

Hong Kong, 18 February 2023

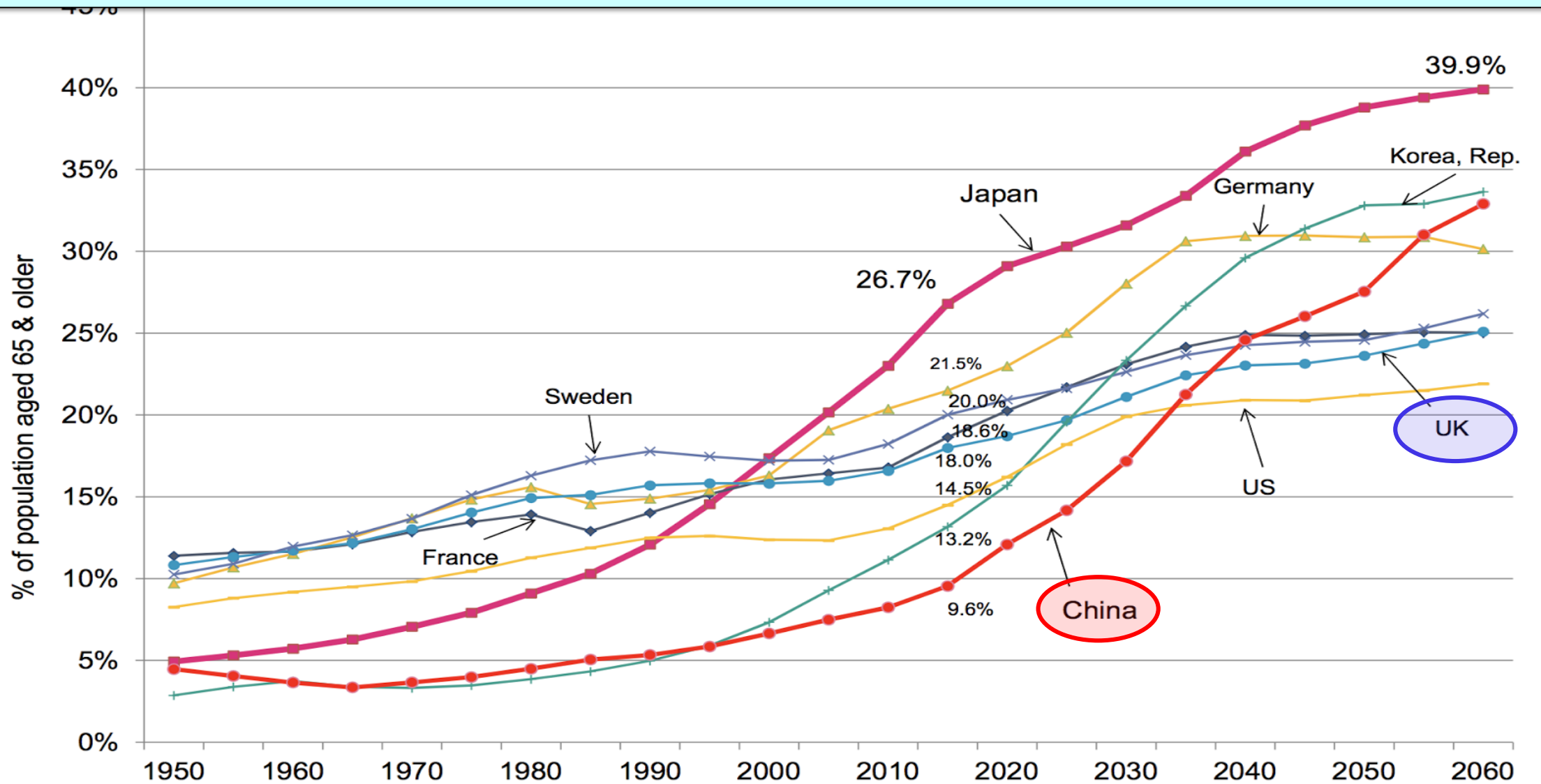
Policy responses to dementia: the global challenge

