



A Global Perspective

Paola Barbarino, CEO
Alzheimer's Disease International



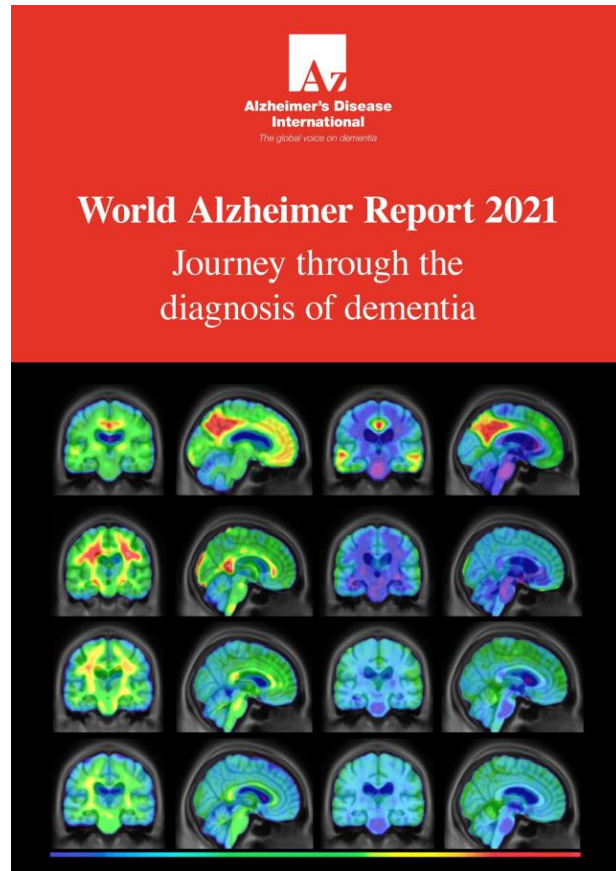
40 years of ADI



Celebrating 40 years as the
global voice on dementia



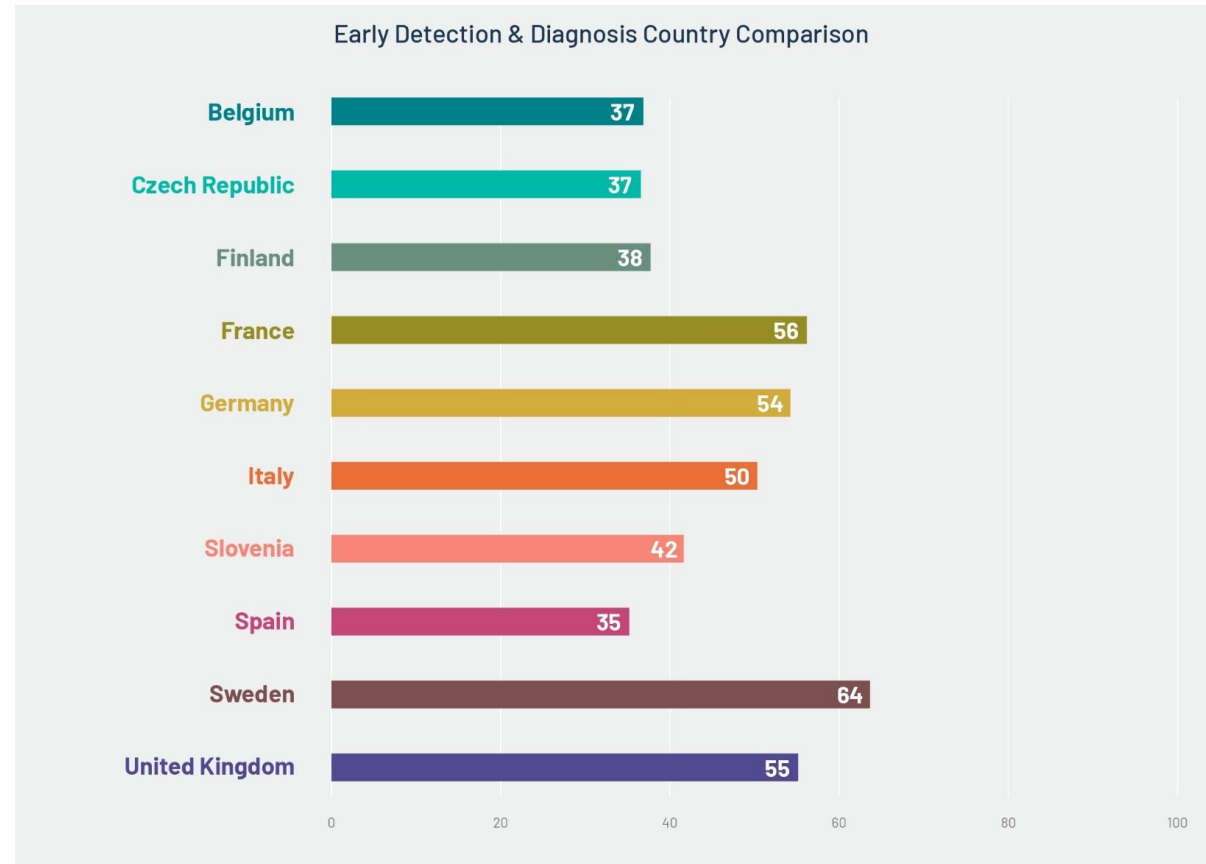
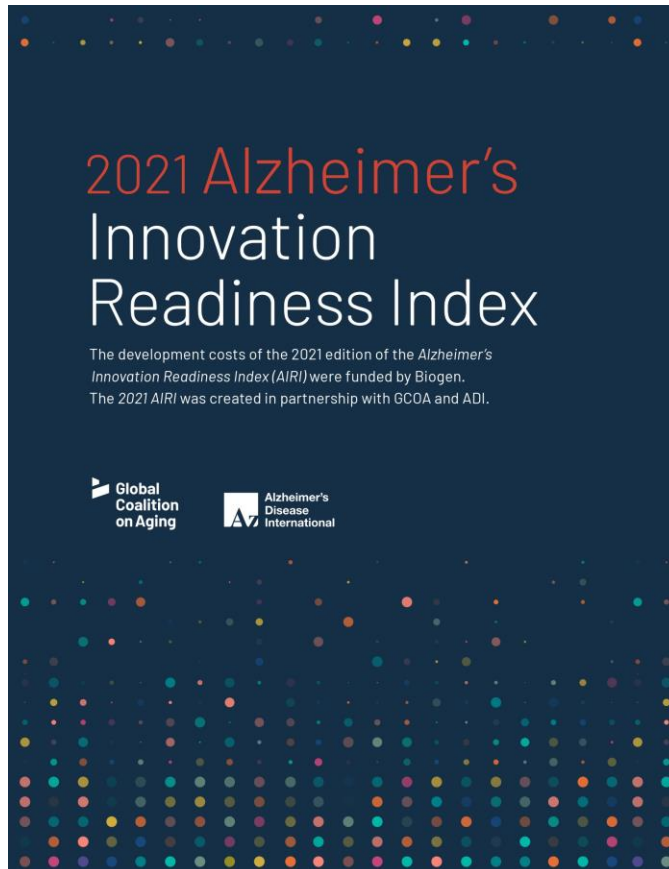
World Alzheimer Report 2021



