

Living well: the community challenge

Moderator: Paola Barbarino
CEO, ADI

#DefeatingDementia

Introducing the concept of dementia friendliness in global dementia policy



Paola Barbarino
Chief Executive, ADI

The global impact of dementia



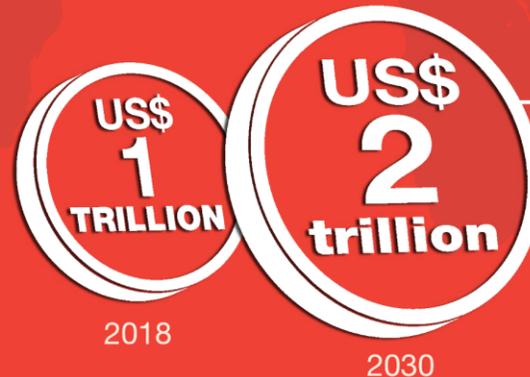
**Alzheimer's Disease
International**

The global voice on dementia



Around the world,
there will be one new case
of dementia
**every
3 seconds**

50 million people worldwide are
living with dementia in 2018.
This number will more than
**triple to 152
million by 2050**



The total estimated
worldwide cost of dementia
in 2018 is US\$1 trillion.
This figure will rise to
**US\$ 2 trillion
by 2030**

Source: World Alzheimer Report 2018

About Alzheimer's Disease International (ADI)



**Alzheimer's Disease
International**

The global voice on dementia

- **Established in 1984**
- **100 Alzheimer country member associations**
- **Awareness raising**
- **Advocacy**
- **Socioeconomic content and analysis**

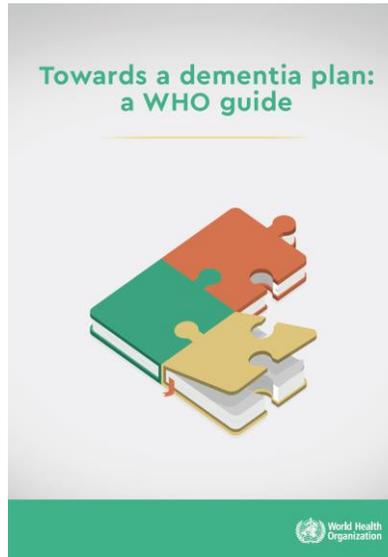
**Our vision is prevention, care and inclusion today, and
cure tomorrow.**