Martin Knapp

**Care Policy and Evaluation Centre
London School of Economics and
Political Science**

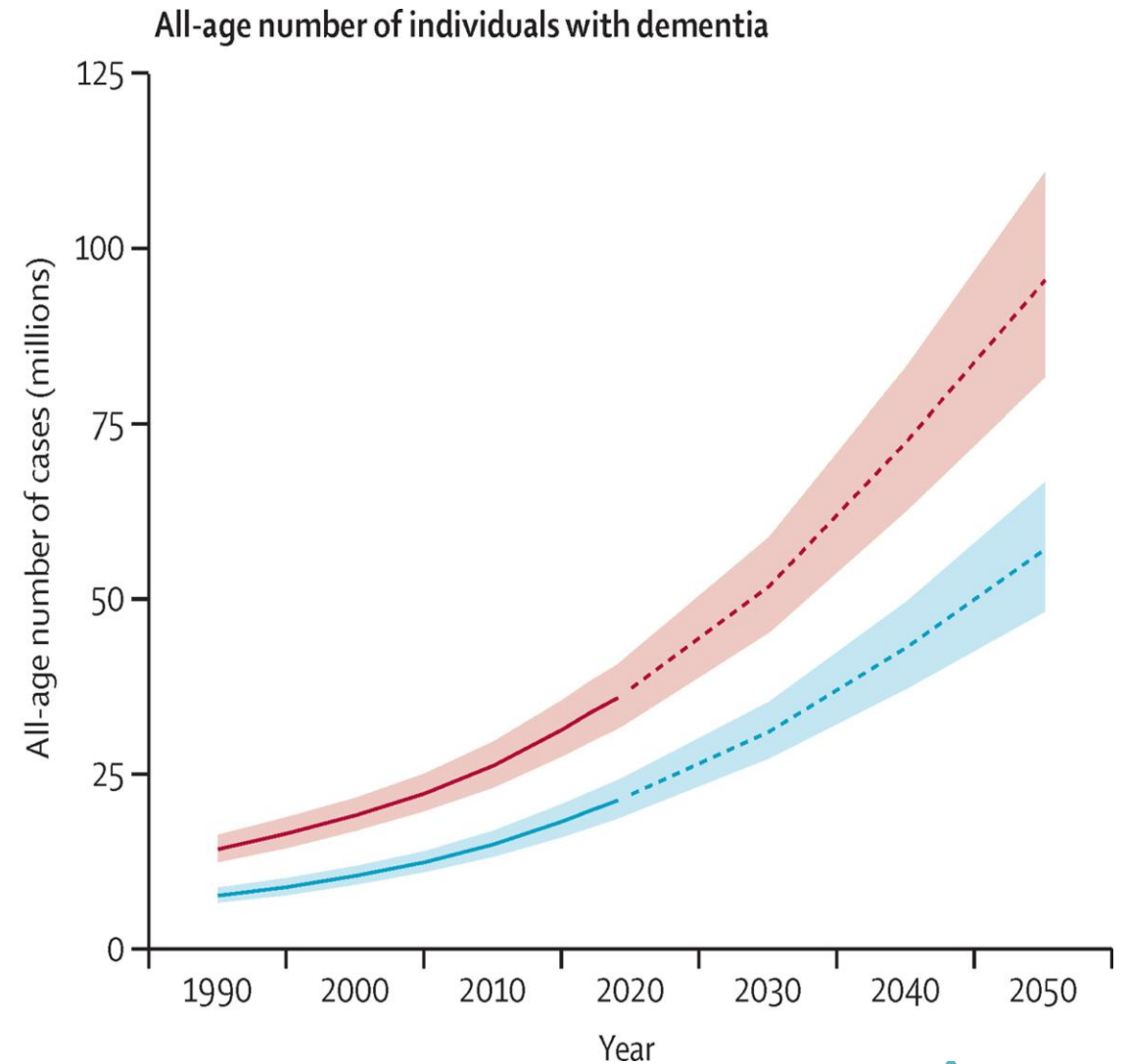
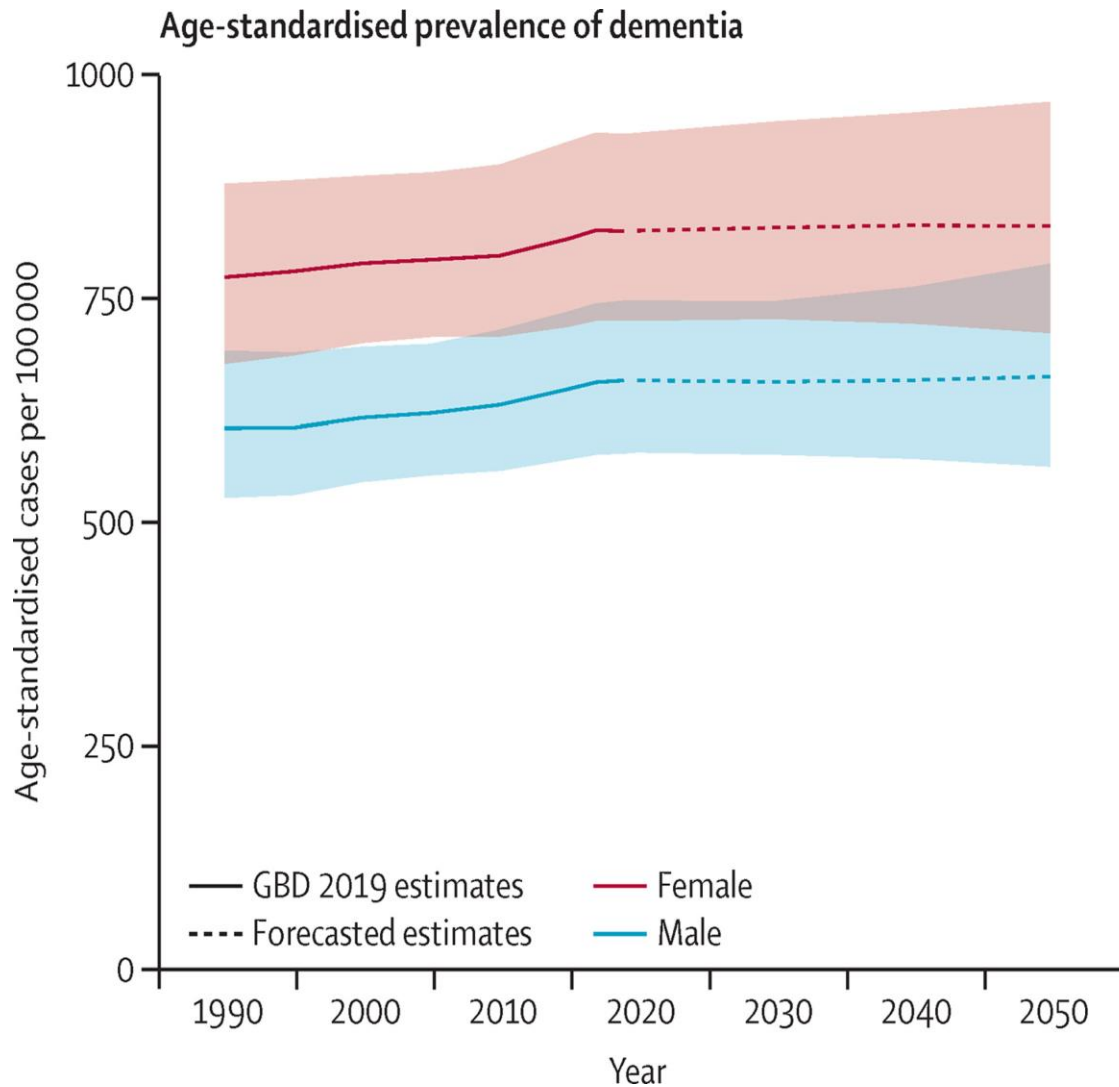


