADLs), %	Direct costs, %		Total costs, %
		Medical	Social	
Low	57.6	28.2	14.3	100
Lower middle	64.7	23.1	12.2	100
Upper middle	42.2	32.1	25.7	100
High	<u>40.3</u>	14.5	<u>45.2</u>	100
All	41.7	16.0	42.3	100

Aggregated costs types as percentages of total costs in the different World Bank income regions.

## Cost per person with dementia by World Bank income region

World Bank income region	Informal care (all ADLs), US\$	Direct costs, US\$		Total costs, US\$
		Medical	Social	
Low	<u>500</u>	244	<u>124</u>	868
Lower middle	<u>2012</u>	717	<u>380</u>	3109
Upper middle	2879	2194	1755	6827
High	13,244	4766	14,855	32,865
All	7084	2711	7191	16,986

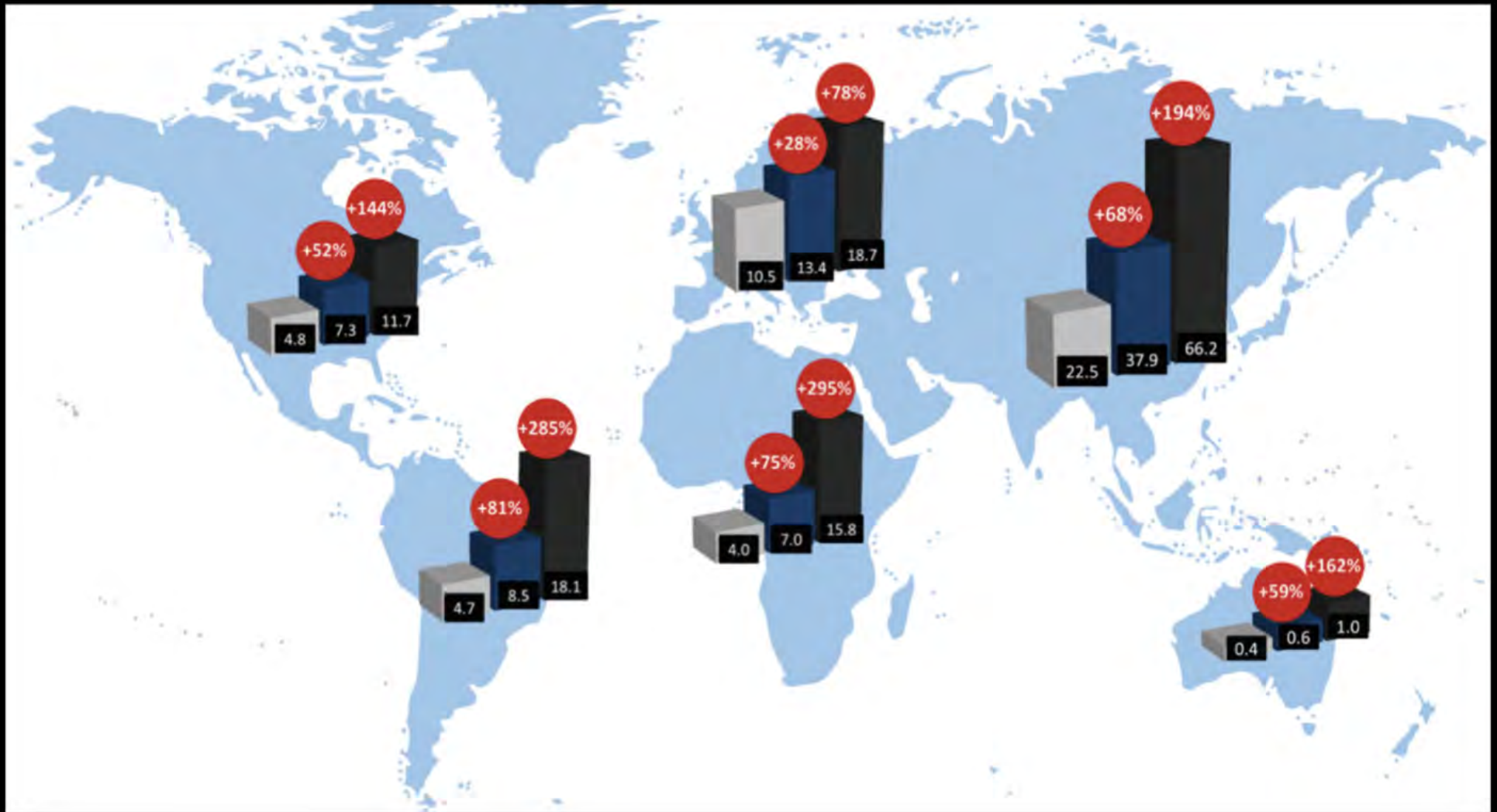
Per capita (US\$) and aggregated costs of dementia (in billions of US\$) by World Health Organization global burden of disease region and World Bank income classification

