

Stigma: Global changes in attitudes to dementia

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CENTRE FOR CO-CREATED
AGEING RESEARCH



**Alzheimer's Disease
International**

The global voice on dementia

World Alzheimer Report 2024

Global changes in attitudes to dementia



Negative stereotypes
Ideas and assumptions

Prejudice
Feelings

Discrimination
Actions



Dementia stereotypes

People with dementia are:

- a burden on families
- a danger to themselves
- old
- weak
- incompetent
- distressed
- untrustworthy

*Stigma is harmful
Unfair treatment*

Figure 3: Negative stereotypes of people with dementia

Figure 2: Three components of stigma, adapted from Rüsch, Angermeyer and Corrigan (2005)

Public fear = discrimination

Negative feelings = withdrawal

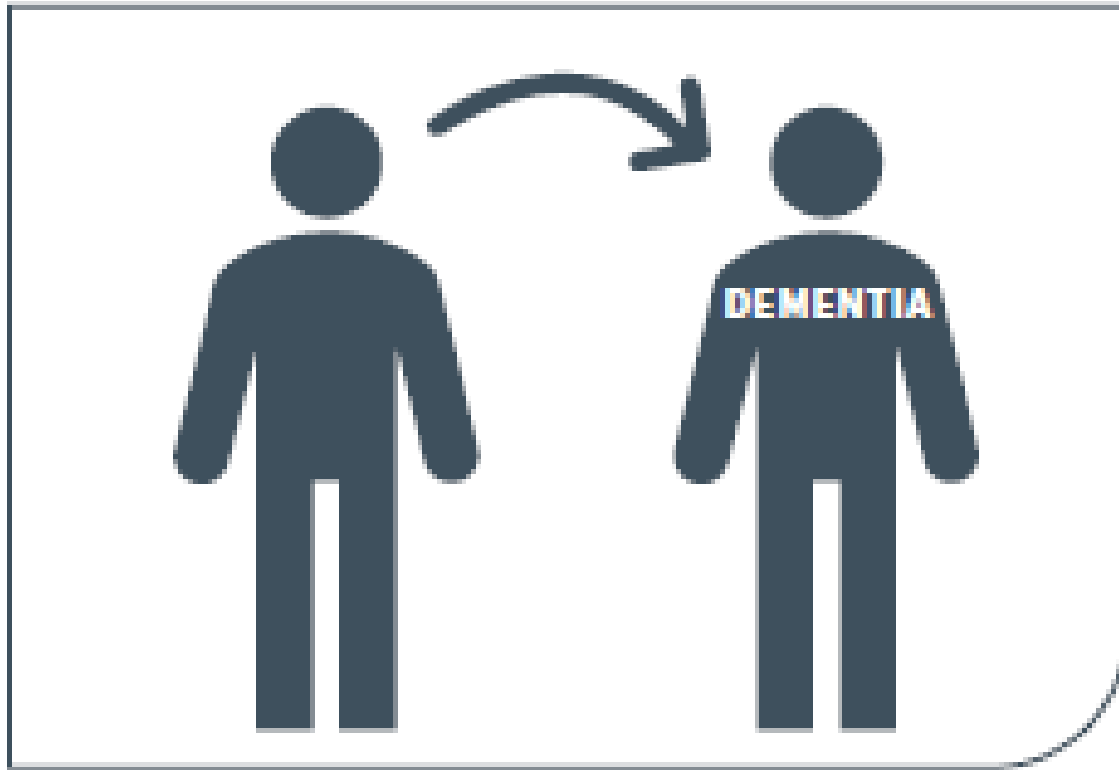


Figure 4 Public stigma

Figure 5: Self-stigma

Self-stigma of families



Figure 7: Affiliate stigma

Discrim against families

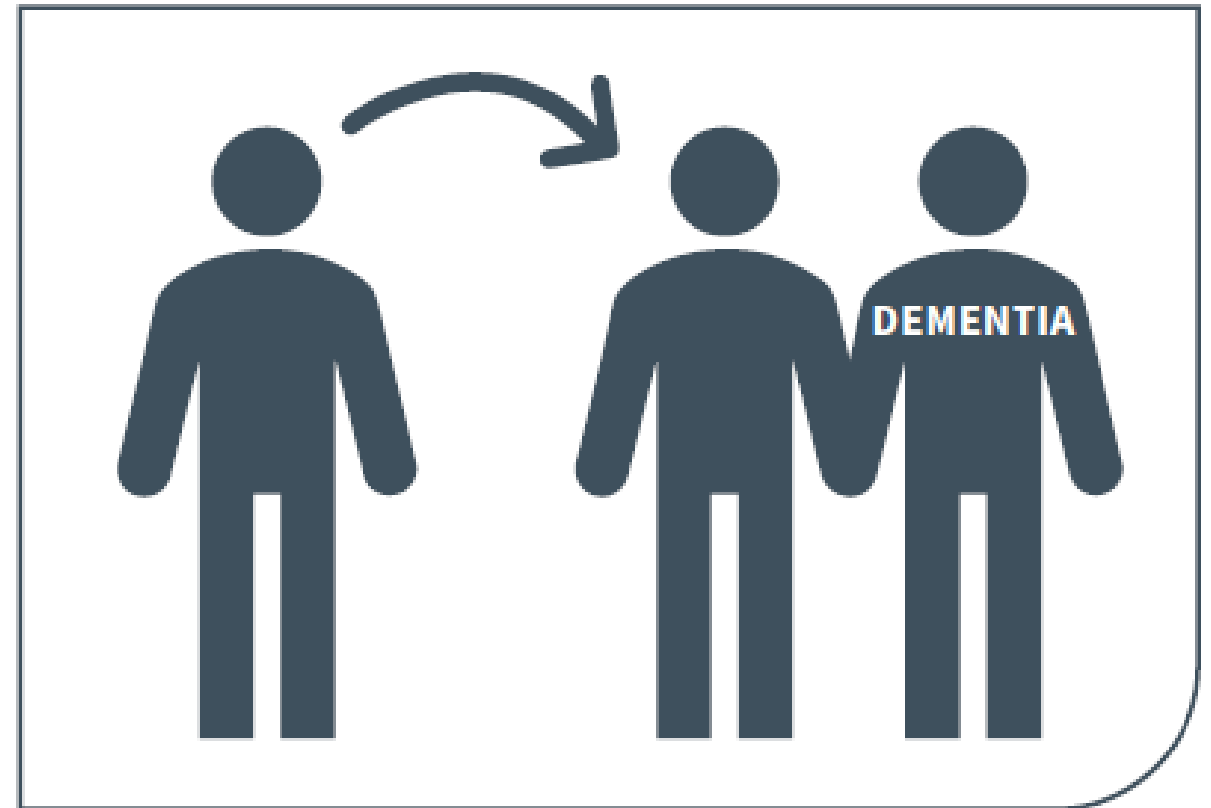


Figure 6: Courtesy stigma

Rationing by dementia
Health services
Opportunities
Restrict access to
families
Restrict education
about dementia



Figure 8: Structural stigma



75% college education, more women

The survey. 2019-2024

- 40,000 people
- 789 people living with dementia (2.3% of total)
- 10,605 carers for a PLWD (30.6%),
- 8,797 health and care professionals (25.4%)
- 14,428 members of the general public (41.7%).
- 166 countries, 35 language.
- Online and in person (targeted)
- high-income countries (57.7%). low-income and lower-middle income 2.6% and 11.7% , 28.1% resided in upper-middle income countries.