Changes in percentage of population aged >65



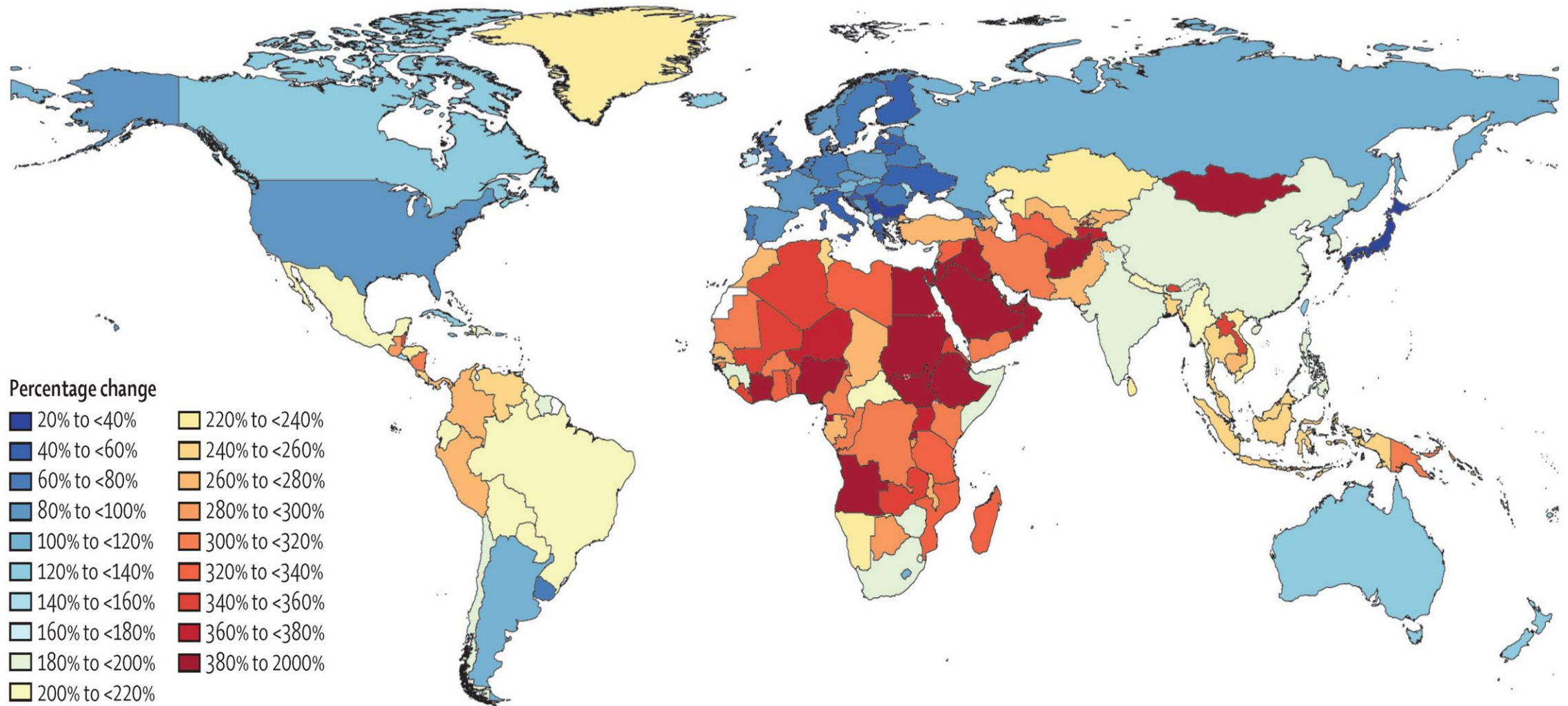
Sources: For Japan – Ministry of Internal Affairs and Communications, Population Census; National Institute of Population and Social Security Research – “Population Projections for Japan (January 2012 estimate): Medium-Fertility & Medium-Mortality Assumption” (Figures as of Oct. 1 of each year)
 For other countries – United Nations, World Population Prospects 2010

Global trends in dementia prevalence, 1990-2050



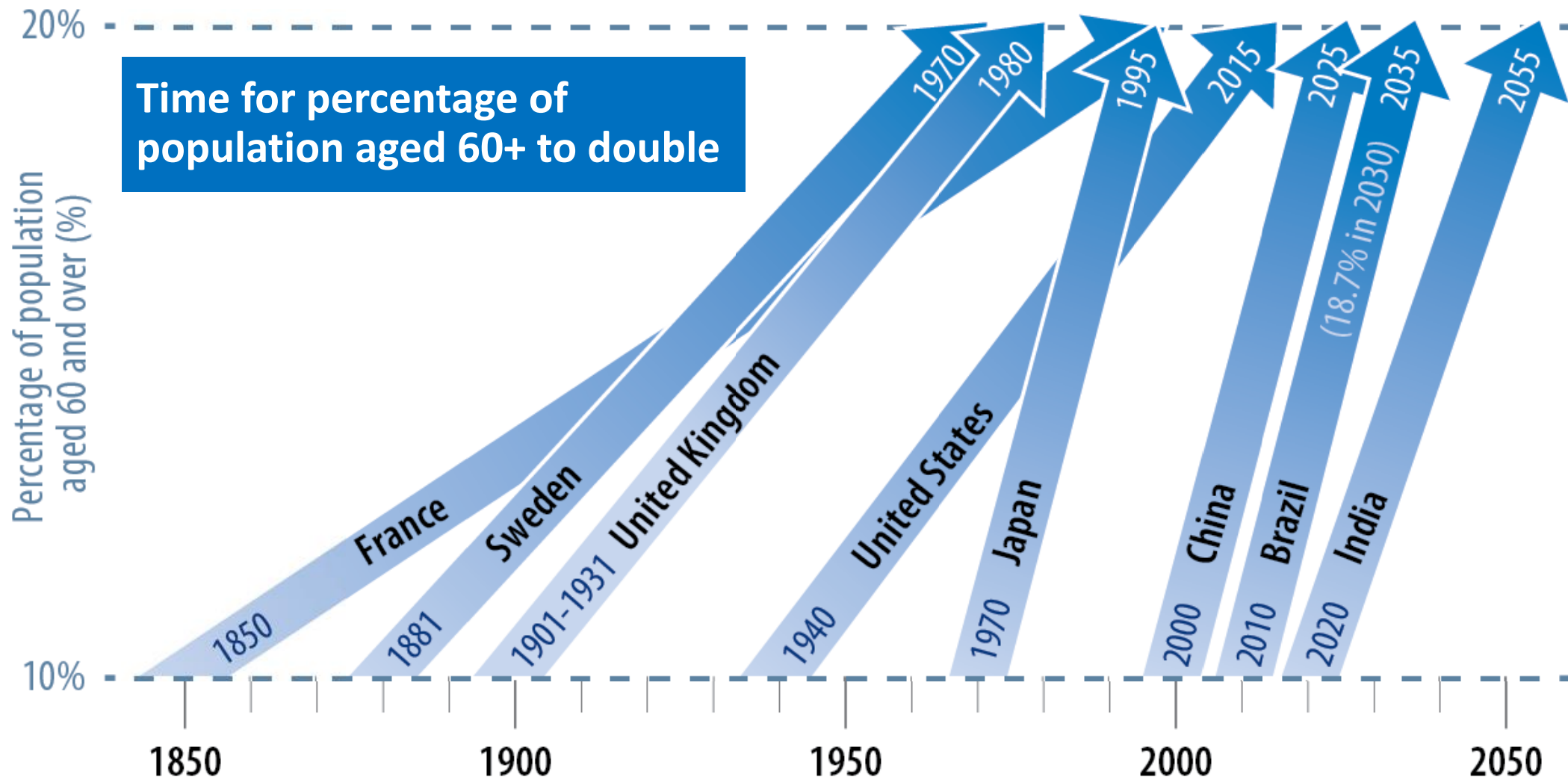
GBD 2019 Dementia Forecasting Collaborators, *Lancet Public Health* 2022