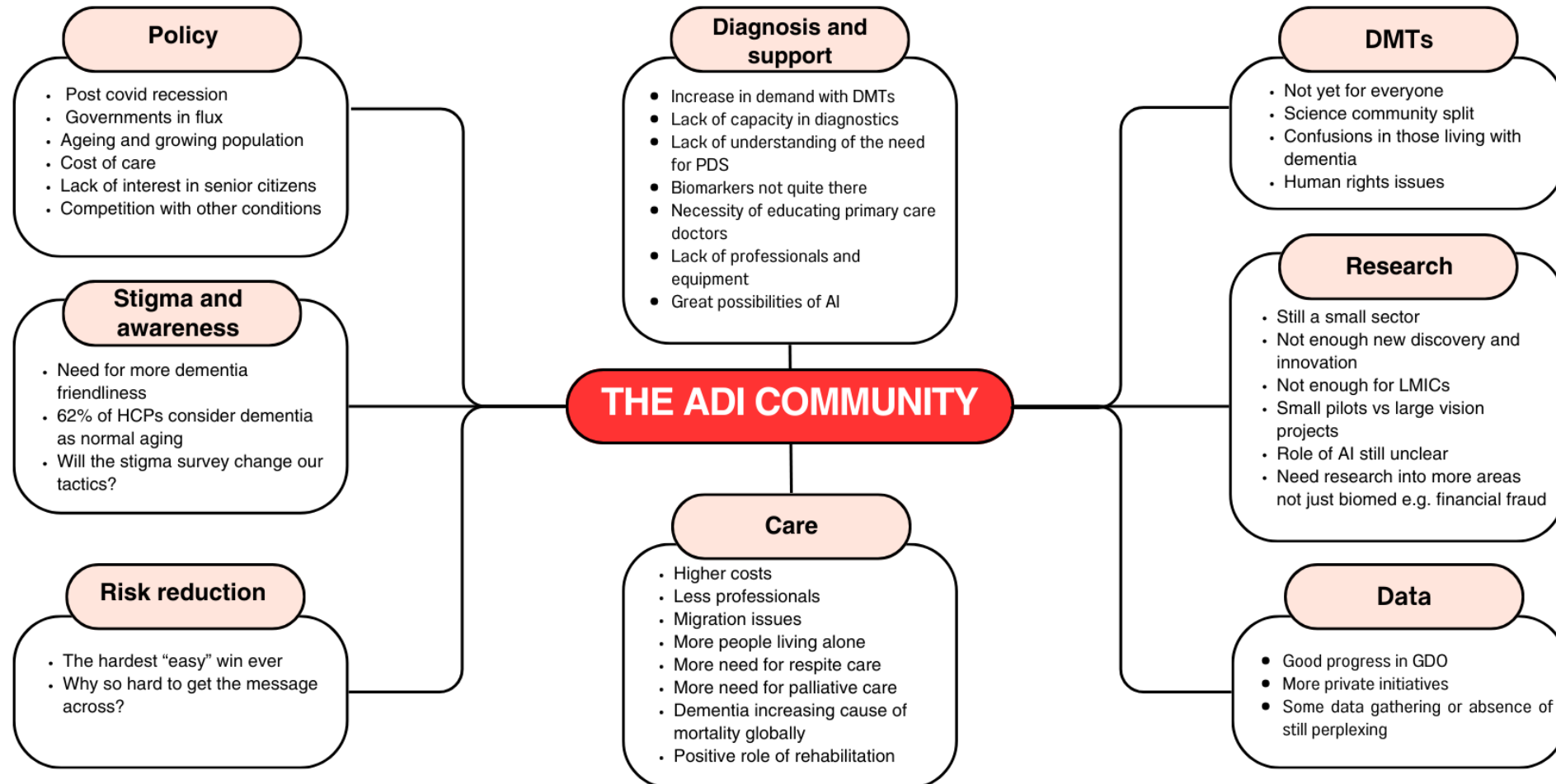
There is a perfect storm gathering on the horizon and governments all over the world should get to grips with it.



Diagnostic capacity is insufficient

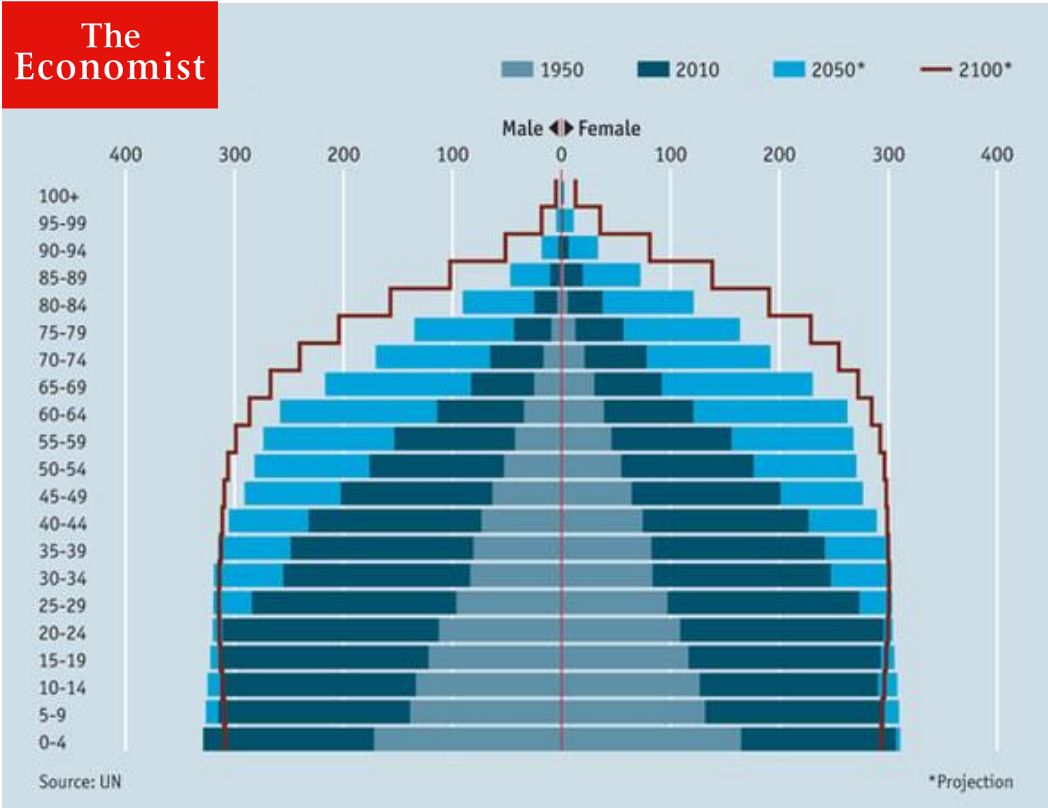


All of the issues in my mind right now



Care

Populations are increasing and aging



Adapted from: The Economist: The world in 2100. Accessible at:
<https://www.economist.com/graphic-detail/2011/05/13/the-world-in-2100>

Care

Costs of care



Global estimates of informal care

Alzheimer's Disease International and Karolinska Institutet



The total estimated annual worldwide cost of dementia is over US\$ 1.3 trillion. This figure is forecast to rise to US\$ 2.8 trillion by 2030*

*WHO Global status report 2021



50%
of the annual cost is
informal care



34%
of the annual cost is
long-term care



16%
of the annual cost is
direct medical care

Middle and right adapted from WHO Global Status Report on the public health response to dementia, 2021