WHO region	Per capita costs, US\$	People with dementia, n	Aggregated costs, billions of US\$					
			Total costs	Total costs as a% of GDP	Direct costs as a% of GDP	Informal care (all ADLs)	Direct medical costs	Direct social costs
Low income		5,036,979	4.37	0.24	0.10	2.52	1.23	0.62
Lower middle income	3109	9,395,204	29.21	0.35	0.12	18.90	6.74	3.57
Upper middle income	6827	4,759,025	32.49	0.50	0.29	13.70	10.44	8.35
High income	32,865	16,367,508	537.91	1.24	0.74	216.77	78.00	243.14
<b>Total</b>	16,986	35,558,717	603.99	1.01	0.59	251.89	96.41	255.69

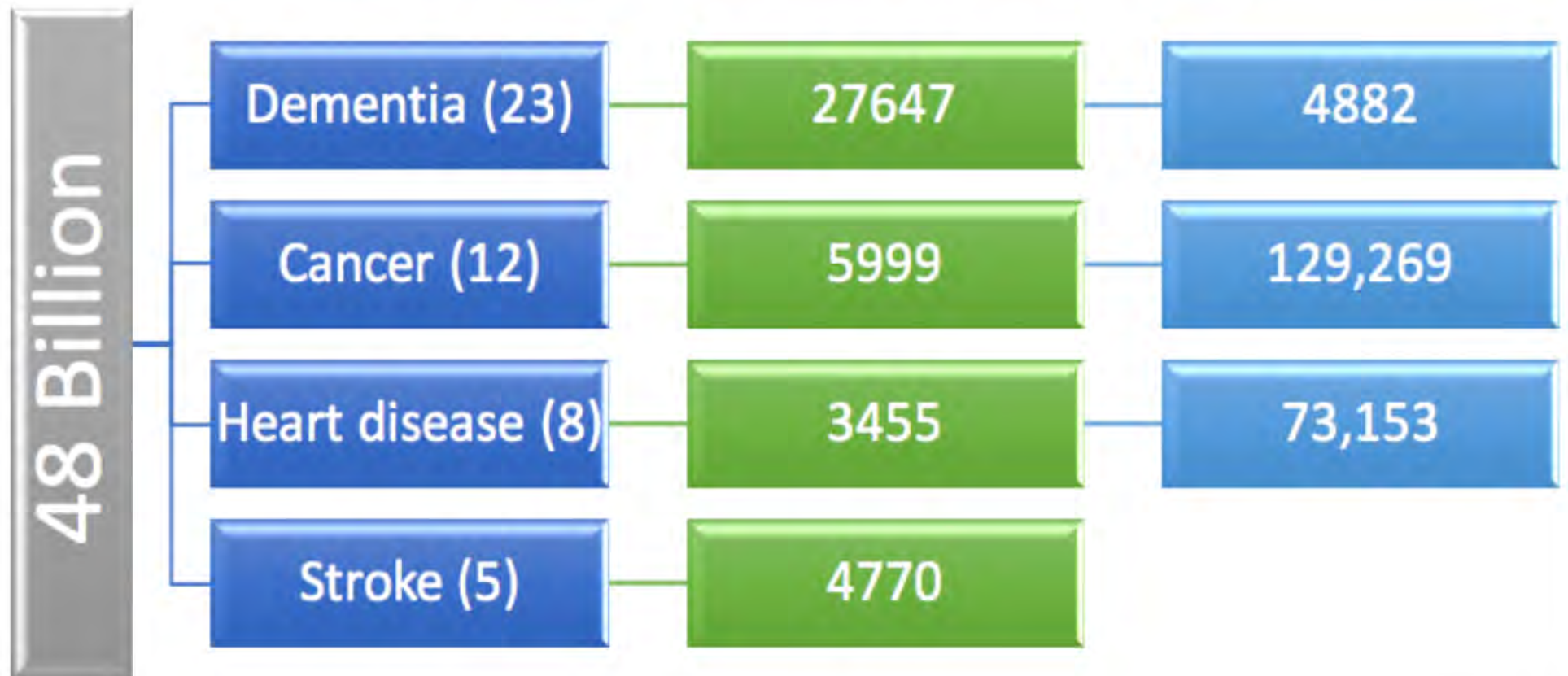
## The contribution of each World Bank income region to the global prevalence of Dementia and to global costs

