Global status report on the **public health response to dementia**

World Health Organization

Global status report on the **public health response to dementia**

World Health Organization

Global status report on the public health response to dementia

ISBN 978-92-4-003324-5 (electronic version)
ISBN 978-92-4-003325-2 (print version)

© World Health Organization 2021

Some rights reserved. This work is available under the Creative Commons Attribution-NonCommercial-ShareAlike 3.0 IGO licence (CC BY-NC-SA 3.0 IGO; https://creativecommons.org/licenses/by-nc-sa/3.0/igo).

Under the terms of this licence, you may copy, redistribute and adapt the work for non-commercial purposes, provided the work is appropriately cited, as indicated below. In any use of this work, there should be no suggestion that WHO endorses any specific organization, products or services. The use of the WHO logo is not permitted. If you adapt the work, then you must license your work under the same or equivalent Creative Commons licence. If you create a translation of this work, you should add the following disclaimer along with the suggested citation: "This translation was not created by the World Health Organization (WHO). WHO is not responsible for the content or accuracy of this translation. The original English edition shall be the binding and authentic edition".

Any mediation relating to disputes arising under the licence shall be conducted in accordance with the mediation rules of the World Intellectual Property Organization (http://www.wipo.int/amc/en/mediation/rules/).

Suggested citation. Global status report on the public health response to dementia. Geneva: World Health Organization; 2021. Licence: CC BY-NC-SA 3.0 IGO.

Cataloguing-in-Publication (CIP) data. CIP data are available at http://apps.who.int/iris.

Sales, rights and licensing. To purchase WHO publications, see http://apps.who.int/bookorders. To submit requests for commercial use and queries on rights and licensing, see http://www.who.int/about/licensing.

Third-party materials. If you wish to reuse material from this work that is attributed to a third party, such as tables, figures or images, it is your responsibility to determine whether permission is needed for that reuse and to obtain permission from the copyright holder. The risk of claims resulting from infringement of any third-party-owned component in the work rests solely with the user.

General disclaimers. The designations employed and the presentation of the material in this publication do not imply the expression of any opinion whatsoever on the part of WHO concerning the legal status of any country, territory, city or area or of its authorities, or concerning the delimitation of its frontiers or boundaries. Dotted and dashed lines on maps represent approximate border lines for which there may not yet be full agreement.

The mention of specific companies or of certain manufacturers' products does not imply that they are endorsed or recommended by WHO in preference to others of a similar nature that are not mentioned. Errors and omissions excepted, the names of proprietary products are distinguished by initial capital letters.

All reasonable precautions have been taken by WHO to verify the information contained in this publication. However, the published material is being distributed without warranty of any kind, either expressed or implied. The responsibility for the interpretation and use of the material lies with the reader. In no event shall WHO be liable for damages arising from its use.

Design and Layout by Café.art.br

Contents

Foreword

The proportion of older people in the population is increasing in almost every country. By 2050, around two billion people globally will be aged 60 years or over. Dementia is currently the seventh leading cause of death among all diseases and one of the major causes of disability and dependency among older people globally. It can be overwhelming not only for the person living with dementia, but also for carers, families and society as a whole.

The alarming estimates of increasing numbers of people living with dementia worldwide, especially in lower income settings, cannot be ignored. Left unaddressed, such an increase would significantly undermine social and economic development globally.

The COVID-19 pandemic presents health systems, economies and societies globally with an unprecedented challenge, particularly for older populations. Older populations are most at risk from severe disease and death from COVID-19, and for people living with dementia, the profound disruptions of the pandemic are even more acute.

To achieve the goals of the *Global action plan on the public health response to dementia 2017-2025*, we need a concerted effort by all stakeholders to improve the lives of people with dementia and their families. We must work together as a global community, coordinating research efforts and leveraging the tools and knowledge at our disposal.

WHO is fully committed to working with our Member States, civil society, the private sector and people living with dementia and their carers, to fulfil the targets in the Global dementia action plan.

We are all ageing, and many of us will one day need services for dementia. Building the services and systems to prevent, delay and mitigate the effects of dementia and providing quality care for people with dementia and their families is essential now, and for the future in our ageing world.

Dr Tedros Adhanom Ghebreyesus
Director-General
World Health Organization

Preface

The increasing global prevalence of dementia and consequent social and economic impacts on people living with dementia and their families pose significant challenges for societies. Ageism, stigma and social exclusion faced by people living with dementia, their families and carers cannot have a place in our society.

In recent years, the international community has recognized the urgent need for action on dementia. The Global action plan on the public health response to dementia 2017-2025 represents this international commitment to meaningfully improve the lives of people with dementia, their families and carers. The Global action plan proposes recommendations across seven key action areas: dementia policy; awareness and friendliness; risk reduction; diagnosis, treatment, care and support; support for carers; health information systems; and research and innovation.

The Global status report on the public health response to dementia takes stock of progress made four years into the Global action plan. Data presented in this report shows that we must act urgently. We need renewed, coordinated efforts by all stakeholders across all action areas if we are to achieve the targets set by the Global action plan.

Dementia affects every country. A challenge of this size cannot be tackled by working in silos. We must combine forces, improve the capacity of health systems to prevent and treat dementia, share quality data, reach beyond our traditional ways of conducting research, and address dementia as a global community.

It is my hope that this report will shine a light on ongoing challenges in the field of dementia and present opportunities for accelerating action globally. We must all work together to ensure that people living with dementia, their families and carers can continue to live in their communities with respect and dignity, while receiving the care and support they need and deserve.

Dévora Kestel
Director
Department Mental Health and Substance Use
World Health Organization

Acknowledgements

Vision and conceptualization

This report was developed under the overall guidance of, and conceptualized by, Tarun Dua and Dévora Kestel of the WHO Department of Mental Health and Substance Use.

Project coordination and writing

The development of the document was coordinated by Katrin Seeher, Brain Health Unit, Department of Mental Health and Substance Use. The data analysis and writing team included Rodrigo Cataldi, Neerja Chowdhary, Stéfanie Fréel and Kavitha Kolappa of the Brain Health Unit.

Technical contribution and review

Valuable input was received from WHO staff at headquarters and in regional and country offices, as well as from many international dementia experts. These contributions were central to the development of the data analyses and discussions contained in this report.

WHO headquarters

Zoe Brillantes (Data Exchange Unit); Elaine Brohan (Brain Health Unit); Bochen Cao (Monitoring, Forecasting and Inequalities); Jorge Castro (Brain Health Unit); Vanessa Cavallera (Brain Health Unit); Matteo Cesari (UHC/Life Course); Alarcos Cieza (Sensory Functions, Disability and Rehabilitation); Natalie Drew (Policy, Law and Human Rights); Tessa Edejer (Economic Evaluation and Analysis); Diana Estevez Fernandez (Monitoring, Forecasting and Inequalities); Batool Fatima (Brain Health Unit); Michelle Funk (Policy, Law and Human Rights); Zeea A Han (UHC/Life Course); Kaloyan Kamenov (Sensory Functions, Disability and Rehabilitation); Annet Mahanani (Monitoring, Forecasting and Inequalities); Aiysha Malik (Mental Health Unit); Alana Officer (Demographic Change and Healthy Ageing); Alexandra Rauch (Sensory Functions, Disability and Rehabilitation); Nicoline Schiess (Brain Health Unit); Chiara Servili (Brain Health Unit); Yuka Sumi (UHC/Life Course); and Jotheeswaran Thiyagarajan (UHC/Life Course).

WHO regional offices

Florence Baingana (Regional Office for Africa); Claudina Cayetano (Regional Office for the Americas); Dan Chisholm (Regional Office for Europe); Chencho Dorji (Regional Office for South-East Asia); Ledia Lazeri (Regional Office for Europe); Carmen Martínez-Viciana (Regional Office for the Americas); Manju Rani (Regional Office for South-East Asia); Khalid Saeed (Regional Office for the Eastern Mediterranean); Elena Shevkun (Regional Office for Europe); Renato Oliveira Souza (Regional Office for the Americas); and Martin Vandendyck (Regional Office for the Western Pacific).

Technical reviewers

Emiliano Albanese (Università della Svizzera Italiana and University of Geneva, Switzerland); Kaarin Anstey (University of New South Wales, Australia); Paola Barbarino (Alzheimer's Disease International, United Kingdom of Great Britain and Northern Ireland); Carol Brayne (University of Cambridge, United Kingdom); Henry Brodaty (University of New South Wales, Australia); Franca Gatto (Public Health Agency of Canada, Canada); Maëlenn Guerchet (French National Research Institute for Sustainable Development, France); Yun-Hee Jeon (University of Sydney, Australia); Michael Lefevre (Alzheimer's Disease International, United Kingdom); Chris Lynch (Alzheimer's Disease International, United Kingdom); Déborah Oliveira (Federal University of São Paulo, Brazil and Inter-American Development Bank, United States of America (USA)); Louise Robinson (Newcastle University, United Kingdom); DY Suharya (Alzheimer's Disease International, Indonesia); Lindsay Wallace (University of Cambridge, United Kingdom); Karen Watchman (Alzheimer's Disease International, United Kingdom); and Wendy Weidner (Alzheimer's Disease International, United Kingdom); and Anders Wimo (Karolinska Institute, Sweden).

Chapter contributors

Chapter 1: Katrin Seeher (chapter lead, Brain Health Unit).

Chapter 2: Emiliano Albanese (Università della Svizzera Italiana and University of Geneva, Switzerland); Rodrigo Cataldi (Brain Health Unit); Maëlenn Guerchet (French National Research Institute for Sustainable Development, France); Emma Nichols (Institute for Health Metrics and Evaluation, USA); Martin Prince (Kings College London, United Kingdom); Katrin Seeher (chapter lead, Brain Health Unit); and Anders Wimo (Karolinska Institute, Sweden).

Chapter 3: Rodrigo Cataldi (Brain Health Unit); Joe Dielemann (Institute for Health Metrics and Evaluation, USA); Oskar Frisell (Linköping University, Sweden); Maëlenn Guerchet (French National Research Institute for Sustainable Development, France); Linus Jönsson (Karolinska Institute, Sweden); Martin Knapp (London School of Economics, United Kingdom); Angeladine Kenne Malaha (University of Limoges, France); Emma Nichols (Institute for Health Metrics and Evaluation, USA); Martin Prince (Kings College London, United Kingdom); Katrin Seeher (Brain Health Unit); and Anders Wimo (chapter lead, Karolinska Institute, Sweden).

Chapter 4: Matthew Baumgart (Alzheimer Association, USA); Rodrigo Cataldi (Brain Health Unit); Jean Georges (Alzheimer Europe, Luxembourg); Stéfanie Freel (chapter lead, Brain Health Unit); Franca Gatto (Public Health Agency of Canada, Canada); and Katrin Seeher (Brain Health Unit).

Chapter 5: Rodrigo Cataldi (Brain Health Unit); Stéfanie Freel (chapter lead, Brain Health Unit); Katrin Seeher (Brain Health Unit); DY Suharya (Alzheimer's Disease International, Indonesia); and Wendy Weidner (Alzheimer's Disease International, United Kingdom).

Chapter 6: Rodrigo Cataldi (Brain Health Unit); Neerja Chowdhary (Brain Health Unit); Kaarin Anstey (University of New South Wales, Australia); Miia Kivipelto (Karolinska Institute, Sweden); Kavitha Kolappa (chapter lead, Brain Health Unit); and Katrin Seeher (Brain Health Unit).

Chapter 7: Henry Brodaty (University of New South Wales, Australia); Rodrigo Cataldi (Brain Health Unit); Adelina Comas Herrera (London School of Economics, United Kingdom); Meredith Gresham (University of New South Wales, Australia); Yun-Hee Jeon (University of Sydney, Australia); Kavitha Kolappa (chapter lead, Brain Health Unit); Lee-Fay Low (University of Sydney, Australia); Katrin Seeher (Brain Health Unit); and the COGNISANCE research group.

Chapter 8: Rodrigo Cataldi (Brain Health Unit); Stéfanie Freel (chapter lead, Brain Health Unit); Déborah Oliveira (Federal University of São Paulo, Brazil and Inter-American Development Bank, USA); Anne Margriet Pot (Health and Youth Care Inspectorate, Ministry of Health, Welfare and Sport and Erasmus University Rotterdam, Netherlands); Katrin Seeher (Brain Health Unit); Soraia Teles de Souza (University of Porto, Portugal); Huali Wang (Peking University, China); and Anders Wimo (Karolinska Institute, Sweden).

Chapter 9: Rodrigo Cataldi (chapter lead, Brain Health Unit); and Katrin Seeher (Brain Health Unit).

Chapter 10: Taghreed Adam (Science Division); Carol Brayne (University of Cambridge, United Kingdom); Rodrigo Cataldi (chapter lead, Brain Health Unit); Neerja Chowdhary (Brain Health Unit); Katrin Seeher (Brain Health Unit); and Lindsay Wallace (University of Cambridge, United Kingdom).

Chapter quote contributors

Berrie Holtzhausen (Namibia); Howard Gordon (Global Dementia Observatory Knowledege Exchange (GDO KE) Platform Focus Group Member, United Kingdom); Jim Mann (GDO KE - Platform Focus Group Member, Canada); Roger Marple (GDO KE Platform Focus Group Member, Canada); James McKillop (GDO KE Platform Focus Group Member, United Kingdom); Emily Ong (GDO KE Platform Focus Group Member, Singapore); Alister Robertson (GDO KE Platform Focus Group Member, New Zealand); and Helen Rochford-Brennan (GDO KE Platform Focus Group Member, Ireland); Sheshadri K. S. (India); Peach Wattanavitukul (Thailand).

Contributors of boxes and country case studies

(if not authored by WHO Brain Health Unit)

Box 3: Alberto Fernández Seco and José Angel Portal Miranda (Ministry of Public Health, Cuba).

Box 5: Hana Marie Broulíková (Ministry of Health, Czechia).

Box 6: DY Suharya (Alzheimer's Disease International, Jakarta, Indonesia).

Box 7: Ieva Petkutė (Social art projects, Lithuania).

Box 8: Marta Ciułkowicz; Maria Maćkowiak; Joanna Rymaszewska, Dorota Szcześniak and Julia Rymaszewska (Wroclaw Medical University, Poland).

Box 13: Kaarin Anstey (University of New South Wales, Sydney, Australia).

Box 14: Seija Viljamaa (Ministry of Social Affairs and Health, Finland); Teija Hammar and Pia Pulkkinen (Finnish Institute for Health and Welfare, Finland).

Box 17: Miia Kivipelto (Karolinska Institute, Sweden).

Box 20: STRiDE Project (Strengthening responses to dementia in developing countries).

Box 21: Nadja Cobal (Ministry of Health, Slovenia).

Box 23: Alexandra Rauch (Sensory Functions, Disability and Rehabilitation).

Box 24: Charles Scerri (University of Malta, Malta).

Box 25: Berit Kvalvaag Grønnestad (Norwegian Directorate of Health, Norway).

Box 26: Albert Kern, Doreen Klepzig and Dahl Nils (Ministry of Health, Germany).

Box 28: ADDI (Alzheimer's Disease Data Initiative, USA).

Box 29: Gavin Kennedy and Helen Lamont (United States Department of Health and Human Services, USA).

WHO administrative and editorial support

Zahiri Malik (Brain Health Unit); Grazia Motturi (Department of Mental Health and Substance Use); Diana Suzuki (Brain Health Unit).

Technical editing: David Bramley.

Financial support

Financial support for this publication was provided by the Consumers, Health, Agriculture and Food Executive Agency (CHAFEA, an Executive Agency of the European Union), the Governments of Germany, Japan, the Netherlands, Switzerland and the United Kingdom, and the Public Health Agency of Canada.

Abbreviations

ADI	Alzheimer´s Disease International
ADL	Activities of daily living
BADL	Basic ADL
BPSD	Behavioural and psychological symptoms of dementia
COVID-19	Coronavirus disease 2019
CRPD	(United Nations) Convention on the Rights of Persons with Disabilities
CME	Continuing medical education
DALY	Disability-adjusted life year
DFI	Dementia-friendly initiative
FDA	U.S. Food and Drug Administration
GBD	Global burden of disease
GDO	Global Dementia Observatory
GLM	Generalized Linear Model
GDI	Gross Domestic Income
GHE	Global Health Estimates
HICs	High-income countries
IADL	Instrumental activities of daily living
ICOPE	Integrated care for older people
IHME	Institute for Health Metrics and Evaluation
ILO	International Labour Organization
LMICs	Low- and middle-income countries
LTC	Long-term care
LTIC	Long-term institutional care
mhGAP	Mental Health GAP Action Programme
NCDs	Noncommunicable diseases
NICE	National Institute for Health and Care Excellence
PIR	Package of interventions for rehabilitation
STRiDE	Strengthening responses to dementia in countries
SHA	System of Health Accounts
UHC	Universal health coverage
US$	United States dollar
WAR	World Alzheimer Report
WB	World Bank
WHO	World Health Organization
UN	United Nations
YLD	Years of life lost to disability
YLL	Years of life lost due to premature mortality

"People with dementia should be involved in all stages in order to create a positive dementia society."

Berrie Holtzhausen,
Namibia

Executive summary

Chapter 1 **Introduction**

Dementia is a leading cause of disability and dependency globally. Lack of awareness and understanding lead to widespread stigmatization and discrimination against people with dementia, which may prevent them from accessing diagnosis and care.

The Global action plan on the public health response to dementia 2017-2025 represents the formal commitment by WHO Member States to develop comprehensive multisectoral responses to address dementia worldwide. It contributes to WHO's Triple Billion Targets and achieving the United Nations Sustainable Development Goals (SDGs) by improving timely diagnosis, treatment, (long-term) care and rehabilitation for people with dementia; promoting population-wide risk reduction efforts for dementia; and ensuring that the needs of people with dementia and their carers are met within the context of humanitarian crises and emergencies, such as the ongoing COVID-19 pandemic which has had a disproportionate impact on older people and especially people living with dementia.

Halfway into the implementation of the Global dementia action plan, the *Global status report on the public health response to dementia* aims to provide essential information to assess the global progress. It takes stock of actions driven by Member States, WHO and civil society since the adoption of the Global dementia action plan in 2017, identifies barriers to its implementation especially in light of the COVID-19 pandemic, and highlights areas where urgent, accelerated action is required. It is hoped that the report will lead to increased international and national advocacy efforts and the prioritization of dementia on the global health agenda.

Target audience

This report is written for national and state policy-makers, health-sector planners, academics and researchers, organizations involved in dementia education and service provision, as well as people living with dementia, their carers and families.

Methodology

This report is based on the first wave of Global Dementia Observatory (GDO) data collection, conducted between 2017 and 2020 and supplemented by WHO's *Global health estimates* (2019), the Global Burden of Disease (GBD) study (2019) as well as case studies and country examples.

The GDO collates country data on 35 key dementia indicators that can strengthen countries' ability to respond to the needs of people with dementia, their carers and families. GDO data have been collected in a phased approach across countries in WHO's six regions. To date, 62 Member States have submitted GDO data, of which 56% are high-income countries (HICs), while 44% are low and middle-income countries (LMICs). Together, countries participating in the GDO account for 65.5% of the global population and 76% of the population aged 60 years or older. While a report that is largely based on survey data from a subset of Member States certainly bears its limitations, the fact that these countries represent a large proportion of the global population, especially for older adults, lends credibility and confidence in the results presented here.

The overall completion of GDO indicators by countries was largely satisfactory but the response rate was low for indicators that reflected quantitative availability of services/personnel/health infrastructure as well as the number of people providing/receiving such services. If the preparedness and response to dementia is to be improved, it is key to support countries in collecting quality and standardized data in order to inform the design of sizeable responses and targeted interventions.

Chapter 2 **Global burden of dementia**

Improvements in health care in the past century have contributed to people living longer and healthier lives. As a result, the world's population is ageing. However, this has also led to an increase in the number of people with noncommunicable diseases (NCDs), including dementia.

For this report, dementia prevalence estimates have been updated on the basis of GBD2019 data, using age-specific prevalence estimates for all-cause dementia by sex and age group. Prevalence rates continue to increase progressively with age, both for males and females.

It is estimated that in 2019 55.2 million people worldwide were living with dementia. WHO's Western Pacific Region has the highest number of people with dementia (20.1 million), followed by the European Region (14.1 million), the Region of the Americas (10.3 million), the South-East Asia Region (6.5 million), the Eastern Mediterranean Region (2.3 million) and the African Region (1.9 million).

Assuming that there will be no change in the age-specific prevalence rates over the next decades and applying UN population forecasts, it is estimated that there will be about 78 million people with dementia worldwide in 2030 and about 139 million in 2050. However, the prevalence of dementia risk and protective factors has been changing – and continues to change – in most regions. This can drastically influence projections of dementia prevalence and incidence estimates.

55.2 million
people worldwide living with dementia

Dementia is one of the leading causes of care dependency and disability in old age, both in HICs and LMICs. In people aged 60 years and older, dementia is among the top ten causes of years of healthy life lost due to disability (YLDs). Considering all ages, dementia is the twenty-fifth cause of disability-adjusted life years (DALYs) globally with an alarming trend. Over the past 20 years, DALYs due to dementia more than doubled, representing the biggest rate of increase among the Top 30 causes of DALYs. Also of concern is that globally, DALYs are roughly 60% higher for women than for men.

Population growth and improved longevity, combined with increases of certain dementia risk factors, have led to a dramatic increase in the number of deaths caused by dementia in the last 20 years. In 2019, 1.6 million deaths occurred worldwide due to dementia, making it the seventh leading cause of death. Nearly half of these deaths occurred in HICs and, similarly to what is observed for DALYs, women represented roughly 65% of the total number of dementia-related deaths.

While dementia risk may decline as societal conditions improve with concerted efforts to reduce risk factors and enhance protective factors, persistent inequalities need to be addressed in order to ensure that these changes are equitable across societies. Several barriers stand in the way of the effective collection and sharing of quality data. Accurate estimation of the impact of dementia relies on robust and standardized data with geographical and wide economic representation. Enhancement in data quality can be achieved by improving the overall data infrastructure in countries, and especially in LMICs, with accurate diagnosis and reporting, with continuous and standardized epidemiological data collection and with relevant disaggregated information.