Stigma and awareness

Attitudes To Dementia World Alzheimer Report 2024 Survey

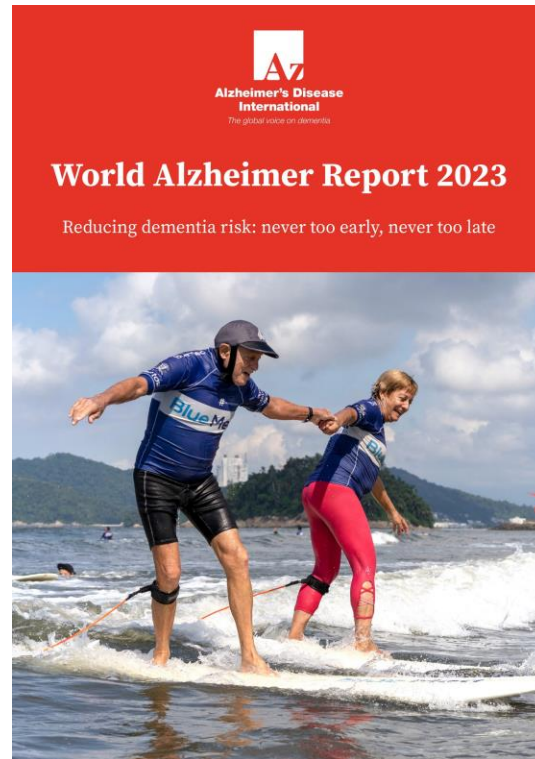
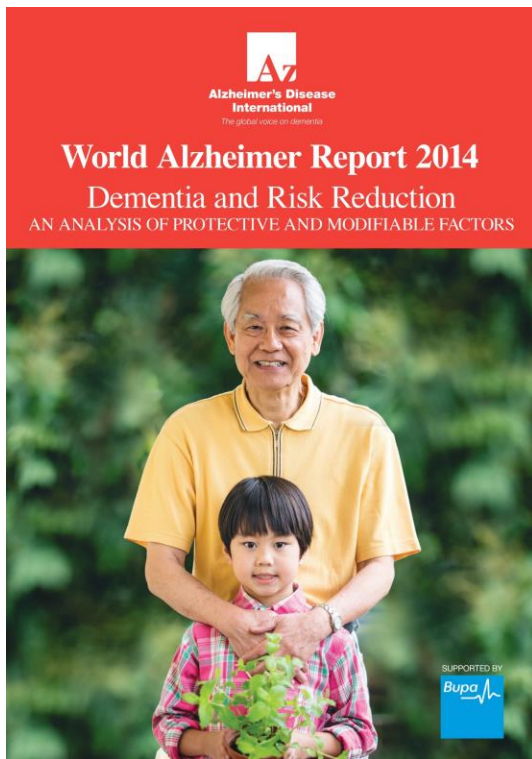
www.bit.ly/World-Alzheimer-Report-2024-Survey

- Help us to build the world's largest international survey on attitudes towards dementia.
- 5-year follow up to the 2019 survey and report
- Survey will be online – but options for offline are available
- Translated into over 30 languages with many more to be added soon
- Scan the QR code or follow the link to access the survey



Risk Reduction

The hardest “easy win”



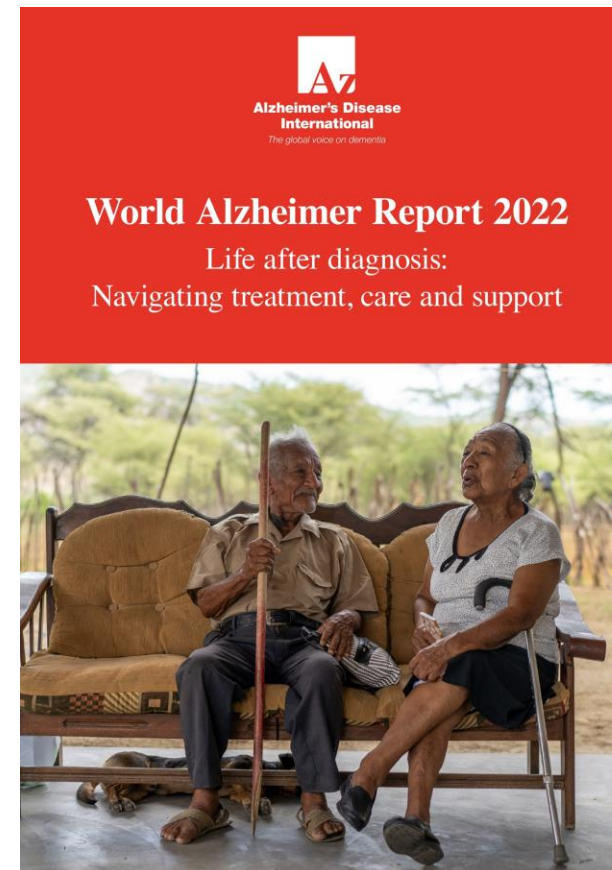
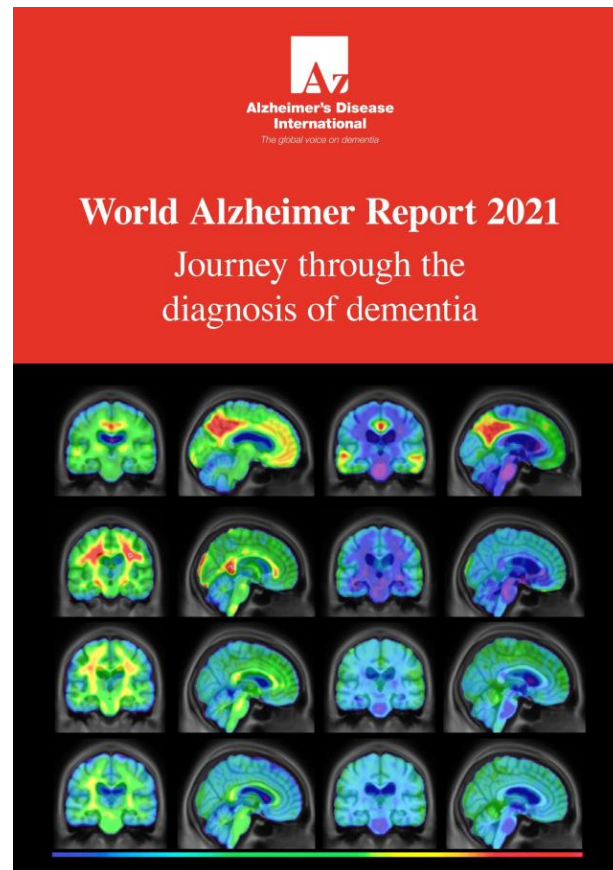
Source: Livingston et al. A, et al. Dementia prevention, intervention, and care: 2020 report of the Lancet Commission