The Survey

- 90% of people said they would come forward IF a treatment was available – fear of dementia is a core element
- 80% said yes they would have a genetic test if available
- 80% think dementia a normal part of ageing
- 62% 2019 – 65% in 2023 of healthcare professionals believe dementia part of normal ageing

Worse

Figure 4. Percentage of the general public agreeing with the statement 'There is nothing we can do to prevent dementia' by World Bank country income group in 2019 and 2024

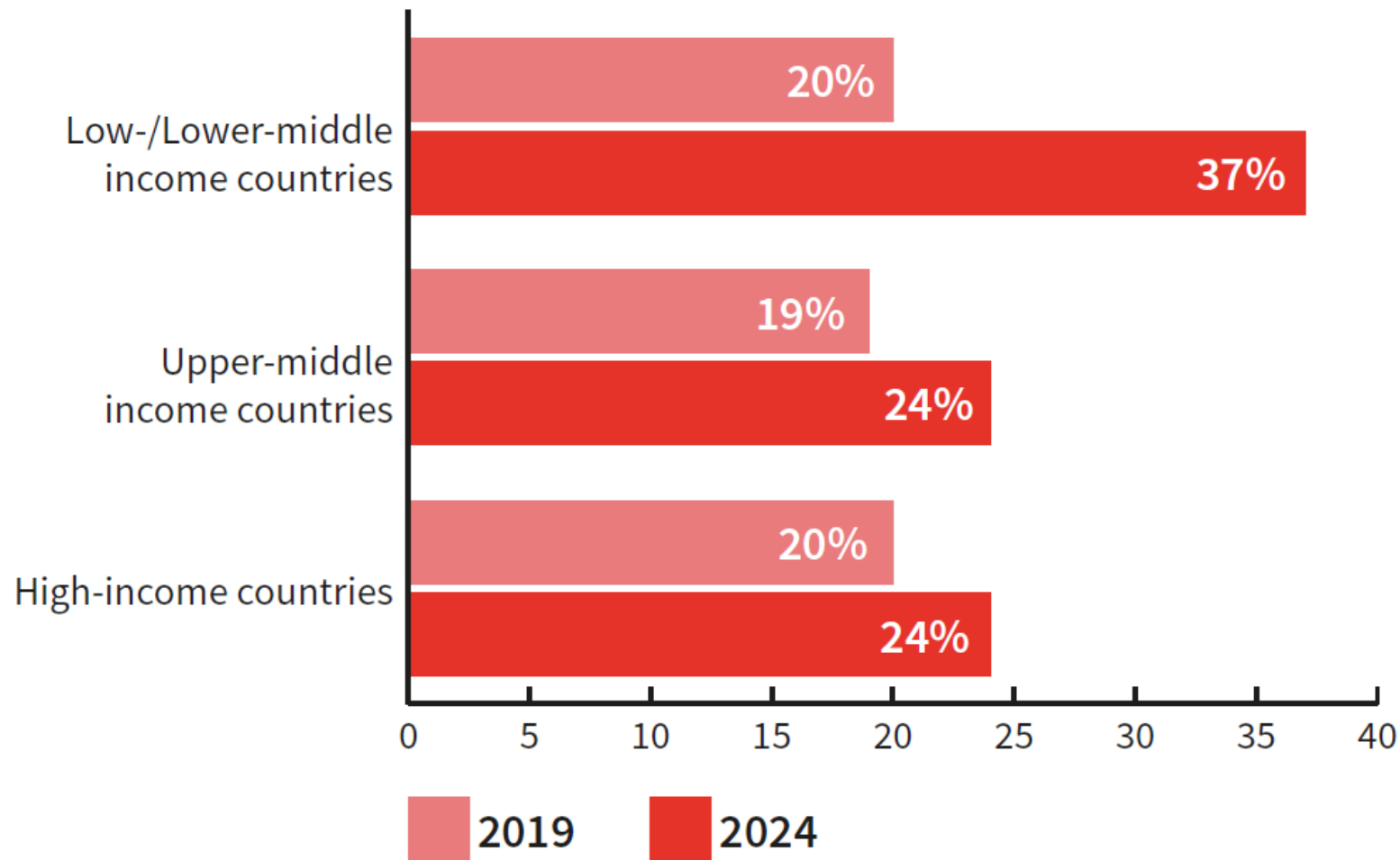
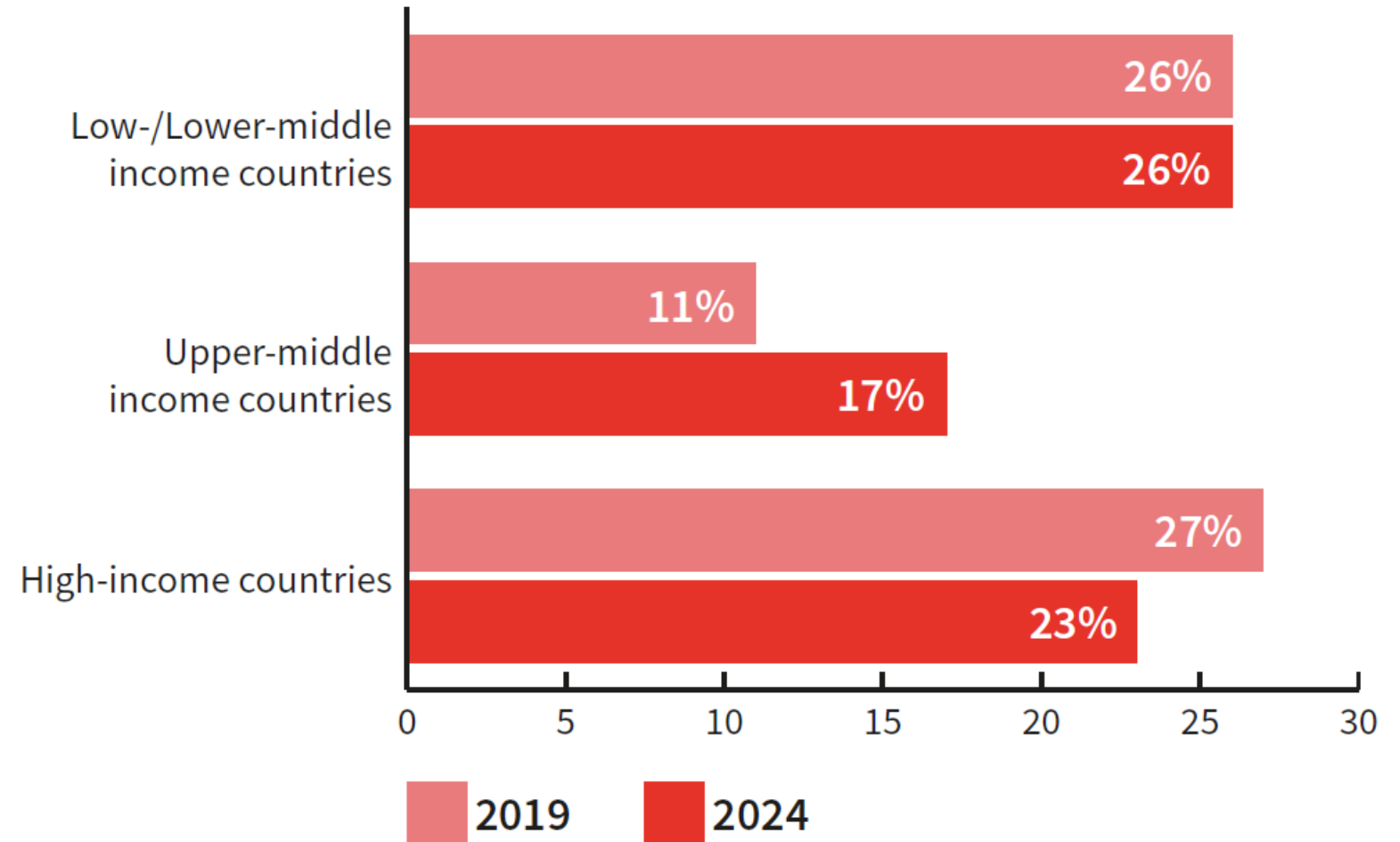