World Bank income region	Proportion of overall population, %	Proportion of people with dementia, %	Informal care (all ADLs), %	Direct costs, %		Total costs, %
				Medical	Social	
Low	30.6	<u>14.2</u>	1.0	1.3	0.2	0.7
Lower middle income	38.5	<u>26.4</u>	7.5	7.0	1.4	4.8
Upper middle income	13.0	<u>13.4</u>	5.4	10.8	3.3	5.4
High	17.8	<u>46.0</u>	86.1	80.9	95.1	<u>89.1</u>
<b>Total</b>	100	100	100.0	100.0	100.0	100.0

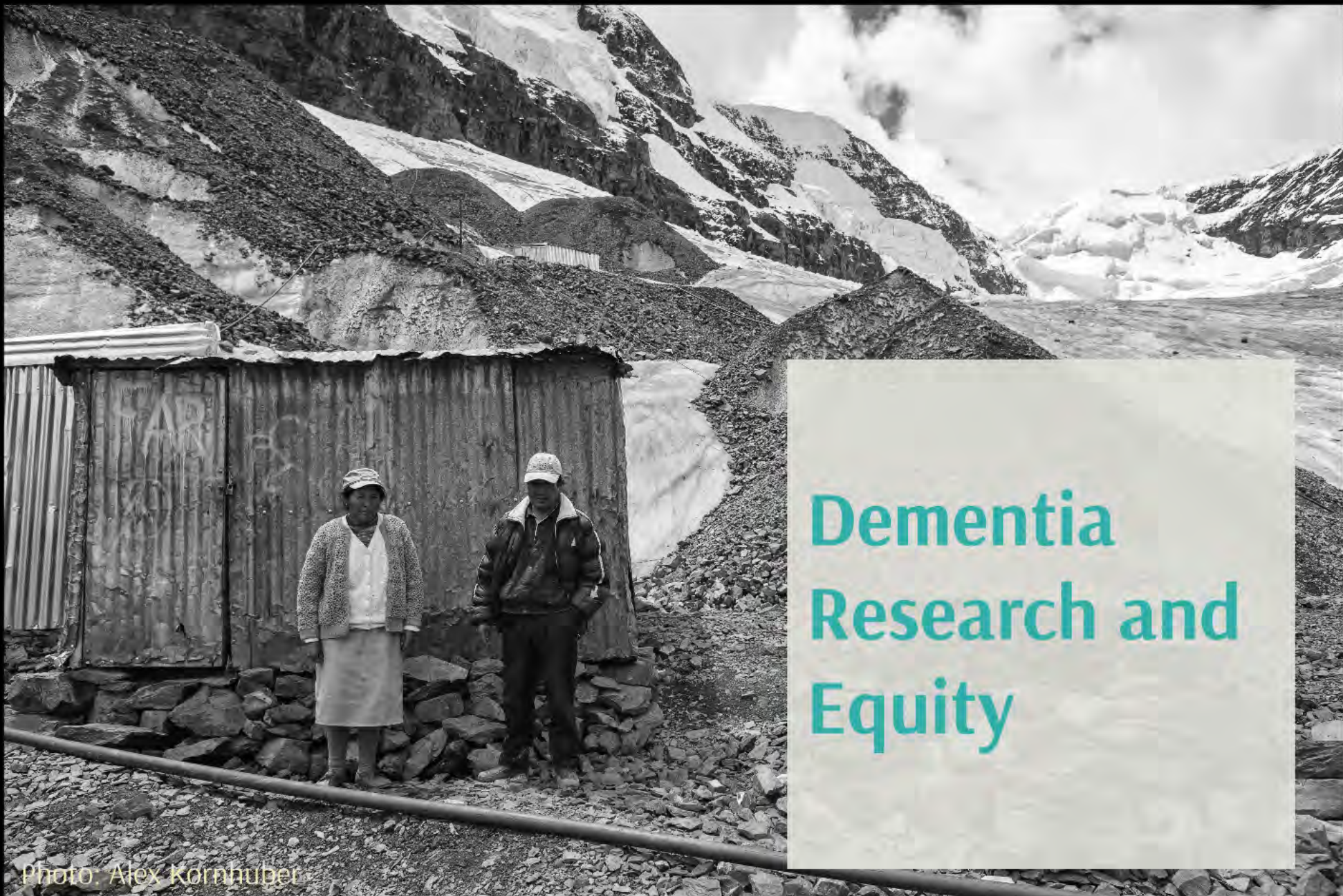
Number of people living with dementia in millions (black box) per geographic area in 2015 (light grey), with projections for 2030 (dark blue) and 2050 (dark grey). Corresponding percentage increase compared to 2015 is depicted in red labels.