Change (%) in dementia prevalence, 1990-2050



GBD 2019 Dementia Forecasting Collaborators, *Lancet Public Health* 2022

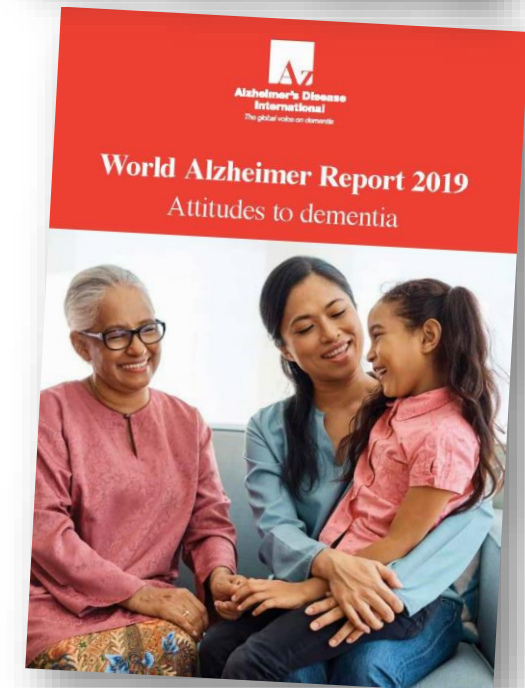
Rapidity of population ageing



WHO World Report on Ageing and Health; <http://www.who.int/ageing>

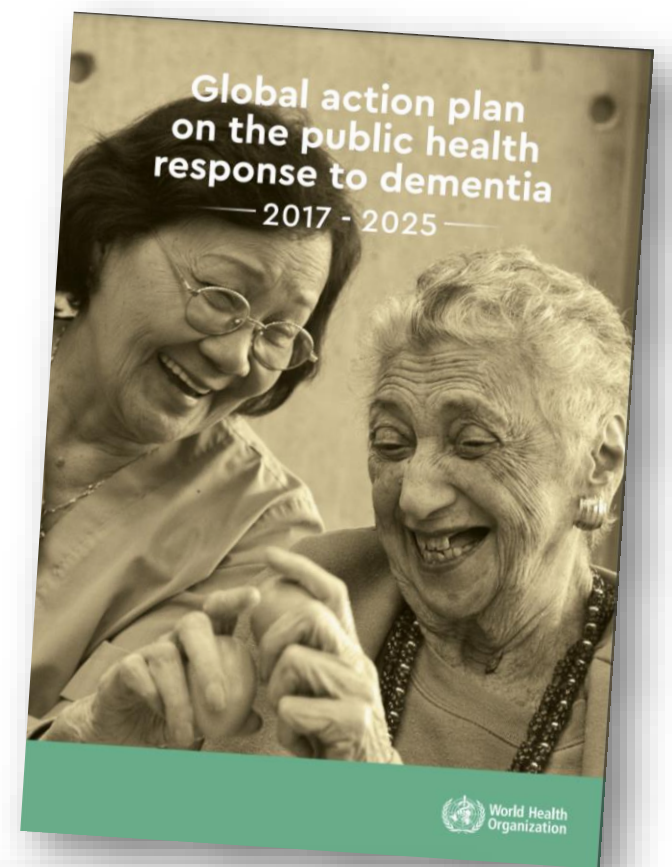
Challenges in many countries (especially, but not only, LMICs)