WHO Global action plan on dementia

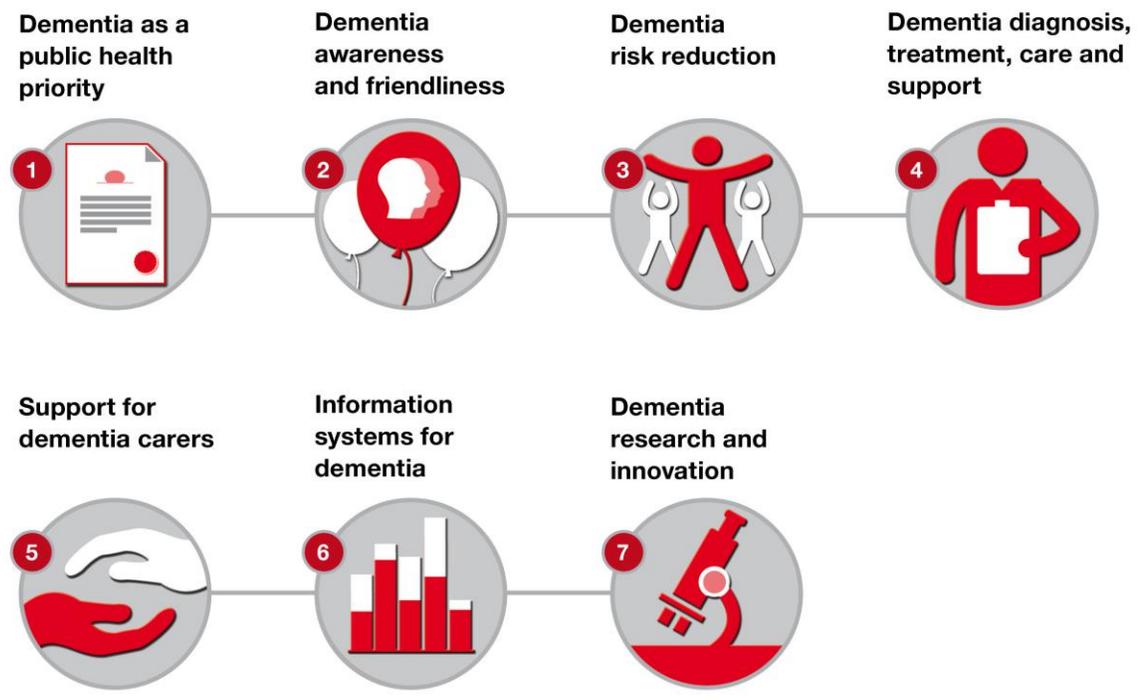


Alzheimer's Disease International

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Action areas



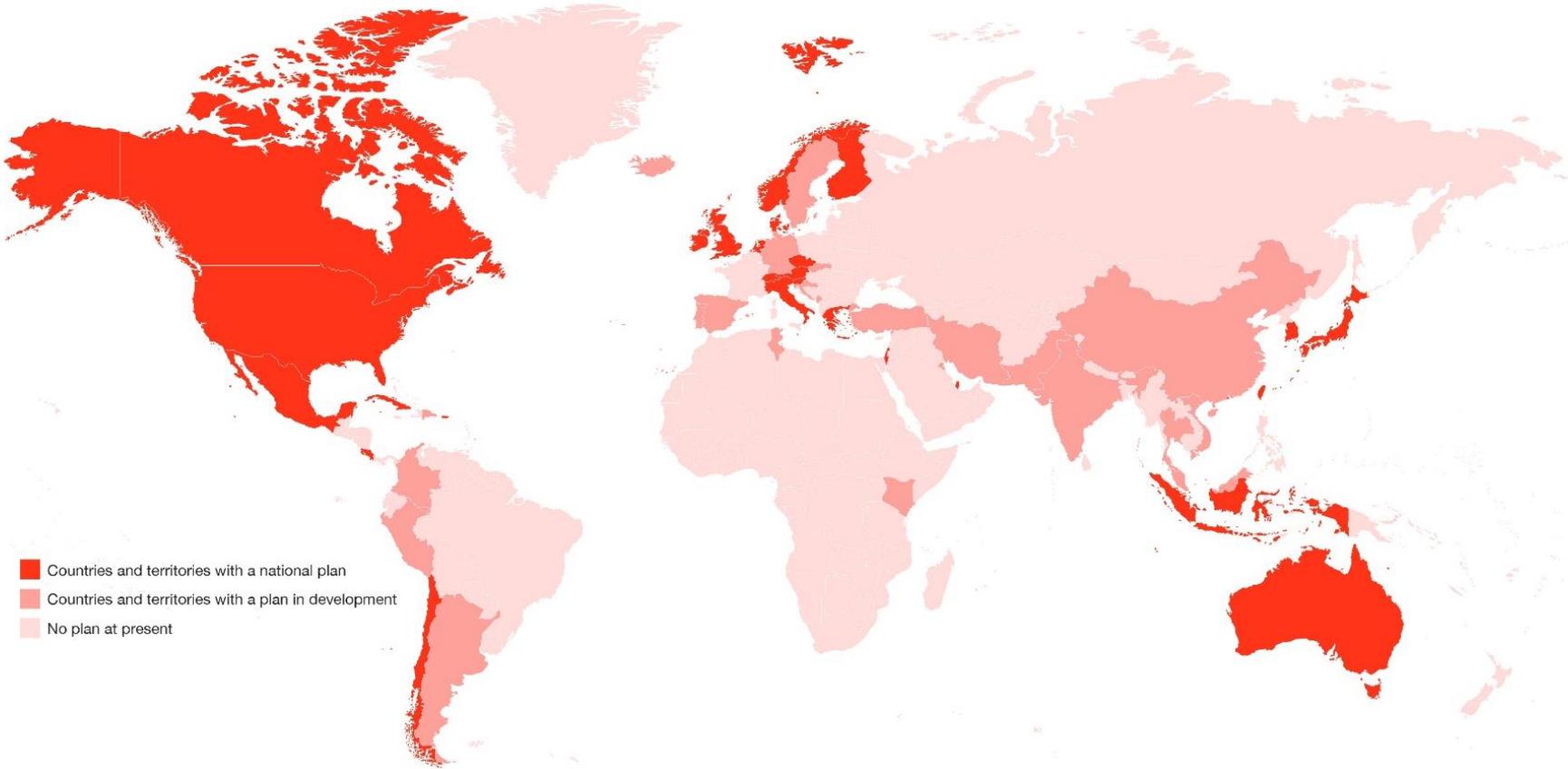


Alzheimer's Disease International

The global voice on dementia

National Dementia Plans

Countries with plans on dementia or in development in 2019



- Countries and territories with a national plan
- Countries and territories with a plan in development
- No plan at present

Countries with national dementia plans

Australia	Czech Republic	Italy	Mexico	Slovenia	USA
Austria	Denmark	Ireland	Netherlands	Singapore	
Canada	Finland	Japan	Norway	Switzerland	
Chile	Greece	Luxembourg	Puerto Rico	TADA Chinese	
Costa Rica	Indonesia	Macau SAR	Qatar	Taipei	
Cuba	Israel	Malta	Republic of Korea	UK	

Countries with national dementia plans in development

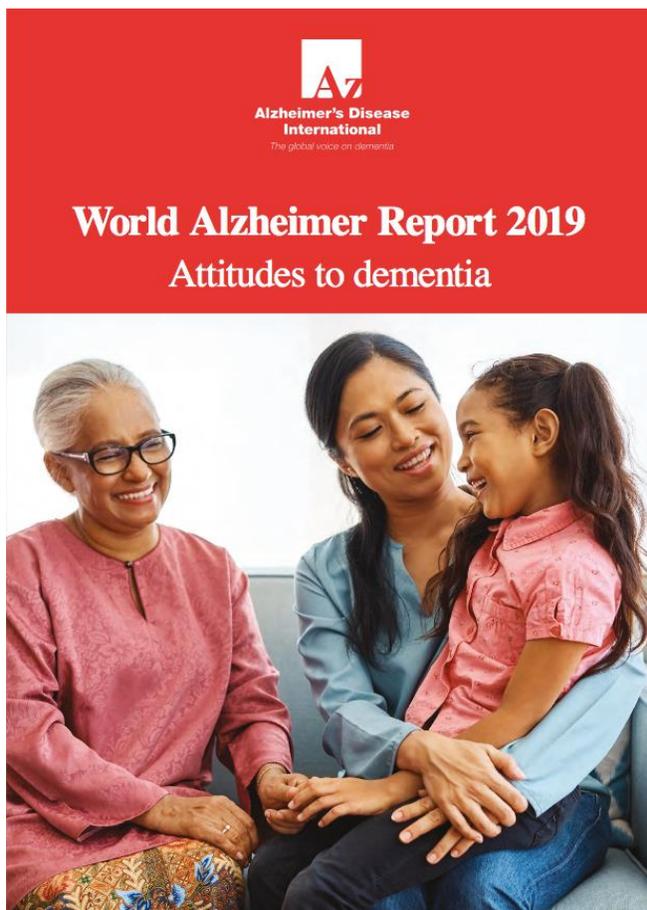
Argentina	Colombia	Germany	Kuwait	Peru	Thailand
Barbados	Croatia	Iceland	Malaysia	Portugal	Tunisia
Bonaire	Curacao	India	Mauritius	Spain	Turkey
Brunei	Cyprus	Iran	Montenegro	Slovak Rep	Vietnam
China	Dominican Rep.	Kenya	Pakistan	Sweden	

Action area 2: Dementia awareness and friendliness

People with dementia must be involved as equal partners – non negotiable

- **Well being.** Supporting the person to achieve the best quality of life reasonably possible
- **Autonomy/Independence**
- **Reduced stigma and social isolation**
- **Equality.** People with dementia and their carers are **respected** and **included** in society, with their rights and capabilities recognized - CRPD

World Alzheimer Report 2019



- World's largest survey on attitudes to dementia – almost 70,000 respondents
- Commissioned London School of Economics & Political Science (LSE)
- Essays and case studies bring the survey to life

www.alz.co.uk/worldreport2019

World Alzheimer Report 2019: revealing the gap in dementia friendliness and awareness



1 in 4 people think
there is nothing we can
do to prevent dementia



35% of carers globally have
hidden the diagnosis of a person
with dementia



62% of healthcare practitioners
still believe that dementia is
part of normal ageing



2 in 3 people still think
that dementia is caused
by normal ageing

Almost 70,000 respondents from 155 countries



2 in 3 people think that dementia is caused by normal ageing

1 in 4 people think that there is nothing we can do to prevent dementia

95% of the general public think they could develop dementia at some point in their lifetime

Just under 40% of the general public think that there are adequate community services in place for people living with dementia and carers

54% of respondents think lifestyle factors play a part in developing dementia

91% of respondents say that people should not hide the fact they have dementia



Men are more likely to hold stigmatising views about dementia than women

Although they were more likely to let a relative with dementia move in with them



Attitudes of healthcare practitioners to dementia

62% of healthcare practitioners still believe that dementia is part of normal ageing



Around 40% of the public think healthcare practitioners ignore people with dementia



"My neurologist ignored my presence when my diagnosis was discussed with my husband."

"They sometimes talk to my wife about things like I'm not even there, but I'm sitting right there."

"Neurologist diagnosed me with Alzheimer's at 56, telling me to go home and get my final affairs in order and wait until my premature death."

"Many healthcare practitioners often do not believe I have dementia - which is abusive and offensive. But, also, they then talk over me, about me, and never to me..."

Experiences of carers



Over 50% of carers expressed positive sentiments about their role



Over 50% of dementia carers said their health suffered as a result of their caring responsibilities



35% of carers globally have hidden the diagnosis of a person with dementia



Over 60% of dementia carers said their social life suffered as a result of their caring responsibilities

Dementia, intimacy and relationships

Between 35% in high income and 57% in low and lower-middle income countries reported being treated unfairly in dating or intimate relationships

People with dementia said:

"To be honest, NO ONE wants to date a 58-year-old guy with Alzheimer's."

"I don't date at all now. As soon as I mention I have dementia, they presume the worst..."

"I call it the friendship divorce. I have lost a fair amount of people in my life that at one time considered friends."

"My last boyfriend wanted to hide me away and I spoke openly about my dementia. Hence why that relationship didn't work..."

"... my wife and I divorced due to my Alzheimer's... her decision."

Dementia: not a laughing matter?