www.alzint.org



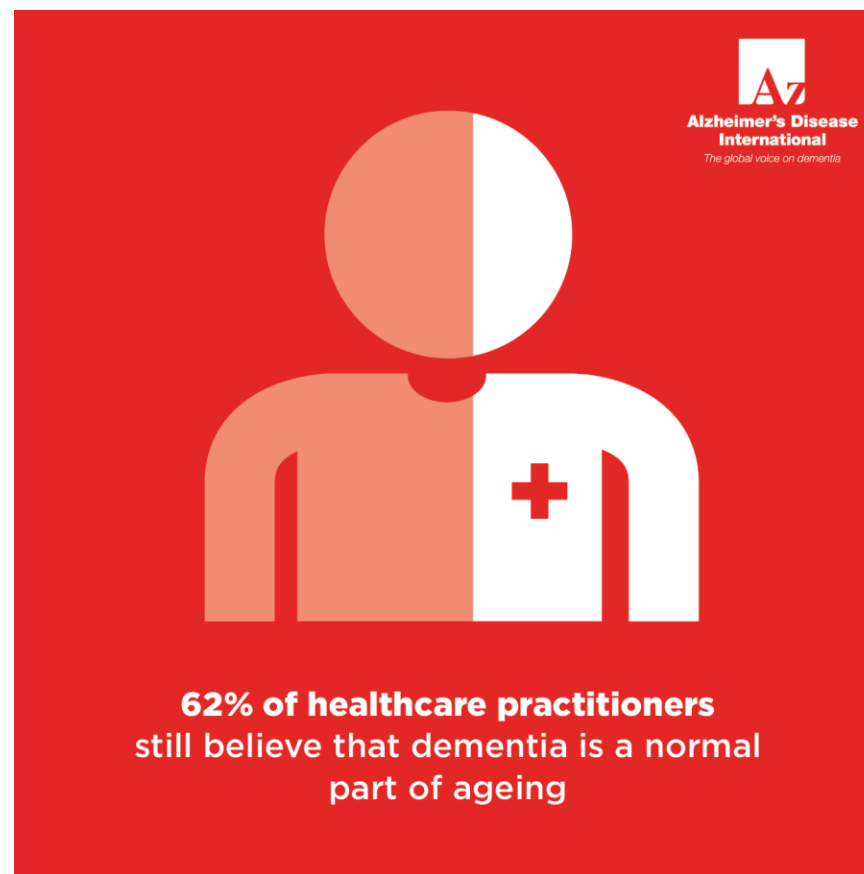
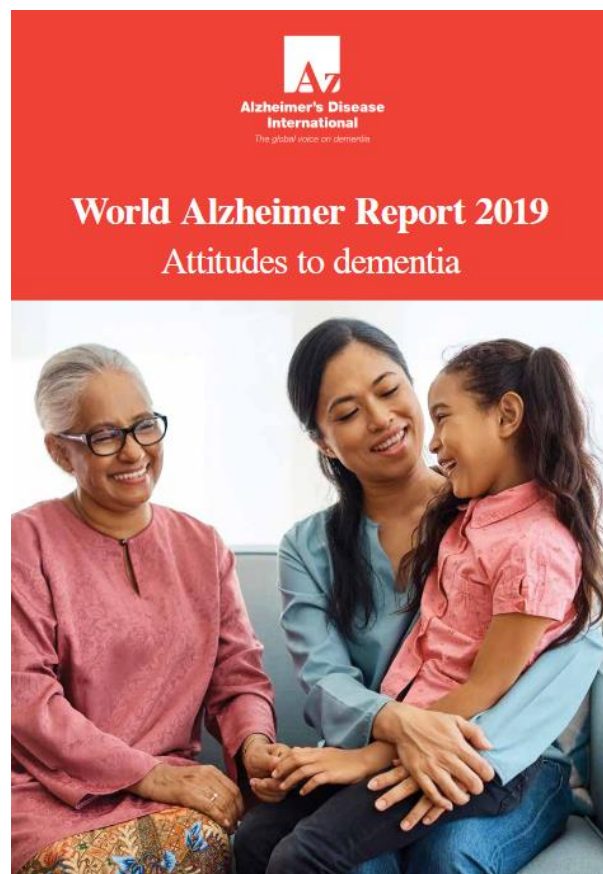
Diagnosis and support