Chapter 3 **Global societal costs of dementia**

The overall consequences of dementia are challenging for any health care system. Aside from understanding the impacts on people with dementia and their families, data on resource use and costs in combination with prevalence figures are essential for planning care infrastructure. The availability of such data is also vital to inform the design of public policies that aim to mitigate the tremendous direct and indirect economic impact of dementia on the society and the implications that the economic burden has for national health-care systems.

In 2019, the global cost of dementia was estimated to be US$ 1.3 trillion. Most of these costs occur in HICs although the majority of people with dementia live in LMICs. Based on the expected increase in people with dementia over the next 10 years, the global costs of dementia will increase to a projected US$ 1.7 trillion by 2030. If these projections are corrected for increases in care costs, global dementia costs will even reach US$2.8 trillion by 2030.

Dementia care costs can be split into direct medical costs, direct social (non-medical) costs and informal care costs. Other cost drivers for society and families include, for example, the loss of carers' productivity and the early retirement of adults with young-onset dementia, but are generally not included in the estimates presented in this report.

Informal care accounts for about half the global cost of dementia, while social care costs make up over one third. In LMICs, the majority of dementia care costs are attributable to informal care, while in HICs informal and social care costs each amount to approximately 40%. Particularly in the African, South-East Asian and Eastern Mediterranean regions, the proportion of the social care sector cost is low (<15%).

In 2019, informal dementia carers spent over 89 billion hours providing support with activities of daily living (ADLs) – about 5 hours per day per person with dementia. Informal care provision – the bulk of it provided by women (about 70%) – is particularly high in countries with low resources where there is a scarcity or lack of formal support services for dementia.

Dementia severity is an important driver of cost and the proportion of mild, moderate, and severe dementia cases living in a country can influence the cost estimates. The annual per-patient costs increase steadily with increasing dementia severity, ranging from US$16000 for mild dementia, US$27000 for moderate dementia to US$36000 for severe dementia.

The cost of dementia worldwide has a significant impact on care systems. Worryingly, long-term care systems in LMICs are not well-prepared, placing a heavy burden on carers and families and although the current estimates of the impact and cost of dementia are markedly high, these numbers are likely underestimating the true cost.

The estimation of global economic costs of dementia is complex for various reasons. There is a lack of data from many parts of the world, particularly from LMICs, and a scarcity of population-based cohort studies that represent their diverse communities. Available studies are often conducted in small geographical areas and then extrapolated to whole countries, and even regions. Moreover, many people with dementia are not detected by the health-care system or may not have a formal diagnosis and, as such, their numbers are not routinely captured by national health information systems, adding complexity to cost studies and potentially leading to an underestimation of costs.

Informal care accounts for half the global costs of dementia

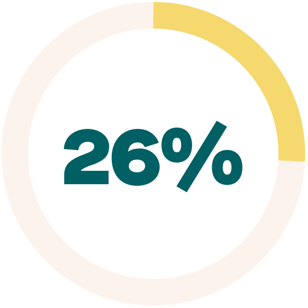
Chapter 4 **Dementia policy and legislation**

National dementia plans represent important commitments by governments to address dementia in partnership with other relevant stakeholders such as civil society, academia, health and social care providers, the private sector and people with dementia. The Global dementia action plan reflects this by setting the global target of 75% of Member States having developed or updated a national policy, strategy, plan or framework for dementia, either stand-alone or integrated into other policies by 2025.

Using GDO data and other available sources, 50 countries (26% of Member States) currently meet this target. The majority of existing national dementia plans are well aligned with the seven action areas of the Global dementia action plan, although fewer address the strengthening of health information systems for dementia or prioritize dementia research and innovation. In addition, while national dementia plans often put emphasis on person-centred care, it is less common for them to outline how care pathways are to be implemented, monitored and integrated into existing service models across sectors.

Many national dementia plans also reflect the cross-cutting principles of the Global dementia action plan by recognizing the importance of human rights, multisectoral collaboration, equity, empowerment and UHC. However, the needs of minority and vulnerable populations remain largely unaddressed in national dementia plans and people with dementia, their carers and families need to be more comprehensively involved in policy development and implementation processes.

The distribution of national dementia plans is largely uneven across WHO regions, with half of the policies (*n*=26) originating from the European Region and the remaining reported from other regions. However, even within the European Region, many plans are expiring, or have expired, and require renewed commitment by governments to prioritize dementia. HICs are more likely to create stand-alone national dementia plans while LMICs tend to integrate dementia into existing policies such as those for mental health or ageing.



of WHO Member States have a dementia plan (stand-alone, integrated or subnational)

Among countries with a dementia plan, there is vast heterogeneity in funding allocation as well as in implementation and monitoring targets. While many national dementia plans identify the need for financial investment, few delineate mechanisms for mobilizing and allocating funding (e.g. between national and subnational levels of the health and social care system). Similarly, while many GDO countries (90%) include dementia in their ministry portfolio, fewer (68%) have appointed a dementia-specific government unit or representative.

Of all GDO countries, just over two thirds report having legal provisions that protect the rights of people with dementia; few have adopted dementia-specific legislation. The use of coercive practices continues to exist in countries with weak legislative and regulatory regimes.

In summary, many countries have insufficient technical expertise and capacity to implement national dementia policies, and there is an ongoing lack of earmarked funding in national health budgets. WHO resources such as the Global Dementia Observatory Knowledge Exchange Platform (www.globaldementia.org) can help foster mutual learning and policy exchange between countries, while WHO's *Towards a dementia plan: a WHO guide* can provide support in developing and operationalizing national dementia plans. Technical support provided through national and regional workshops in partnership with WHO can also help strengthen national capacity, facilitate intercountry learning, and assist in rationalizing available resources to improve the lives of people with dementia, their carers and families.

Chapter 5 **Dementia awareness and inclusion**

People with dementia, their carers and families worldwide continue to experience stigma, discrimination and human rights violations. Moreover, dementia is frequently misconceived as a natural and inevitable part of ageing. The first step to dispelling myths and stereotypes is to provide accurate information to improve public understanding of dementia.

The Global dementia action plan recognizes this by focusing one action area on increasing public awareness, acceptance and understanding of dementia and sets global targets of reaching 100% of countries with at least one functioning public awareness-raising campaign on dementia and 50% of countries with at least one dementia-friendly initiative (DFI) to foster a dementia-inclusive society.

Across WHO regions, countries have made good progress in implementing public awareness campaigns to improve public understanding of dementia, with strong leadership by civil society. Of all GDO countries, approximately two thirds reported running awareness raising campaigns. Similarly, two thirds of GDO countries reported implementing initiatives to improve the accessibility of the physical and social environment for people with dementia.

of WHO Member States with awareness raising campaign

Common dimensions addressed by DFIs include increasing accessibility of public spaces and buildings, creating community places where older people can meet, and offering social opportunities and accessible information on leisure and social activities. Placing people with dementia, and their carers and families, at the centre of dementia awareness campaigns and DFIs represents an important success factor for impact.

The Global dementia action plan further recommends developing programmes to encourage positive attitudes towards dementia in the community, informed by experiences of people with dementia. One way of accomplishing this is through training and education on dementia for groups outside the health and social sector. According to GDO data, two thirds of countries across all six WHO regions provide training and education on dementia to populations outside the health and social sector, with volunteers, police, fire services and first responders/paramedics being the most commonly trained groups. Further efforts are needed to educate other population groups such as judges, solicitors, notaries, community and city workers, and financial and retail staff, particularly in LMICs.

While notable progress is being made in both HICs and LMICs to raise public awareness and improve the understanding of dementia, there remains much stigma and discrimination globally against people with dementia and their carers. Well-resourced public awareness campaigns implemented in partnership with civil society, people with dementia and their carers, and other relevant stakeholders represent an important actionable step towards achieving the targets included in the Global dementia action plan. Regional awareness-raising campaigns such as the joint Let's Talk about Dementia campaign of the Pan American Health Organization (PAHO) and Alzheimer's Disease International (ADI) can provide strong impetus to implement national efforts and a good example that can be replicated in other regions of the world. Creating strategic links with the UN Decade of Healthy Ageing 2020–2030 and integrating dementia into existing initiatives – such as WHO's Global network for age-friendly cities and communities can ensure that dementia is reflected within the context of broader political agendas and thereby support the scale-up and sustainability of dementia awareness raising efforts. WHO resources such as *Towards a dementia-inclusive society: WHO toolkit for dementia-friendly initiatives* can also provide support for training and building the capacity of non-health and social care professionals on dementia.

Chapter 6 **Dementia risk reduction**

Growing evidence suggests an interrelationship between dementia on one side and NCDs and behavioural risk factors – such as physical inactivity, unhealthy diets, tobacco use and the harmful use of alcohol – on the other. NCDs that are associated with the risk of cognitive impairment and dementia include depression, hypertension, diabetes, hearing impairments, mid-life hypercholesterolemia and obesity. Additionally, air pollution and traumatic brain injuries are increasingly being recognized as risk factors. At the same time, access to formal education, employment and other opportunities for cognitive stimulation – as well as social connections – are considered protective.

The Global dementia action plan recognizes the inherent links between dementia and other NCDs by linking its risk reduction target directly to the Global action plan for prevention and control of NCDs. Globally, from 2000 to 2016, the probability of dying from cardiovascular diseases, cancer, diabetes and chronic lung diseases has declined from 22% to 18% . Additionally, there has been a roughly 2% decrease in both tobacco smoking and heavy episodic drinking among people 15 years of age or older, and a 1% reduction in the prevalence of high blood pressure. However, these changes fall short of global NCD targets. Physical inactivity in adults remains unchanged and the prevalence of diabetes and obesity in adults have increased.

2%
decrease in tobacco smoking and heavy episodic drinking and

1%
reduction in the prevalence of high blood pressure

Physical activity in adults remains unchanged

Increase in the prevalence of diabetes and obesity

Importantly, the COVID-19 pandemic has presented major challenges to NCD prevention and control. WHO's two Pulse surveys on continuity of essential health services during the COVID-19 pandemic showed that many countries experienced disruptions in services for diagnosis and treatment of NCDs. Although 2021 showed improvements over 2020, persistent disruptions still continued, potentially impeding global progress with respect to NCD targets and thereby also impacting dementia risk reduction efforts.

GDO data on efforts to reduce dementia risk show that a large number of countries (58%) have plans or guidelines for reducing dementia risk. Of the countries that report having clinical guidelines for dementia risk reduction, about 78% are high-income and most are in the European Region.

Almost half the GDO countries (45%) – again most of them high-income – have run dementia risk reduction campaigns by television, radio, print, billboards and social media. Most of these campaigns have aimed either to reduce behaviours known to be associated with cognitive decline or to promote behaviours that prevent or slow such decline. The majority of these campaigns were organized at the national level by the government, nongovernmental organizations (NGOs) or the private sector.

Numerous barriers impede progress in the area of dementia risk reduction – including stigma and the lack of public awareness of its importance, lack of financial resources available for dementia risk reduction programmes, inequitable distribution of services, human resource limitations, and lack of coordination between sectors both nationally and locally. More recently, the disruptions caused by the COVID-19 pandemic have held up dementia risk reduction programmes.

Addressing the myriad of obstacles to dementia risk reduction requires action in multiple disciplines and sectors. First, dementia risk reduction should be linked with other programmes, policies, and campaigns on NCDs. Second, evidence-based risk reduction interventions should be developed, delivered and promoted within primary care settings. Both actions will require widespread availability of training and education on dementia risk reduction for the health workforce. In support of these efforts, WHO Regional Office for the Western Pacific has implemented a successful awareness raising campaign through social media. Finally, progress can be achieved by developing national and local dementia risk reduction guidelines, utilizing WHO's *Guidelines on risk reduction of cognitive decline and dementia* and devising national risk reduction programmes using *mDementia (prevention)*.

Chapter 7 **Dementia diagnosis, treatment and care**

In line with the principle of universal health coverage, the Global dementia action plan emphasizes that people with dementia should have access to health and social services when and where they need them, without financial hardship.

However, dementia is associated with complex care needs and high levels of dependency and morbidity in its later stages. Thus, dementia requires a range of services from both within and outside the health sector – such as primary health care, specialist medical care, community-based services, rehabilitation, long-term care, and palliative care. Diagnosis is the first step to accessing any dementia care and support. The critical importance of early diagnosis is reflected in target 4 of the Global dementia action plan (i.e., that in at least 50% of countries, the diagnostic rate for dementia is at least 50%).

Yet, less than half of GDO countries are currently able to report on dementia diagnostic rates, falling short of the first condition of the global target. This is of concern since GDO countries are likely to be more "dementia-ready". Therefore, the global proportion of countries able to report on diagnostic rates is expected to be far lower. Moreover, limited access to diagnostic services creates barriers into achieving the second condition of the global target, diagnosing at least 50% of dementia cases.

Only 29

GDO countries can report on dementia diagnostic rate

While most GDO countries (89%) report providing some community-based services for dementia, provision is overall 19% higher in HICs than in LMICs. Similarly, HICs report up to 51% more coverage in rural areas for community-based dementia services compared to LMICs.

Anti-dementia medication, hygiene products, assistive technologies and household adjustments are also more available in wealthier countries and their cost is more likely to be reimbursable than in LMICs, which has implications for out-of-pocket costs to people living with dementia and their families.

Across GDO countries, the availability of, or access to, dementia specialists – namely neurologists, geriatricians, or psychogeriatricians – varies greatly. The median number of (psycho)geriatricians, for instance, ranges from 0.02 per 100 000 population in LMICs to 2.2 per 100 000 in HICs.

With the exception of few LMICs, mainly HICs provide routine dementia training to all professionals (e.g. doctors, specialists and nurses) but not necessarily to all relevant cadres (e.g. pharmaceutical personnel). The majority of countries only train some health professionals. Similarly, although dementia-specific clinical guidelines, standards and protocols are essential for strengthening workforce capacity, fewer than two thirds of GDO countries report having them available.

Many barriers impede progress in the area of dementia diagnosis, treatment, care and support. These include limited financial resources, urban-versus-rural inequities, lack of coordination between sectors, lack of public awareness of dementia and pervasive stigma.

These barriers were further exacerbated during the COVID-19 pandemic with disruption of essential services for all NCDs, as well as services for people with dementia. Urgent investment in the scale-up and coordination of evidence-based, culturally appropriate services and interventions for dementia across sectors and in all parts of world is crucial for achieving not only the Global dementia action plan's vision but also universal health coverage.

WHO has developed guidelines, tools and packages which can be used to accelerate action – such as WHO's Mental Health Gap Action Programme (mhGAP) and its derivative products. Additionally, WHO's Package on Integrated Care for Older People (ICOPE) give guidance on community-level interventions to prevent, slow or reverse declines in the physical and mental capacities of older people. WHO's Compendium of interventions for UHC contains 22 actions related to dementia risk reduction, diagnosis and management.

Chapter 8 **Support for carers of people living with dementia**

Most people with dementia are cared for by family members or other unpaid carers, especially in LMICs. Carers often face financial, social and psychological stressors which have an impact on their physical and mental health. To prevent this from happening, dementia carers need access to information, training, and services, as well as social and financial support. Reflective of this, the Global dementia action plan set the target of 75% of countries providing support and training programmes for carers and families of people with dementia by 2025.

While three out of four GDO countries offer services, supports or programmes for carers of people with dementia, most of these are provided in HICs. Yet, the bulk of informal care is provided in LMICs. The most common types of carer services include training and education on dementia management across the course of the disease, psychosocial support for carers, respite services and information or advice on legal rights. Fewer countries provide comprehensive financial and social security benefits to protect carers from financial risk. Moreover, caregiving disproportionately affects women who are responsible for roughly 70% of informal care hours globally, with the highest proportion in LMICs.

In many LMICs, existing services and supports are concentrated in the capital and main cities and tend to be underutilized due to lack of knowledge about these programmes and associated stigma. Carer services and supports are supplied by a mix of non-profit, public and private providers, with NGOs providing the majority of services in LMICs. While monitoring carer service availability and effectiveness is important, including ensuring that under-represented carer groups receive appropriate support, much needs to be done to strengthen health and social information systems in this area.

Across GDO countries, efforts to train the health and social care workforce in dementia core competencies, including assessment and treatment of carer distress, remain insufficient. Moreover, few countries have standards, guidelines or protocols for carer treatment and support.

In summary, carer policies, programmes and services remain underfunded and underdeveloped due to an overreliance on informal caregiving, which may in turn affect carers' likelihood to seek support. As a result, the availability of – and access to – carer services remains particularly limited in LMICs. There continues to be a global lack of legislation for ending discrimination and ensuring carer protection in the form of social, financial and disability benefits.

Health and social care workers in particular need to be appropriately trained to manage carer stress and guide carers through accessing services and resources. This has proven particularly important within the context of COVID-19 which for many carers resulted in increased social isolation, greater carer burden, and deterioration of physical and mental health. In times of lockdowns and physical distancing, digital interventions have gained momentum in facilitating

70%
of informal care is provided by women

Up to 80%
higher access to carer services in rural areas in HICs

carer access to training and support. WHO's iSupport, mDementia and e-mhGAP represent opportunities to overcome barriers related to access and cost as well as service discontinuation due to COVID-19, if adapted to the cultural, accessibility and socioeconomic needs of carers.

Chapter 9 **Dementia health information systems and monitoring**

Effective and routine data collection on key dementia indicators is crucial to support the formulation and implementation of policy, service planning and delivery and to track progress. Similarly, regular monitoring helps to identify trends in the prevalence of dementia risk factors, disease impact and mortality. The Global dementia action plan set the global target of 50% of countries routinely collecting a core set of dementia indicators every two years by 2025.

As of 2020, 62 Member States (32%) participated in the GDO, thus contributing to the global target. However, fewer than 20% of GDO countries report that they collect dementia data at national level and report on it in a specific dementia report.

Similarly, routine collection of health information on people with dementia is very limited. Less than one third of GDO countries report routine monitoring of people with dementia. Those that do use sources such as clinical records, administrative data, and facility and household surveys. At the policy level, however, of the countries that indicated having a dementia plan, the majority include the promotion of monitoring and information systems. Though, fewer than half routinely monitor the number of people with dementia, revealing a gap between policy and implementation. Many countries also lack routine monitoring of medicine prescriptions, outpatient care and hospital admissions for dementia.

of WHO Member States reporting on a core set of dementia indicators through the GDO

Several barriers stand in the way of strengthening health information systems for dementia. Resources are scarce to collect data across different sectors, and adequate digital infrastructure such as electronic medical records using unique patient identifiers are often lacking, hampering the integration of data across sectors and providers into national surveillance systems or patient registries, especially in low-income settings. Moreover, there is a pressing need to monitor health inequality, using health data disaggregated by relevant inequality dimensions to identify who is being "left behind".

WHO initiatives such as the GDO can help countries to collect key dementia data to strengthen their response to the needs of people with dementia. Though overall, more Member States need to participate by contributing their data. WHO's SCORE technical package supports the development and strengthening of health data and information systems, while the WHO Health Equity Monitor makes tools and resources available for monitoring health inequalities.

Chapter 10 **Dementia research and innovation**

Developing new prioritization strategies and implementing innovative health technologies is paramount to advancing capabilities for prevention, risk reduction, early diagnosis, therapies and care for people with dementia. Social and medical priorities must be identified for dementia research to increase the likelihood of effectiveness and real progress. To stimulate dementia research overall, the Global dementia action plan set a target for doubling dementia-related research output between 2017 and 2025.

Indexed peer-reviewed publications in biomedical and life sciences databases serve as a proxy for the amount of research being conducted globally and can also be used to track research output on different disease areas. These data show that the research output on other NCDs such as cancer, heart conditions, kidney disease, diabetes and depression is up to 14 times higher compared to research on dementia. If the trend over the last 10 years is sustained until 2025, we will not meet the 2025 target. Instead, we need more research, steeper curves to meet the target and achieve similar research outputs as other NCDs.

Whether or not a country has a research plan appears to be linked to the country's income, as no low-income or lower-middle-income countries in the GDO reported having such a plan. This contrasts with countries of higher wealth, where almost one third of upper-middle-income countries and half of HICs report having national or subnational dementia research plans.

The implementation of research plans needs to be accompanied by appropriate funding and infrastructure. Although funding allocation for Alzheimer's disease and other dementias has increased in recent years, it is chiefly found in HICs such as Canada, the United Kingdom and the United States of America.

Other NCDs have up to

14x higher

research output compared to dementia

Another important issue in dementia research is the meaningful inclusion of people with dementia, their carers and families in the entire research process, including conceptualization and priority setting, decision in funding allocation as well as evaluation of research outcomes. GDO data show that, although some countries involve people with dementia in the research process "frequently", two thirds of countries involve people with dementia either "rarely" or not at all. If progress is to be realized, people with dementia – from a diversity of backgrounds and areas – must be seen as key stakeholders in research.

Global coordination is needed to address these challenges and cultivate an equitable and collaborative environment in which the output of dementia research can yield innovative results. WHO strongly supports the inclusion of LMICs in dementia research, while acknowledging country-specific needs.

The lack of dementia awareness, insufficient funding and a fragmented research landscape represent major barriers to effective research development and implementation. The under-representation of LMICs due to scarce funding and insufficient research capacity, together with the exclusion of people with dementia and their carers from the development of research, hinders inclusiveness which is an essential approach in dementia research. Given the complexity of the disease, dementia cannot be solved by working in silos.

In order to support worldwide innovation in our approach to dementia, address the gaps and barriers that stand in the way of effective actions, and increase research collaboration, WHO is developing the Dementia Research Blueprint, a global coordination mechanism to facilitate policy in dementia research.

Conclusion

The report clearly shows that renewed and concerted efforts across all stakeholders are needed to realize the vision of the Global dementia action plan *"to prevent dementia and ensure that people with dementia and their carers live well and receive the care and support they need to fulfil their potential with dignity, respect, autonomy and equality"*. While important progress has been made in achieving global targets, there is much work left to be done. Too few countries have prioritized dementia in national policies, too many people with dementia continue to lack access to diagnostic and post-diagnostic services, and too high a number of carers remain socially isolated due to a lack of support.