63% of respondents living with dementia in South-East Asia said their dementia symptoms were joked about by others

67% of respondents living with dementia in Africa said their dementia symptoms were joked about by others



Carers of people with dementia said:

"So-called Alzheimer's humour does much more than annoy and hurt those who work hard to make life better for the 50 million plus people in the world living with dementia. It trivialises the disease."

People with dementia said:

"It is 100% offensive, and inexcusable to joke about my symptoms (unless it is me joking about it)."

"When others who also have a dementia diagnosis joke this is just an expression that we are able to maintain a sense of humour and is a great stress reliever."

"Laughter is good for the soul and if you can laugh about your circumstances it can reduce anxiety. So we laugh from time to time when something incoherent comes out of my mouth."



Some conclusions

- **Need to encourage development of dementia friendly societies in order to:**
 - **Improve the lived experience with dementia**
 - **To seek the inclusion of dementia in the CPRD**
- **People with dementia must be equal partners**
- **Requires funding and support from all levels of government, as well as business and the community**

Hope In The Age Of Dementia.

NEW SCIENCE. NEW KNOWLEDGE. NEW SOLUTIONS.



19-21 March 2020

 adi2020.org





Alzheimer's Disease International

The global voice on dementia

Thank you!



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www.alz.co.uk

Living well: the community challenge

Dr Tarun Dua
World Health Organization

#DefeatingDementia



Towards a dementia-inclusive society: a WHO toolkit for dementia-friendly initiatives (DFIs)

Tarun Dua

Department of Mental Health and Substance Use, World Health Organization

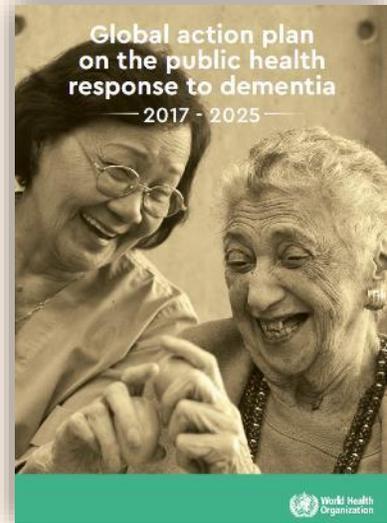
Global action plan on the public health response to dementia

The Seventieth World Health Assembly, having considered the draft global action plan on the public health response to dementia 2017–2025,¹ decided:

- (1) to endorse the global action plan on the public health response to dementia 2017–2025;
- (2) to urge Member States² to develop, as soon as practicable, ambitious national responses to the overall implementation of the global action plan on the public health response to dementia 2017–2025;
- (3) to request the Director-General to submit a report on progress made in implementing this decision to the Seventy-third, Seventy-sixth and Seventy-ninth World Health Assemblies.

(Tenth plenary meeting, 31 May 2017)

WHO tools to support countries



		Tools/resources
	Dementia as a public health priority	Policy guide
	Dementia awareness & friendliness	Dementia-friendly toolkit
	Dementia risk reduction	Dementia risk reduction guidelines
	Dementia treatment, care & support	mhGAP toolkit for health & community workers
	Support for dementia carers	iSupport
	Information systems for dementia	GDO e-tool and platform
	Dementia research & innovation	BRAINS for dementia

Global Dementia Observatory (GDO)

Rationale for developing a DFI toolkit

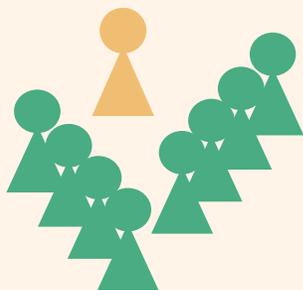


Ongoing lack of awareness and understanding of dementia globally

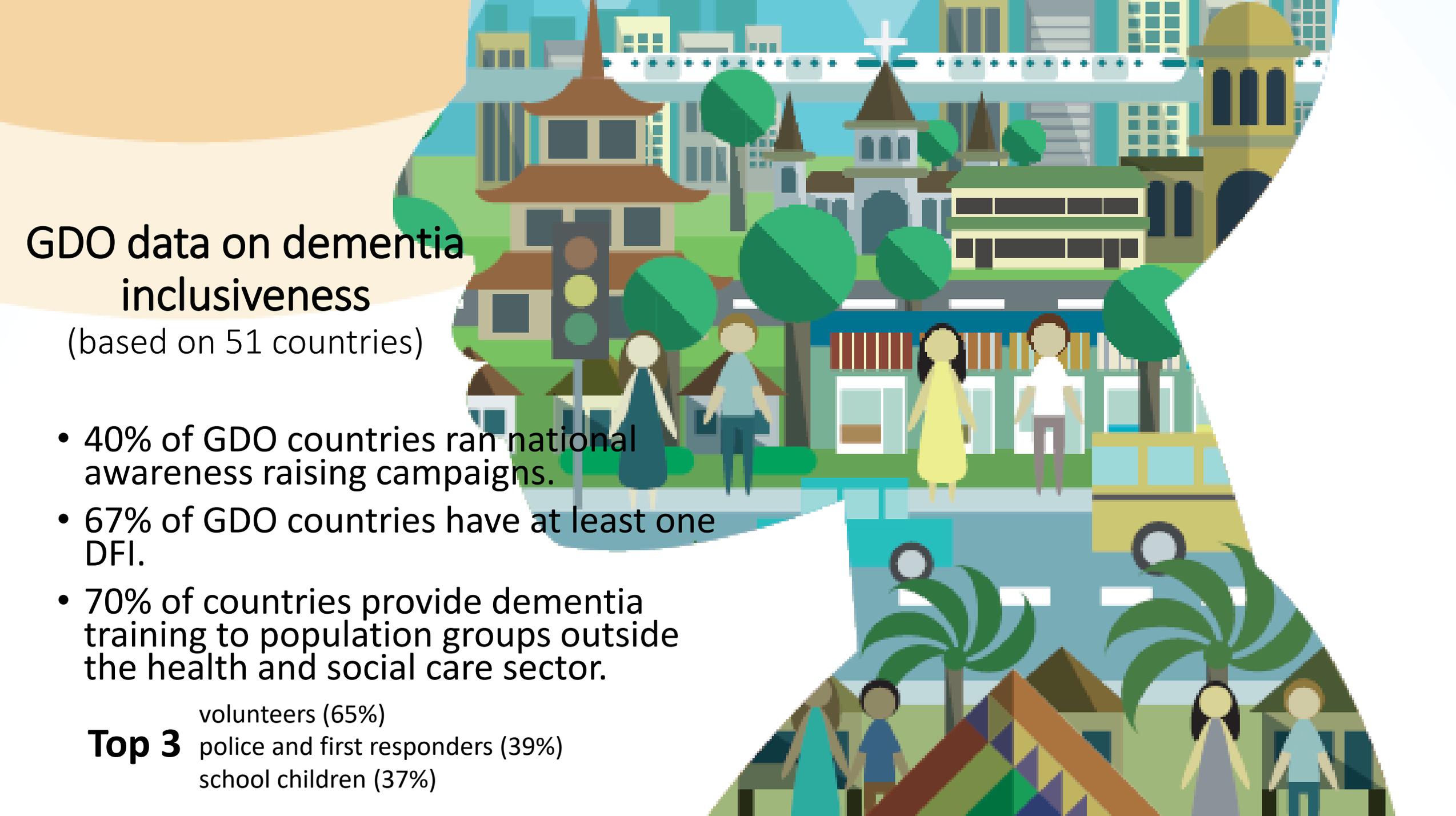
FACTS

~~MYTHS~~

Misconception, false beliefs and stigma in many countries



Discrimination and human rights violations against people with dementia



GDO data on dementia inclusiveness

(based on 51 countries)

- 40% of GDO countries ran national awareness raising campaigns.
- 67% of GDO countries have at least one DFI.
- 70% of countries provide dementia training to population groups outside the health and social care sector.