Diagnostic and post-diagnostic support



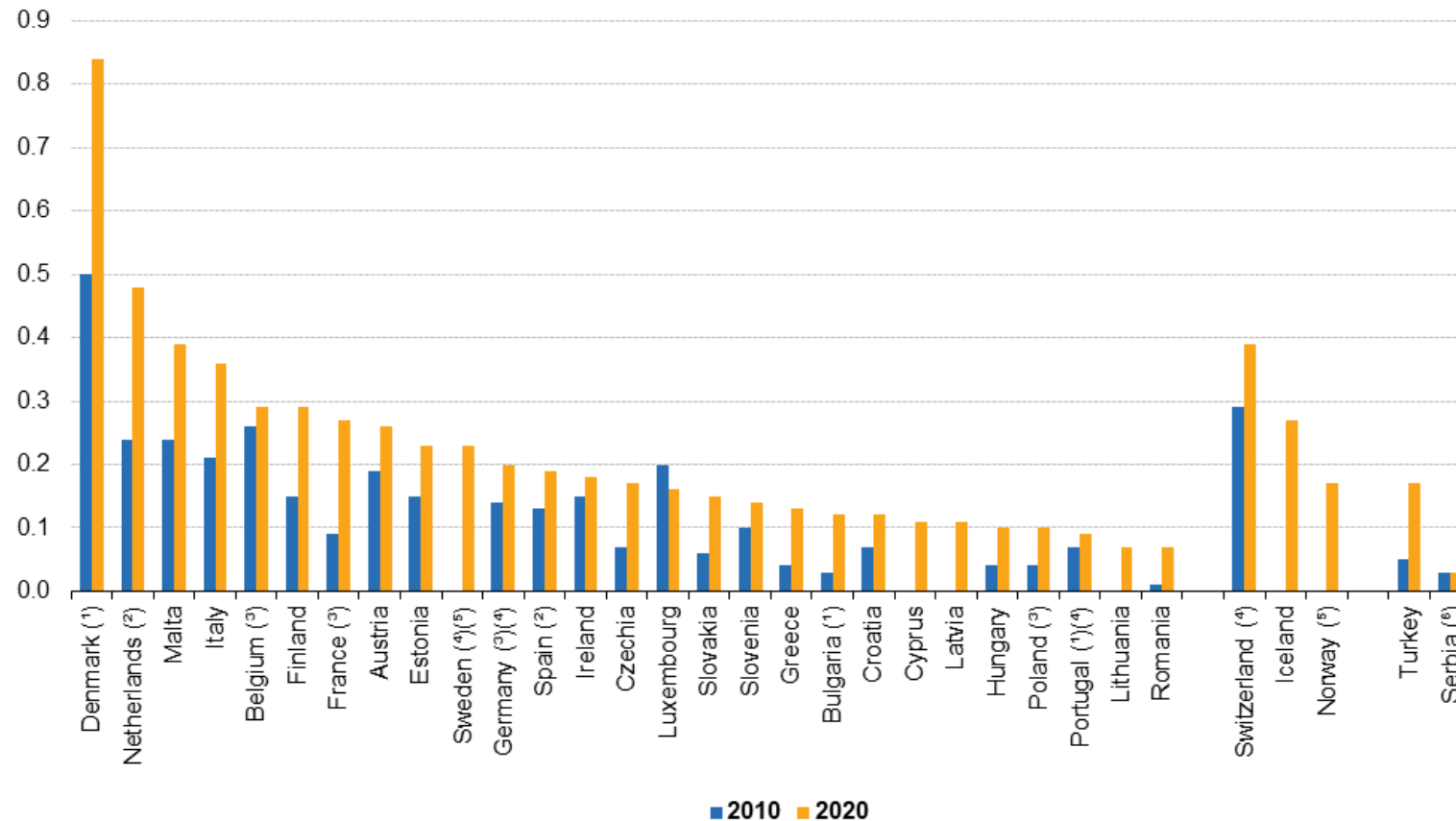
Stigma and awareness

World Alzheimer Report 2019



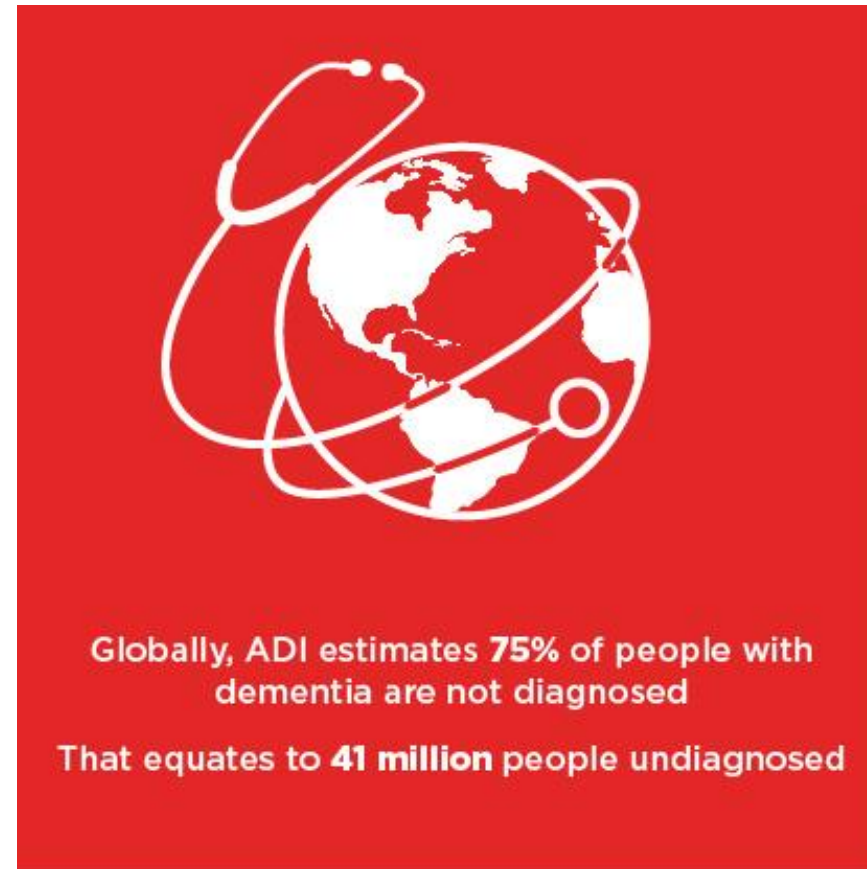
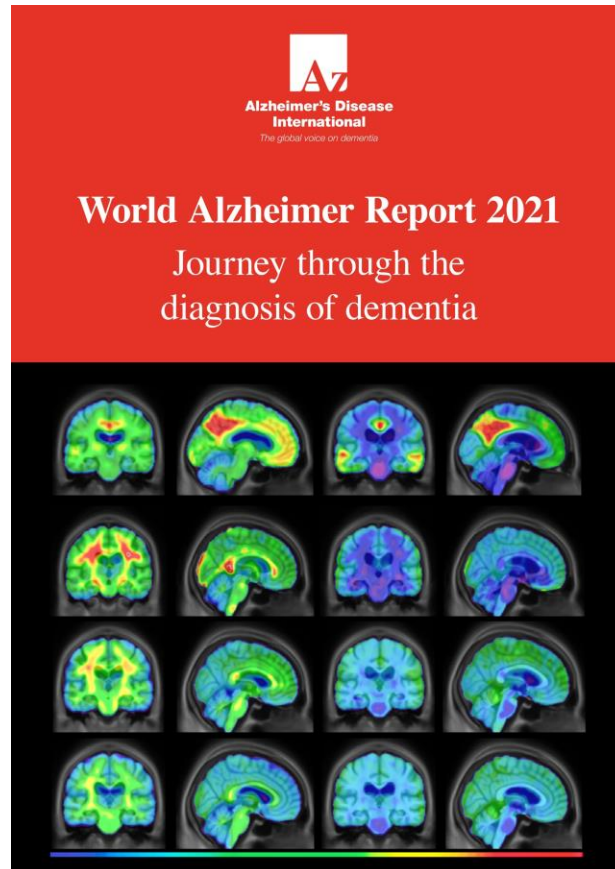
PET-scanner availability in Europe

Availability of PET scanners, 2010 and 2020
(per 100 000 inhabitants)



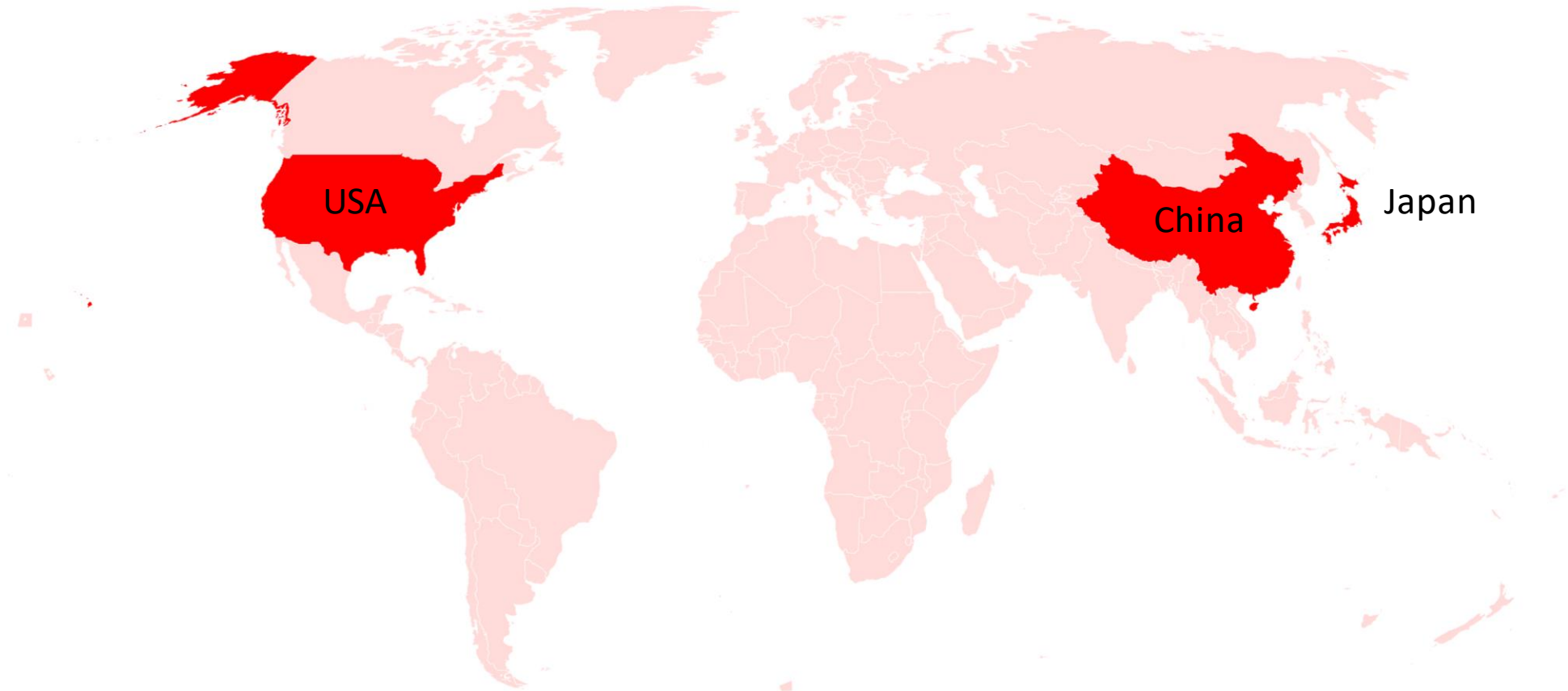
Diagnosis and support

Diagnosis rates are low



DMTs

Lecanemab approvals



DMTs

CMS and EMA advocacy



Alzheimer's Disease International's statement on the Centers for Medicare & Medicaid Services proposed decision memo on Monoclonal Antibodies Directed Against Amyloid for the Treatment of Alzheimer's Disease