Figure 5. Percentage of the general public agreeing with the statement ‘Dementia is caused due to bad luck’ by World Bank country income group in 2019 and 2024



Better and worse

Figure 6. Percentage of the general public agreeing with the statement 'Dementia is caused due to unhealthy lifestyle' by World Bank country income group in 2019 and 2024

Self blame

Encourage prevention

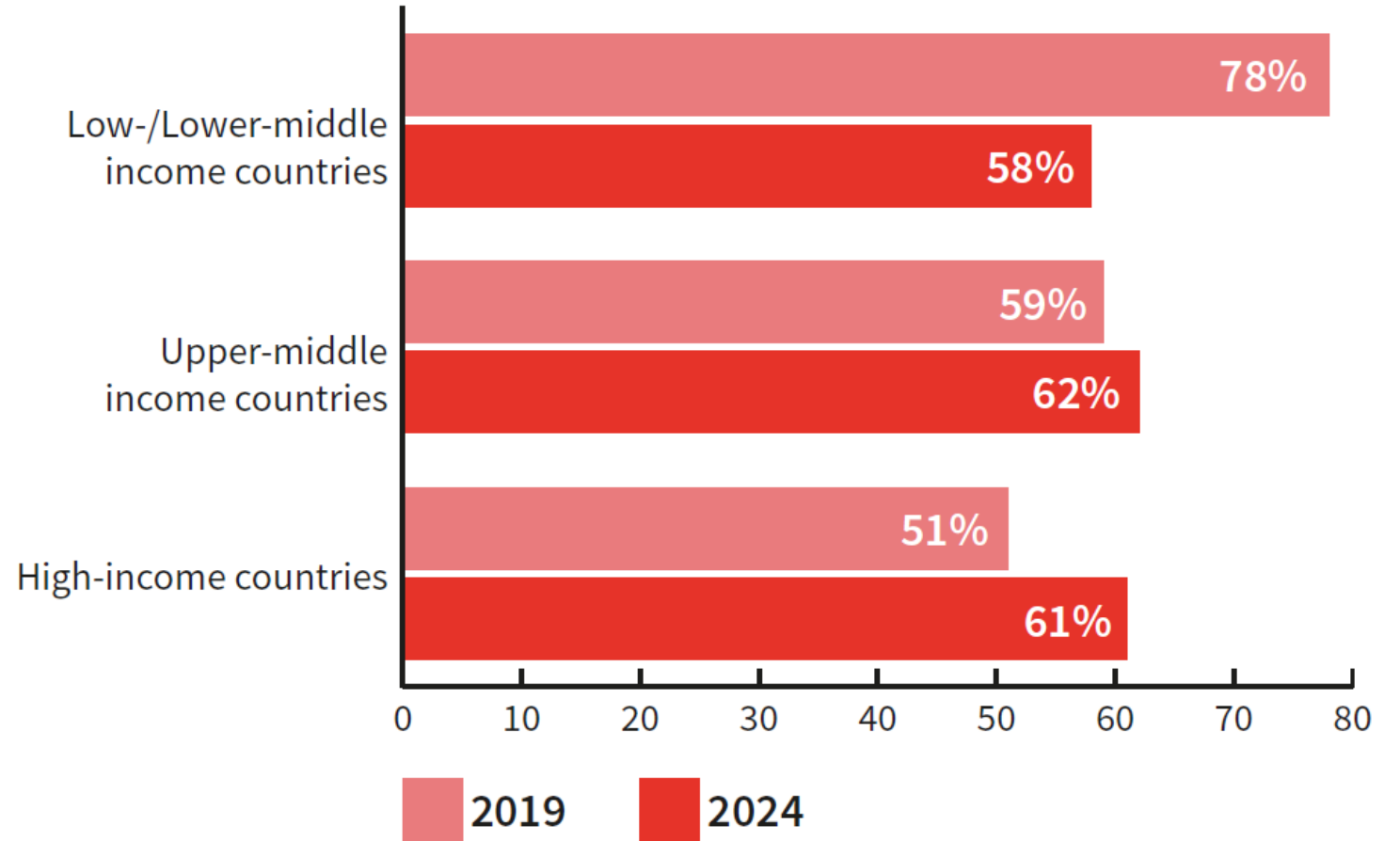


Figure 7. Percentage of the general public agreeing with the statement ‘Dementia is caused due to lack of family support’ by World Bank country income group in 2019 and 2024