There is a global need to place dementia on national health agendas through policy forums (including the G7 and G20) in order to achieve the targets outlined in the Global dementia action plan as well as create strategic links with existing global commitments such as the 2030 Agenda for Sustainable Development and its Sustainable Development Goals (SDGs), UHC and the UN Decade of Healthy Ageing 2021–2030. The forthcoming Intersectoral global action plan on epilepsy and other neurological disorders also represents a unique opportunity to renew concerted action for dementia within the broader context of addressing neurological disorders.

Building back better in light of the COVID-19 pandemic necessitates working together as a global community – with people with dementia, their carers, governments, civil society, the private sector, academia and international organizations – to better coordinate their efforts and leverage the tools and knowledge that are available.

Urgent action is needed to ensure that all countries have dementia policies and plans (either stand-alone or integrated), including components of dementia awareness, stigma reduction, inclusiveness and risk reduction. Strengthened health and social care systems are required to ensure universal access to dementia diagnosis, treatment and care, and especially to reduce income and urban–rural inequities. Carer programmes and services must be developed and funded to reduce the burden of informal caregiving and support carers. Everywhere in the world, countries' capacity needs to be increased to maintain health information systems for dementia and monitor core indicators to guide evidence-based actions and monitor progress. Finally, global investment and the meaningful participation of people with lived experience are imperative for dementia research programmes, especially in LMICs.

WHO stands ready to work hand-in-hand with Member States, civil society and other partners to increase efforts to accelerate dementia actions worldwide, bringing us closer to the 2025 targets and making sure we leave no one behind.

> **“I was Helen before the diagnosis, and I’m still the same Helen after the diagnosis.”**
>
> **Helen Rochford-Brennan,**
> Ireland

1. Introduction

A global public health matter

of the older population will be living in LMICs by 2050

World demographic changes will challenge societies in many ways. For instance, increasing life-expectancy and population ageing lead to increases in certain noncommunicable diseases (NCDs) such as dementia. However, although dementia mainly affects older people and age is the most important risk factor for dementia, dementia is not an inevitable part of ageing.

Dementia is one of the major causes of disability and care dependence among older people worldwide *(1)*. It can be overwhelming not only for the individuals who have dementia but also for their carers and families. There is often a lack of awareness and understanding of dementia, resulting in stigmatization and barriers to diagnosis and care. In many countries, health and social care systems are not prepared for the current – let alone future – numbers of people with dementia. The World Health Organization (WHO) has been working in collaboration with Member States to make dementia a public health priority through the implementation of the Global action plan on the public health response to dementia 2017-2025 *(2)*. See Annex 1 of this report for more information.

BOX 1

What is dementia?

Dementia is a syndrome, usually of a chronic or progressive nature, that leads to deterioration in cognitive function (i.e. the ability to process thought) beyond what might be expected from the usual consequences of biological ageing. Dementia affects memory, thinking, orientation, comprehension, calculation, learning capacity, language and judgement. Consciousness is not affected. The impairment in cognitive function is commonly accompanied, and occasionally preceded, by changes in mood, emotional control, behaviour or motivation.

Dementia results from a variety of diseases and injuries that primarily or secondarily affect the brain, such as Alzheimer's disease or stroke.

COVID-19 and dementia

The world was transformed in 2020 by the COVID-19 pandemic which continues to present health systems, economies and societies globally with one of the biggest challenges of the past 100 years. The burden and losses in terms of mortality and morbidity have been particularly high among older people, and especially people with dementia, for multiple reasons. First, people with pre-existing neurological conditions, including dementia, are more vulnerable to SARS-CoV-2 infection, including having higher risks of severe outcomes and mortality *(3)*.

A WHO-commissioned rapid review on pre-existing neurological conditions and COVID-19 showed that cerebrovascular disease and dementia/neurodegenerative diseases were most frequently associated with severe COVID-19 disease *(4)*. These conditions were also independently associated with longer hospital stays and greater mortality, with a high proportion of deaths due to COVID-19 in residents of long-term care facilities, many of whom have underlying neurological conditions *(5)*.

Moreover, in addition to a high proportion of deaths related to COVID-19 in long-term care facilities, there were reports in some countries of unexplained increased numbers of deaths among people with dementia, with 83% more deaths than expected among people with dementia reported in England and Wales in April 2020 *(6)*. These increased deaths reported in 2020 may be due to factors such as interruptions in routine care, breaks in medication supply chains and resultant medication stock-outs, decreased access to emergency services, and the psychosocial impacts of public health measures designed to control the pandemic *(7, 8)*.

In addition to the direct impacts of COVID-19, the societal impacts of the pandemic (namely persistent stress, economic scarcity and social isolation) can affect brain health. Studies around the world are beginning to show the impacts of the pandemic on outcomes in people living with dementia – including brain health, quality of life, mental well-being and overall health *(9)*. It is therefore more important than ever to review progress and develop plans to build back better in order to strengthen health and social care systems for people with dementia.

WHO's response to the COVID-19 pandemic

From the earliest days of the pandemic, WHO took the lead in providing important information about the virus to the global community, including for people with neurological conditions, older adults, and people living with dementia and their carers.

> **"The burden and losses of the COVID-19 pandemic have been particularly high among older people, and especially people with dementia and their carers."**

BOX 2

WHO COVID-19 guidance and tools relevant to dementia and other neurological conditions

WHO has highlighted the direct and indirect impacts of the pandemic on older adults, including people living with dementia and their carers, with the following guidance, tools and reports:

- ✓ WHO Clinical management of COVID-19: interim guidance, 27 May 2020
- ✓ WHO COVID-10 Clinical management: living guidance, 25 January 2021
- ✓ Coronavirus disease (COVID-19): Risks and safety for older people, 8 May 2020
- ✓ UN policy brief: The Impact of COVID-19 on older persons
- ✓ IASC older adults toolkit: Living with the Times, a toolkit specifically to help older adults maintain good mental health and well-being during the pandemic
- ✓ iSupport Lite
- ✓ WHO infection prevention and control guidance for long-term care facilities in the context of COVID-19, update 8 January 2021
- ✓ Disability considerations during the COVID-19 outbreak, 26 March 2020.
- ✓ Maintaining essential health services: operational guidance for the COVID-19 context (interim guidance), 1 June 2020
- ✓ Pulse survey on continuity of essential health services during the COVID-19 pandemic: interim report, 27 August 2020
- ✓ Second round of the national pulse survey on continuity of essential health services during the COVID-19 pandemic, 23 April 2021
- ✓ The impact of COVID-19 on mental, neurological and substance use services: results of a rapid assessment, 5 October 2020
- ✓ Preventing and managing COVID-19 across long-term care services: policy brief, 24 July 2020
- ✓ Rehabilitation considerations during the COVID-19 outbreak, 26 April 2020
- ✓ Support for rehabilitation: self-management after COVID-19 related illness, 25 June 2020
- ✓ WHO Neurology & COVID-19 Global Forum, established by WHO's Brain Health Unit in June 2020 in order to address the myriad challenges raised by the pandemic related to neurology. A working group was set up to examine the Provision of Essential services and disruptions to care. A rapid review was undertaken to identify effective mitigation strategies for disruptions *(10)*.

Aims and objectives of this report

2020 marked five years since the first WHO Ministerial Conference on Global Action Against Dementia *(11)* and coincided with the first progress report on the Global dementia action plan to the Seventy-third World Health Assembly. It was therefore an opportune time to take stock of the actions carried out by Member States, WHO and civil society since the adoption of the action plan and to identify existing gaps. Most importantly, this was an opportunity to outline ways in which progress can be accelerated during the remaining five years of the Global dementia action plan with the aim of achieving the SDGs by 2030.

The *Global status report on the public health response to dementia* aims to provide essential information to gauge global progress in implementation of the Global dementia action plan. The report highlights the progress made to date and identifies areas where accelerated action is required. It is hoped that the report will lead to continued (and intensified) high-level commitment and investment in dementia, increased international and national advocacy efforts and the prioritization of dementia on the global health agenda.

2017-2025
Global dementia action plan

Target audience

The target audiences for the report include not only national and state ministries of health, policy-makers and health sector planners, but also academics and researchers, organizations involved in education and in health and social service provision for older people and people living with dementia, and people living with dementia and their carers and families.

Methodology

Global monitoring of dementia

Visit the GDO data portal
www.globaldementia.org

The *Global status report on the public health response to dementia* uses information collected from countries through the Global Dementia Observatory (GDO), which is WHO's monitoring mechanism for the Global dementia action plan. GDO data collection started in 2017 with 21 countries and has since been expanded. The information outlined in this report represents a subset of the data collected and serves as both an accountability mechanism and a tool for countries to monitor dementia policy and service delivery across the seven action areas of the Global dementia action plan. Member States are encouraged to submit up-to-date data to the GDO approximately every two years to allow for accurate and relevant progress monitoring.

The information provided in this report highlights the persistent need for strengthened health information systems for dementia in order to collect and use reliable data that will ultimately inform the development of evidence-based policies. The COVID-19 pandemic has reinforced the need to develop robust health information systems in all countries to enable accurate monitoring of health information, resources and service provision. Especially in the case of dementia, given the predicted rise in prevalence, the existence of efficient and reliable health information systems will play a vital role.

The Global Dementia Observatory (GDO)

As the monitoring and accountability mechanism for the Global dementia action plan, the GDO collates data from WHO Member States on 35 key dementia indicators.

Together, the 35 GDO indicators and sub-indicators from a comprehensive logic model of input, output and outcome measures to monitor progress and impact across the Global dementia action plan's seven strategic areas at national and global level.

Monitoring this information over time will strengthen countries' ability to respond to the needs of people with dementia, their carers and families and enable us collectively to achieve the vision of the Global dementia action plan (**Figure 1**, page 26).

FIGURE 1

The Global Dementia Observatory (GDO) framework

ACTION AREA	INPUTS OUTPUTS OUTCOMES Indicators:	IMPACT
POLICY AND LEGISLATION	1 governance **2 policy/plan** 3 legislation for dementia 5 care coordination mechanism	Dementia is a public health priority for countries
AWARENESS/ FRIENDLINESS	2 policy/plan **13 awareness raising campaigns** **14 dementia-friendly environments** **15 training and education of population groups**	Society is aware of dementia and inclusive of people with dementia and their carers
RISK REDUCTION	2 policy/plan 4 standards & guidelines 13 risk reduction campaigns **28-35 prevalence of dementia risk factors**	Dementia risk factors are reduced at population-level
DIAGNOSIS, TREATMENT AND CARE	2 policy/plan 4 standards & guidelines 5 care coordination mechanism 6 workforce **7 diagnostic rate** 8 community-based services 9 dementia care facilities 10 anti-dementia medicines/care products 11 dementia NGO	People with dementia are diagnosed in a timely manner and receive the services that they need
CARER SUPPORT	2 policy/plan 4 standards & guidelines **12 carer support services**	Dementia carers receive the support that they need
INFORMATION SYSTEMS	**16 dementia monitoring** 21-22 prevalence and incidence 23-24 mortality/deaths 25-26 disability associated with dementia 27 economic costs	Disaggregated key dementia data are available at country-level
RESEARCH AND INNOVATION	17 research agenda 18 research investment 19 involvement of people with dementia in research **20 research output**	Dementia research is strengthened and streamlined

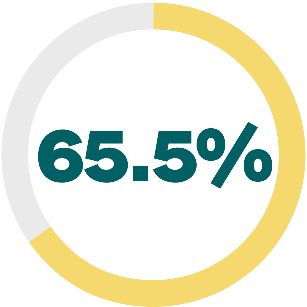
Dark green indicators are used to monitor global targets

VISION OF GLOBAL ACTION PLAN

A world in which dementia is prevented and people with dementia and their carers live well and receive the care and support they need to fulfil their potential with dignity, respect, autonomy and equality

Data collection process

GDO data have been collected in a phased approach across countries in WHO's six regions. WHO worked closely across its three organizational levels (headquarters, regional and country level) to identify high-income countries (HICs) and low- and middle-income countries (LMICs) interested in participating in the GDO. Each country identified a national GDO focal point responsible for coordinating data collection across government agencies and national and subnational stakeholders. WHO supported national GDO focal points through onboarding/orientation meetings with relevant stakeholders and ongoing technical assistance. Onboarding meetings provided national GDO focal points with an overview of the GDO framework and indicators, how the GDO was developed, the data collection process and the supporting resources available, including the GDO Reference Guide[1]. The GDO e-tool, a smart online survey, facilitated the data collection process. A unique password was shared with each country's GDO focal point to access the e-tool, which included questions corresponding to each of the GDO's 35 indicators. The GDO e-tool could be shared by the GDO focal point with relevant stakeholders for data-collection purposes before data were submitted.



of world's population covered by the GDO

---

[1] The Global Dementia Observatory (GDO) Reference Guide, available here https://www.who.int/publications/i/item/who-msd-mer-18.1

Countries participating in the Global Dementia Observatory by WHO region

African Region

- Eswatini
- Mauritius
- South Africa
- Togo

Region of the Americas

- Belize
- Brazil
- Canada
- Chile
- Costa Rica
- Dominican Republic
- Grenada
- Guyana
- Saint Lucia
- Trinidad and Tobago
- United States of America

South-East Asia Region

- Bangladesh
- India
- Maldives
- Myanmar
- Thailand

European Region

- Austria
- Belgium
- Cyprus
- Czechia
- Denmark
- Estonia
- Finland
- France
- Germany
- Greece
- Hungary
- Ireland
- Israel
- Italy
- Lithuania
- Malta
- Netherlands
- Norway
- Poland
- Slovenia
- Sweden
- Switzerland
- Turkey
- United Kingdom

Eastern Mediterranean Region

- Iran (Islamic Republic of)
- Jordan
- Lebanon
- Morocco
- Oman
- Pakistan
- Qatar
- Tunisia

Western Pacific Region

- Australia
- Brunei Darussalam
- China
- Cook Islands
- Fiji
- Japan
- Malaysia
- Republic of Korea
- Singapore
- Viet Nam

Country spotlights/case studies

GDO data analyses in this report are complemented by a selection of country spotlights. These relate to one of the seven action areas and/or cross-cutting principles included in the Global dementia action plan. Case studies focusing on advances or changes in legislation, policy, or reforms with an impact on dementia were also accepted. The country spotlights included in this report were selected on the basis of: 1) their potential to illustrate good practice in one of the seven action areas of the Global dementia action plan; 2) their relevance to key messages identified in each of the chapters; and 3) representation across income levels and geography. All case studies submitted by countries to WHO can be accessed on the GDO Knowledge Exchange Platform.

Limitations

A number of limitations should be taken into consideration when reading this report. The information presented here represents the first wave of GDO data collection. Over a period of three years (2018–2020), 62 countries formally submitted their GDO data to WHO. While these countries account for almost two thirds of the world's population, this represents a response rate of only 31.9% (62 of 194 WHO Member States) globally, with large regional variation. Although GDO data coverage in the WHO European and South-East Asia regions reaches 45%, response rates in other regions are substantially lower, especially in the African Region (8.5%, or 4 out of 47 countries). While a report that is largely based on survey data from a subset of Member States certainly bears its limitations, the fact that these countries represent a large proportion of the global population, especially for older adults, lends certain credibility and confidence in the results presented here.

Another limitation is the fact that the data included in the report are self-reported by the appointed representatives in WHO Member States. Moreover, the long time lag between the first and last country submissions of GDO data necessitates timely repetitions of the data-collection effort to ensure data currency and recency. An additional limitation is observed in the small number of GDO indicators pertaining to social care services.

Furthermore, most available GDO data come from high-income or upper-middle-income countries, where the availability of services is higher when compared to LMICs.

Throughout the report, data displayed in tables and graphs may not sum up to the total number of GDO countries because not all countries were able to provide data for all indicators or sub-indicators. Additionally, one GDO country, Cook Islands, does not have a World Bank classification for the reference year, and for this reason their responses were not included in analyses disaggregated by income-levels.

Thus, monitoring of the Global dementia action plan and dementia activities globally continues. As countries participate in future rounds of GDO data collection, more comprehensive analyses concerning dementia trends will be the subject of future reports. A particular effort will be made to support the submission of data from LMICs, thus improving the accuracy of data on dementia at global and regional levels.

Contents of this report

The *Global dementia status* report dedicates one chapter each to the global burden and economic costs of dementia, as well as one chapter each to the seven strategic action areas of the Global dementia action plan. Throughout the report, reference is made to the ongoing COVID-19 pandemic and how it has affected, and continues to affect, progress in each area.

It should be noted that the chapters do not represent comprehensive literature reviews. Rather, the goal is to provide a global overview of the current status relative to each of the action areas and associated targets included in the Global dementia action plan based on GDO data, complemented by illustrative examples and information from peer-reviewed and grey literature. The chapters are as follows:

- ✓ **Chapter 2: Global burden of dementia** – This chapter provides an overview of the epidemiology of dementia, with updated estimates for dementia prevalence derived from GBD 2019 data and latest disability and mortality figures based on WHO's *Global health estimates* of 2019. Estimates are reported globally, by WHO region as well as World Bank income classification from 2019 and are disaggregated by age and sex where feasible.

- ✓ **Chapter 3: Global societal costs of dementia** – This chapter discusses the global societal costs of dementia, showing costs associated with direct medical care, direct social care and indirect/informal care. Data are presented globally, by WHO region, World Bank income level, and for different types of dementia severity. This chapter also puts a focus on the disproportionate cost of dementia on women (since the majority of care providers, both formal or informal, are women).

- ✓ **Chapter 4: Dementia policy and legislation** – This chapter provides an overview of global progress to date in the area of dementia as a public health priority, including as it relates to dementia policy and legislation. It begins by assessing country-driven progress based on GDO data and other sources and provides a complementary analysis of national dementia policies, including continuing gaps and opportunities as well as country case studies. The chapter closes with activities of WHO's secretariat to support countries in developing and implementing national dementia plans, and recommendations to accelerate future action.

- ✓ **Chapter 5: Dementia awareness and inclusion** – This chapter highlights global progress made to date in dementia awareness and friendliness. The chapter begins by assessing country-driven progress based on available GDO data. It also identifies success factors associated with dementia awareness campaigns and dementia initiatives that have had positive impacts, ongoing gaps and opportunities to improve the social and built environments, good practices in including people with dementia and their carers in decision-making, and the impact of COVID-19 on efforts related to dementia awareness and friendliness. The chapter outlines spotlight activities carried out by WHO's secretariat and regional offices to support countries in raising public awareness of dementia and fostering dementia-inclusive environments.

- ✓ **Chapter 6: Dementia risk reduction** – This chapter showcases the best available evidence for reducing dementia risk, including WHO's normative work in this area and progress reported by countries in addressing dementia risk factors – including high-level commitments agreed on for the prevention and control of NCDs. Data are presented by WHO region and World Bank income classification. The chapter additionally outlines spotlight activities, country case studies and opportunities to accelerate action for dementia risk reduction.

- ✓ **Chapter 7: Dementia diagnosis, treatment and care** – This chapter summarizes the global progress made in improving dementia diagnosis and care pathways, beginning with diagnosis and continuing through post-diagnostic support, treatment and rehabilitation to palliative and end-of-life care. The chapter makes linkages to WHO's normative work in this area, including mhGAP, Guidelines on Integrated Care for Older People (ICOPE), the Package of Interventions for Rehabilitation (PIR) for dementia and quality services for Mental Health. The chapter additionally outlines spotlight activities, country case studies and opportunities to accelerate action in the area of dementia care pathways.

- ✓ **Chapter 8: Dementia carer support** – This chapter details global progress in the area of dementia carer support based on GDO data and complementary evidence-based examples and information. The chapter addresses the impact of COVID-19 on carers' mental health and outlines spotlight activities carried out by WHO's secretariat to assist countries in supporting carers of people with dementia. Country case studies are also included.

- ✓ **Chapter 9: Health information systems for dementia** – This chapter focuses on demonstrating the importance of health information systems and their capacity to monitor population-level core dementia indicators systematically and routinely. It discusses how data collection is vital to guide evidence-based actions to improve services and to measure progress in the implementation of national dementia policies. It also identifies gaps and opportunities associated with monitoring dementia data across countries.

- ✓ **Chapter 10: Dementia research and innovation** – This chapter provides an overview of country-driven progress in implementing and funding dementia research programmes, as well as the current status of dementia research output. Data are reported globally, as well as being disaggregated by WHO regions and World Bank income levels. The chapter analyses the current status of dementia research worldwide, draws attention to the participation of people with dementia and their carers in research processes, and identifies existing gaps and opportunities for improvement.

> **"It is hoped that the report will lead to increased international and national advocacy efforts and the prioritization of dementia on the global health agenda."**

> **“There is not enough focus or not enough information available about dementia”**
>
> **Sheshadri K. S.**
> India

2. Global burden of dementia

Context

55 million
people with dementia

The world’s population is ageing. Improvements in health care in the past century have contributed to people living longer and healthier lives. However, this has also resulted in an increase in the number of people with NCDs, including dementia *(12)*. Today, dementia is one of the commonest neurological disorders and, according to the latest *Global health estimates 2019*, released in December 2020, it is the seventh leading cause of death *(1)*. Although dementia mainly affects older people and its incidence increases with age, it is not an inevitable part of ageing.

Based on WHO’s *Global health estimates 2019 (1)*, the Global Burden of Disease (GBD) 2019 estimates *(13)* and UN population data *(14)*, this chapter provides updated global, regional estimates of dementia prevalence, disability and mortality.