Summary

A summary of our main concerns on the draft Centers for Medicare & Medicaid Services (CMS) memorandum are below. Further detail can be found in the accompanying statement

- This decision will limit the autonomy of those living with dementia to make informed decisions about their own care. This is a rights-based argument.
- Potential for inequitable access to treatment resulting from the requirement for clinical trials
- The application of this decision to a whole class of treatments and the potential stifling of future research
- The determination of what constitutes a clinical meaningful benefit and the methodology applied to ascertain this.
- The CMS decision to limit treatment in this way is at variance with the purpose of accelerated approval process by the FDA

Statement

Alzheimer's Disease International is the international NGO representing those living with Alzheimer's disease and other dementias and their carers, through a network of 105 member associations from around the world, including the US. We are in official relations with the World Health Organization. There are currently 55 million people living with dementia around the world. When considering family and friends, those affected by dementia is likely to exceed this number by a large margin. In relation to the draft Centers for Medicare & Medicaid Services (CMS) memorandum we submit the following comments, at the behest of our global membership who are observing these proceedings very closely, with interest and concern. To that end we have included a quote from a person living with Alzheimer's to contextualise the impact of this decision:

"All of us living with Alzheimer's disease are grateful for the strides the US are making in medical research and hoping for new therapeutics. What will happen in the next few months will have huge consequences for the years to come. It is important access is considered without exclusion or discrimination." **Birgitta Martensson, Former Board Member, Alzheimer's Disease International; Former CEO, Alzheimer Switzerland**

Alzheimer's Disease International are cognisant of the burden that these new therapeutics will place on healthcare systems, both practically and fiscally. As an organisation we have commissioned research into these very topics, noting the unpreparedness of healthcare systems worldwide to handle the demand which will be placed on them due to new therapeutics entering the market and improved diagnostics. It is, however, not the fault of those living with dementia and their carers that we are now faced with this healthcare crisis, nor should they be unfairly penalized by it.

We note that the proposed memorandum references the whole class of anti-amyloid therapies rather than the currently approved therapeutic. On this note, we question the justification of providing such guidance to all therapies, including those currently undergoing FDA approval, or more questionably, those which are

Alzheimer's Disease International, The International Federation of Alzheimer's Disease and Related Disorders Societies, Inc.
In official relations with the World Health Organisation.



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15 Bluelion Place
London, SE1 4PU
United Kingdom

Ms Emer Cooke
Executive Director
European Medicines Agency
Domenico Scarlatilaan 6
1083 HS Amsterdam
Netherlands

Re: EMA assessment of new therapeutics for Alzheimer's Disease

Dear Ms Emer Cooke,

Cognisant of a number of new disease modifying therapies for the treatment of Alzheimer's disease currently undergoing, or soon to be assessed by the European Medicines Agency (EMA), I write to you in my capacity as CEO of Alzheimer's Disease International to reiterate our offer to aid the EMA with the assessment of unmet need for those living with dementia and their carers in this area. Alzheimer's Disease International is the federation of 105 Alzheimer and dementia association from around the world and a non-state actor in official relations with the World Health Organization. We have 37 European member nations in our association.

As you are aware, dementia is the 7th leading cause of death globally, with 55 million people living with dementia globally. 7.8 million of which are estimated to be living in the 27 European Union Member States. Dementia also disproportionately affects women, both in terms of those most at risk of developing the condition but are also those most likely to adopt caring responsibilities, with evidence suggesting that two-thirds of carers for dementia are women. Global caring responsibility for those living with dementia is estimated to stand at 133 billion hours each year, the equivalent of 67 million full time workers. The economic impact is also profound, with the condition predicted to cost the global economy \$1.3 trillion USD annually, a figure set to increase to \$2.8 trillion USD annually by 2030.

We write in conjunction with the expectation in our community that there will be important decisions taken by EMA relating to therapeutics for Alzheimer Disease soon. While we do not seek to provide commentary on the merits of any particular therapy for Alzheimer's disease, in particular in relation to areas such as efficacy or safety, of which we delegate to the experts within the Committee for Medicinal Products for Human Use, Alzheimer's Disease International does believe that those living with dementia have the right to take an active role in their healthcare, in consultation with healthcare professionals and their families. Having noted that there are considerable safety implications of some treatments in other disease areas, which are often associated with moderate increases in life expectancy, for example oncology (particularly in the early stages of treatment development), it is our hope that the CHMP and EMA will consider new therapeutics for Alzheimer's disease under the same lens, particularly as currently there are no approved disease modifying therapies for Alzheimer's disease in the EU. In summary, it is our strong belief that those living with Alzheimer's disease should be provided with something, as fundamental and basic as a choice to decide how to manage their condition, be that with or without medical intervention.

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Care

Good care remains vital



Care

Healthcare professionals in Mestre hospital



Research

Research for dementia is still behind other fields



**The
Guardian**

‘This looks like the real deal’: are we inching closer to a treatment for Alzheimer’s?

“ Earlier this year, De Strooper searched the US medical database PubMed for dementia. He found 250,000 studies. He then searched for cancer and found 4.7m. Next, he searched for Covid, a disease that didn’t exist before 2019, and found 300,000 studies. It’s a rough metric, but it suggests that more research has been done on Covid in the past three years than on dementia in the past century

”

LMICs are largely being excluded

- Clinical trials sites are rarely found in LMICs.
- Of the 149 ongoing trials for Alzheimer's Disease listed on <https://clinicaltrials.gov>, just 6 have trial sites in LMICs





Global Dementia Observatory



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Global Dementia Observatory (GDO)



WHO/Cathy Greenblat

The Global Dementia Observatory (GDO) is the monitoring and accountability mechanism for the Global action plan on the public response to dementia 2017-25. It collates data from WHO Member States on 35 key dementia indicators to strengthen countries' ability to respond to the needs of people with dementia, their carers and families.

The 35 GDO indicators and sub-indicators build a comprehensive logic model that can track progress across the seven strategic areas of the Global dementia action plan, including all recommended dementia actions at national, regional and global levels. Specifically, a core set of GDO indicators is used to measure individual countries' contributions towards achieving the global targets of the Global dementia action plan.

As of August 2021, 62 countries have contributed data to the GDO during the first round of data collection (2018-2020). The next round of GDO data collection is planned to commence in 2022.