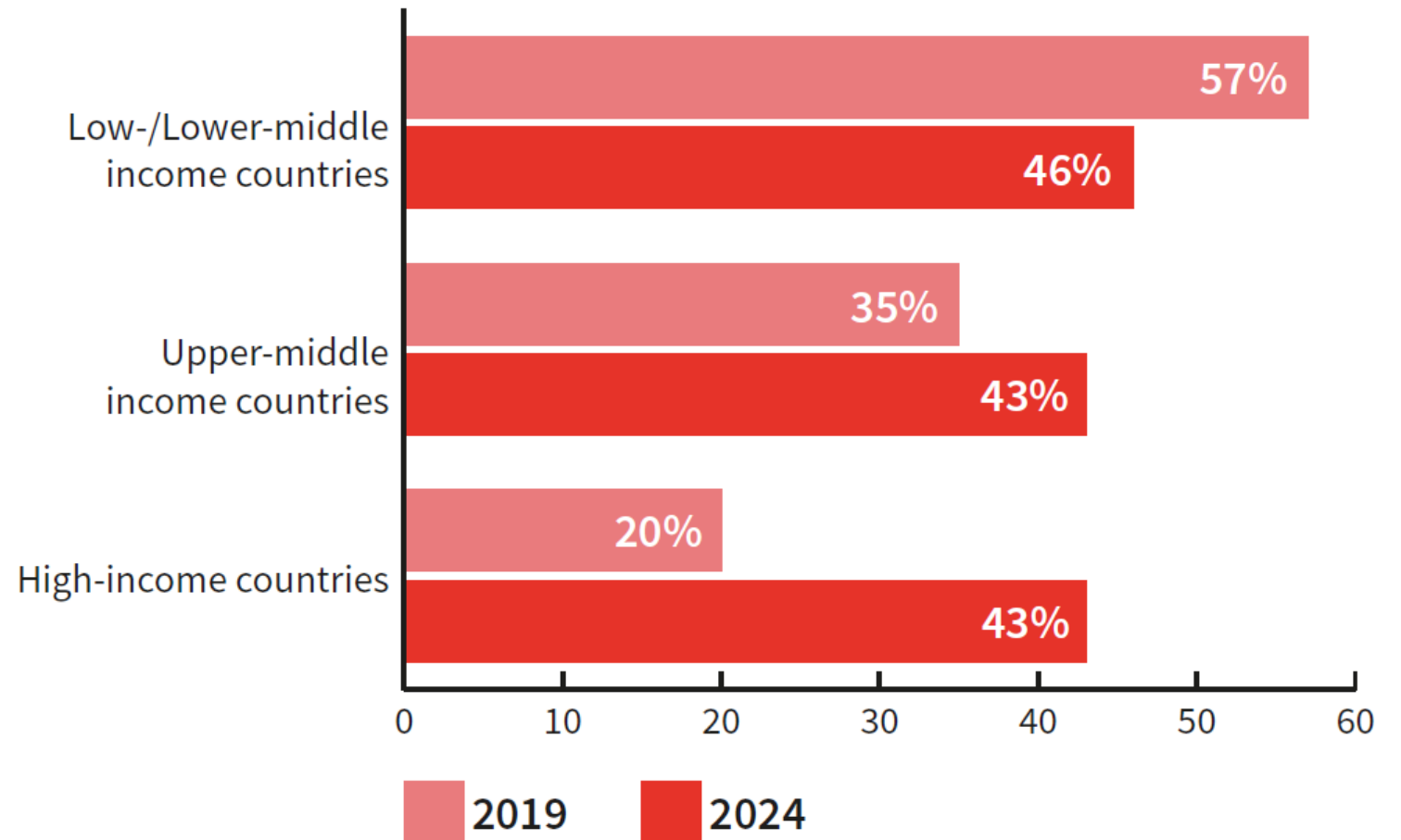
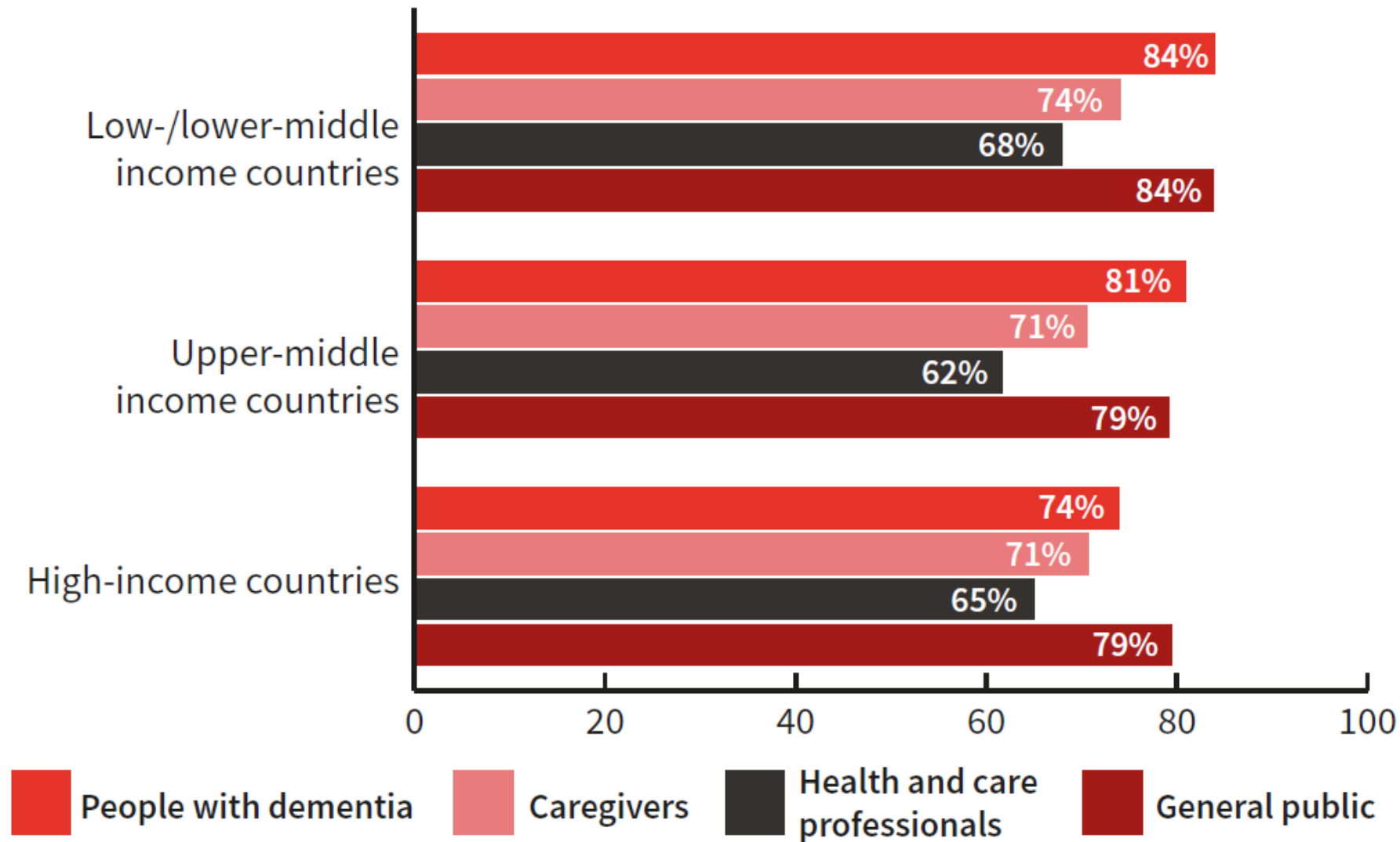


Figure 8. Agreeing with the statement ‘Dementia is a normal part of ageing’, % very or somewhat likely by World Bank country income group in 2024



worse

Figure 11. Percentage of the general public agreeing with the statement 'People with dementia are dangerous more often than not' by World Bank country income group in 2019 and 2024