- Lack of awareness and stigma → risk of abuse and neglect
- Unprepared health systems, lack of professional knowledge → missed opportunities for risk reduction, diagnosis and treatment
- Underdeveloped care systems → families (mostly women) bear full costs of dementia; unregulated private sector
- ‘Competition’ from other health challenges → health and other care needs of older people are low priorities
- Unsupported family care is unsustainable, putting many at risk of impoverishment and neglect



WHO – Global action plan on the public health response to dementia, 2017-2025

- A public health priority
- Awareness and friendliness
- Risk reduction
- Diagnosis, treatment, care and support
- Support for carers
- Information systems
- Research and innovation



National dementia guidelines, England

- Involving people living with dementia
- Providing information
- Advance care planning
- Diagnosis
- Review after diagnosis
- Care coordination
- Making services accessible
- Interventions to promote cognition, independence and wellbeing
- Medications for AD and non-AD at different disease stages
- Managing non-cognitive symptoms (agitation, aggression, psychosis, ...)
- Treating comorbidities
- Carer (caregiver) support

**National Institute for Health
and Care Excellence (NICE) 2018**



Strengthening responses to dementia in developing countries

HOME ABOUT TEAM RESEARCH PUBLICATIONS CONTACT



BRAZIL



INDIA



INDONESIA



JAMAICA

Building research capacity and providing evidence on dementia care in seven developing countries



KENYA



MEXICO



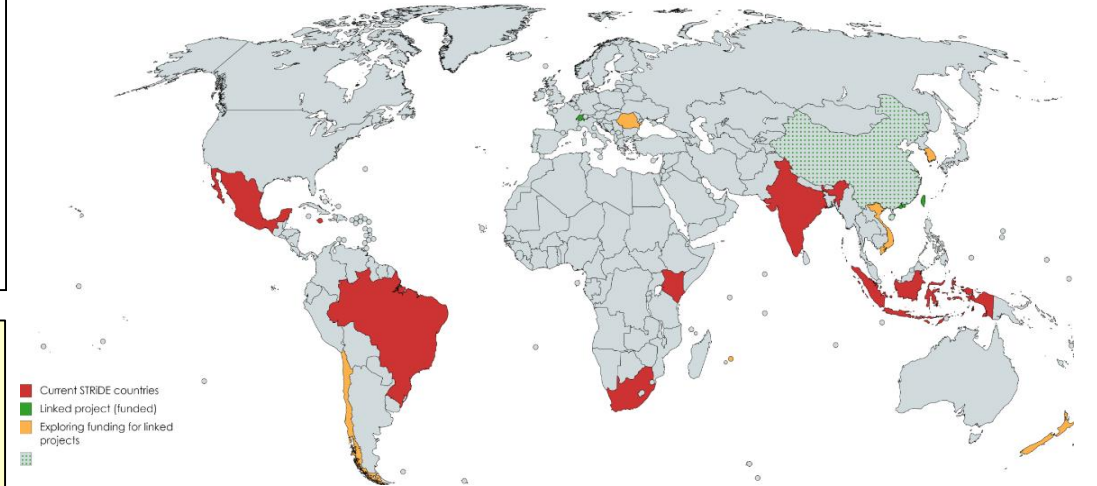
SOUTH AFRICA

STRiDE

Building capacity in generating and using research evidence to support policies to improve dementia care, treatment and support...

... particularly to help develop, finance, plan, implement and evaluate national dementia plans.

Partnerships with NGOs, universities, people living with dementia and families in seven middle-income countries



Core collaborators



Academic partners

London School of Economics & Political Science (UK)
University of Cape Town (South Africa)
Brighton & Sussex Medical School (UK)
University of Plymouth (UK)
Universidade Federal de São Paulo (Brazil)

National Institute Mental Health & Neuro Sciences (India)
Atma Jaya Catholic University of Indonesia (Indonesia)
University of the West Indies (Jamaica)
Africa Mental Health Foundation (Kenya)
National Institute of Geriatrics (Mexico)

NGOs

Alzheimer's Disease International (ADI)
Dementia Alliance International (DAI)
FEBRAZ - Federation of Brazilian Alzheimer's Associations
ARDSI - Alzheimer's and Related disorders Society of India

Alzheimer's Indonesia
Alzheimer's Jamaica
Alzheimer's & Dementia Organisation Kenya
FEDMA - Mexican Federation of Alzheimer's
Alzheimer's South Africa NPC

Policy advisers

WHO
Inter-American Development Bank
Asian Development Bank

Help Age International
National stakeholders – governments, universities, other
NGOs, GCRF (RCUK)

STRiDE Theory of Change workshops

Intensive discussions with a wide range of stakeholders in each country to identify what needs to change and why.