Dementia prevalence

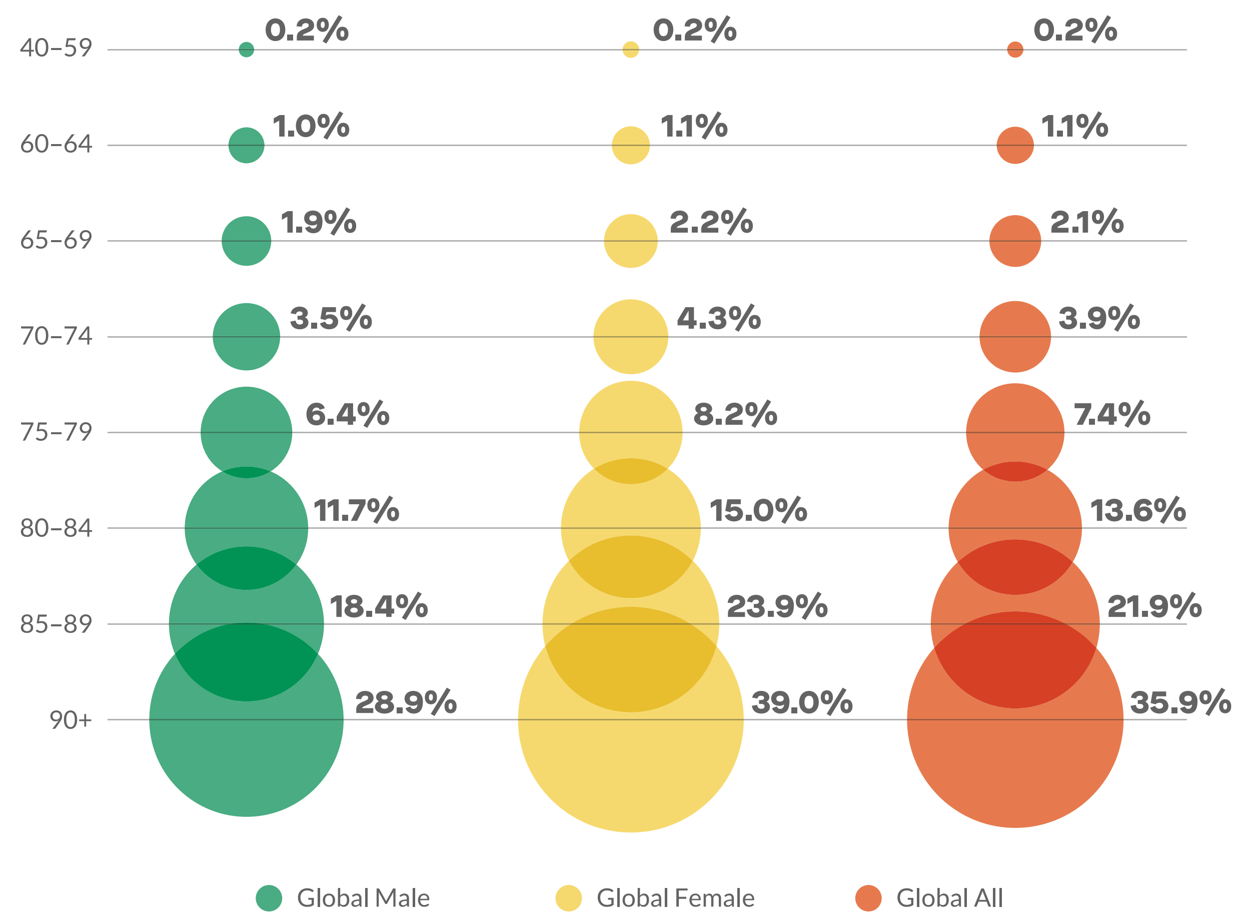
In 2017, the number of people living with dementia worldwide was estimated at approximately 50 million and was anticipated to triple by 2050 because of the expected changes in the world population's demographic structure *(15)*.

These estimates have been updated using a new approach based on the latest GBD data.

The updated prevalence estimates for all-cause dementia by sex and age group are presented in **Figure 2** and **Table 1**. The progressively increasing risk of dementia associated with age is reflected in higher prevalence rates in older age groups for both males and females.

FIGURE 2

Global dementia prevalence rates by sex and age



There is a marked variation in prevalence among adults aged 65 years and over across regions, ranging from 4% in the South-East Asia Region to 8.5% in the European Region. However, most of the estimated prevalence figures lie in a band between 5% and 8%.

TABLE 1

Dementia prevalence estimates (%), by sex (male, female, all), age group (5-year age bands) and WHO regions

WHO region	Sex	Age group (years)								Dementia prevalence 60+	Dementia prevalence 65+
		40-59	60-64	65-69	70-74	75-79	80-84	85-89	90+		
African Region	M	0.14%	0.81%	1.49%	2.73%	5.00%	9.10%	15.47%	27.84%	2.53%	3.57%
	F	0.15%	0.94%	1.89%	3.75%	7.05%	12.43%	19.90%	32.81%	3.65%	5.13%
	All	**0.15%**	**0.88%**	**1.71%**	**3.30%**	**6.17%**	**11.07%**	**18.15%**	**30.86%**	**3.14%**	**4.44%**
Region of the Americas	M	0.23%	1.07%	2.12%	4.19%	7.43%	12.88%	19.89%	32.70%	5.05%	6.83%
	F	0.24%	1.03%	2.10%	4.35%	8.13%	14.64%	23.40%	40.54%	6.67%	8.88%
	All	**0.23%**	**1.05%**	**2.11%**	**4.27%**	**7.82%**	**13.89%**	**22.05%**	**37.95%**	**5.94%**	**7.97%**
South-East Asia Region	M	0.13%	0.75%	1.37%	2.50%	4.55%	8.10%	12.79%	19.32%	2.49%	3.50%
	F	0.16%	0.99%	1.84%	3.17%	5.36%	9.10%	14.01%	22.22%	3.31%	4.52%
	All	**0.15%**	**0.87%**	**1.61%**	**2.85%**	**4.99%**	**8.67%**	**13.49%**	**21.04%**	**2.92%**	**4.04%**
Europe Region	M	0.19%	0.86%	1.65%	3.27%	6.55%	12.20%	19.07%	29.07%	4.76%	6.34%
	F	0.22%	0.99%	2.02%	4.19%	8.45%	15.64%	24.98%	39.05%	7.73%	9.95%
	All	**0.21%**	**0.93%**	**1.85%**	**3.79%**	**7.67%**	**14.35%**	**22.96%**	**36.32%**	**6.47%**	**8.46%**
Eastern Mediterranean Region	M	0.16%	1.03%	2.00%	3.70%	6.85%	12.54%	20.80%	32.98%	3.81%	5.44%
	F	0.18%	1.12%	2.24%	4.29%	7.84%	13.83%	22.19%	36.94%	4.51%	6.33%
	All	**0.17%**	**1.07%**	**2.12%**	**4.01%**	**7.37%**	**13.22%**	**21.54%**	**35.25%**	**4.17%**	**5.89%**
Western Pacific Region	M	0.22%	1.23%	2.24%	3.90%	7.09%	12.63%	19.49%	29.46%	4.26%	5.68%
	F	0.25%	1.35%	2.62%	5.08%	9.90%	17.84%	27.44%	42.87%	6.96%	9.21%
	All	**0.23%**	**1.29%**	**2.43%**	**4.52%**	**8.63%**	**15.66%**	**24.53%**	**39.01%**	**5.68%**	**7.59%**

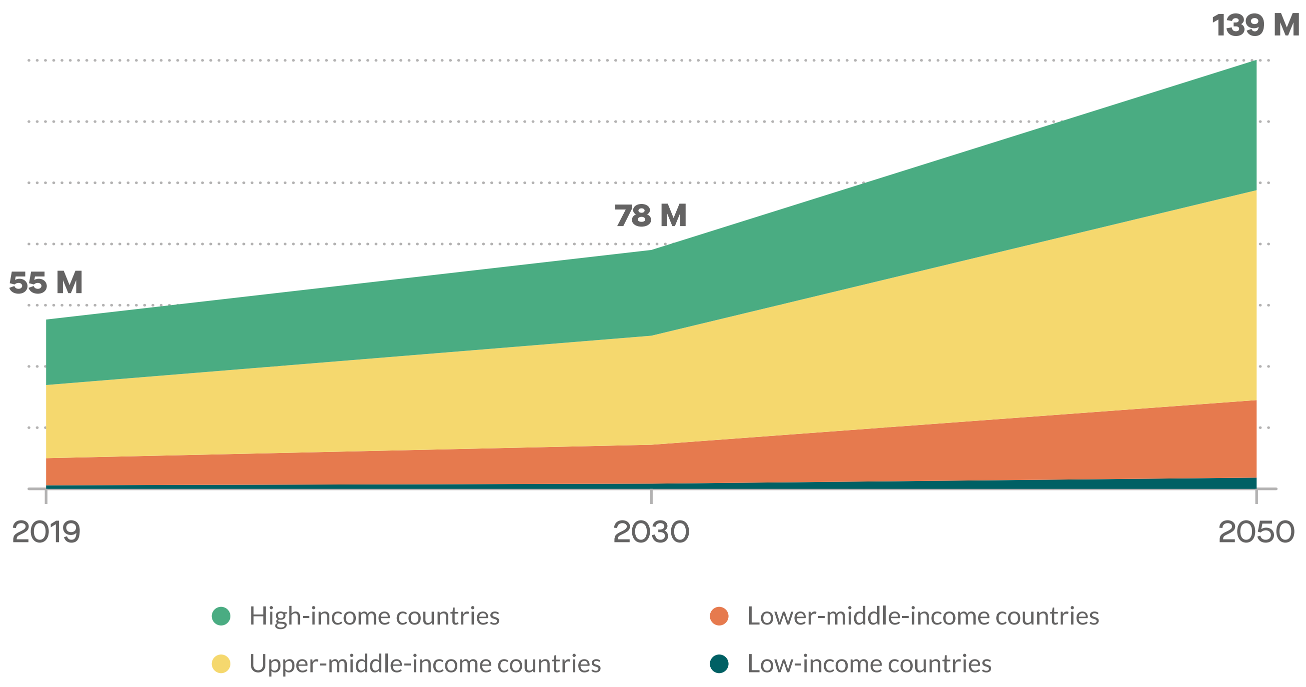
Note: Data are derived from IHME age-specific prevalence and UN population statistics.

Having applied the age-specific, or age- and sex-specific, prevalence estimates to UN population projections *(14)*, it was estimated that, in 2019, 55.2 million people worldwide were living with dementia (**Table 2**). WHO's Western Pacific Region has the highest number of people with dementia (20.1 million), followed by the European Region with 14.1 million and the Region the Americas with 10.3 million. These differences are only in part explained by the different demographic structures across regions and may represent other geographical variations that are worth exploring.

On the assumption that there will be no change in the age-specific prevalence rates over the coming decades and applying UN population forecasts, it is estimated that there will be some 78 million people with dementia in 2030 and about 139 million with dementia in 2050 (**Figure 3**).

FIGURE 3

Number of people living with dementia in 2019, 2030 and 2050 (in million) by country income group



These estimates are slightly lower than previously calculated *(15)*. The primary data and the modelling approaches used for the previous and new estimates calculations both differed as they are based on slightly different assumptions. Moreover, these discrepancies should be interpreted with caution because direct estimates of dementia occurrence and impact are still lacking or are out-of-date for most countries worldwide. The extrapolation of epidemiological data between neighbouring countries within regions relies on assumptions that may not hold as the epidemiological transition unfolds, and the prevalence of dementia risk factors varies markedly over time and between countries.

Importantly, the prevalence of dementia is higher for women than men over the age of 65 years in all WHO regions and also globally (5.4% versus 8.1%, respectively). Many reasons have been posited for this trend, including potential biological differences between women and men (including epigenetic and hormonal differences), differential exposure to risk and protective factors across the life course (including opportunities for education and cognitive stimulation), and longer life expectancy for women in many parts of the world, among other factors *(16)*.

TABLE 2

Estimated number of people living with dementia (millions) by WHO region

Region	Population over 65 years (millions)	Crude estimated prevalence (%) over 65 years	Number of people with dementia (millions) over 65 years	Number of people with dementia (millions)
GLOBAL	697.3	6.9	48.4	55.2
WHO region				
African Region	34.1	4.4	1.5	1.9
Region of the Americas	115.8	7.9	9.2	10.3
South-East Asia Region	130.7	4.0	5.3	6.5
European Region	154.3	8.5	13.1	14.1
Eastern Mediterranean Region	32.6	5.9	1.9	2.3
Western Pacific Region	229.8	7.6	17.5	20.1
Income level				
Low-income	22.0	5.0	1.1	1.4
Lower-middle-income	164.6	4.4	7.2	8.8
Upper-middle-income	291.7	6.9	20.1	23.6
High-income	219.7	9.1	20.0	21.4

Since population ageing is occurring at an unprecedentedly fast rate in low- and, particularly, middle-income countries, the bulk of the increase in numbers through to 2050 will occur in those regions *(17)*. The prevalence of dementia risk and protective factors is also changing in most of these regions. While average educational attainment increases and other modifiable risk factors are better addressed and treated, inequalities may become more marked and create barriers to preventative measures. Moreover, other factors such as air pollution, unhealthy diets, reduced physical activity and social isolation may contribute to worsen risk profiles in populations. As such, addressing modifiable risk factors by finding synergies with other risk reduction campaigns, implementing existing evidence into policies and tackling social inequalities can drastically influence future dementia prevalence and impact.

Disability associated with dementia

Dementia is one of the leading causes of care dependence and disability in old age, both in HICs and LMICs *(11)*. While older people can often cope well and can remain relatively independent even with marked physical disability, the onset of cognitive impairment may compromise their ability to carry out complex but essential tasks in daily life. In addition, people living with dementia will increasingly have difficulty in meeting their basic personal care needs *(11)*. It should be noted that this is highly dependent on a person's social and familial context, with potential for maintenance of independence in many settings for considerable periods.

One of the parameters used to estimate disease burden is the number of years of life lived in states of less than full health, or years of healthy life lost due to disability (YLDs). Based on age-disaggregated data for people aged 60 years and older, dementia is among the top ten causes of YLDs. Disease burden can be assessed by using the disability-adjusted life year (DALY), a time-based measure that combines years of life lost due to premature mortality (YLLs) and the aforementioned YLDs *(18)*. One DALY represents the loss of the equivalent of one year of full health.

Based on recent data from the WHO *Global health estimates* and considering all ages, dementia is the twenty-fifth leading cause of DALYs (**Table 3**).

TABLE 3

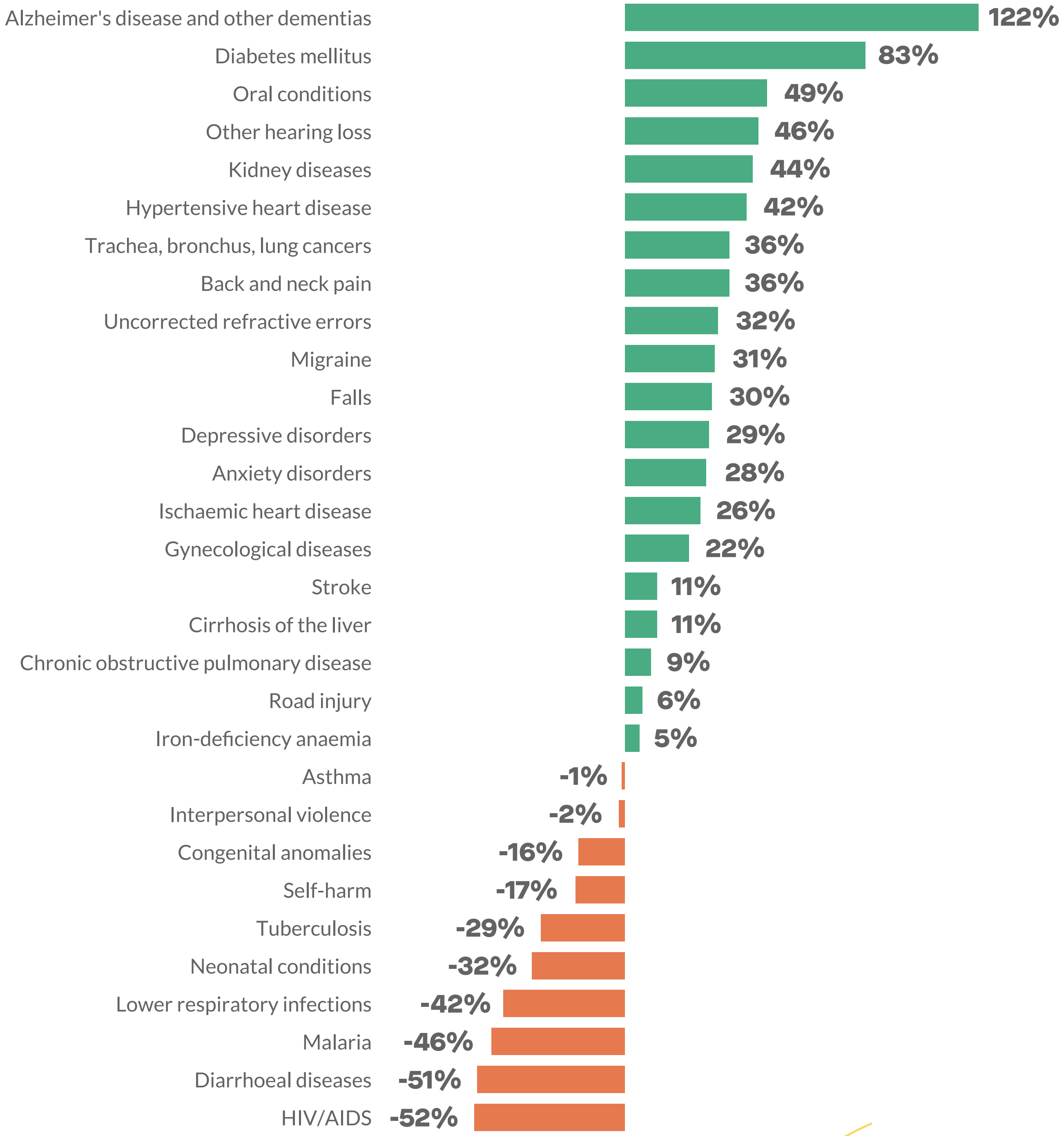
Top 30 causes of DALYs in 2019

Rank	Cause	DALYs (000s)
1	Neonatal conditions	201 820
2	Ischaemic heart disease	180 846
3	Stroke	139 428
4	Lower respiratory infections	105 652
5	Diarrhoeal diseases	79 311
6	Road injury	79 115
7	Chronic obstructive pulmonary disease	73 980
8	Diabetes mellitus	70 410
9	Tuberculosis	66 024
10	Congenital anomalies	51 796
11	Back and neck pain	46 531
12	Depressive disorders	46 358
13	Cirrhosis of the liver	42 798
14	Trachea, bronchus, lung cancers	41 377
15	Kidney diseases	40 570
16	HIV/AIDS	40 146
17	Other hearing loss	39 476
18	Falls	38 215
19	Malaria	33 398
20	Uncorrected refractive errors	31 981
21	Self-harm	31 864
22	Interpersonal violence	30 254
23	Gynecological diseases	28 448
24	Anxiety disorders	28 415
25	**Alzheimer's disease and other dementias**	**28 352**
26	Iron-deficiency anaemia	28 287
27	Migraine	26 832
28	Other circulatory diseases	25 470
29	Other endocrine, blood and immune disorders	23 739
30	Asthma	21 706

It is concerning that, when compared to the top 30 causes of DALYs between 2000 and 2019, dementia yields the highest rate of increase, with DALYs due to dementia more than doubling in this 20-year period (**Figure 4**).

FIGURE 4

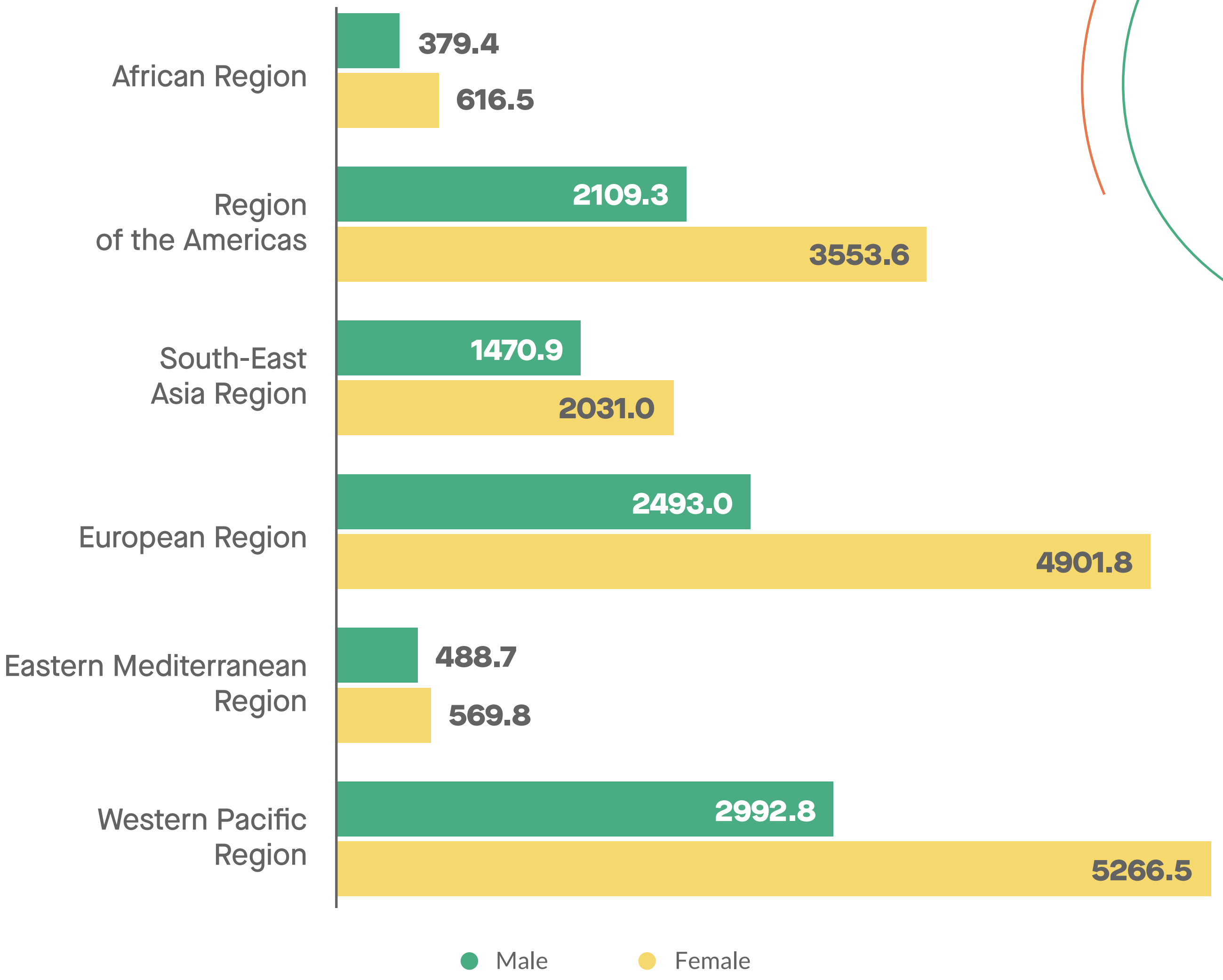
DALYs variation among the top 30 causes (2000–2019)



The disease burden expressed as DALYs disaggregated by sex allows us to further understand the different impact on women and men. The *Global health estimates* data show the disproportional impact of dementia on women, with DALYs being roughly 66% higher for women considering the 60 year and over population. Although large variations can be found regionally, the burden of disease is higher on women across all regions, being 62.5% higher in the African Region, 68.5% in the Region of the Americas, 38% in the South-East Asia Region, 95.5% in the European Region, 16% in Eastern Mediterranean Region, and 76% higher in the Western Pacific Region (**Figure 5**).