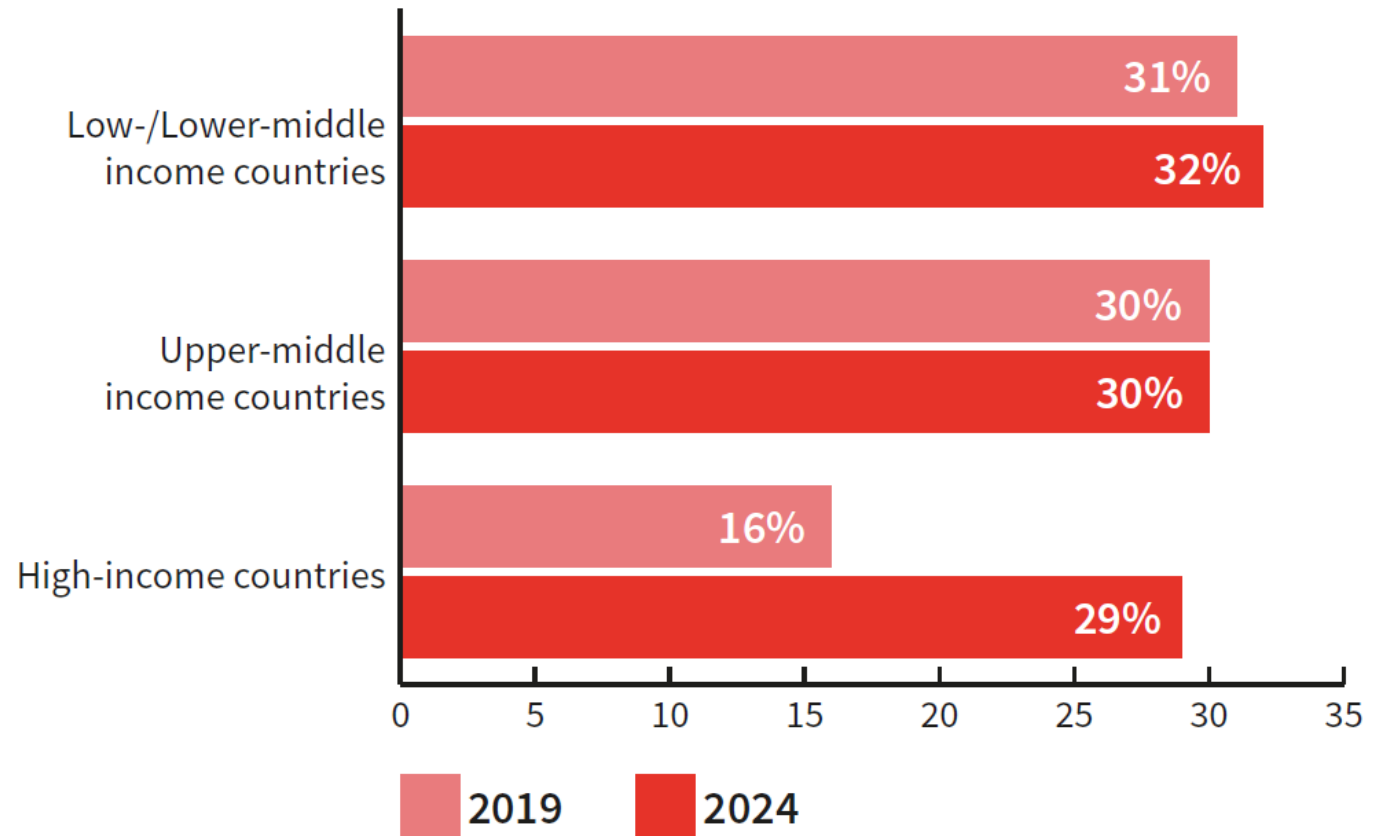
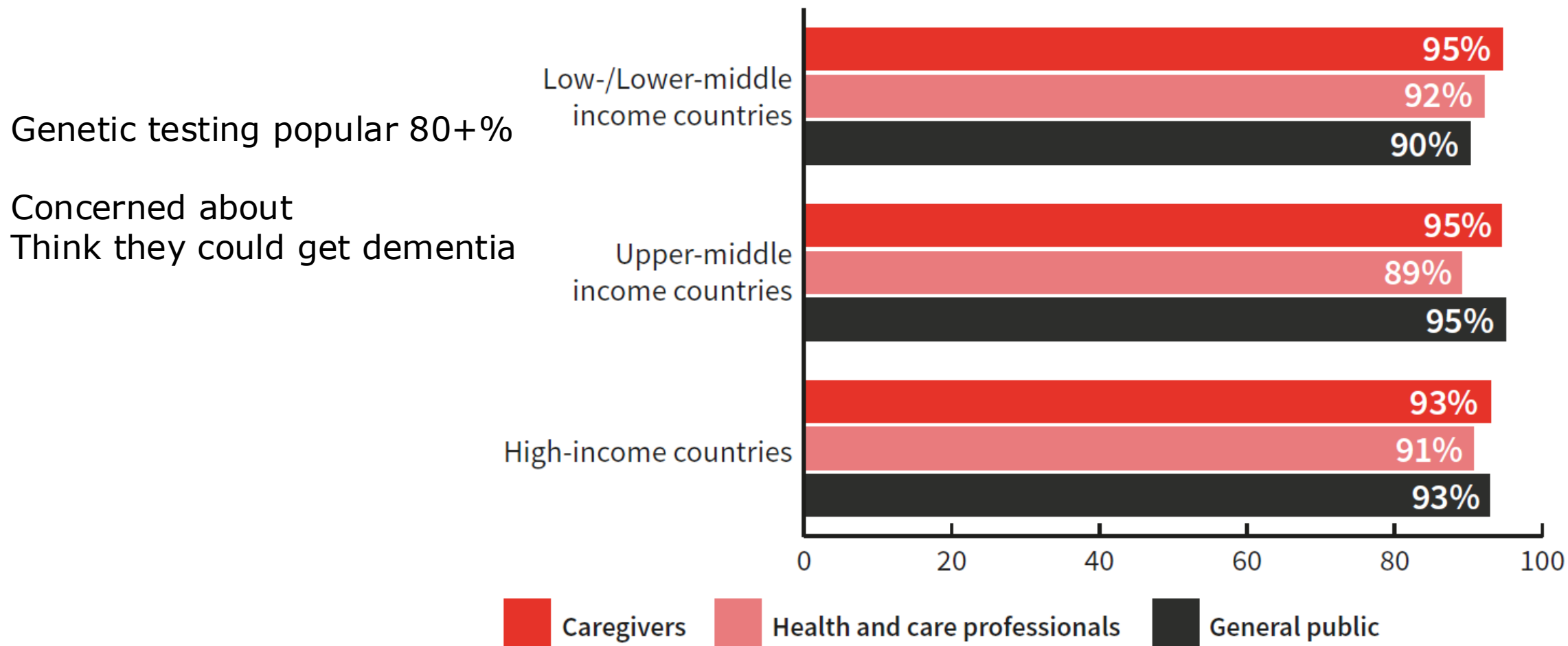
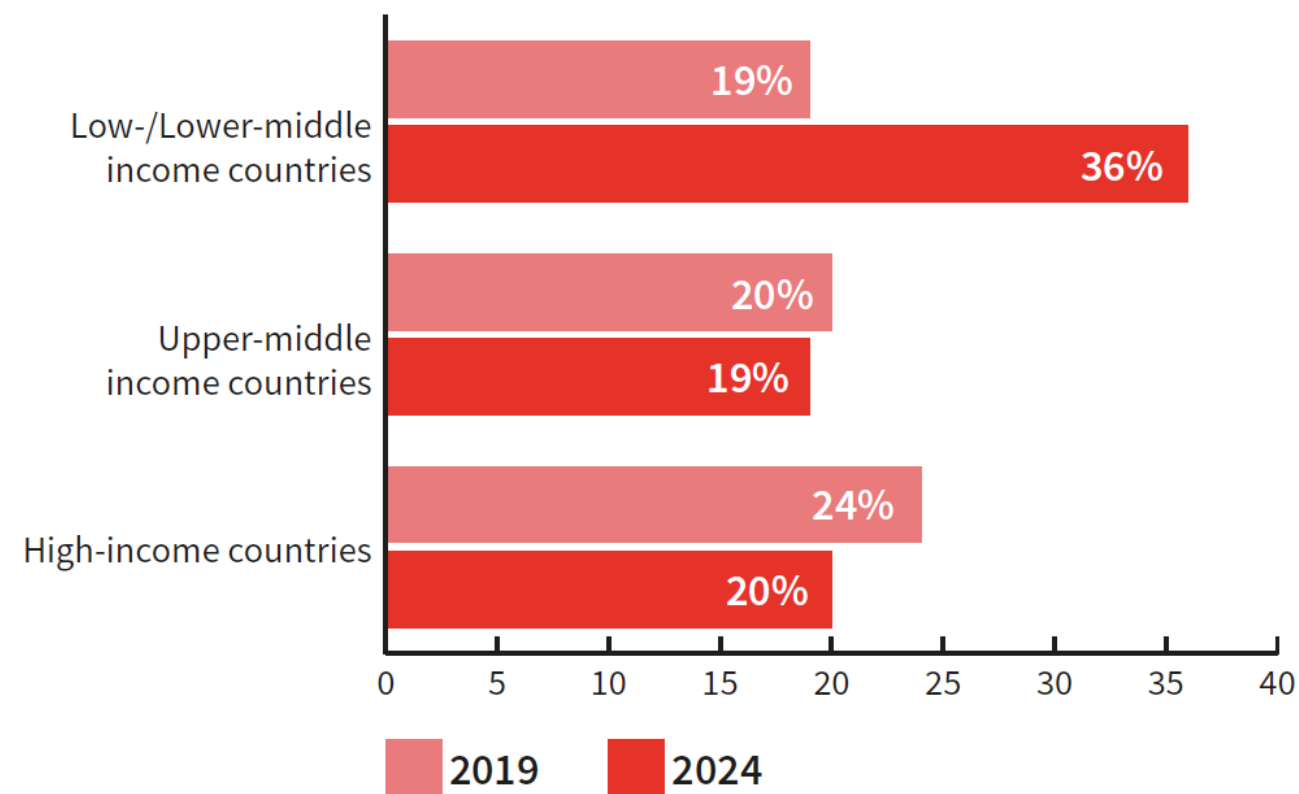