Top 3 volunteers (65%)
police and first responders (39%)
school children (37%)

Development of the DFI toolkit

1. Global landscaping	Review of relevant WHO documents and DFI literature
2. Framework	Conceptual cross-mapping of emerging themes and building of framework
3. Stakeholder consultation	Expert consultation and feedback round
4. Toolkit	Based on framework and existing toolkits
5. M&E indicators	Based on framework and steps outlined in the toolkit Aligning with other work
6. Pilot testing	In selected countries from WHO regions

Stakeholder consultation



20 in-depth interviews

- With civil society and policy makers
- Across all 6 WHO regions and all country income levels

6 focus groups

- With people living with dementia
- Including one in Japan and one in Australia
- Conducted by Dementia Alliance International (DAI)

Online survey

- 129 respondents from 46 countries

Towards a dementia-inclusive society: a WHO toolkit for dementia-friendly initiatives (DFIs)



A look inside the toolkit

- The toolkit supports individuals working in communities to create dementia-inclusive societies.
- It includes practical guidance, tools and exercises that can be used as facilitation tools by non-expert programme implementers in group settings.

Part I

Dementia and human rights

How to use this toolkit

The DFI framework

Part II

Module A

Developing a new DFI

Module B

Integrating dementia into an existing initiative

Module C

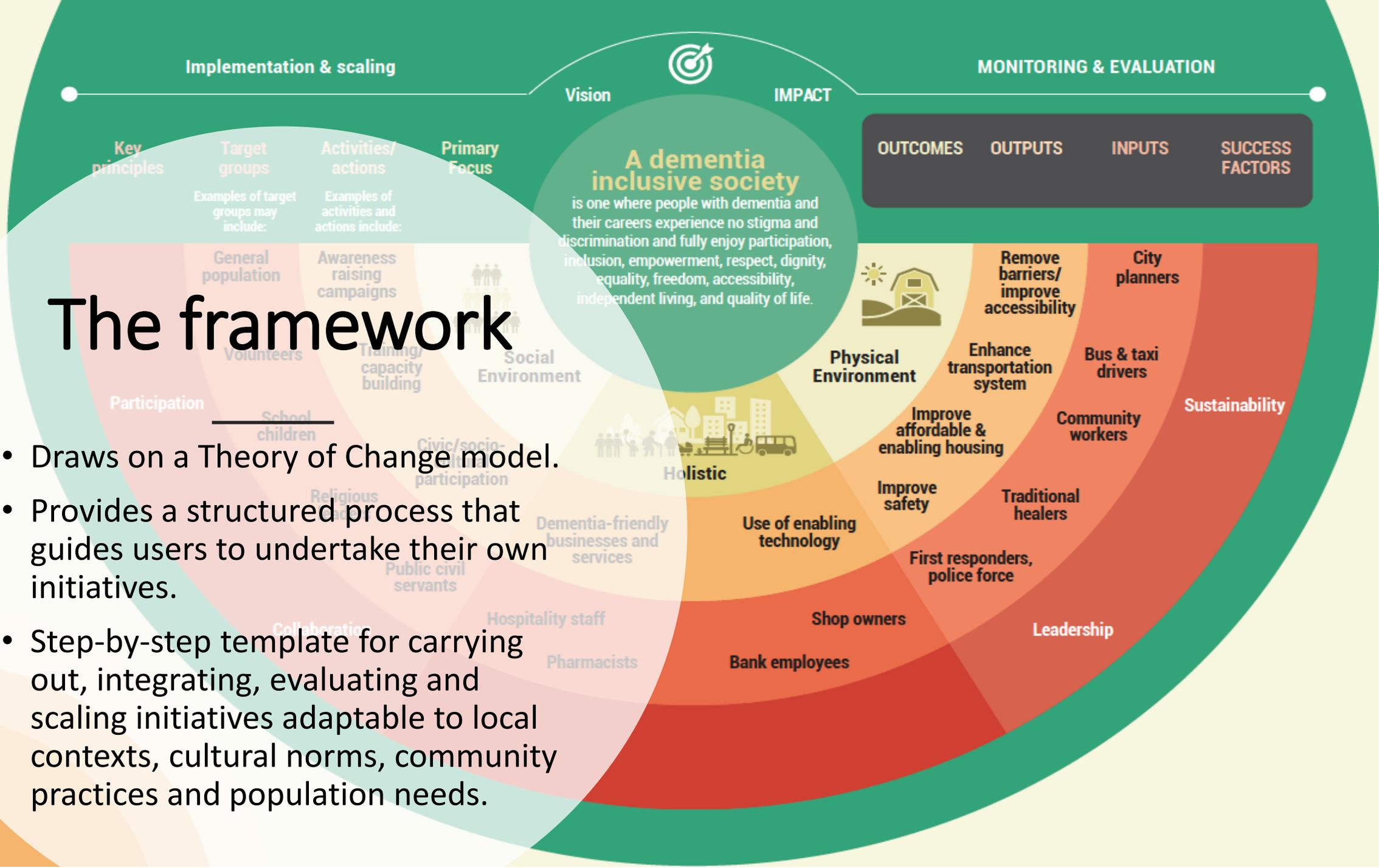
Monitoring and evaluation (M&E)

Module D

Scaling up a DFI

The framework

- Draws on a Theory of Change model.
- Provides a structured process that guides users to undertake their own initiatives.
- Step-by-step template for carrying out, integrating, evaluating and scaling initiatives adaptable to local contexts, cultural norms, community practices and population needs.



Framework components

Vision

Make society inclusive of people living with dementia, their carers and families so that they are free to make their own choices and are protected from discrimination.