FIGURE 5

DALYs by sex in the six WHO regions (population over 60)

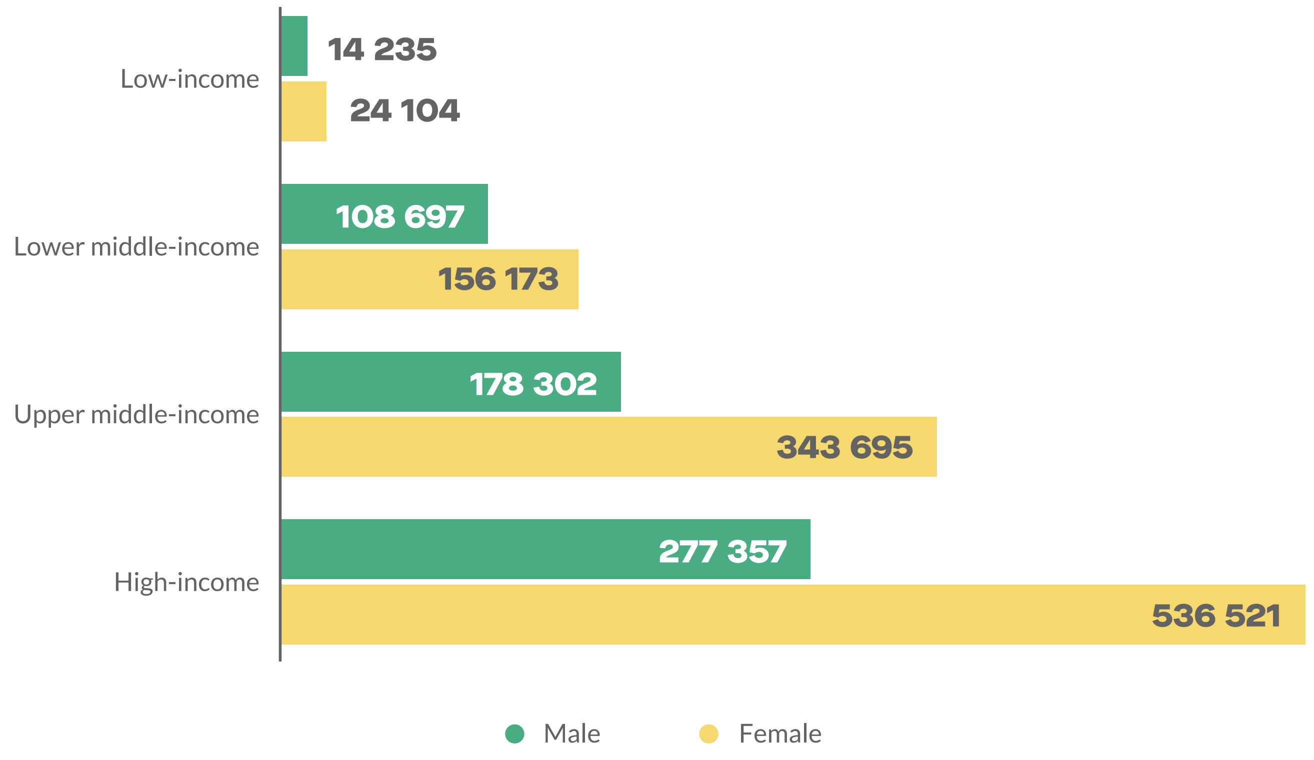


Mortality

In 2019, a total of 1.6 million deaths occurred worldwide due to dementias, including Alzheimer's disease. As many as 50% of these deaths occurred in HICs and, similarly to what is observed for DALYs, women represented roughly 65% of the total number of dementia-related deaths. (**Figure 6**).

FIGURE 6

Deaths caused by Alzheimer's disease and other dementias worldwide, 2019



Population growth and improved longevity, probably combined with an increase in the prevalence of risk factors, has led to a dramatic increase in the number of deaths caused by dementia over the past 20 years. Dementia and its clinical subtypes, including Alzheimer's disease, have become the seventh leading cause of death among all diseases (**Table 4**).

7th
leading cause of death

TABLE 4

Top 20 causes of death in 2000 and 2019

2019				
Rank	**Cause**	**Deaths (000s)**	**% of total deaths**	**% change in deaths from 2000 to 2019**
0	All Causes	55 416	100.0	8%
1	Ischaemic heart disease	8 885	16.0	32%
2	Stroke	6 194	11.2	13%
3	Chronic obstructive pulmonary disease	3 228	5.8	8%
4	Lower respiratory infections	2 593	4.7	-15%
5	Neonatal conditions	2 038	3.7	-36%
6	Trachea, bronchus, lung cancers	1 784	3.2	48%
7	**Alzheimer's disease and other dementias**	**1 639**	**3.0**	**181%**
8	Diarrhoeal diseases	1 519	2.7	-43%
9	Diabetes mellitus	1 496	2.7	71%
10	Kidney diseases	1 334	2.4	64%
11	Cirrhosis of the liver	1 315	2.4	20%
12	Road injury	1 282	2.3	10%
13	Tuberculosis	1 208	2.2	-30%
14	Hypertensive heart disease	1 149	2.1	58%
15	Colon and rectum cancers	916	1.7	53%
16	Stomach cancer	831	1.5	5%
17	Self-harm	703	1.3	-11%
18	Falls	684	1.2	53%
19	HIV/AIDS	675	1.2	-51%
20	Breast cancer	640	1.2	44%

Concluding remarks

As populations age, the number of people with dementia is expected to rise substantially. With the only approved disease-modifying treatment yet to show clinical benefit, it is essential to focus on the development of public health policies for implementing risk reduction and prevention strategies aimed at averting brain damage and/or buffering its effect on the expression of clinical symptoms. The postponement of dementia onset by an average of five years would greatly contribute to mitigating the impact of dementia on society and on health systems (see Chapter 6 for more details). It should be noted that, while dementia risk may decline as societal conditions improve with concerted efforts to reduce risk factors and enhance protective factors, persistent inequalities must be addressed in order to ensure that these changes are equitable across society.

"It is imperative to support the wide-spread collection of epidemiological data, especially from low-resource settings, to reduce data gaps and improve estimation methods."

> **“Do you want our healthcare system and our economy to prosper? Address dementia. The return on investment will be ten-fold.”**
>
> **Roger Marple,**
> Canada

3. Global societal costs of dementia

Context

Informal care accounts for nearly 50% of the global cost of dementia

The tremendous societal cost of dementia can be attributed to several direct and indirect factors. Worldwide, there is a hidden but enormous cost associated with informal care provided by families and carers. Current care models and pharmacological treatments are not highly cost-effective, despite improving the quality of life of people with dementia and their carers. The adoption of risk reduction strategies targeting modifiable risk factors can substantially help to mitigate the economic impact of dementia, although the fact that longer follow-up periods are needed to observe outcomes hinders implementation. Additionally, potential new disease-modifying therapies can play a huge role in meaningfully improving the lives of people with dementia and alleviating the consequent economic burden caused by the disease, but problems of affordability may create barriers in accessing such treatments.

The overall consequences of dementia are challenging for any care system. Aside from understanding the impacts on people with dementia and their families, data on resource use and costs in combination with prevalence figures are essential for planning care infrastructure.

Methodology

The estimation of the global economic costs of dementia is complex as a result of several factors. First, there is a lack of data from many parts of the world, particularly from LMICs. Second, even for countries with data, there is a lack of population-based cohort studies that represent diverse communities with data on resource use and costs. Consequently, most costing studies are based on clinical or convenience samples without being anchored to known populations. Many of the studies providing data are conducted only in limited geographical areas where research capacity is sufficient and are extrapolated to whole countries, and even regions. Third, many people with dementia are not detected by the health-care system or may not have a formal diagnosis. As a result, their numbers are not routinely captured by national health information systems. Additionally, nationwide dementia case registries are largely missing *(19, 20)*, leading overall to an underestimation of costs. Fourth, while the quantification and costing of informal care have a great impact on global cost estimates, the nature of support will vary according to the sociocultural environment, with an assumption of generalizability of findings across the world from limited research bases; this lack of transparency complicates comparisons of informal care costs. Sixth, certain indirect drivers of overall dementia costs such as the loss of carers' productivity and the early retirement of adults with young-onset dementia are difficult to determine and were not included in the indirect cost aggregate reported here. Additional challenges include insufficient demographic data on older adults, data aggregated over different years, lack of country-specific prevalence data and national data on care systems, and resource use of persons with dementia. Finally, delineating expenditure reporting in the literature for health (i.e. direct medical care) versus social care (e.g. support with activities of daily living) in the sense of WHO's System of Health Accounts (SHA)*(21)*, is extremely difficult, especially in the context of long-term care where the boundaries of what constitutes medical care and assistance are blurry. For the purpose of this report, costs for long-term care are included under direct social care, not without acknowledging though that a proportion of these costs are attributable to medical care.

All costs reported in this chapter are expressed as US dollars by exchange rates and inflated to 2019 by the use of inflation and average consumer prices derived from the International Monetary Fund, World Economic Outlook Database, October 2020 *(22)*.

Acknowledging these limitations, this chapter provides an overview of the economic costs associated with dementia based on the age-specific prevalence data for all-cause dementia presented in Chapter 2 of this report. These prevalence estimates were derived from the Global Burden of Disease Study (GBD 2019). World population prospects from the UN were used as the source for the country- and age-specific population data *(14)*.

The model underlying these cost estimates uses available GDO data as well as information collected through systemic reviews and the work of other institutions such as the the World Bank, the International Monetary Fund, the Organisation for Economic Co-operation and Development (OECD), the International Labour Organization (ILO), the Institute of Health Metrics and Evaluation (IHME), ADI, the 10/66 Dementia Research Group *(23)*, and the United Kingdom's initiative Strengthening responses to dementia in developing countries (STRIDE) *(24)*. Throughout this chapter, the term "estimate" is used to acknowledge that exact calculations pertaining to the economic costs of dementia are not possible. For a detailed description of the methodology, refer to the Web annex.

Global dementia costs

In 2019, the global cost of dementia was estimated to be 1.3 trillion US$ **(Table 5)**, with 74% of costs occurring in HICs while the majority of people with dementia live in LMICs (61%). On the basis of the expected increase in people with dementia, as outlined in Chapter 2, the global costs of dementia will increase to about 1.7 trillion US$ in 2030. In addition, if projections are corrected for the expected increases in costs for providing care, global dementia costs will increase to almost 2.8 trillion US$ in 2030.

1.3 trillion
US$ estimated cost of dementia in 2019

> **" Delineating expenditure reporting for health (i.e. direct medical care) versus social care (e.g. support with activities of daily living) is extremely difficult, especially in the context of long-term care where the boundaries of what constitutes medical care and assistance are blurry."**

TABLE 5

Estimated worldwide costs of dementia in 2019 (billion US$), by WHO region and World Bank country classification, 2019

WHO region	Number of people with dementia (millions)	%	Costs (billion US$)	Costs 95% CI	%	Costs per person (US$)	Number of countries
African Region	1.9	3.4	15.6	10.3-20.9	1.2%	8202	47
Region of the Americas	10.3	18.6	364.6	279.6-449.7	27.8%	35501	35
South-East Asia Region	6.5	11.8	23.9	16.3-31.4	1.8%	3651	11
European Region	14.1	25.5	438.8	375.0-502.5	33.4%	31144	53
Eastern Mediterranean Region	2.3	4.2	31.2	19.1-43.3	2.4%	13428	21
Western Pacific Region	20.1	36.4	439.3	313.0-565.5	33.4%	21890	27
All	**55.2**	**100**	**1 313.4**	**1157.8-1468.9**	**100.0%**	**23796**	**194**
Income level							
Low-income	1.4	2.5	3.5	2.6-4.4	0.3	2575	29
Lower-middle-income	8.8	16.0	44.3	31.4-57.2	3.4	5010	49
Upper-middle-income	23.6	42.8	293.2	259.9-326.5	22.3	12414	56
Low- and middle-income	33.8	61.3	341.0	304.7-377.4	26.0	10083	134
High-income	21.4	38.7	972.3	895.2-1049.5	74.0	45500	60
All	**55.2**	**100.0**	**1313.4**	**1157.8-1468.9**	**100.0%**	**23796**	**194**

Dementia costs by type of care

This section gives an overview of costs associated with different types of dementia care (i.e. direct medical care, direct social care and informal care).

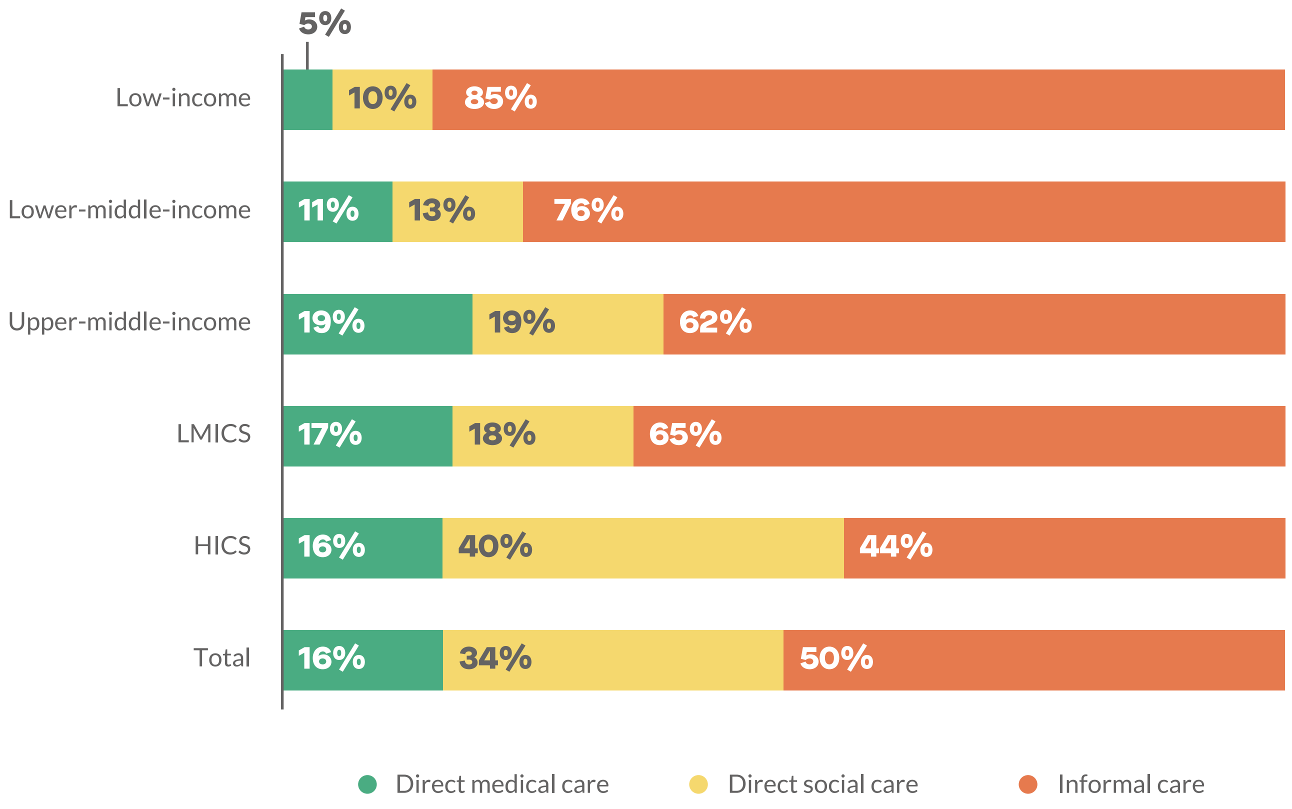
- **Direct medical costs** refer to direct health expenditures or costs incurred by the medical care system, such as hospital care, medicines, diagnostic tests and visits to clinics.
- **Direct social (nonmedical) costs** (sometimes referred to as "direct nonmedical costs") arise from services provided outside the medical care system – such as community-based services to assist with activities of daily living, but also including costs for providing long-term institutional care.
- **Informal care costs** are more difficult to measure directly and are usually approximated on the basis of the time required by family members or informal carers to provide support and assistance with basic and instrumental activities of daily living (ADL). Supervision time, which makes up a substantial proportion of carer time and the associated burden for family members, is listed separately.

Table 6 presents dementia care costs associated with different types of care, broken down by WHO region and World Bank income classification. When direct care costs are expressed as a proportion of the cumulated Gross Domestic Product (GDP), a clear income gradient is visible.

Globally, approximately half of the dementia care costs are attributable to informal care with huge variations by country income classification. In LMICs, almost two thirds of dementia care costs are attributable to informal care, while direct medical and social care together account for a bit over one third of the costs. In HICs, on the other hand, informal care and social care costs contribute almost equally to 84% of the overall cost, with direct medical costs accounting only for 16% (**Figure 7**).

FIGURE 7

Percentage of costs associated with different types of dementia care, by World Bank income level



The costs per person with dementia are also strongly linked to World Bank income classifications (**Table 7**). In low-income countries, the costs for the social care sector (including long-term institutional care) are very low.

TABLE 6

Sub-category costs of dementia in 2019 (billion US$, and % of total costs), by WHO region and World Bank income level

	Direct medical costs		Direct social sector costs		Informal care costs		Total costs	
WHO region	Billion US$	%	Billion US$	%	Billion US$	%	Billion US$	Direct costs % of cumulated GDP
African Region	0.4	2.8	1.0	6.3	14.2	90.9	15.6	0.07
Region of the Americas	74.4	20.4	124.8	34.2	165.4	45.4	364.6	0.70
South-East Asia Region	7.5	31.4	3.0	12.6	13.4	55.9	23.9	0.21
European Region	51.0	11.6	184.9	42.2	202.8	46.2	438.8	1.02
Eastern Mediterranean Region	0.9	2.9	1.7	5.4	28.6	91.8	31.2	0.08
Western Pacific Region	78.9	18.0	133.3	30.3	227.1	51.7	439.3	0.86
All	**213.2**	**16.2**	**448.7**	**34.2**	**651.4**	**49.6**	**1313.4**	**0.76**
Income level								
Low-income	0.2	4.6	0.4	10.5	3.0	84.9	3.5	0.11
Lower-middle-income	4.8	10.9	5.8	13.2	33.6	75.9	44.3	0.17
Upper-middle-income	54.4	18.5	54.8	18.7	184.0	62.8	293.2	0.42
Low- and middle-income	59.4	17.4	61.0	17.9	220.6	64.7	341.0	0.37
High-income	153.9	15.8	387.7	39.9	430.8	44.3	972.3	1.00
All	**213.2**	**16.2**	**448.7**	**34.2**	**651.4**	**49.6**	**1313.4**	**0.76**

TABLE 7

Sub-category costs of dementia per person (US$) in 2019 by WHO region and World Bank income level

WHO region	Direct medical costs	Direct social sector costs	Informal care costs	Total costs
African Region	226	519	7 457	8 202
Region of the Americas	7 247	12 152	16 102	35 501
South-East Asia Region	1 147	462	2 043	3 651
European Region	3 624	13 128	14 393	31 144
Eastern Mediterranean Region	384	720	12 323	13 428
Western Pacific Region	3 934	6 640	11 316	21 890
All	**3 864**	**8 130**	**11 803**	**23 796**
Income level				
Low-income	118	270	2 187	2 575
Lower-middle income	546	660	3 804	5 010
Upper-middle income	2 302	2 321	7 790	12 413
Low- and middle income	1 755	1 805	6 523	10 083
High-income	7 201	18 140	20 159	45 500
All	**3 864**	**8 130**	**11 803**	**23 796**

Direct medical care costs

As seen in **Table 7**, with the exception of low-income countries where direct costs are very low (due to a lack of availability of diagnostic and care services), direct medical care costs are relatively stable across different income levels, with some variations by WHO region.

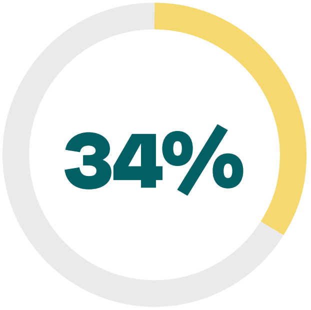
In HICs, the costs of long-term institutional care represent a large proportion of both the direct social costs (about 50%) and total social costs (about 25%) of dementia, while such resources are scarce in LMICs. As such, there is an inverse relationship between the costs of institutional care and the costs of informal care in relation to income level. Urbanization and migration, which results in generation and nuclear family splits in many countries *(25)*, also makes the prerequisites for informal care weaker.