Figure 16. Agreeing with the statement ‘If I knew there was a medicine or treatment that could prevent or slow the progression of dementia, it would encourage me to get a diagnosis’ by World Bank country income and respondent group in 2024



- <10% feel embarrassed going out in public w PLWD
- <10% would hide their dementia from their doctor
- >70% would feel comfortable spending a day with someone with dementia.

Figure 22. Percentage of the general public agreeing with the statement 'If I had dementia, I would make an effort to keep my dementia a secret when meeting people' by World Bank country income group in 2019 and 2024



11-19% of health care professionals

Behaviours – anticipated discrimination

People living with dementia:

- 36% stopped applying for or continuing work
- 29% avoid or discontinue close personal relationships
- 24% (nearly a quarter) avoid seeking help, care, or treatment due to concerns about potential treatment by pharmacists or other customers.
- 22% avoid visiting banks due to fear of judgement
- 31% avoid social situations due to concerns regarding the reactions of others

Carers

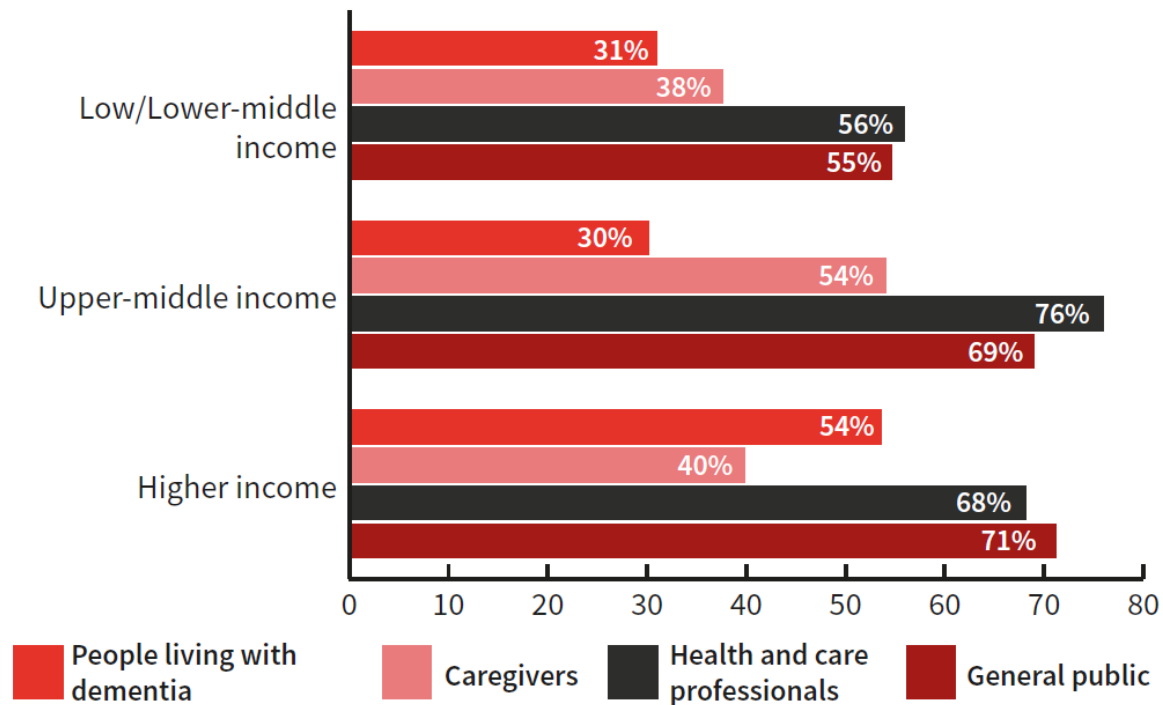
- 43% stopped inviting friends over due to concerns about how they might treat their loved one
- 40% avoided joining social groups or activities due to concerns about reactions to their loved one
- 47% stopped accepting invites to visit friends or family
- 34% avoided going out in public with the person they care for due to fears of perception
- 41% of carers avoid travel or taking vacations due to concerns that the person they care for could be treated

Experiences of discrimination – all worse.

Impact

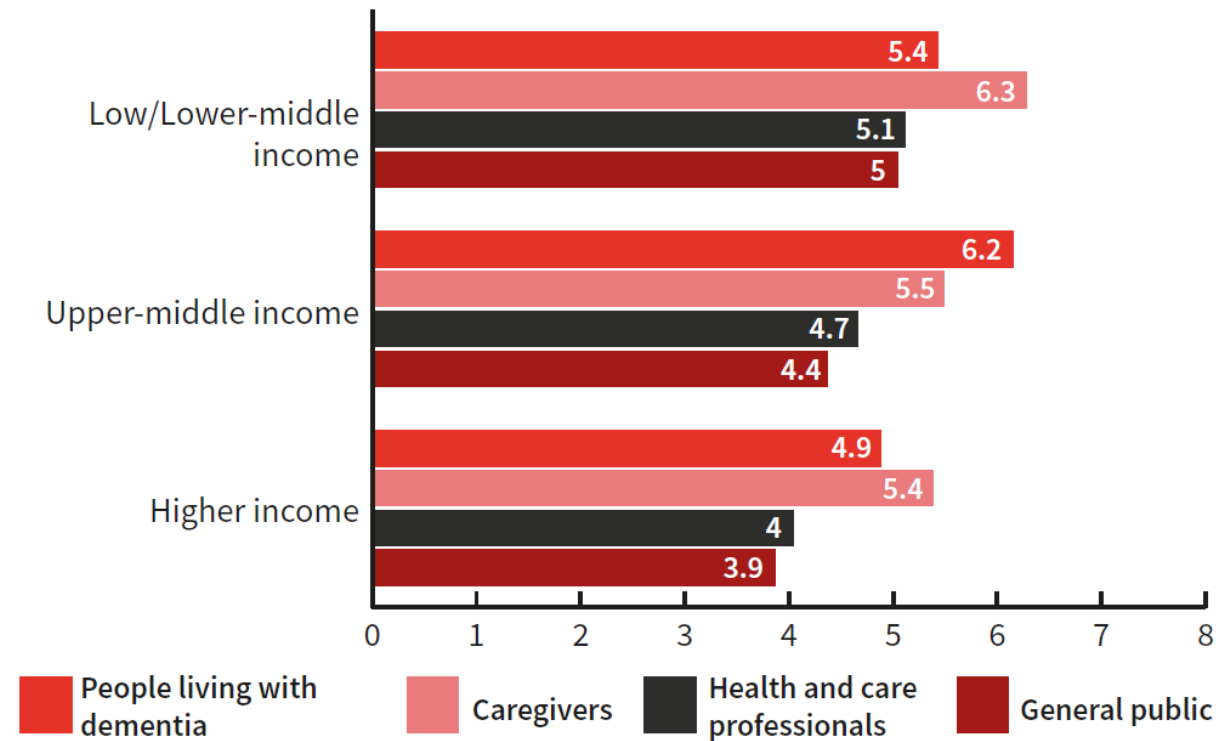
Satisfaction with life

Figure 25. Satisfied with life every day or almost every day (%) by World Bank country income group.