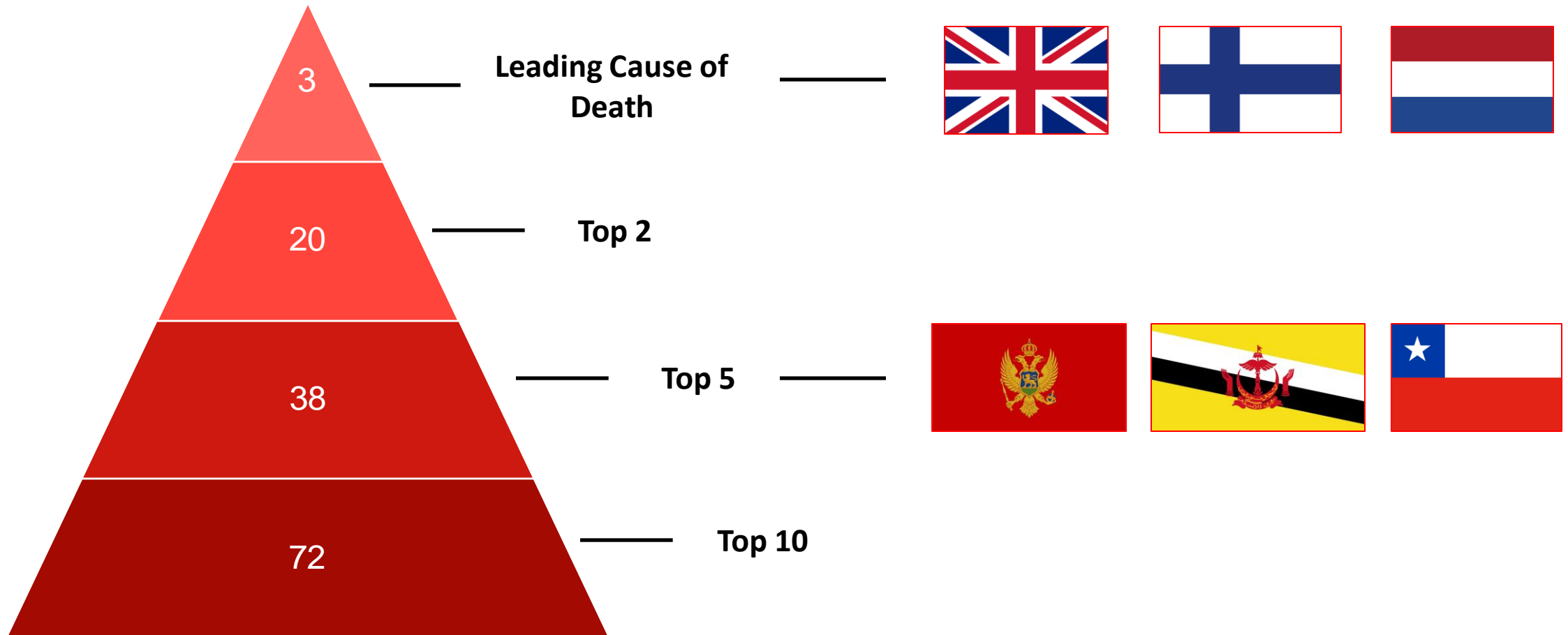
From Plan to Impact VII

From Plan to Impact VII
Lauching 29 May



Data

Dementia mortality



194 WHO Member States total

WHO Global Health Observatory: Cause-specific mortality, 2019

40 years of ADI



Celebrating 40 years as the
global voice on dementia

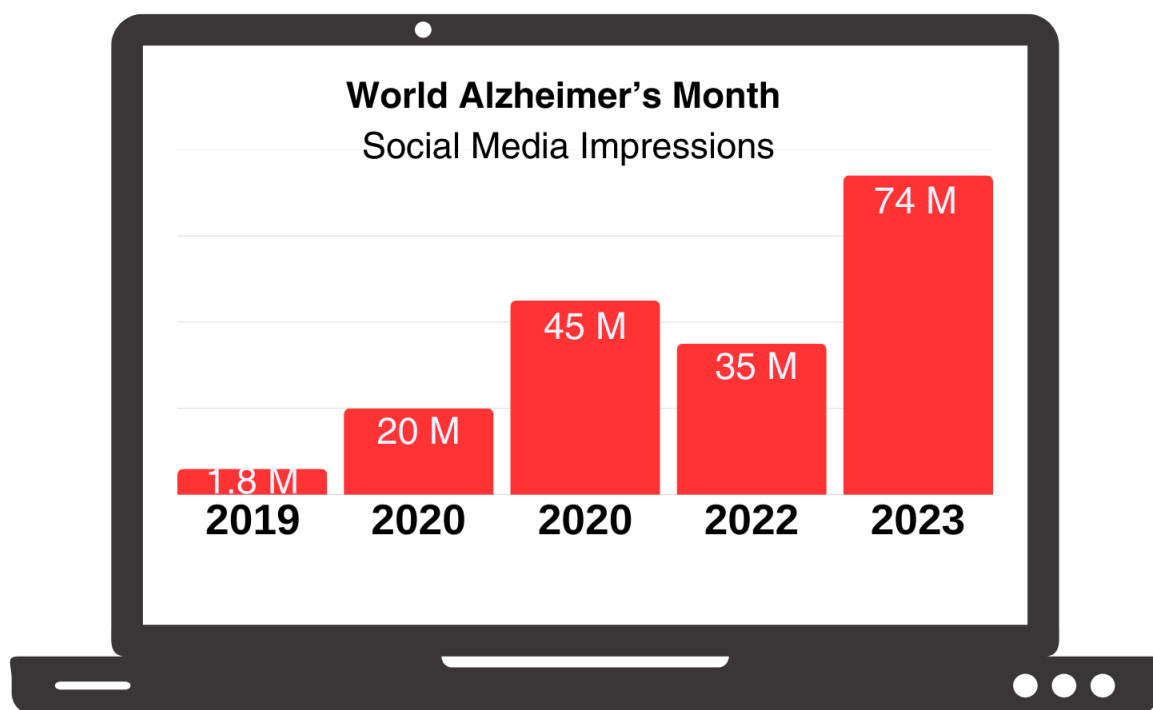
40 years of Conference



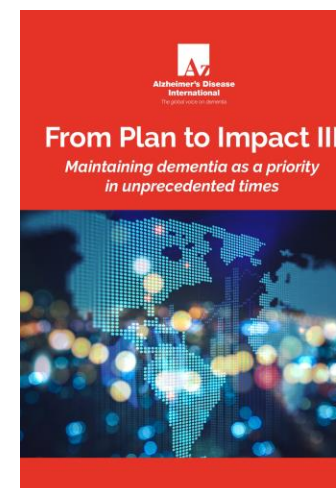
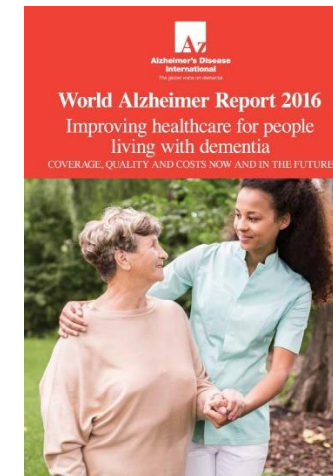
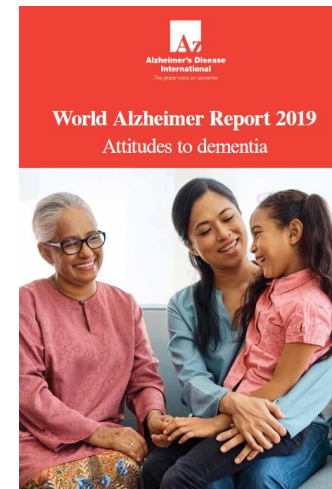
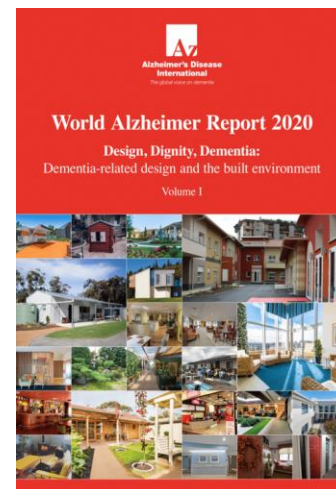
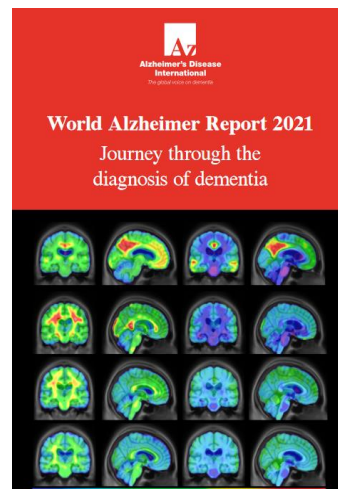
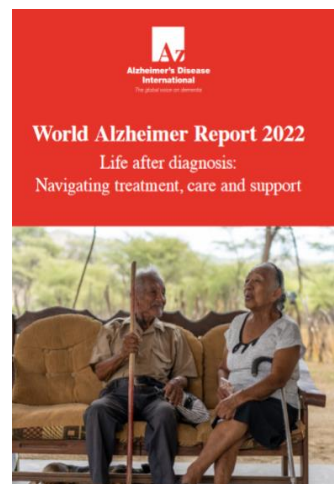
40 years of Alzheimer's University