> **" In HICs, the costs of long-term institutional care represent a large proportion of both the direct social costs (about 50%) and total social costs (about 25%) of dementia, while such resources are scarce in LMICs."**

Direct social care costs

The social care sector costs constitute some 34% of the total societal costs of dementia, with a clear gradient in terms of income level: about 18% in LMICs and 40% in HIC. In the WHO regions of Africa, South-East Asia and the Eastern Mediterranean, the proportion of the social care sector is particularly low.

The largest contributor to cost in the social care sector is the cost of long-term institutional care (LTIC). For the purpose of this report, LTIC is defined as part of the social care sector, although it is acknowledged that a proportion of LTIC associated costs could be attributed to direct health care costs as well. As of 2019, it was estimated that some 8.5 million people with dementia were cared for in LTC facilities. This corresponds to roughly 15% of the global dementia population, ranging from about 2% in LIC to 25% in HIC. LTIC constitutes about 25% of the total societal costs and about 50% of direct costs associated with dementia. In HICs the figures are higher, corresponding to 27% of the societal costs and about 50–60% of direct care costs.



of total dementia costs are attributable to social care costs

89 billion
hours of informal care

Informal care provided by family, friends, and neighbours

In 2019, informal dementia carers spent over 89 billion hours providing ADL support, corresponding to approximately 5 hours per day per person with dementia (**Table 8**). When accounting for supervision time, this figure increases to some 133 billion hours (about 8 hours per day). Informal care provision is particularly high in countries with low resources, generally reflecting the scarcity or lack of available formal support services for dementia.

TABLE 8
Hours of informal care by WHO region and World Bank income level, 2019

	All ADLs		Supervision		Total hours	
WHO region	Million hours	Hours per day	Million hours	Hours per day	Million hours	Hours per day
African Region	5 799	8.6	2 827	4.2	8 626	12.9
Region of the Americas	12 168	4.2	10 137	3.5	22 305	7.6
South-East Asia Region	12 454	5.4	5 156	2.2	17 610	7.6
European Region	21 038	5.3	8 601	2.2	29 639	7.4
Eastern Mediterranean Region	5 222	6.4	3 070	3.7	8 292	10.1
Western Pacific Region	32 692	5.2	14 092	2.2	46 783	7.4
Total	**89 373**	**5.2**	**43 882**	**2.6**	**133 255**	**7.8**
Income level						
Low-income	3 871	8.0	1 807	3.7	5 678	11.7
Lower-middle-income	18 693	6.0	7 229	2.3	25 922	8.3
Upper-middle-income	40 874	5.3	16 864	2.2	57 739	7.5
Low- and middle-income	63 438	5.6	25 901	2.3	89 339	7.9
High-income	25 935	4.5	17 982	3.1	43 916	7.6
Total	**89 373**	**5.2**	**43 882**	**2.6**	**133 255**	**7.8**

Note: The accumulated figures for hours spent per day providing informal care are adjusted to represent the proportion of people with dementia who live at home.

If the proportions of caregiving hours are compared to costs, there is a discrepancy between LMICs and HIC (**Figure 8**). Most hours spent providing informal care are in LMICs, while most costs across all categories occur in HICs (**Table 8**). If it is assumed that a full-time worker works 2000 hours per year, the informal care hours correspond to about 45 million full-time workers (for support to ADL only) and approximately 67 million full-time workers if supervision time is also included (**Table 9**). The greatest number of full-time workers would be in upper-middle-income countries. Women provide a disproportionate amount of informal care hours (roughly 70%), particularly in low-income countries (77%). Additional information on the impact on carers is discussed on chapter 8 of this report.

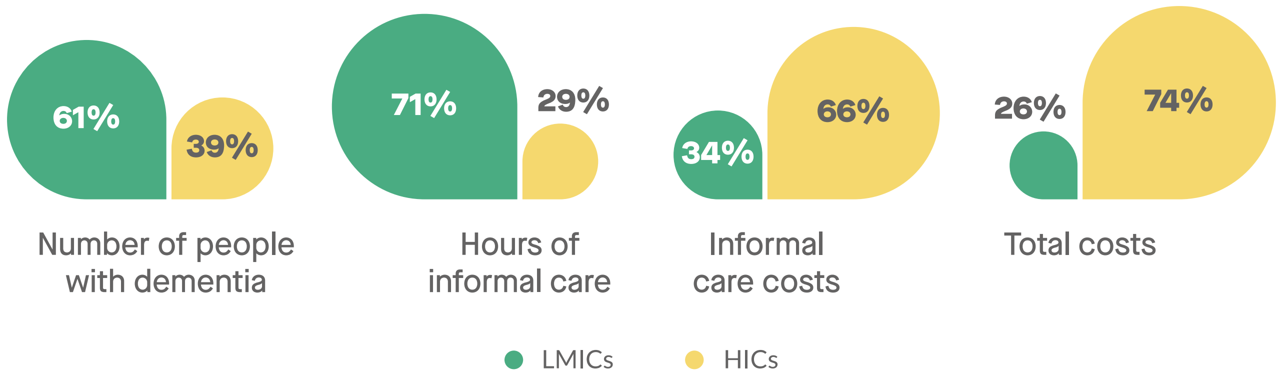
TABLE 9

Corresponding number of full-time workers (millions) to amounts of informal care by WHO region and World Bank income level, 2019

WHO Region	All ADLs	Supervision	Total hours
African Region	2.9	1.4	4.3
Region of the Americas	6.1	5.1	11.2
South-East Asia Region	6.2	2.6	8.8
European Region	10.5	4.3	14.8
Eastern Mediterranean Region	2.6	1.5	4.1
Western Pacific Region	16.3	7.0	23.4
Total	**44.7**	**21.9**	**66.6**
Income level			
Low-income	1.9	0.9	2.8
Lower-middle-income	9.3	3.6	13.0
Upper-middle-income	20.4	8.4	28.9
Low- and middle-income	31.7	13.0	44.7
High-income	13.0	9.0	22.0
Total	**44.7**	**21.9**	**66.6**

FIGURE 8

Comparison of the percentages of number of people with dementia, informal care hours, informal care costs and total costs in HIC and LMICs.



> **"Women provide a disproportionate amount of informal care hours (roughly 70%), particularly in low-income countries (77%)."**

Costs and dementia severity

The severity of dementia is an important driver of cost. Based on the 2019 dementia prevalence figures in Chapter 2 and estimated dementia severity rates derived from IHME[2], there were approximately 26.9 million people with mild dementia, 14.9 million people with moderate dementia and 13.4 million with severe dementia. The model for estimating dementia costs based on severity contains fewer records and thus produces slightly different overall cost estimates (i.e. US$ 23 764 per patient/year versus US$ 23 796 per patient/year in the base model).

Severity-specific cost estimates (accumulated as well as per patient) for WHO regions and World Bank income groups are listed in **Table 10**. Annual per-patient costs increase steadily with increasing dementia severity, ranging from US$ 15 899 for a person with mild dementia to US$ 36 180 for a person with severe dementia (**Table 10b**). Given the greater number of people with mild dementia, this gradient gets diluted when looking at accumulated costs (**Table 10a**).

cost by severity per person with dementia (US$)

15 889
mild dementia

26 859
moderate dementia

36 180
severe dementia

---

[2] Based on personal communications about a forthcoming IHME report

TABLE 10

Worldwide costs in relation to dementia severity, by WHO region and World Bank country classification, 2019: cumulated (billion US$) (10a), per person with dementia (US$) (10b)

10a								
Severity	Mild		Moderate		Severe		Total costs	
WHO region	Billion US$	%	Billion US$	%	Billion US$	%	Billion US$	%
African Region	6.5	1.5	4.2	1.1	5.5	1.2	16.2	1.2
Region of the Americas	91.6	21.4	130.6	32.7	147.5	30.5	369.7	28.2
South-East Asia Region	16.4	3.8	12.0	3.0	12.2	2.5	40.7	3.1
European Region	193.6	45.2	162.6	40.7	186.0	38.5	542.1	41.3
Eastern Mediterranean Region	13.6	3.2	8.6	2.2	9.3	1.9	31.6	2.4
Western Pacific Region	106.8	24.9	81.7	20.4	122.7	25.4	311.3	23.7
All	428.5	100.0	399.7	100.0	483.4	100.0	1311.6	100.0
Income level								
Low-income	1.5	0.3	1.0	0.3	1.5	0.3	4.0	0.3
Lower-middle-income	24.8	5.8	17.2	4.3	18.9	3.9	60.9	4.6
Upper-middle-income	99.7	23.3	72.4	18.1	103.1	21.3	275.1	21.0
Low- and middle-income	126.0	29.4	90.6	22.7	123.4	25.5	340.0	25.9
High-income	302.5	70.6	309.2	77.3	359.9	74.5	971.6	74.1
All	428.5	100.0	399.7	100.0	483.4	100.0	1 311.6	100.0

10b

WHO region	Mild	Moderate	Severe	Average cost
African Region	6 683	8 424	12 781	8 531
Region of the Americas	18 675	46 110	58 168	35 993
South-East Asia Region	4 880	7 053	8 312	6 220
European Region	29 204	42 010	51 817	38 482
Eastern Mediterranean Region	11 343	14 499	17 681	13 591
Western Pacific Region	10 803	15 184	25 575	15 511
All	**15 899**	**26 859**	**36 180**	**23 764**
Income level				
Low-income	2 122	2 836	4 897	2 942
Lower-middle-income	5 486	7 448	9 385	6 884
Upper-middle-income	8 453	11 558	18 518	11 647
Low- and middle-income	7 405	10 150	15 654	10 052
High-income	30 445	51 869	65 749	45 464
All	**15 899**	**26 859**	**36 180**	**23 764**

> **"The greatest methodological challenge is the lack of research and evidence from many parts of the world."**

Concluding remarks

The cost of dementia worldwide is very high and has a significant impact on care systems across the world. The burden on unpaid informal carers is substantial, including stress and role strain as well as deterioration of mental and physical health (see Chapter 8). Additionally, there is an important imbalance between how people with dementia live and the distribution of costs (and thereby resources). The majority of people with dementia live in LMICs but the highest costs are in HICs. In many LMICs, long-term care systems are not well-prepared, placing a heavy burden on carers and families.

The estimation of dementia costs is hampered by a variety of issues. The greatest methodological challenge is the lack of research and evidence from many parts of the world – even from HICs but particularly from LMICs. In addition, the few available studies may not always be representative of the entire population or reflective of the variation within populations in terms of inequalities and specific areas of need. Most studies included in the costing model are in fact based on convenience or clinical samples, which may overestimate dementia direct costs, particularly the few studies from LMICs which mostly in these countries are conducted in urban areas. Since there are no cost studies from low-income countries, the consequent imputation method probably over-estimates direct costs in these countries. On the other hand, the same problems with representativity may result in underestimating costs of informal care in LMICs.

Population-based cohort studies with data on resource use and costs continue to be rare, preventing us from developing more robust and representative dementia costing models. Moreover, sociocultural factors which could not be quantified in these cost estimates also have an impact on the societal costs of dementia.

Another challenge is the under-reporting of dementia, both in registries and in clinical practices *(20, 26, 27)*. Because of lacking awareness and the presence of stigma and misconceptions, dementia is often undetected and undiagnosed. This is a problem not only for the quality of care but also for studies on cost. An undiagnosed person with dementia will nevertheless incur some cost. Therefore, if cost estimates are based only on a fixed dementia diagnosis in registry-based studies, costs will be underestimated.

Finally, the quantification and costing of informal care greatly impact global cost estimates. It is obvious that without transparency it is very difficult to make any comparisons of the costs of informal care. A forthcoming WHO report on global dementia costs, will include a comprehensive review of all methodological issues linked to the costing of informal care.

> **“There is a stigma around dementia that compounds the existing ageism within society, which emphasizes the need for a groundswell of support from the worldwide community to push local governments to address dementia and to implement better policies and improve the long-term care system with rights-based, person-centred care.”**
>
> **Jim Mann,**
> Canada

4. Dementia policy and legislation

Context

Addressing dementia requires a whole-of-government, multisectoral and multistakeholder public health response. Such a response should be developed in close collaboration with people with dementia, their carers and other relevant stakeholders such as civil society and the private sector. The importance of dementia policy and legislation is reflected in global target 1 of the Global dementia action plan: *75% of Member States will have developed or updated a national policy, strategy, plan or framework for dementia, either stand-alone, or integrated into other policies/plans by 2025.*

Dementia plans indicate political commitment to address the challenges and impacts associated with dementia and to improve health and social system readiness to address the needs of people living with dementia and their carers. Dementia plans also serve to raise public awareness, create mutual understanding of dementia and protect the human rights of people living with dementia, their carers and families *(28-30)*. The 2019 Okayama Declaration of the G20 Health Ministers *(31)* reiterated political commitment to developing and implementing multisectoral national action plans through integrated approaches to improve the quality of care and quality of life of people with dementia, their families and carers. The UN Decade of Healthy Ageing 2021–2030 *(12)* endorsed by the UN General Assembly in August 2020 also highlights the central role of policy change in promoting healthy ageing, including for people with dementia.

This chapter provides an overview of global progress made to date in achieving the global target associated with Action area 1 of the Global dementia action plan. It begins by assessing country-driven progress based on GDO data and other sources and provides a complementary analysis of national dementia policies – including ongoing gaps and opportunities as well as country case studies. The chapter closes with activities carried out by WHO's secretariat to support countries in developing and implementing national dementia plans and recommendations to accelerate action for the future.

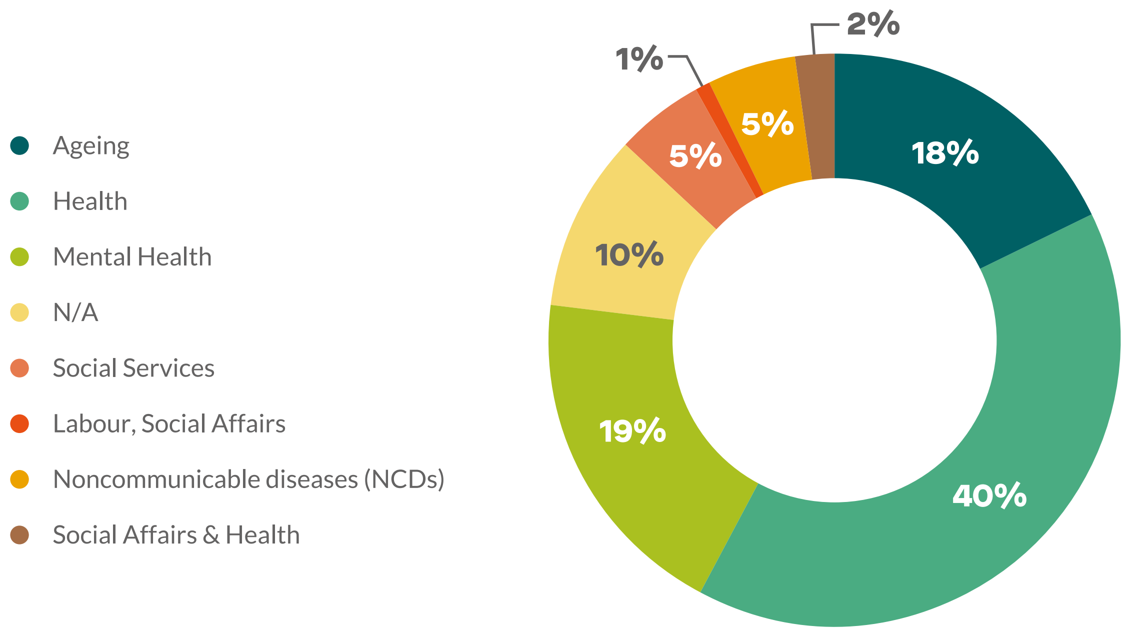
Progress to date

Inclusion of dementia in ministry portfolios

The Global dementia action plan identifies the need for countries to establish a focal point, unit or functional division that is responsible for dementia, or a coordinating mechanism within the entity responsible for NCDs, mental health or ageing within the health ministry (or equivalent body). Doing this helps ensure sustainable funding, clear lines of responsibility for strategic planning, implementation, mechanisms for multisectoral collaboration, service evaluation, monitoring and reporting on dementia. Data submitted by 62 GDO countries show that 90% of these countries include dementia in ministry portfolios and 68% have appointed a dementia-specific representative. **Figure 9** shows the ministry branches under which dementia is included, with most countries including dementia under a ministry branch focused on health (40%), followed by mental health (19%) and ageing (18%). Interestingly, whereas HICs tend to include dementia in the health and ageing branches, LMICs mainly include dementia in mental health.

FIGURE 9

Government branches where dementia is included



Existence of national dementia plans

The Global dementia action plan indicates (in its Global target 1) the need for countries to develop, strengthen and implement national and/or subnational strategies, policies, plans or frameworks that address dementia, whether as separate instruments or integrated into other planned actions for NCDs, mental health or ageing. The GDO measures progress towards achieving this target using three sub-indicators, namely: 1) existence of a stand-alone dementia plan; 2) existence of another relevant policy into which dementia is integrated; and 3) existence of subnational dementia plans that cover more than 50% of the country.

GDO data collected from 62 countries show that 27 currently have a dementia-specific (i.e. stand-alone) national dementia plan, 14 of which have expired in 2020, and 9 countries are developing one. ADI has been monitoring dementia policy development around the world, including for countries that have not yet submitted data to the GDO. On the basis of ADI's 2020 report *(32)*, an additional 7 national stand-alone dementia plans had been adopted as of May 2021. This brings the total number of countries with national stand-alone dementia plans to 34. The distribution of national dementia plans is largely uneven across WHO regions. While many countries in WHO's European Region have developed national dementia plans, this is not the case in other regions.

The GDO also measures whether a country has integrated dementia into existing policies, either in addition to or in lieu of a stand-alone national dementia plan. Of the 62 GDO countries, 31 have integrated dementia into an existing policy, and 5 are in the process of doing so (**Table 11**). **Figure 11** shows that the majority of countries have integrated dementia into a general health/social welfare policy or ageing strategy.

TABLE 11
Number of countries with stand-alone, integrated and subnational dementia plans

WHO region	Stand-alone dementia plan	Dementia plan integrated into other plans	Subnational dementia plan
African Region	0	1	0
Region of the Americas	4	5	3
South-East Asia Region	0	3	1
European Region	17	10	10
Eastern Mediterranean Region	2	5	0
Western Pacific Region	4	8	4
Income level			
Low-and-middle income	2	13	2
High-income	25	18	16

On the basis of GDO data, a total of 43 countries have a dementia plan which may be stand-alone, integrated into another policy or at a subnational level. The additional seven plans reported by ADI bring the total to 50 countries that meet the global target, or 26% of countries. **Figure 10** identifies the countries that currently meet the global target.

FIGURE 10
Countries with a stand-alone or integrated dementia plan

African Region

- Mauritius

Region of the Americas

- Belize
- Canada
- Chile
- Costa Rica
- Cuba
- Dominican Republic
- Mexico
- Trinidad and Tobago
- United States of America

South-East Asia Region

- India
- Indonesia
- Maldives
- Thailand

European Region

- Austria
- Belgium
- Czechia
- Denmark
- Finland
- France
- Germany
- Greece
- Iceland
- Ireland
- Israel
- Italy
- Luxembourg
- Malta
- Netherlands
- Norway
- Russian Federation
- Slovenia
- Spain
- Sweden
- Switzerland
- Turkey
- United Kingdom

Eastern Mediterranean Region

- Iran (Islamic Republic of)
- Jordan
- Morocco
- Oman
- Qatar

Western Pacific Region

- Australia
- Brunei Darussalam
- China (People's Republic of)
- Cook Islands
- Japan
- Malaysia
- Republic of Korea
- Singapore

BOX 3

Cuba's National Strategy for Alzheimer's disease and Dementia Syndromes

The policy of the State and Ministry of Public Health of Cuba includes priority objectives focused on ageing and dementia. In 2014, the National Strategy for Alzheimer's disease and dementia syndromes was developed. In 2017, it was updated with elements related to gender equity, friendly environments, health information system strengthening and the alignment of indicators with those proposed by WHO.

Each province in Cuba has health coverage for cognitive deterioration from primary health care to specialist care through 449 polyclinics and 10 869 family doctor and nurse consultations, with coordination between levels of care. Work is ongoing to improve prevalence registration at primary health-care level.

Ninety-five percent of Cuba's health areas provide care and support for carers of people with dementia. A *Manual for caregivers of care-dependent adults* was developed and there has been an increased focus on carer training in coordination with primary health care and related health-care professionals.

As part of the National Strategy, the Centre for Alzheimer and other cognitive disorders was created on 21 September 2019 as part of the Centre for Research on Longevity, Ageing and Health. The centre functions as a national reference platform and includes an interdisciplinary team specialized in early diagnosis and intervention for Alzheimer's disease and other neurocognitive disorders.

Each year, Cuba organizes activities that contribute to the international dementia awareness campaign through a call launched by the National Alzheimer's Society. Various activities taking place during World Alzheimer's Month and Day are covered by the media.