Key principles

Participation

Collaboration

Leadership

Sustainability

Primary focus

Social environment

Physical environment

Holistic

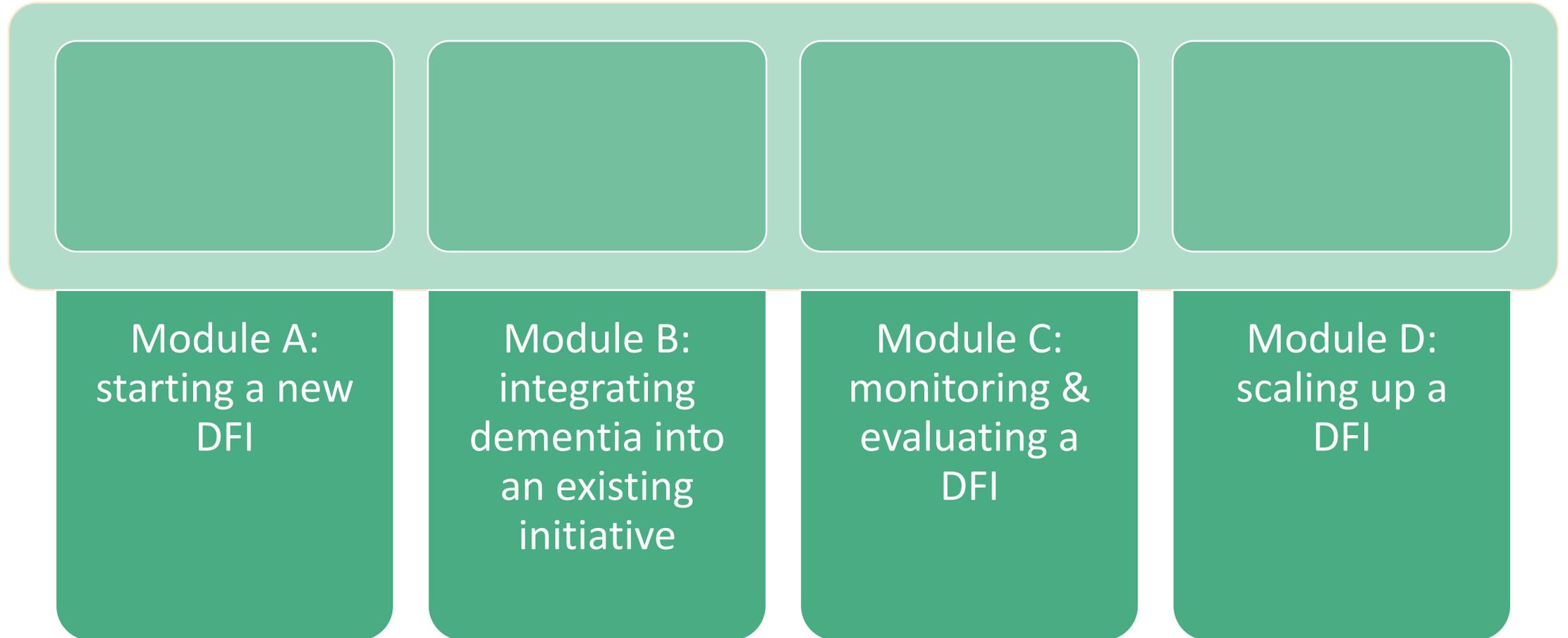
Activities

All activities and actions that promote lasting change to the social and/or physical environment to help build dementia-inclusive societies.

Target groups

The individuals or groups of individuals, targeted by the DFI and its activities.

The implementation section of the toolkit





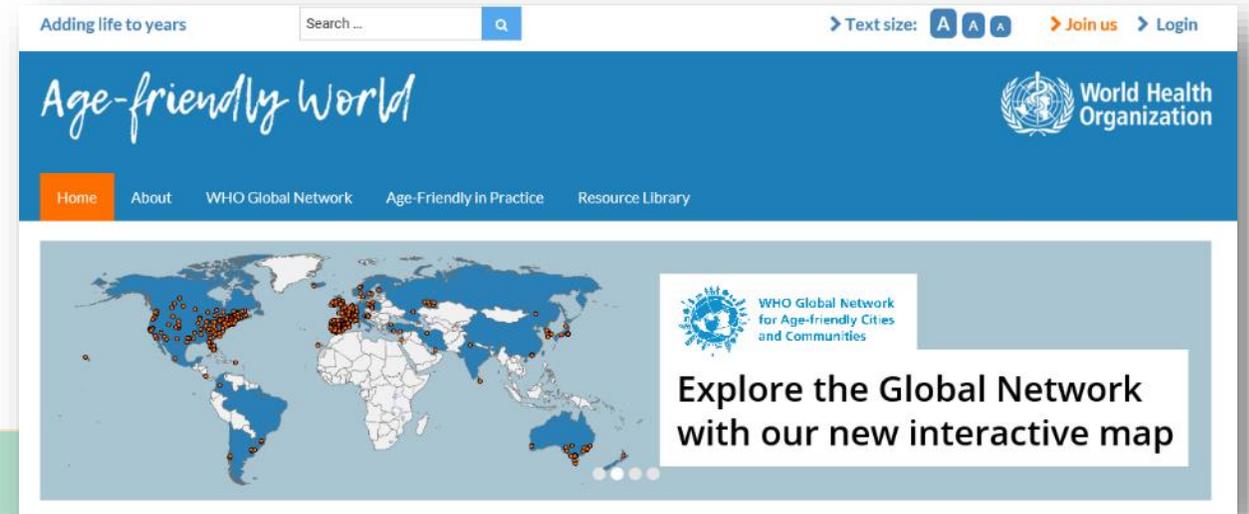
Module A: starting a new DFI

Module A provides practical guidance and tools to **start a new DFI**.

It includes **guided steps and exercises** that help users:

- **identify stakeholders**, partners and a coordination team;
- Define **key issues and a vision** for the initiative;
- Set **goals and outcomes**, and identify primary focus areas;
- Develop activities and a **risk- and resource-management** plan.

Module B: integrating dementia into an existing initiative



Module B provides practical guidance and tools to **integrate dementia into an existing initiative** (e.g. age-friendly community).

It includes **guided steps and exercises** that help users:

- **Identify stakeholders**, partners and a coordination team;
- Gather information to **map relevant, existing initiatives** and identify key issues;
- Set a joint **vision, goals and outcomes**, and determine primary focus areas;
- Develop activities for integration and a **risk- and resource-management** plan.



Module C: monitoring and evaluating a DFI

Module C provides practical guidance and tools to **monitor and evaluate a DFI**.

It includes a series of **steps and exercises** that help users:

- Determine what **type of evaluation** best suits their initiative;
- Develop a **logic model**;
- Formulate **evaluation questions and indicators**.

Module D: scaling up DFIs



Module D provides practical guidance and tools to **scale up a DFI**.

It includes **tips, checklists and exercises** that help users:

- Identify a **DFI for scale-up**;
- Determine the appropriate **type of scale-up** mechanism;
- Develop a **vision, goals and outcomes**, and determine primary focus areas for scale-up;
- Plan and implement activities for integration and a **risk- and resource-management** plan.



DFI steering group: Department of Health, UK; Ministry of Health, Labour and Welfare, Japan; Alzheimer Society UK; Alzheimer's Disease International; and Dementia Alliance International

Thank You

WHO also acknowledges the financial support from Canada, the European Commission, Germany, Japan, the Netherlands, Switzerland and the United Kingdom.