40 years of awareness raising



40 years of research and reports

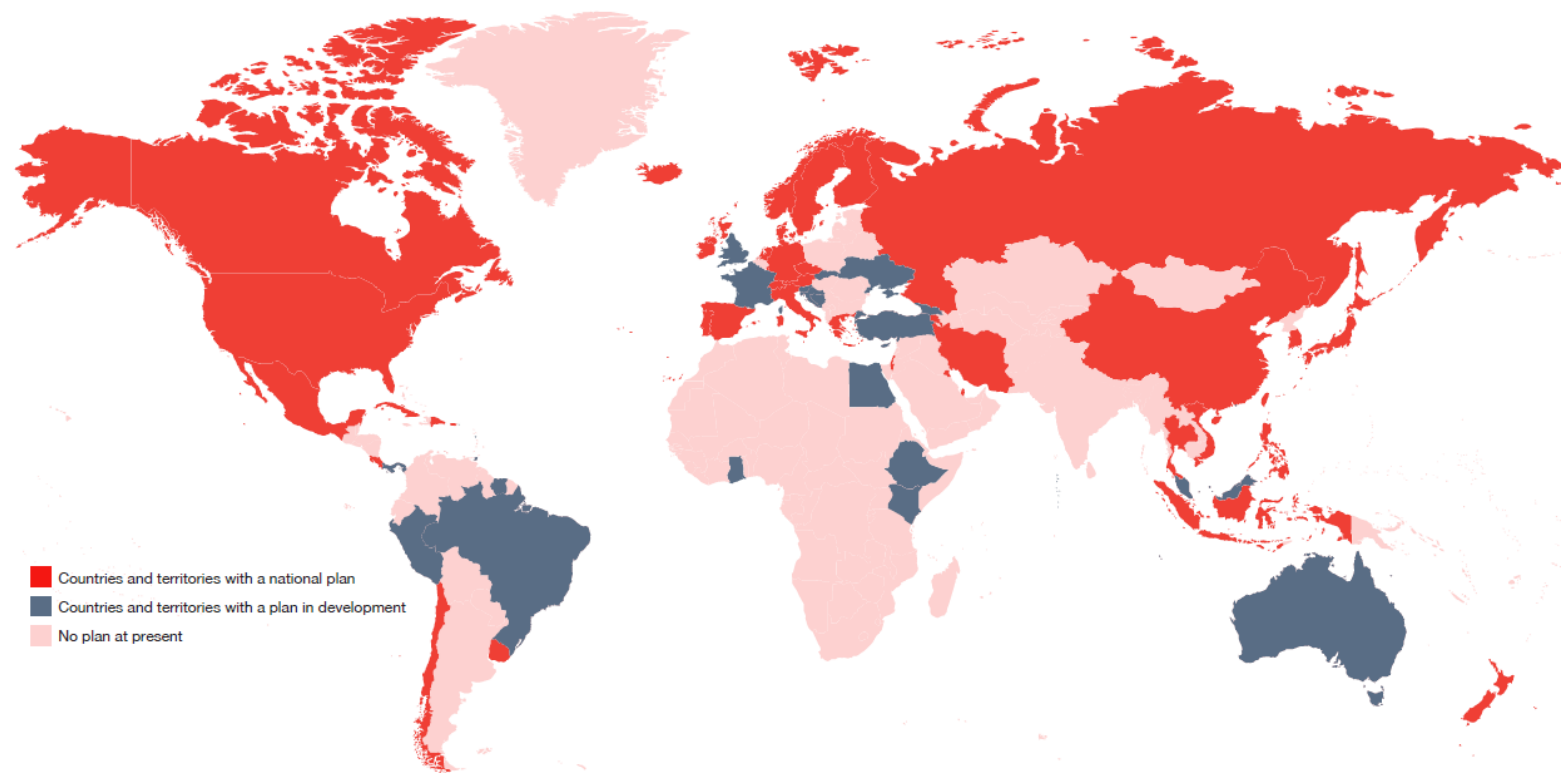
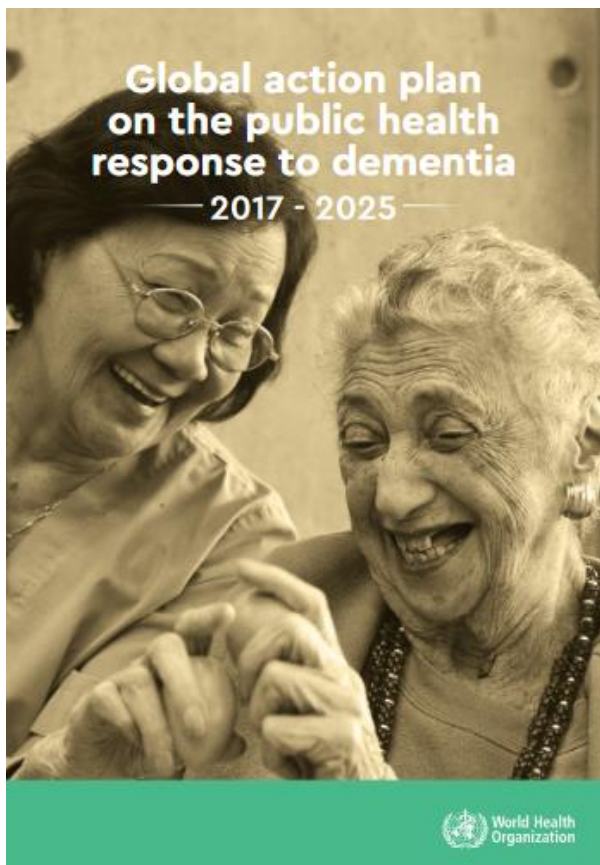


40 years of being friends, advocates, loving and caring people



Policy

Global Action Plan on the public health response to dementia 2017-2025





Alzheimer's Disease International

The global voice on dementia



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