## How does dementia measure up?







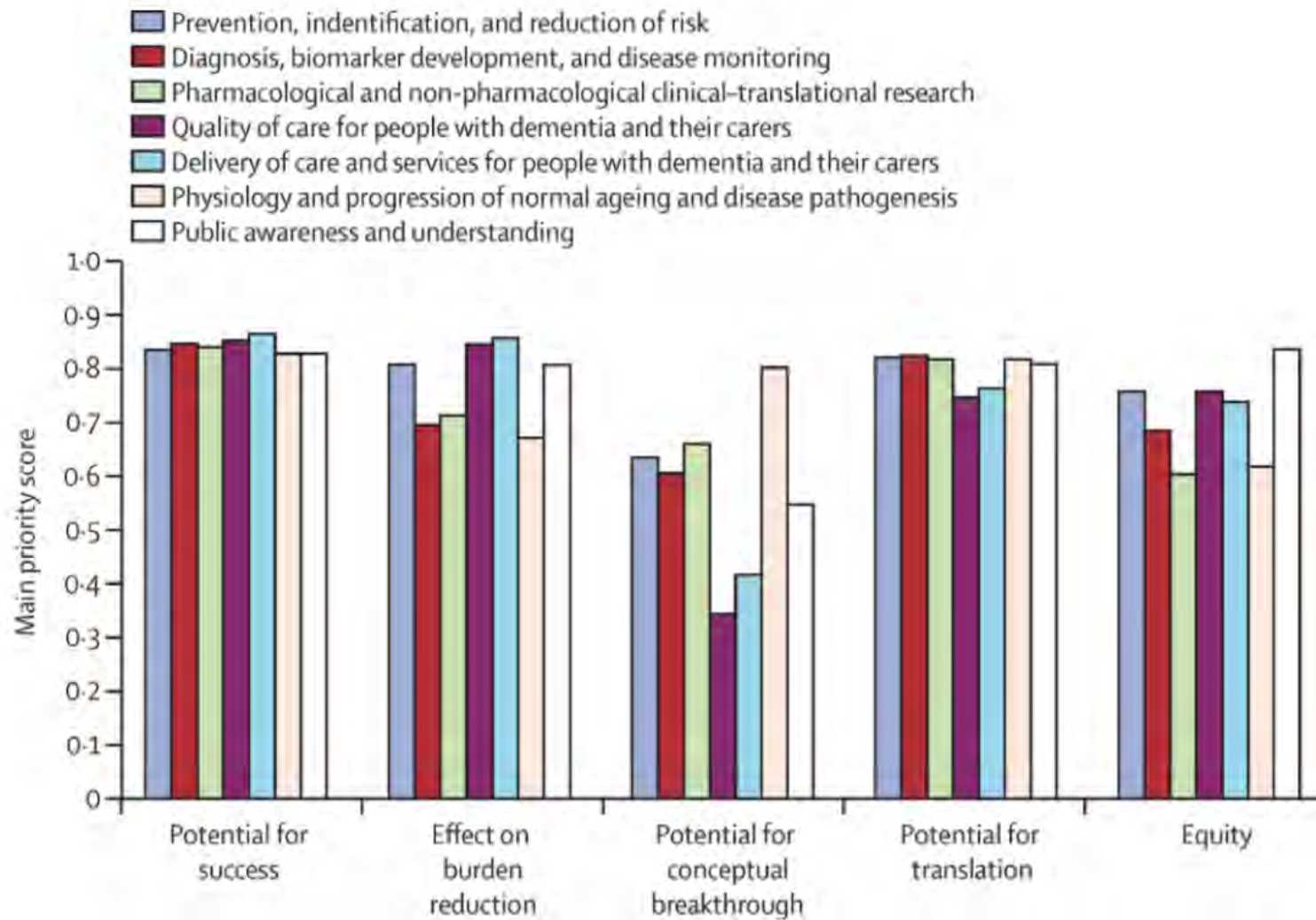
# Dementia Research and Equity

Photo: Alex Kornhuber

# Inequitable Research on Dementia

- Only 10% of studies on dementia are conducted in developing countries.
- The World Health Organization initiated a dementia research prioritization exercise.
  - The theme, "Dementia Risk Reduction" was the most prevalent among the thematic research avenues.

## Mean of the top 20 Thematic Research Avenues' priority scores for each of the seven overarching research goals across the five scoring criteria.



**“Not  
everything  
that is faced  
can be  
changed, but  
nothing can  
be changed  
until it is  
faced.”**

**- James Baldwin  
(American writer  
and activist)**



Source: Wikimedia Commons

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# Thank you

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