Living well: the community challenge

Professor Martin Knapp

London School of Economics, UK

#DefeatingDementia



Global challenges

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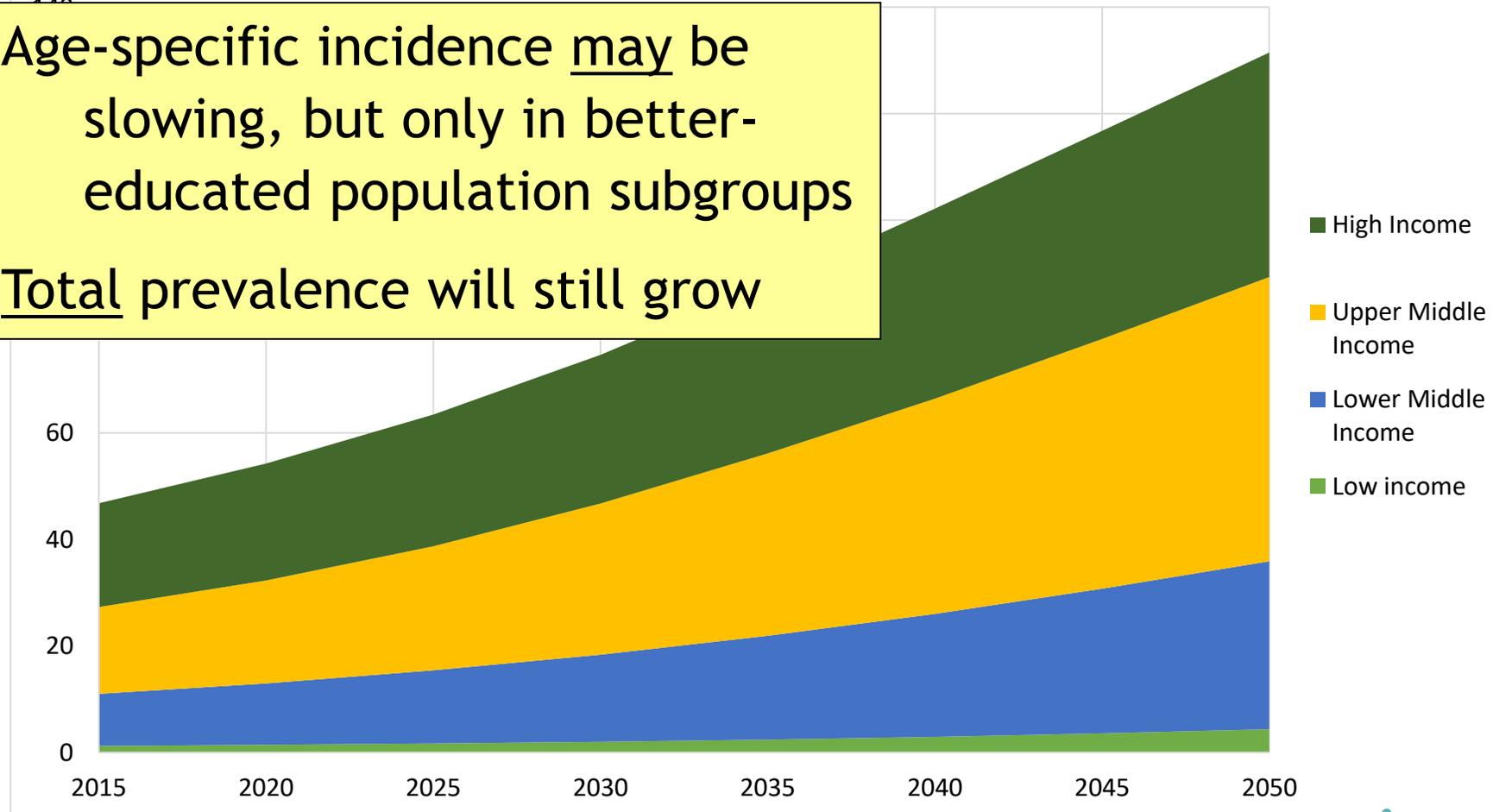
@knappem

1. Scary numbers? Projected global growth in dementia prevalence to 2050

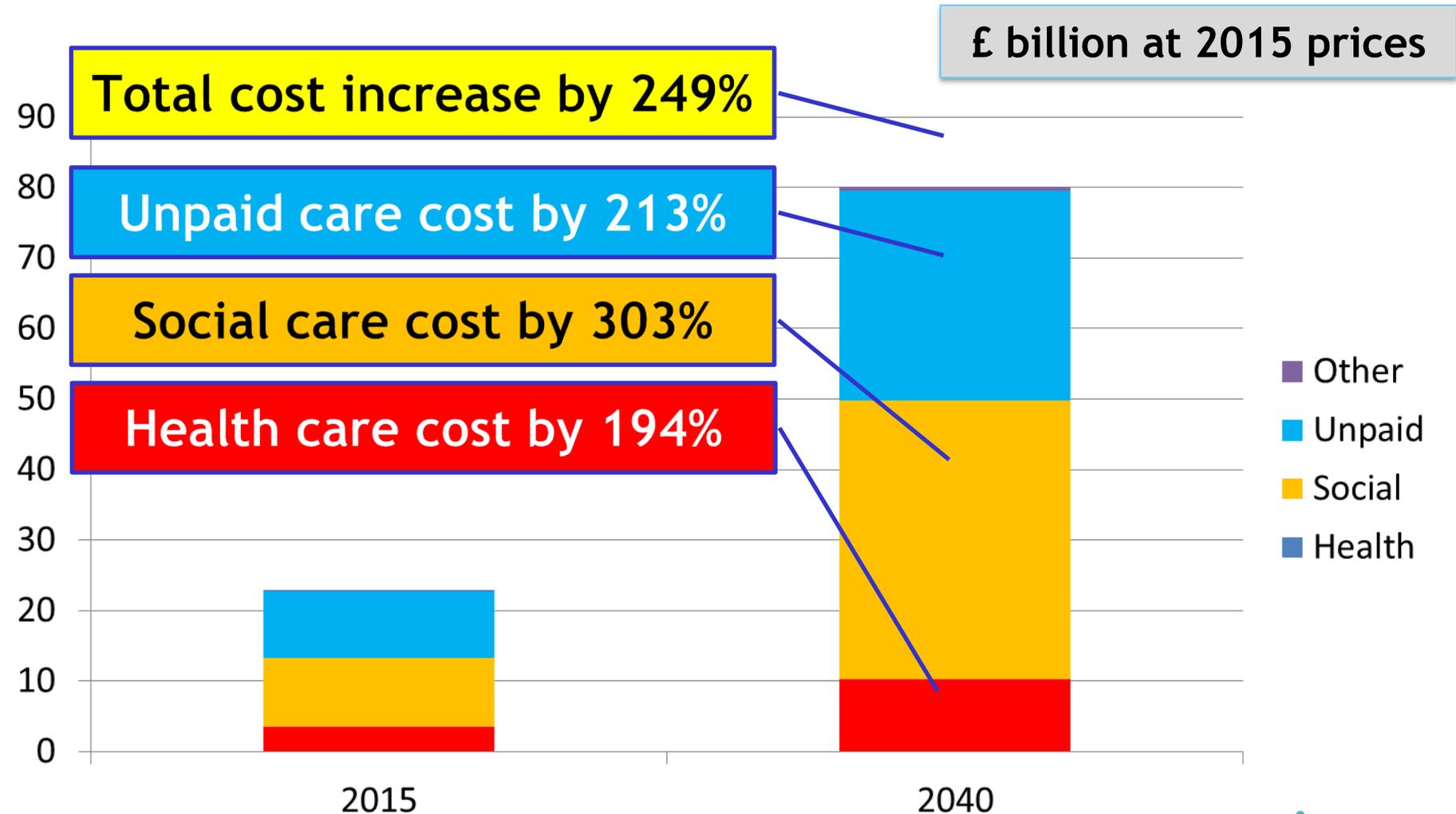
Numbers of people living with dementia (millions)

Age-specific incidence may be slowing, but only in better-educated population subgroups

Total prevalence will still grow



2. Unaffordable costs? Projected costs of dementia care in England



No disease-modifying treatments yet

99.6% failure rate of medication trials for Alzheimer's disease, 2002-2012 (Cummings et al. *Alz Res & Therapy* 2014)

Why?

- Inherent inaccessibility & complexity of the brain
- Symptoms may emerge 10+ years after disease starts
- Not enough research / researchers?
- Insufficient protection for IP?

3. No cure?



Factoring in difficulties & costs of diagnostic tests, when will a 'cure' be affordable globally?