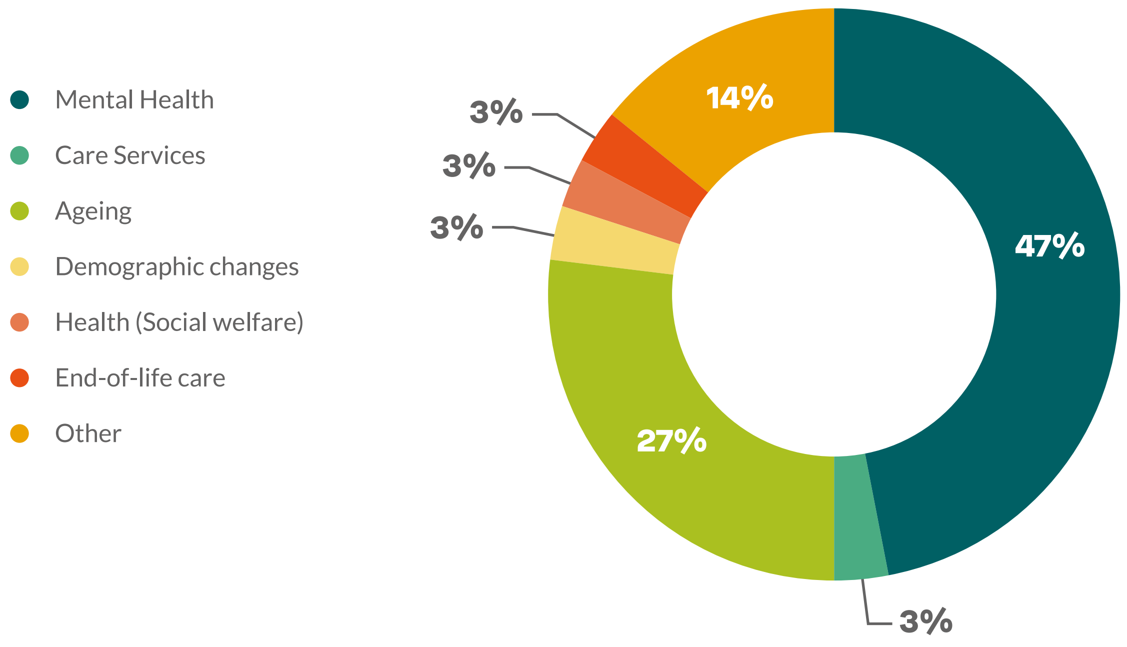
A national protocol for action in nursing homes was developed specifically for residents with dementia during the COVID-19 pandemic.

Across the country, multiple centres are working on research related to early diagnosis, risk factors, treatment efficacy and alternative treatments for mild and major cognitive disorders. Additionally, national courses in the area of dementia are being developed at diploma and master's levels. Cuba counts more than 70 publications, including in high-impact journals.

Multiple programmes focused on non-pharmacological interventions for mild cognitive disorders and dementia have been created in view of supporting scientific evidence.

FIGURE 11

Types of policies into which dementia is integrated



Dedicated funding and implementation targets for national dementia plans

Among the countries with a dementia plan, there is vast heterogeneity in funding allocation as well as in implementation and monitoring targets *(33)*. While many national dementia plans identify the need for financial investment, few delineate the mechanisms for mobilizing and allocating funding – e.g. between national and subnational levels.

The Global dementia action plan recommends the allocation of sustainable financial resources commensurate with the identified service needs and human and other resources required to implement national dementia plans and actions. It also identifies the need to establish mechanisms to track expenditures on dementia in health, social and other relevant sectors such as education and employment.

Of 27 GDO countries for which data are available for this indicator, 70% have allocated dedicated funding to implement their national dementia plan and targets for monitoring implementation. There is a lot of variation between WHO regions: while data reported by countries in the Americas, European and Western Pacific regions have allocated dedicated funding and set implementation targets, few or none have done so in the African, South-East Asia, and Eastern Mediterranean regions. Additionally, only one LMIC has done so, with all other countries being HICs.

Strategic action areas and principles of national dementia plans

Action areas

Thematic analyses reveal that the majority of dementia plans recognize the need to address rapidly changing demographics, including the increase in ageing populations and in numbers of people living with dementia *(33)*. Yet there remains great variation among countries in terms of identifying dementia as a public health imperative. This has important implications in terms of widening health inequities between HICs and LMICs, where the majority of people with dementia live (see Chapter 2). In this respect, it is worth acknowledging the unequivocal impact of the ongoing COVID-19 pandemic on competing priorities, thus placing increased pressure on demands for financing for dementia. The pandemic has also brought to light underlying health system weaknesses, such as those associated with community care coordination and continuity, and has raised issues related to care quality, rights-based access to care and supported decision-making, particularly in long-term care facilities.

Dementia plans typically cover a number of common themes, broadly mapping onto the seven action areas of the Global dementia action plan. These themes include awareness-raising and stigma reduction; dementia risk reduction; timely diagnosis through preventive, quality person-centered approaches to care; integrated health care models and systems; investment in research; specialist training and workforce education; carer support; and dementia health information.

Table 12 shows the areas covered by countries' national dementia plans on the basis of GDO data, stratified by WHO regions and income classification. Globally, most dementia plans (86%) address timely diagnosis, post-diagnostic support and care; workforce training and carer support; followed by dementia awareness, stigma reduction and friendliness (84%) and dementia risk reduction (81%). Fewer countries indicated that their national dementia plans covered monitoring and information systems for dementia, or dementia research and innovation.

TABLE 12

Action areas covered by countries' national dementia plans

	Dementia awareness, stigma reduction and dementia-friendly communities	Dementia prevention and risk reduction	Timely diagnosis, post-diagnostic support and care	Workforce training on dementia	Support for dementia carers and families	Improved monitoring or information systems for dementia	Dementia research and innovation
Global (*n* = 43)	36	35	37	37	37	33	33
WHO region							
African Region (*n* = 1)	1	1	1	1	1	1	1
Region of the Americas (*n* = 6)	4	4	5	5	5	5	4
South-East Asia Region (*n* = 2)	2	2	2	2	2	2	2
European Region (*n* = 19)	19	16	19	19	19	17	18
Eastern Mediterranean Region (*n* = 5)	4	5	3	3	3	2	2
Western Pacific Region (*n* = 7)	6	7	7	7	7	6	6
Income level							
Low-and-middle income (*n* = 12)	9	10	9	9	9	9	8
High-income (*n* = 28)	27	25	28	28	28	24	25

Note: Numbers reported by region and/or World Bank income classification do not necessarily add up to 100%, as some information was missing.

GDO data indicate that national dementia plans generally cover most of the seven action areas of the Global dementia action plan. However, a more detailed analysis of national policies reveals that many documents do not explicitly identify *how* person-centered care pathways are to be implemented, monitored and integrated into existing service models across sectors. This is despite the identified need for integrated health and social care *(30, 33)*. Similarly, dementia plans scarcely identify *what* the key components of such pathways ought to be (see Chapter 7). Moreover, while the burden of caregiving is well recognized in national dementia plans, there continues to be a significant over-reliance on informal carers, a disproportionate amount of whom are women, with the majority living in LMICs *(6)* (see Chapters 3 and 8).

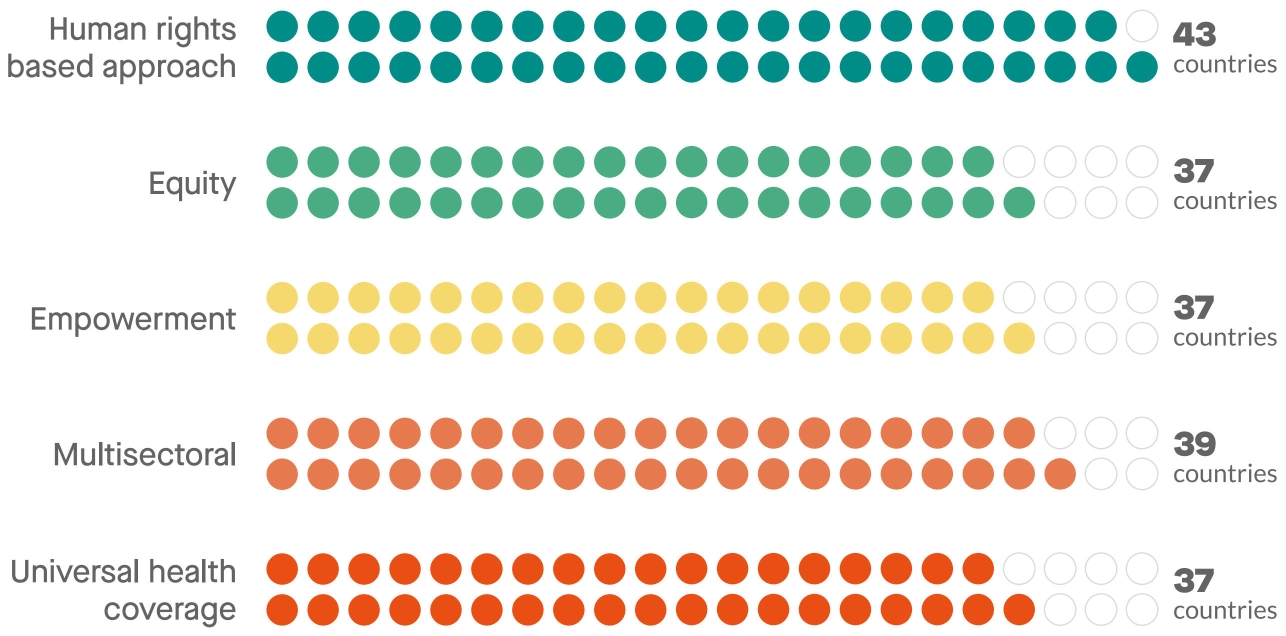
Finally, the role of technology (e.g. assistive technologies, artificial intelligence-based technologies, remote diagnosis and post-diagnostic support) in enhancing the quality of life of people living with dementia and improving service delivery remains under-addressed in national dementia plans *(5)*. Additional research is needed to enable evidence-based decision-making related to the role and impact of technology in service delivery and daily living. These gaps are particularly salient within the context of the COVID-19 pandemic and its impact on the discontinuation of services. Technology could help ensure that people with dementia can continue to live at home in the community for longer by preventing delays in accessing diagnostic and post-diagnostic services, providing needed supports to carers and reducing social isolation. Additional research-specific data is discussed in Chapter 8.

Multisectoral coordination, human rights and equity

Existing dementia plans can be assessed as to whether they address cross-cutting principles such as multisectoral coordination as well as issues relating to human rights, equity and UHC that are embedded in the Global dementia action plan. These principles also include a focus on empowering and engaging people with dementia and their carers in decision-making and policy development. For the 43 GDO countries with national dementia plans (either stand-alone, subnational or integrated), over 90% stated that their dementia policy document takes a human rights-based approach and focuses on multisectoral collaboration, while more than 85% of countries indicated that their policies address principles related to equity, empowerment and UHC (**Figure 12**).

FIGURE 12

Cross-cutting principles included in dementia plan



The Global dementia action plan recognizes the importance of engaging people with dementia in policy and legislative development and implementation processes. Yet, people with dementia, their carers and families continue to be largely outside these processes *(33, 34)*. Formal mechanisms aimed at consistently, meaningfully and comprehensively involving people with dementia and their carers are required in order to avoid tokenism, improve trust in the social–political contract between citizens and government, and ultimately augment the effectiveness of service delivery, foster rights-based care and improve health outcomes.

Vulnerable population groups

Although the GDO indicator related to equity promotes a gender-sensitive perspective and includes migrants, gender minorities and sexual minorities as vulnerable groups, it does not allow for disaggregation by population subgroups. As revealed in the literature, the needs of ethno-cultural minorities and vulnerable populations – e.g. migrants and refugees, gender minorities and sexual minorities, people living with disabilities (including physical or psychosocial disabilities or sensory impairments), and people with a comorbid mental health or substance use condition, or in extreme poverty) remain largely unaddressed in national dementia plans *(33)*.

A study of 35 countries in the European Union and the European Free Trade Association indicates that more than half of those with a national dementia plan (*n* = 23) do not refer to migration *(35)*. When addressed, references tend to be cursory, with few countries having specific health services for people with migration backgrounds *(36)*. This is important in view of the sharp increase in global migration patterns over the past two decades, and the projected increased prevalence of dementia among this population subgroup *(36, 37)*. While vulnerable populations have specific and complex social, economic and health needs, they are less likely to utilize health-care services. Particular attention is required to understand the specific impact of dementia, prevent marginalization and reduce inequities in health outcomes among vulnerable populations *(38)*. Evidence-based, culturally-sensitive resources and services should be available and should be appropriately tailored for the needs of subpopulations.

Legislation addressing dementia

To protect the human rights, wishes and preferences of people with dementia, the global dementia action plan recommends that countries implement accountability mechanisms and relevant legislation in line with the CRPD and other international human rights instruments. Of the 62 GDO countries, only 21% (*n* = 13) adopted dementia-specific legislation. However, 68% (*n* = 42) have included legal provisions in other legislation to protect the rights of people with dementia (universal laws). It is worth noting that only one LMIC has dementia-specific legislation although 12 out of 40 have included legal provisions in other universal laws.

As part of the GDO, countries are also asked to identify whether they have legislation that safeguard concepts such as legal capacity, self-determination, supported decision-making, power of attorney and protection against exploitation and abuse of people with dementia in institutions and the community. As identified in **Table 13**, legal provisions may be adopted specifically within the context of dementia-specific legislation or be incorporated into other laws related to, or that apply to, protection of the rights of people living with dementia (i.e. universal laws). Importantly, countries differ in the extent to which they have such legal provisions, and the limitations of self-reporting with regard to these provisions should be noted since interpretations of these criteria may vary from what is intended by human rights standards.

TABLE 13

Legal provisions in countries to protect human rights of people with dementia

	Total	Dementia-specific legislation	Universal law
Legal frameworks to promote supported decision-making	38	5	33
Legal procedures to protect the human rights of people with dementia	40	1	39
Promote the transition of dementia care to community-based services	28	5	23
Regular inspections of human rights conditions and/or care quality by an independent body in facilities where people with dementia reside	36	2	34
Advance care directives	29	0	29
Legislation to end discrimination against people with dementia	36	1	35
Legislation to end discrimination against carers of people with dementia	28	2	26

The GDO also measures whether countries prohibit, regulate or allow coercive practices – including seclusion and the use of mechanical/physical/chemical restraints – against people with dementia. Coercive practices are prohibited (*n* = 8) or regulated (*n* = 29) by the majority of countries. However, this is predominantly the case in HICs and no such legal provisions exist in the five LMICs from different WHO regions that reported on that indicator.

> **"The limitations of self-reporting with regard to legal provisions should be noted since interpretations of these criteria may vary form what is intended by human rights standards."**

The way forward

As demonstrated by GDO data, a concerted effort to develop and renew appropriately funded national dementia plans, with clear implementation targets is needed globally. The 2019 G20 Health Ministers' Declaration included a commitment to "*develop and implement multi-sectoral national action plans, and adopt integrated approaches on dementia in line with the Global Action Plan to improve the quality of care and the quality of life of people with dementia, their families and caregivers*" *(31)*. However, in many countries the ongoing lack of political leadership for dementia represents an important barrier to moving from discourse to action. There is a need for concerted efforts at national and global levels to place dementia on national health agendas through policy forums (including the G7 and G20) in order to achieve the targets outlined in the Global dementia action plan. In doing so, strategic links with existing global commitments such as the 2030 Agenda for Sustainable Development and its SDGs, UHC and the UN Decade of Healthy Ageing 2021–2030 can be leveraged to mobilize action on dementia on the basis of findings from this report.

Moreover, the forthcoming Intersectoral global action plan on epilepsy and other neurological disorders (requested in World Health Assembly resolution WHA 73.10) also represents a unique opportunity to renew concerted action for dementia within the broader context of addressing neurological disorders, on the basis of an integrated public health approach. **Figure 13** outlines the actions included in the Global dementia action plan, key barriers to implementing the actions, and opportunities to overcome the barriers through accelerators for action.

Where national dementia plans exist, GDO data demonstrate that appropriate funding and implementation targets are often lacking. In fact, low levels of national health budget expenditure and technical capacity in the area of dementia represent significant barriers to implementation. Technical support provided through national and regional workshops in partnership with WHO can help build national capacity, facilitate intercountry learning and assist in rationalizing resources to improve the lives of people with dementia, their carers and families. WHO resources such as the GDO Knowledge Exchange Platform also foster mutual learning and knowledge-sharing, including in related to policy and legislation.

FIGURE 13

Proposed actions for Member States, identified barriers and accelerators

PROPOSED ACTIONS

- Develop, strengthen and implement national or subnational dementia policy or plans
- Allocate sustainable resources to dementia plans/policies
- Establish a focal point, unit or functional division responsible for dementia
- Implement legislation and mechanisms to promote the human rights of people with dementia and their carers

BARRIERS

- Lack of political leadership for dementia
- Lack of earmarked funding to dementia and low proportion of national health budgets allocated to mental health and ageing
- Insufficient technical expertise and capacity to implement national dementia policies

OPPORTUNITIES TO ACCELERATE ACTION

- Advocate for renewed political commitment to dementia through relevant international forums
- Foster mutual learning and policy exchange through WHO's Global Dementia Observatory Knowledge Exchange Platform : www.globaldementia.org
- Leverage WHO resources such as *Towards a dementia plan: a WHO guide* to develop and operationalize national dementia plans
- Create strategic linkages with global commitments such as the 2030 Agenda for Sustainable Development and its SDGs, and UHC
- Implement national and regional dementia workshops, with technical assistance from WHO

BOX 4

WHO national and regional dementia workshops

To catalyze commitment to achieving Global target 1, WHO initiated regional workshops that focus on strengthening countries' comprehensive, multisectoral public health response to dementia. Since 2017, WHO has conducted a series of national and regional workshops that involved 76 countries from all six WHO regions and brought together stakeholders – including people with dementia, policy-makers, health-care practitioners, academic researchers and civil society representatives. Workshops represent a unique opportunity for countries to exchange lessons learned and good practices to inform the development of both regional and country-specific responses to dementia. Workshops also enable participants to learn about WHO's Global dementia action plan, including its global targets, key actions areas and available WHO tools.

Photo: Participants of a bi-regional European/Eastern Mediterranean dementia workshop in Malta in September 2019, organized and hosted by the Government of Malta

Workshops provide a forum for participants to work collaboratively towards addressing dementia on global and local scales. They facilitate the cross-pollination of ideas and foster new opportunities for collaboration both across sectors and WHO regions. Post-workshop survey findings highlight high levels of participant satisfaction, a strong intent to apply lessons learned and a recognition of value in terms of national capacity-building and intercountry knowledge exchange to strengthen the development and implementation of comprehensive public health responses to dementia at national and regional levels.

A virtual workshop held in December 2020 for the Eastern Mediterranean Region indicated the feasibility and success of conducting similar capacity-building efforts through the use of digital technology during the COVID-19 pandemic.

Tools such as WHO's *Towards a dementia plan: a WHO guide* provide actionable means of developing and operationalizing national dementia plans *(28)*. This might involve developing a new, stand-alone dementia plan, strengthening an existing dementia plan, or integrating dementia into related policies. The guide describes the process of creating a dementia plan in three phases: preparation, development and implementation. The first phase focuses on the steps involved in gathering evidence and setting priorities. The second phase guides countries through the creation of a strategic framework, assessing resource needs and obtaining political and stakeholder approval. Finally, the third phase outlines the steps involved in implementing and evaluating the dementia plan.

The WHO guide identifies the process of developing a dementia plan as both iterative and dynamic, with stakeholder engagement and multisectoral collaboration throughout. The resource is linked closely to the GDO and includes associated aids such as a checklist for the preparation, development and implementation of the dementia plan as well as stakeholder mapping and priority-setting tools. The guide has been successfully used by several Member States to develop their own national dementia plans.

Towards a dementia plan: a WHO guide

> **"A concerted effort to develop and renew appropriately funded national dementia plans, with clear implementation targets is needed globally."**

BOX 5

Towards a dementia plan: a WHO guide – adaptation in Czechia

In accordance with WHO recommendations in the Global dementia action plan, the Ministry of Health of Czechia introduced systemic changes to strengthen dementia policy. The first step was to appoint a national dementia focal point within the ministry. The role of the focal point was twofold: 1) to gather information about gaps in the system in Czechia itself, as well as creating a platform for key stakeholders; and 2) to connect the country to international structures such as WHO or Alzheimer Europe.

While the first activity mainly indicated *what* needs to be done, the latter provided valuable methodological support in *how* to achieve it. As a result of this effort, three specific activities stand out in the current dementia policy in Czechia.

First, Czechia joined the *Global Dementia Observatory* (GDO) initiative and created a structured situation analysis on the basis of GDO indicators.

Second, *The National Action Plan for Alzheimer's Disease and Related Illnesses 2020–2030* was developed during 2019 in line with the document *Towards a dementia plan: a WHO guide*. To ensure multisectoral collaboration, the Plan is a joint initiative of both the Ministry of Health and the Ministry of Labour and Social Affairs and is currently being approved by the Cabinet.

Third, thanks to established collaboration and experience with methodological support from WHO, Czechia decided to do a rapid adaptation of *iSupport* as a response to Covid-19 which had created additional burden for family carers (see Chapter 8).

Concluding remarks

While some progress is being made to develop, strengthen and implement national and subnational dementia plans, there continue to be wide variations between countries. Allocating earmarked funding and identifying clear targets to ensure the development and effective implementation of national dementia plans constitute significant challenges, particularly in LMICs. A renewed focus on ensuring equity of access to dementia services from prevention to diagnosis, treatment and palliative care is also needed in order to reach all groups of the population, especially the most vulnerable. In this respect, additional efforts are required to strengthen legislation aimed at protecting the human rights of people with dementia, their families and carers in line with the principles of the CRPD.

"A renewed focus of policies on ensuring equitable access to dementia services is needed to reach all population groups, especially the most vulnerable."

‘Don’t talk about people living with dementia in a way that rip off their dignity as a person or make them feel ‘not good enough’ to be part of the community.’

Emily Ong
Singapore

5. Dementia awareness and friendliness

Context

62%
of health care practitioners believe that dementia is a natural and inevitable part of ageing

International human rights instruments such as the CRPD were developed to prevent human rights violations and discrimination, including against people with dementia. These instruments provide the foundation for identifying and eliminating barriers to ensure that people with dementia can live safely in their own communities and enjoy equitable access to their environment. However, people with dementia, their carers and families worldwide continue to experience stigma, discrimination and human rights violations. These include coercive or forced treatment or institutionalization, disregard for an individual’s legal capacity to make decisions and depriving a person of dignity and autonomy. Moreover, dementia is frequently misconceived as a natural and inevitable part of ageing rather than as a syndrome, which raises barriers to diagnosis and care.