STRiDE components: in *all* countries



Co-production of priorities
(for the project and for
national policy) through
Theory of Change

Qualitative research to learn
about understanding and
attitudes towards dementia
and stigma

Analysis of 'dementia
situation' / political economy:
health and LTC systems,
policies, contextual factors,
views of stakeholders

Case vignettes to capture
expert knowledge of
dementia care experiences,
filling evidence gaps and
enabling systems analysis

Systematic reviews of
prevalence of dementia in
seven countries and of
dementia interventions
evaluated in LMICs

Research and policy /
advocacy capacity-building,
"learning by doing"
approach

STRiDE components: in *some* countries



Qualitative study of costs and impacts on families providing care to people with dementia (*India, Jamaica & Mexico*)

Development, implementation and evaluation of an intervention to reduce stigma (*Brazil and Kenya*)

Household survey to establish prevalence of dementia & other needs, caregiving, service use, and costs (*Indonesia and South Africa*)

Costs of care of people with dementia and resources needed for improved access to care (underway in *India, and some other countries*)

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PART 00. ABOUT THIS REPORT

The dementia care landscape in Kenya: context, systems, policies and services

STRIDE Desk Review

Christine Musyimi, Elizabeth Mutunga, Levi Muyela, David Ndetei, Adelina Comas-Herrera, Sumaiyah Docrat, Stefania Ilinca, Klara Lorenz-Dant, Marguerite Schneider, Wendy Weidner

April 2022



The COVID-19 Long-Term Care Situation in Indonesia

Tara P. Sani, Marselia Tan, Kevin Kristian Rustandi, Yuda Turana

Last updated 30 May 2020

Authors

Tara P. Sani (Atma Jaya Catholic University of Indonesia and Alzheimer's Indonesia)
Marselia Tan (School of Economics and Political Sciences)

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ALZHEIMER'S DISEASE INTERNATIONAL: WORLD ALZHEIMER REPORT 2019

4.5 Stigma in Brazil: The narrative of a person with young-onset dementia

Contributors: Prof Cleusa Ferri, Federal University of Sao Paulo (UNIFESP), Prof Elaine Mateus, Brazilian Federation of Alzheimer's Associations (FEBRAZ), Dr Deborah Oliveira, UNIFESP, Dr Fabiana da Mata, UNIFESP

My name is Andrea, I am 56 years old and married, with four children, and I was diagnosed with Alzheimer's disease eight months ago. My mother has Alzheimer's and so do her two sisters, but I had never imagined that this would happen to me. And then suddenly, I started to forget things, to forget my friends' names, and the things I had to do. I also misplaced objects that I would find days later. I felt frustrated, got mad at myself many times, and wondered what was going wrong with me. At first, my husband Eduardo was angry too. He also could not understand what was going on. After the diagnosis and the beginning of the treatment, I felt less stressed. Now I go out by myself and drive in the neighbourhood. I am going to start swimming classes and I want to go back to my English lessons. I am slowly getting back on my feet. It is never going to be the same again, but I want to get involved with different things.

a strategy for a smoother transition into her new reality. Often, most people living in poverty in Brazil would not have such rapid access to a diagnosis. It is also common for people in Brazil to believe that dementia only affects older people, which may explain why the diagnosis of dementia came as a shock to Andrea at the age of 56, even though she has several family members with dementia. It is common for such stereotypes to hinder middle-aged and older adults in Brazil from seeking help when their first dementia symptoms appear. This also reflects a common belief in Brazil that dementia is inevitable in later life, which may hinder the prevention of modifiable risk factors for some dementias.

The diagnosis brought some stigmatising experiences to Andrea, who was kept from going outside on her own as her family feared for her safety. Not only were there small changes in her routine, but also in her social circle. Andrea knows that dementia will change her and anticipates that her friends might leave her in the future due to her illness. Despite her good socioeconomic position, Andrea is very likely to experience the feeling of isolation most people living with dementia experience.