4. Slow, partial prevention?

Known risk factors:

- Genes (*at birth*)
- Education (*early life* +)
- Hearing loss, hypertension, obesity (*mid-life*)
- Smoking, depression, physical inactivity, social isolation, diabetes (*late-life*)

Overall population-attributable risk = 35%

Livingston
et al
Lancet
2017

5. Substantial inequalities?

Many risk-factors have strong (socio)economic links:

- low education
- poor health behaviours
- unaffordability of good diet & exercise
- social isolation
- depression

And inequalities in access to care & support (see next)

6. Inadequate care?

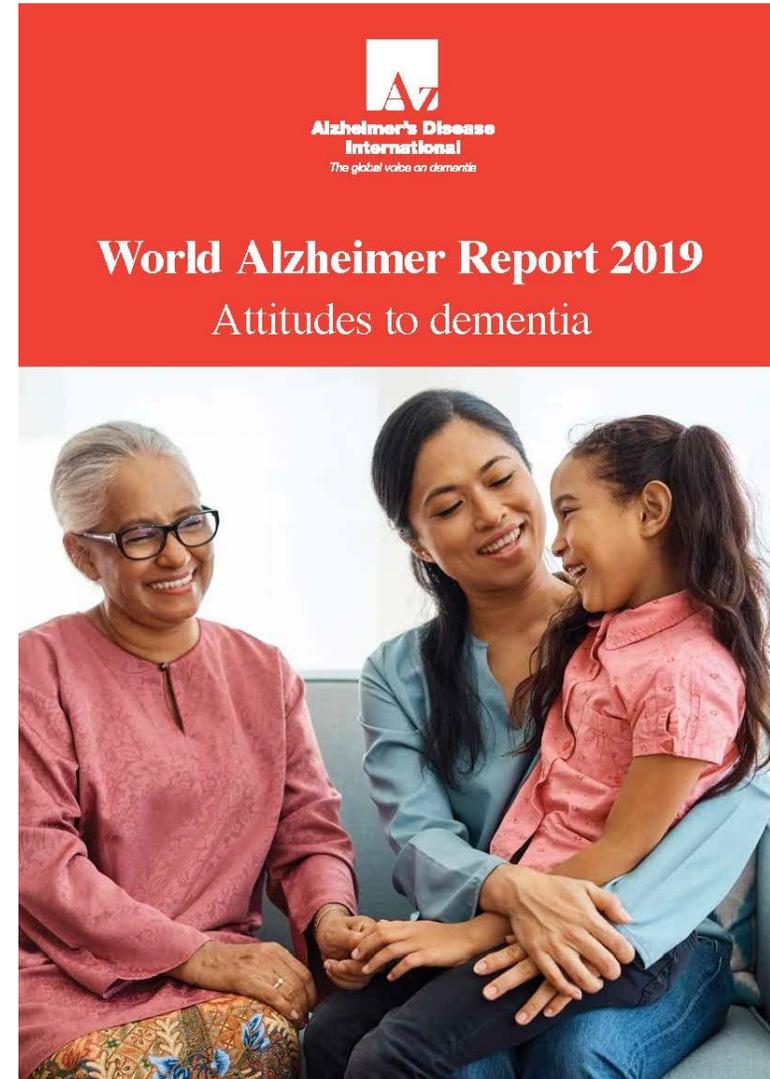
- Yes, there are evidence-based symptomatic treatments, care & support arrangements, but...
- ... few people living with dementia have access to them.
- And there are proven support services for family caregivers...
- ... but again, not widely available.



- Are there enough family & other unpaid caregivers - today and in the future?
- Wide inequalities in access to good care & support
- Treatment & care complicated by comorbid conditions

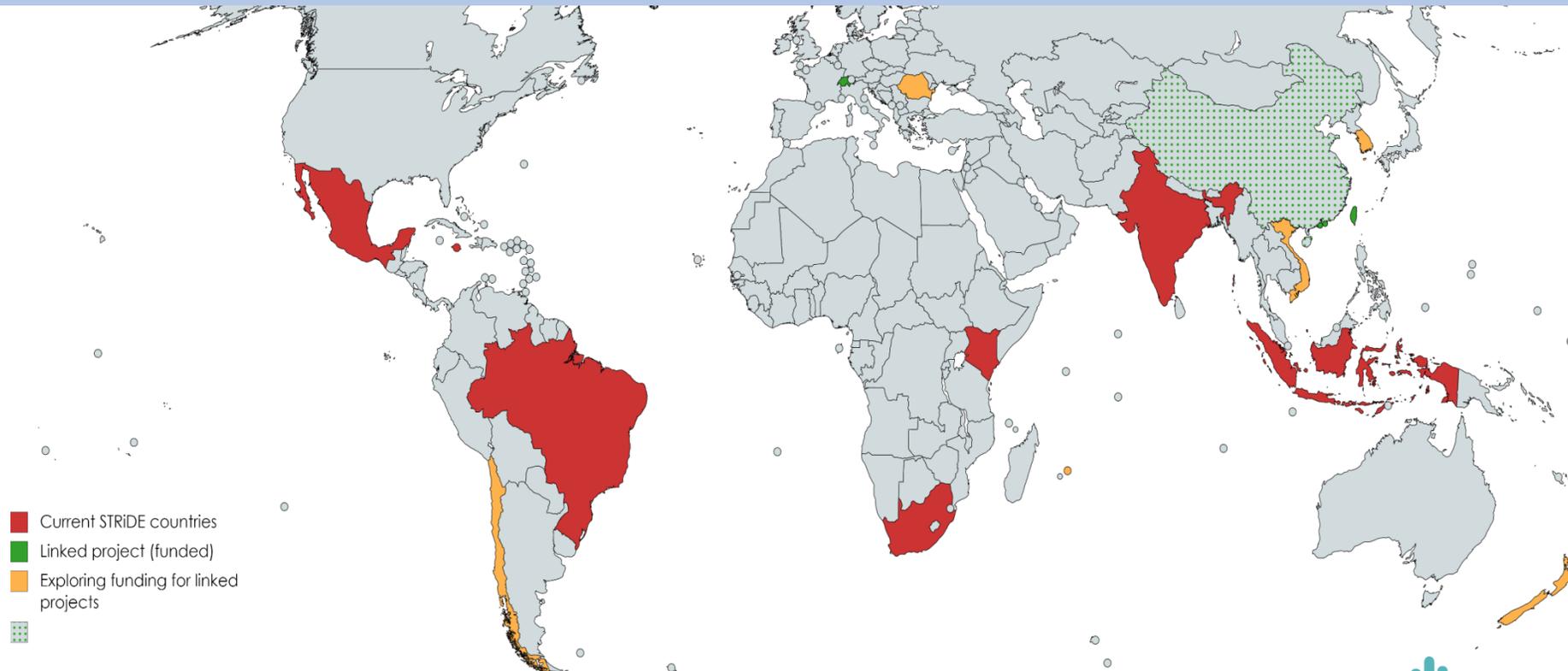
7. Unpreparedness in LMICs?

- Health & care systems unprepared for rapid population ageing
- Lack of awareness re dementia – seen as ‘normal ageing’
- Stigma (*WAR2019*)
- Heavy burdens on families (mainly women)
- ‘Competition’ from other health problems with noisier ‘champions’



STRiDE: Strengthening responses to dementia in developing countries

- Building capacity in generating/using research evidence to support policies to improve dementia care, treatment & support...
- ... particularly to help develop, finance, plan, implement & evaluate national dementia plans. [UKRI-funded, 2018-21]



LSE in partnership with Univ Cape Town, ADI, DAI and others

Living well: the community challenge

Keisuke Naito
Vice President, Eisai

#DefeatingDementia



Session: Living well: the community challenge

Eisai Initiatives for Dementia Total Inclusive Ecosystem

Eisai Co., Ltd.