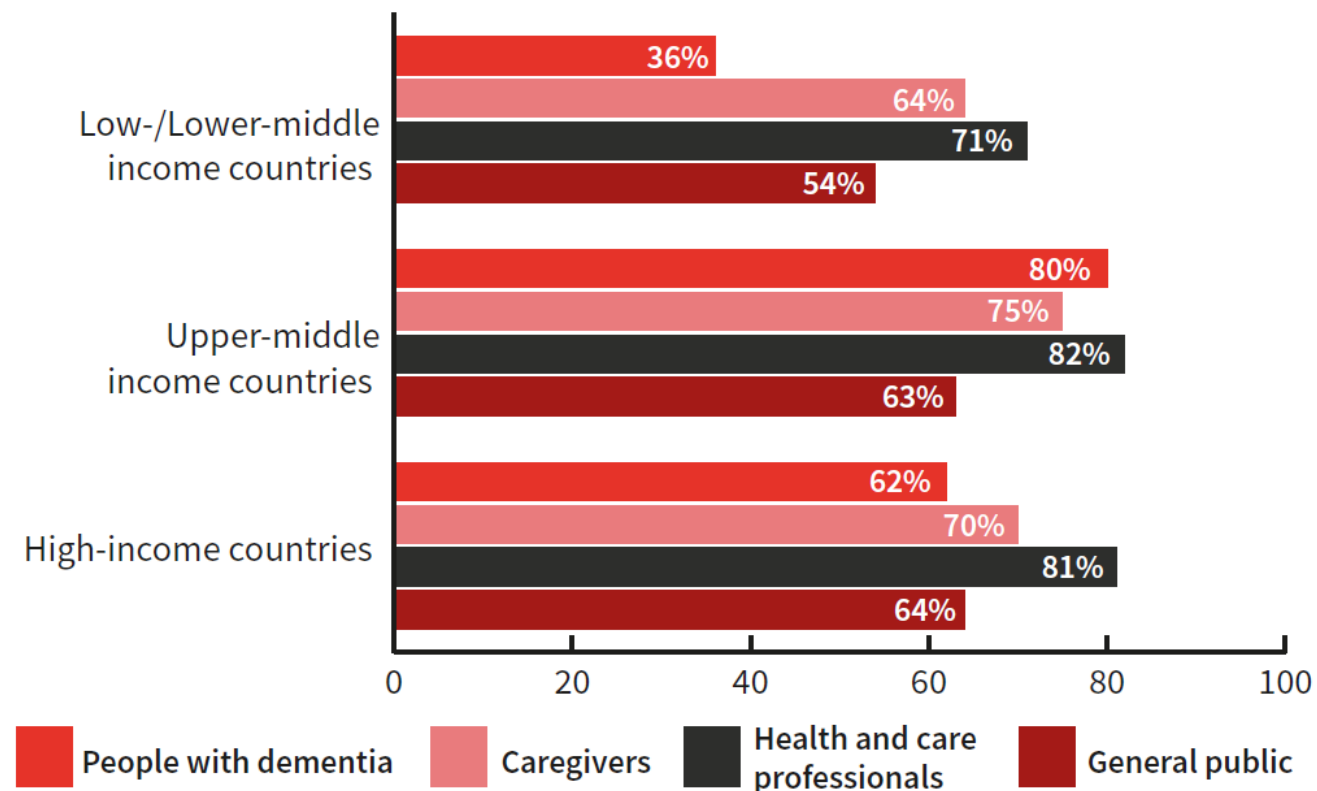
Loneliness (higher score worse)

Figure 26. Loneliness (UCLA Loneliness Scale) by World Bank country income group.



- General sense that there was more awareness and visibility about dementia, even on social media.
- Confidence in challenging stigma and discrimination increasing.
- High confidence that voting could improve things

Figure 32. Compared to five years ago, do you feel more confident now in challenging stigma and discrimination related to dementia when you see it? % responding 'Yes' by World Bank country income group



What can you do?

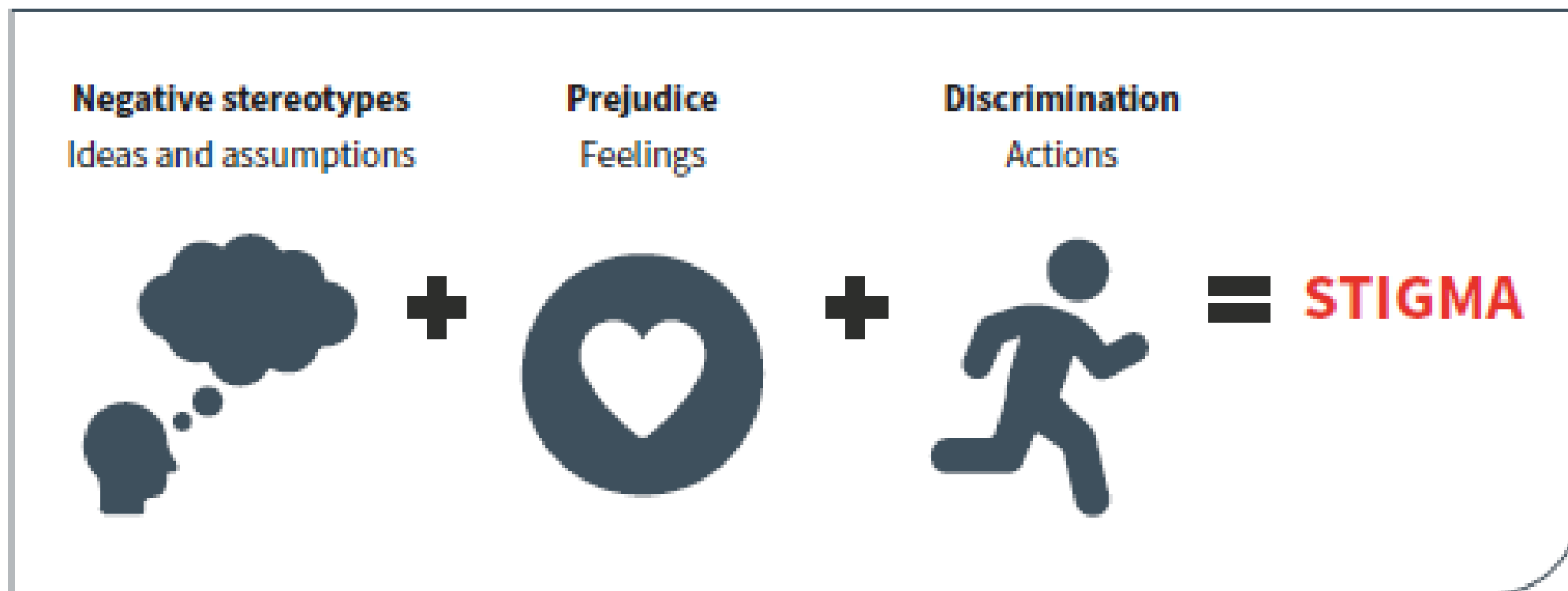


Figure 2: Three components of stigma, adapted from Rüsch, Angermeyer and Corrigan (2005)

What to do – challenge stereotypes

- Media, advocacy organisations, and researchers using **words and images** that **reflect balanced depictions** of dementia. Eg: individuality, person-centred, language such as ‘person with dementia’
- Using **accurate public health information** about dementia
- Providing specific dementia-related **stigma education programmes**
- Paying attention to and following the **advice of advocates** with dementia, such as members of Dementia Alliance International or ADI’s Global Dementia Experts Panel
- **Sharing the capabilities and diverse experiences** of people with dementia. Some recent examples are:
 - BUDI Orchestra- Musical performances by people with dementia
 - ‘Cracked’- Theatre and film about relationships with people with dementia
 - Restaurant run by people living with dementia
- WorldAlzDay- Social media campaigns sharing diverse experiences of dementia

What to do – challenge prejudices

- Understanding how stereotypes shape our feelings about dementia
- Recognising when our actions are led by fear, shame, guilt etc.