Ageing & Society (2022), 1–31
doi:10.1017/S0144686X2200040X

ARTICLE

Stigma and its implications for dementia in South Africa: a multi-stakeholder exploratory study

Roxanne Jacobs^{1*}, Marguerite Schneider¹, Nicolas Farina², Petra du Toit³, Sara Evans-Lacko⁴ and on behalf of the STRiDE team⁴

¹Alan J. Flisher Centre for Public Mental Health, University of Cape Town, Cape Town, S Africa, Bloemfontein, South Africa and ⁴Care Policy and Evaluation Centre, London School of Economics and Political Sciences, London, UK
*Corresponding author. Email: roxanne.jacobs@uct.ac.za

(Accepted 9 March 2022)

Abstract

Stigma and discrimination in relation to dementia has a range of implications for living with dementia and their families worldwide, including help-seeking, social rejection and isolation. Few studies consider the perceptions and stigmatisation from multiple perspectives, such as people living with dementia, carers, and service providers.

Received: 3 June 2021 | Revised: 5 January 2022 | Accepted: 18 January 2022 | Published online: 28 February 2022
DOI: 10.1002/dad2.12293

RESEARCH ARTICLE



Description of the cross-cultural process adopted in the STRiDE (STrengthening Responses to dementia in DEveloping countries) program: A methodological overview

Nicolas Farina¹ | Roxanne Jacobs² | Tara Puspitarini Sani³ | Marguerite Schneider² | Imelda Theresia⁴ | Yuda Turana³ | Fasiah Irfani Fitri⁵ | Emiliano Albanese⁶ | Klara Lorenz-Dant⁷ | Sumaiyah Docrat² | Petra Du Toit⁸ | Cleusa P. Ferri⁹ | Ishtar Govia¹⁰ | Adelina Comas-Herrera⁷ | Aliaa Ibnidris⁶ | Martin Knapp⁷ | Sube Banerjee¹¹

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²University of Cape Town, South Africa
³Atma Jaya Catholic University of Indonesia, Jakarta, Indonesia
⁴Alzheimer's Indonesia, Indonesia
⁵University of Sumatera Utara, Indonesia
⁶Università della Svizzera Italiana, Switzerland
⁷The London School of Economics and Political Science, UK
⁸Alzheimer's South Africa, South Africa
⁹Universidade Federal de São Paulo, Brazil
¹⁰Caribbean Institute for Health Research, St. Augustine, Trinidad and Tobago
¹¹University of East London, London, UK

Abstract

Cross-cultural adaptation is an important part of using countries and settings. Here we describe the cross-cultural adaptation process adopted in the STRiDE (STrengthening Responses to dementia in DEveloping countries) program. We adopted a cross-cultural adaptation process including translations, and cognitive interviews of the STRiDE and 41 carers across sites in Indonesia and South Africa; field notes and verbatim quotes are reported. We describe the cross-cultural adaptation process of process, issues were identified with the translated to cultural appropriateness, terminology equivalence



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A systematic review and meta-analysis of dementia prevalence in seven developing countries: A STRiDE project

N. Farina, A. Ibnidris, S. Alladi, A. Comas-Herrera, E. Albanese, S. Docrat, C. P. Ferri, E. Freeman, I. Govia, R. Jacobs, C.I. Astudillo-Garcia, C. Musyimi, T.P. Sani, M. Schneider, I. Theresia, Y. Turana, M. Knapp, S. Banerjee & on behalf of the STRiDE team

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Case Report

Mapping Long-Term Care in Jamaica: Addressing an Ageing Population

Ishtar Govia^{1*}, Janelle N. Robinson¹, Rochelle Amour¹, Marissa Stubbs¹, Klara Lorenz-Dant², Adelina Comas-Herrera² and Martin Knapp²

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*Correspondence: ishtargovia@gmail.com; Tel.: +1-876-977-6151

Abstract: Jamaica's ageing population, high prevalence of non-communicable diseases (NCDs), and

STRiDE anti-dementia toolkit



NEW STRIDE ANTI-STIGMA TOOLKIT

07 Oct 2022

Brazil

India

Indonesia

Jamaica

Kenya

Mexico

South Africa

WP03 Reducing
stigma



 ***"As many as 84 per cent of people living with dementia report experiencing discrimination"***

Learn more about real life experiences from people living with dementia

#DontForgetImHuman

Check out our anti-stigma tool kit here: <https://stridedementia.turtl.co/story/anti-stigma-toolkit/> | 

[Introducing the new STRiDE Dementia Project Anti-Stigma Toolkit \(PDF\)](#)

In summary – what needs to happen?

- a. Across the world, people are living longer
- b. Old age brings joys and challenges – including dementia
- c. Dementia is a major **health, economic and social challenge** today ...
- d. ... and an even bigger challenge **for the future**, especially in **LMICs**
- e. Responses need to be **global, national, local and individual**...
- f. ... but universally have been **slow**
- g. Projects such as **STRiDE** and **TIP-CARD** can help – highlighting gaps, generating new evidence, supporting action, informing policy ...
- h. But laudable policy intentions must be turned into **properly resourced actions**