18 October, 2019

Chief Digital Officer,

Head of Dementia Total Inclusive Ecosystem



Keisuke Naito

hkc
human health care

Years of Steps living with Dementia Japan Government and Eisai

AD drug was approved in Japan
Long-term care insurance system started

Forgetful → Dementia
Started training doctors for dementia

“Orange Plan”

“New Orange Plan” 「

**Outline for Promoting the Dementia
Plan “Coexistence” and “Prevention”**

1998

2000

2001

...

2004

2005

2006

2007

2008

...

2012

2013

2014

2015

2016

2017

2018

2019

Started “Japan Academy of Alzheimer's disease”
Launched e-65.net (Information website)



Initiated support for co-developing community

Added support map to e-65.net

“Dementia Solution department” was established

Renamed to “hhc solution department”

“DTIE” was established

Started partnership with Cogstate



Series of Tools we have developing Including partnership

Awareness

Dementia DVD and text book for students

Educational materials for correct understanding about Dementia

Obtained feedback such as
“ I could understand the anxiety of my grand father”,
“I have to be generous, not be angry”



Early recognition

Cogstate Brief Battery*1

Self cognitive check tool using digital device (PC, iPad) which takes only 15 minutes.



Supporting people taking medication and their family

Medication administration support device “e-Okusuri-san” *2

Helping patients to reduce unused medicines due to forgetting to take, or to prevent from overdosing by ensuring prescribed dosage of medicine administered at the scheduled time



Outing support tool “Me-MAMORIO”



IoT device to share location of people with dementia and elderly people who go out. Activated community watching over people with dementia and elderly people

*1 : Sold as glossary goods. Not for diagnosis *2: Acclaimed for presenting new value to the stakeholders, "IT business award" was granted

Initiative for Coexistence and Prevention in local government in communities

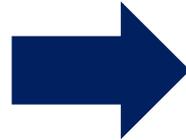
Partnered with 150 organizations such as municipal governments

Awareness

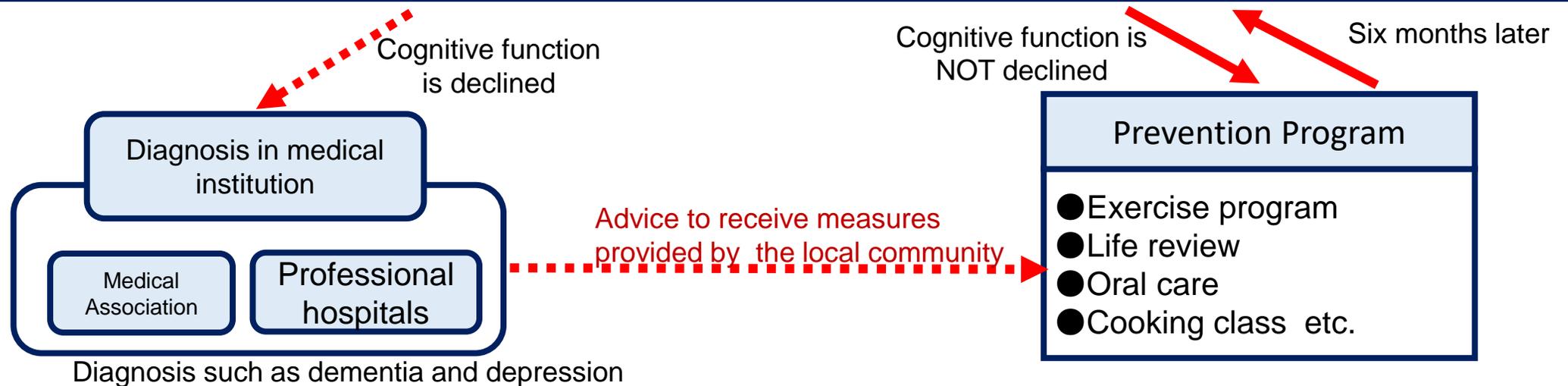
Co-developing Community

Health Check

- Questionnaire
- **Cognitive function check**
- Frail check etc

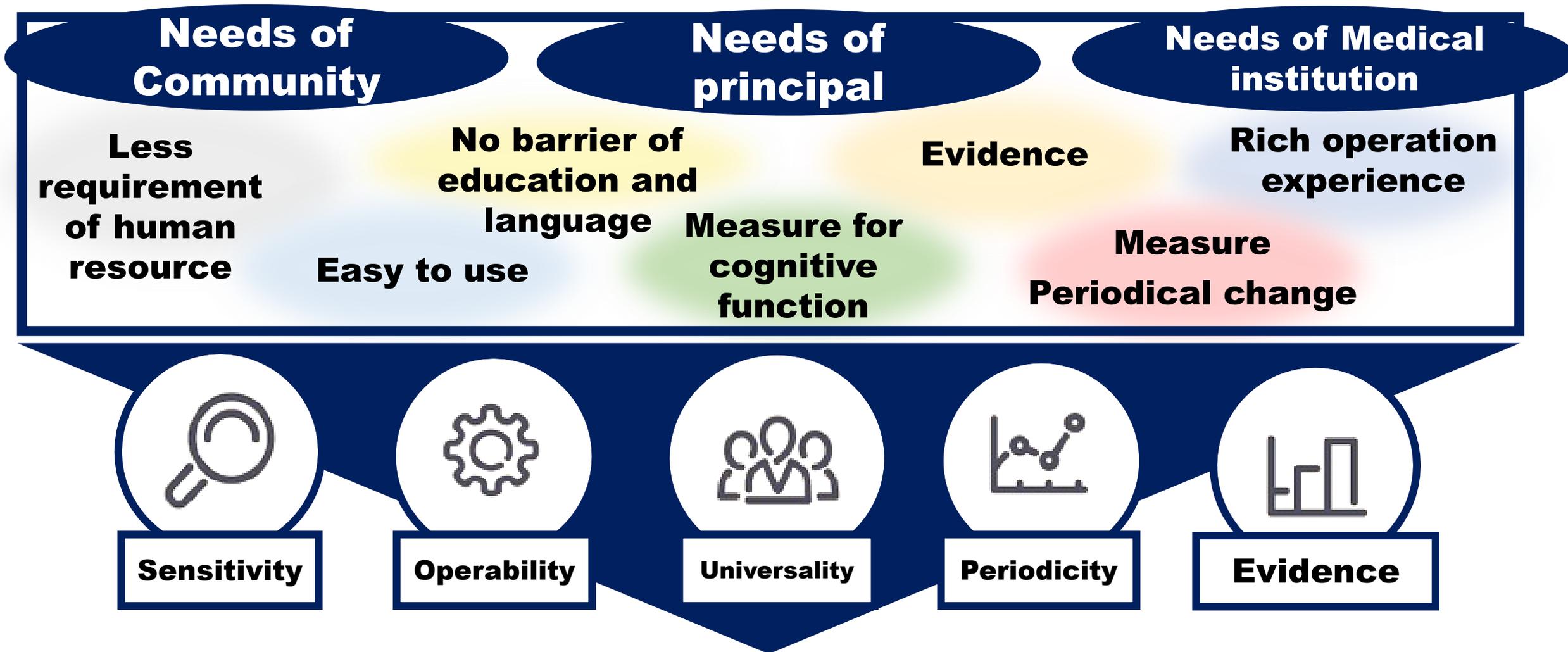


- ✓ Evidence making to maintain and improve cognitive function
- ✓ Reflection to next-year planning



Common scale of community and medical institution, and periodic outcome measurement are required

Appropriate tools to be required



Investigated more than 160 cognitive check