What to do – challenge discrimination

- Understanding how prejudices shape our actions toward people with dementia
- Supporting rehabilitation access
- Supporting social connections for people with dementia and families
- Challenging discriminatory policies and practices
- Supporting people with dementia to inform research, policy development, advocacy, and care services

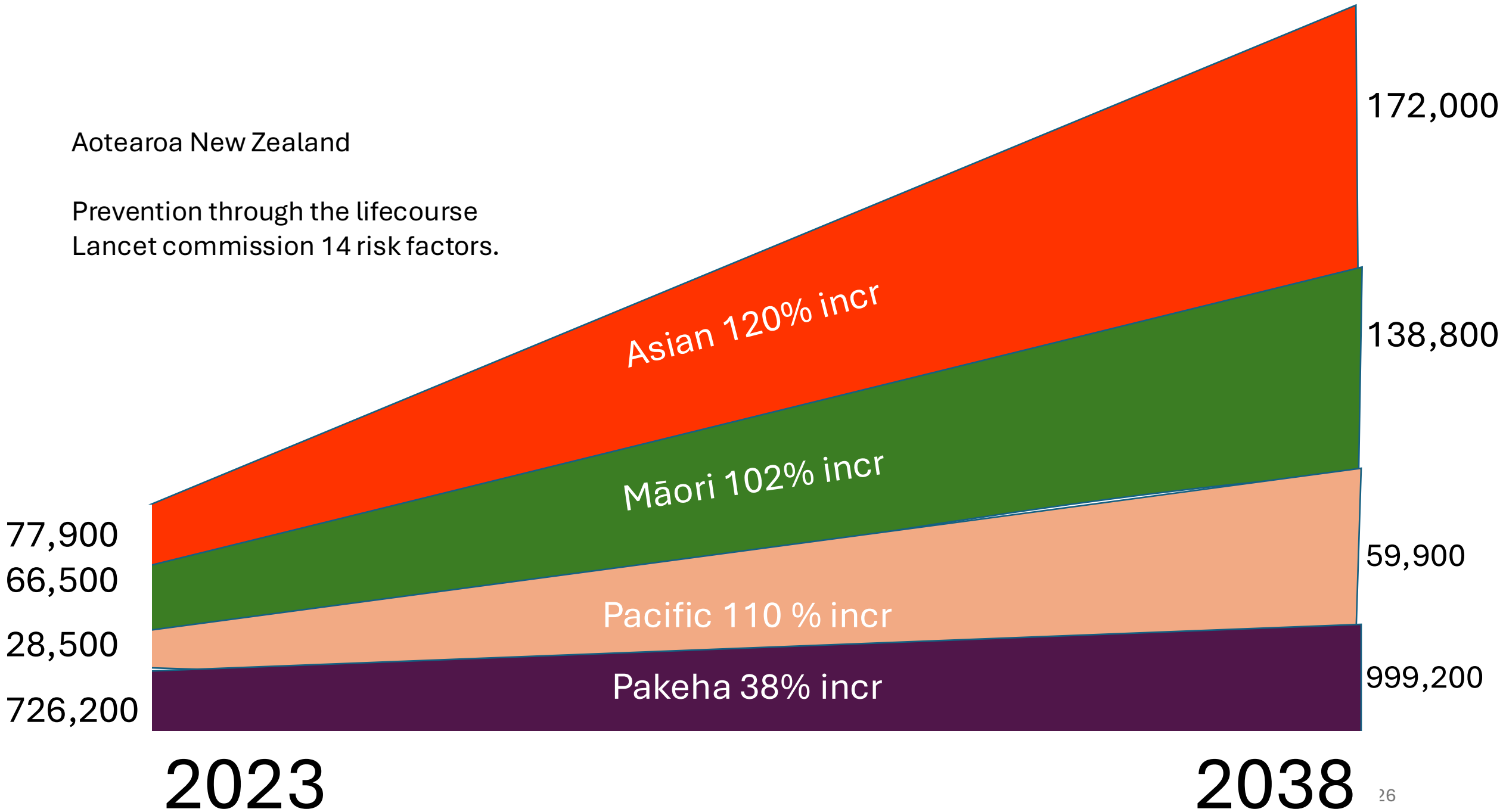
Health professionals

- Call out talking to the family rather than the person with dementia
- Challenge ideas of 'not eligible'
- Advocacy for fair treatment
- Support carers
- Support carers
- Support carers

- Expert Essays
- Case studies of stigma
- Case studies of addressing stigma
- **Addressing dementia stigma and awareness is within reach for compassionate and caring individuals wherever they may be across the globe.**

Aotearoa New Zealand

Prevention through the lifecourse
Lancet commission 14 risk factors.



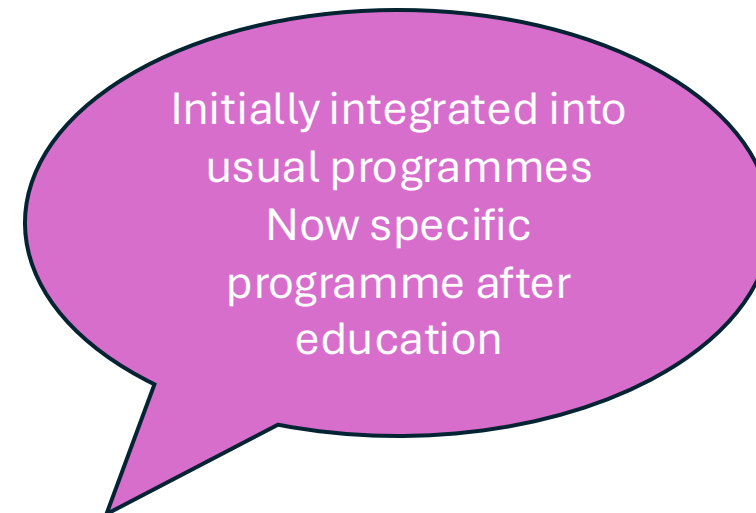
2023

2038

4.16 Māori, Mana and Mate Wareware: Rauawaawa Kaumātua Charitable Trust and its experience in supporting Kaumātua with Dementia

Contributors: Rangimahora Reddy & Pare Meha, Rauawaawa Kaumātua Charitable Trust, Dr Etuini Ma'u, Waikato District Health Board, Prof John Oetzel, University of Waikato

nutshell, the stigma of mate wareware may be enough for Kaumātua to resist sharing what they experience in the early stages, to disagree to having a proper assessment and to decline the opportunity to learn about the illness.



Questions