While there is growing commitment to reduce stigma and increase knowledge and understanding of dementia, much still needs to be done to increase awareness across WHO’s 194 Member States and beyond. In 2019, ADI and the London School of Economics conducted a global survey of almost 70 000 people from 155 countries and territories to understand stigma and to assess the knowledge and understanding of dementia. The survey analysis exposed a startling lack of knowledge about dementia. The report revealed that two thirds of the general public still believe that dementia is a natural and inevitable part of ageing and, more worryingly, 62% of health-care practitioners share this view *(39)*.

The first step to dispelling myths and stereotypes is to provide accurate information to improve public understanding of dementia. Action area 2 of the Global dementia action plan focuses on increasing public awareness, acceptance and understanding of dementia. It also seeks to foster dementia-inclusive societies that enable people with dementia to participate in the community and maximize their autonomy through improved social participation. Global targets 2.1 and 2.2 to be reached by 2025 are that:

- ✓ 100% of countries will have at least one functioning public awareness-raising campaign on dementia; and
- ✓ 50% of countries will have at least one dementia-friendly initiative (DFI) to foster a dementia-inclusive society.

Achieving these targets involves the ongoing and meaningful involvement of people with dementia, their families and carers in planning, implementing and evaluating both dementia awareness campaigns and DFIs. It also requires close collaboration among multiple stakeholders, including governments, civil society, the media and academia.

This chapter provides an overview of progress made to date in achieving the global targets associated with Action area 2. Based on available GDO data. The chapter outlines success factors associated with effective dementia awareness campaigns and DFIs, ongoing gaps in and opportunities to improve the social and built environment, good practices in including people with dementia and their carers in decision-making, and the impact of COVID-19 on efforts related to dementia awareness and dementia-friendliness. The chapter further outlines activities carried out by WHO's secretariat and regional offices to support countries in raising public awareness of dementia and fostering dementia-inclusive environments. Finally, the chapter features country case studies and identifies key accelerators for action.

Progress to date

Dementia awareness campaigns

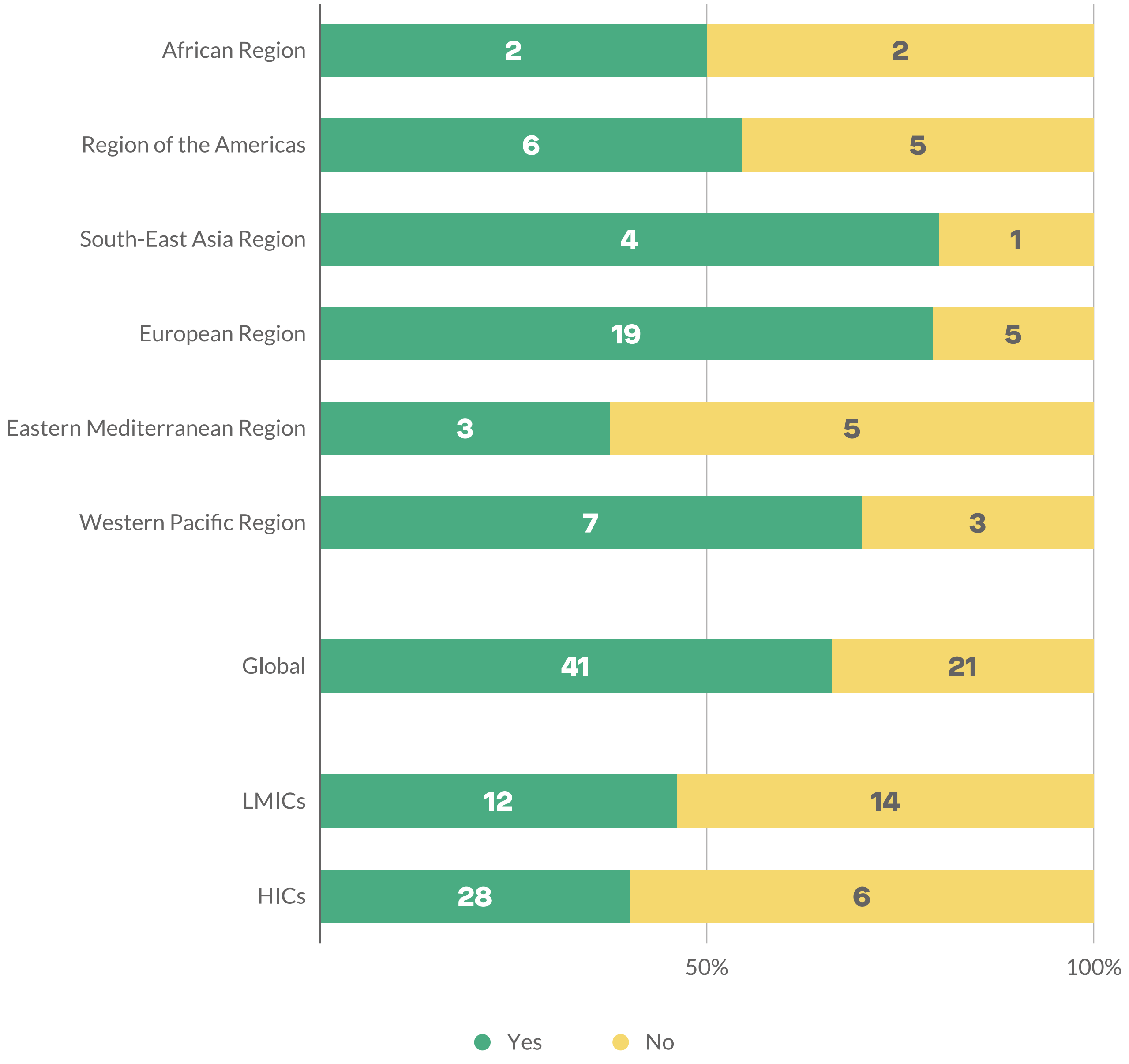
An understanding that dementia is a clinical syndrome associated with the progressive decline of brain function is imperative for promoting dementia risk reduction, timely diagnosis and access to support for people living with dementia and their families. Effective public health and awareness campaigns have the power to change the way people think about dementia, improve the accuracy of public knowledge about dementia, reduce stigmatization, dispel myths, and promote the recognition of human rights of people with dementia. The Global dementia action plan recommends that countries organize national and local public health and awareness campaigns that are both culturally – and community-specific – and to do so in collaboration with people with dementia, their carers and other stakeholders.

Available GDO data indicate that two thirds of countries have implemented at least one functioning public awareness campaign to improve the understanding of dementia and reduce stigma and discrimination. **Figure 14** shows these data disaggregated by WHO region, and by World Bank income classification.

> **"2/3 of GDO countries have implemented at least one functioning dementia public awareness campaign to improve the understanding of dementia and reduce stigma and discrimination."**

FIGURE 14

Numbers of countries with at least one functioning public awareness campaign for dementia



Note: LMICs = Low- and middle-income countries; HICs = High-income countries.

The GDO also measures whether dementia public awareness campaigns were implemented at national or subnational level. Of the 41 GDO countries with at least one national awareness-raising campaign, 73% indicated that the campaign was implemented at national level. A majority of awareness-raising campaigns (25/41) are (at least co-) managed and implemented by nongovernmental organizations (NGOs), indicating the important role of civil society in this work. When asked whether dementia awareness campaigns were tailored to specific audiences, only 5 of 37 countries indicated that this was the case. Of the countries reporting (non-mutually exclusive) delivery channels for their public awareness campaigns, most used social media (*n*=32), followed by print media (*n*=32), television (*n*=24), and radio (*n*=23).

Of the 43 GDO countries with dementia plans (i.e. dementia-specific, integrated or subnational plans), 36 countries stated that their plans included actions or objectives to address dementia awareness, stigma reduction and encouragement of dementia-friendly communities. Of those 36, 87% ran a dementia awareness campaign and 96% implemented a DFI, indicating high implementation rates.

An important first step in establishing a successful campaign is to ensure meaningful inclusion of people with dementia and their carers in planning, implementation and evaluation. Including the voice of those with lived experience will ensure that the campaign uses the right language and that messaging is relevant and clear. The use of accurate messaging based on solid data and evidence is fundamental to any campaign. Data collection through the GDO enables countries to set targets and gather key information to monitor progress and impact in the area of dementia awareness.

> **"An important first step in establishing a successful awareness campaign is to ensure meaningful inclusion of people with dementia and their carers in planning, implementation and evaluation."**

BOX 6

Indonesia: Case study by the Association of Southeast Asian Nations (ASEAN)

Indonesia has the fourth largest population in the world at 270 million. It is made up of over 17 000 islands, and 600 cultures call these islands home. Indonesia was the first ASEAN Member State to launch and implement the Dementia National Strategy in 2016, with support from ADI. In 2013, Alzheimer's Indonesia (ALZI), an ADI member, spearheaded awareness of Alzheimer's in Indonesia by conducting a national campaign titled "Do Not Underestimate Memory Loss". An infographic accordion-style brochure about the 10 warning signs of dementia and Alzheimer's disease was created to raise awareness.

In March 2018, ADI's Asia Pacific Regional Director had the opportunity to attend ASEAN's Health Cluster 1 Meeting in Lao People's Democratic Republic (PDR). The meeting was followed up in September 2020 with a consensus to strengthen collaboration between ADI Asia Pacific and ASEAN across all 10 ASEAN countries in key areas from 2021 to 2025 in the promotion of mental health and the promotion of healthy and active ageing.

In 2019, the ASEAN Women's Circle (AWC) invited ALZI's risk reduction specialist to lead a brain gym exercise at an opening session of a meeting attended by all 10 ASEAN Member States at the ASEAN Secretariat in Jakarta. The session led to an invitation to conduct an educational session for ASEAN's staff. It also resulted in the development and translation of an Indonesian version of the 10 warning signs of the Alzheimer accordion brochure which now also exists in a further nine languages for Brunei Darussalam, Cambodia, Lao PDR, Malaysia, Myanmar, Philippines, Thailand, Singapore and Viet Nam. The Alzheimer's Indonesia ASEAN initiative is an example of a joint civil society – government initiative replicated by the local provincial and national government, which will be implemented in other ASEAN Members States.

Impact of dementia awareness campaigns

Public engagement can be measured as visits to a campaign website to see how often materials are downloaded, or by monitoring media (and social media) attention. However, lasting behaviour change takes time and is a longer-term indicator of success. One example of an ongoing dementia awareness campaign that has been scaled up globally is ADI's World Alzheimer's Month that occurs every September. Alzheimer and dementia associations, as well as other groups in more than 90 countries worldwide, take part in the campaign that enables collaborative engagement with governments and people living with dementia and their families, directly contributing to the global target outlined in the Global dementia action plan *(34)*.

Of the 41 GDO countries that reported having a national dementia awareness campaign, six are located in the WHO Region of the Americas. In 2019, the Dominican Republic, as one of the GDO countries, participated in the joint WHO-ADI regional campaign "Let's Talk about Dementia" with the Pan American Health Organization (PAHO) (see page 111).

By working on this campaign, the local Alzheimer association, Asociación Dominican de Alzheimer, developed a collaborative relationship with both PAHO and the Ministry of Health which contributed to the launch of the country's first National Dementia Plan in July 2020.

Measuring the impact of awareness-raising campaigns on changes in attitudes and beliefs about dementia is complex. It is encouraging that two thirds of GDO countries so far are running awareness campaigns. However, little evidence exists to date on the impact of these campaigns in terms of reducing stigma. This was one of the driving forces behind ADI's *World Alzheimer Report 2019* on stigma, and there are plans to follow up with another global survey in five years to measure the effectiveness and impact of national, regional and global dementia awareness campaigns on stigma reduction.

It is important that dementia awareness campaigns are accessible for all people, including people with all forms of disabilities – including physical, psychosocial and intellectual disabilities, as well as sensory impairments (e.g. vision or hearing). For instance, campaigns and information materials should contain clear messaging and should be provided in easy-to-read formats, including in braille or in audio/video format where appropriate.

Dementia-inclusive societies

Fostering inclusive and age- and dementia-friendly environments is an important way to promote respect, acceptance, participation, safety and inclusion of people with dementia in a manner that meets their needs and those of their families and carers. This means ensuring that people with dementia and their carers can participate fully in society and are empowered to live independently and enjoy respect, freedom, dignity, equality, accessibility and quality of life. Making changes to the social and built environment – such as home modifications, opportunities for social, cultural and community participation, and the provision of person-centred health and social care – is key to this process.

Examples from Kenya and South Africa in ADI's *World Alzheimer Report 2020* demonstrate that simple design solutions within the built environment can reduce risk and improve safety. Families are encouraged to make simple changes such as installing grab bars in the shower or bathtub to support independence and safety, constructing ramps to help prevent falls or enable wheelchair access, or installing night-lights in hallways, bedrooms or bathrooms to help orient people living with dementia. Home modifications such as these are cost-effective and can be done easily and quickly, enabling people living with dementia to remain independent longer, to live safely and with dignity in their own homes *(40)*.

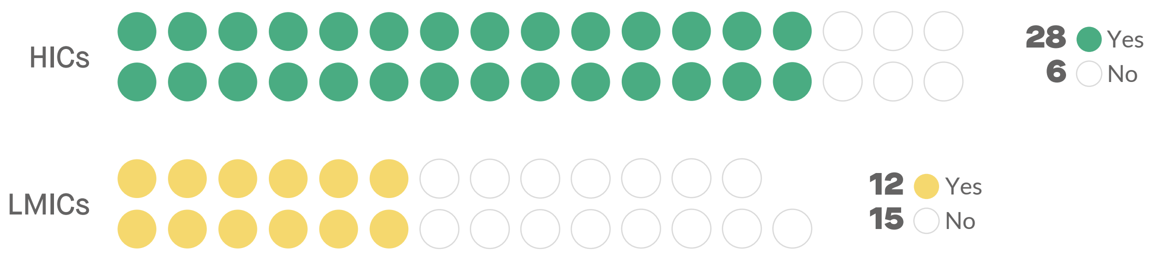
Of the 62 GDO countries, 41 reported that there were initiatives to improve the accessibility of the physical and social environment – including for people with dementia (see **Figure 15**), of which 29% were in LMICs.

2 in 3

GDO countries have initiatives to improve the accessibility of the physical and social environment

FIGURE 15

Number of countries with initiatives to improve accessibility of the physical and social environment



DFIs refer to all activities and actions that promote lasting change to the social and/or physical environment in order to make societies more inclusive of people with dementia, their families and carers. One example of placing people living with dementia at the heart of community development is in Machida City in the suburbs of Tokyo. Once a week, people living with dementia hold a "Living Together with Dementia" meeting at which they discuss their concerns and share knowledge to improve their quality of life. Members of the meeting try to expand opportunities to make meaningful contributions to the local community, such as by giving lectures on dementia in high schools. Importantly, the members have created 16 statements that express a vision for the type of inclusive community in which people living with dementia want to live *(32)*.

GDO data indicate that, of 36 countries that included awareness-raising, stigma reduction and dementia-friendliness in their dementia plan, 90% identified having a DFI and 85% provided training and education on dementia to population groups outside the health and social sector.

BOX 7

Susitikime muziejuje dementia-friendly arts programming in museums in Lithuania

The NGO *Socialiniai meno projektai* (SMP) is a pioneering "arts for health" organization in Lithuania. SMP aims to promote the well-being of various groups of society by making the arts more accessible. Activities based on cross-sectoral partnerships include arts projects (plays, exhibitions, performances and creative experiments), creative arts (participatory) workshop programmes, training and "arts for health" research and publishing.

Since 2014, SMP and a number of partners (museums, social/health-care organizations, Alzheimer's clubs), started implementing a programme called *Susitikime muziejuje* ("Let's meet at the museum"). The programme aims to build access to culture and arts for people living with dementia, their carers and family members, to support their well-being, community and care relationship development. Additionally, by expanding the competencies of educators, the programme aims to increase the availability of museums and galleries to a diversity of audiences who face social difference and the stigmatizing attitude of society in their daily life. *Susitikime muziejuje* includes training for museum staff, museum tours, workshops in residential care settings and the evaluation of the programme's impact on the well-being of people living with dementia, their carers and family members.

According to the results of the evaluation, the programme helped to increase the well-being of the participants. It gave them the opportunity to engage in art activities in a safe, failure-free and friendly environment; it stimulated learning and self-expression in equal participation; it increased participants' self-esteem and helped them to relax; participants learned new things about themselves and each other; participants experienced a range of positive emotions which enhanced their mood; and there was an increased a sense of community and improved communication.

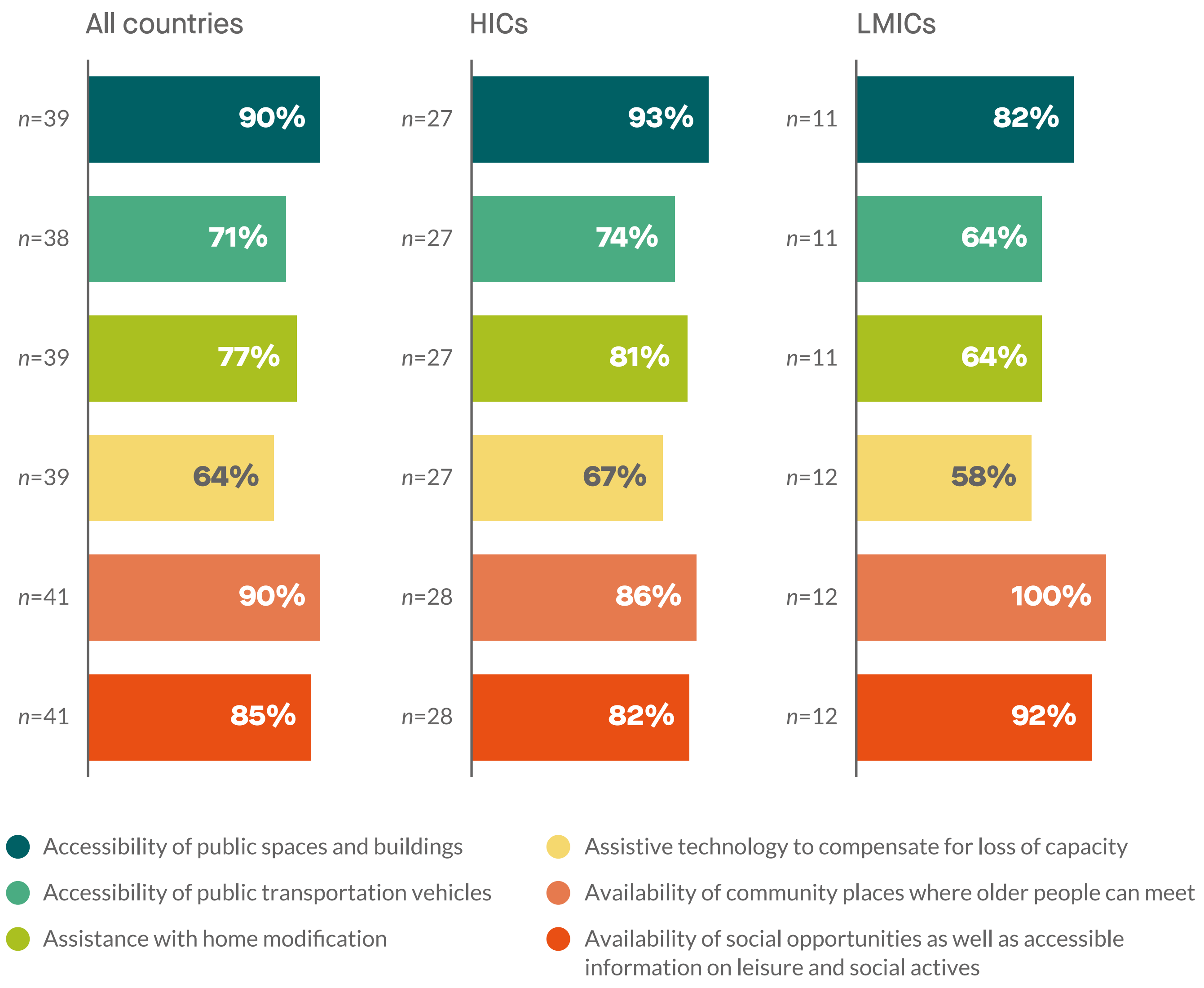
Susitikime muziejuje contributes to the research in dementia care and extends the evidence that cultural interests can play an active role in developing cross-sectoral partnerships and a person-centred approach to dementia care.

Picture on page 115 "Susitikime muziejuje at The National Art Gallery in Vilnius" accredited to: "Socialiniai meno projektai". Photograph by Eglė Gudonytė.

The GDO measures the different dimensions covered by countries' DFIs. **Figure 16** shows the DFI dimensions reported by countries globally and by World Bank income classification. Of the 41 countries that reported having DFIs, most countries addressed accessibility of public spaces and buildings (90%) and creating community places where older people can meet (90%), followed by offering social opportunities and accessible information on leisure and social activities (85%). GDO responses further suggest that, in both LMICs and HICs, DFIs focus the least on assistive technology.

FIGURE 16

Types of DFI dimensions covered by countries (% of countries)



*n reflects the number of countries that replied to the respective indicator.
Bars show the percentage of 'n' where services are available.
Note: LMICs = Low- and middle-income countries; HICs = High-income countries.

Success factors of DFIs

The key to success in any DFI is ensuring that people with dementia and their carers play a central role at all stages of planning, implementation and evaluation. In order to succeed, DFIs need to work across communities. They need to ensure social inclusion, encourage organizations to be responsive to the needs of people living with dementia, and work in partnership with all levels of government and civil society.

Building dementia capacity in the population

The Global dementia action plan recommends the development of programmes to encourage dementia-friendly attitudes in the community, the private sector and among the public, informed by experiences of people with dementia. Such programmes should include evidence-based and culturally appropriate training tailored to specific settings and population groups. As part of the GDO, countries are asked to identify whether groups outside the health and social sector receive training and education on dementia. The purpose of the training is to increase awareness of dementia and enable populations to assist people who are living with dementia. Of the 62 GDO countries, 66% indicated that they provide training and education on dementia to populations outside the health and social care sector (**Figure 17**), of which 29% are LMICs.

66%

of GDO countries provide training and education on dementia to populations outside the health and social care sectors

BOX 8

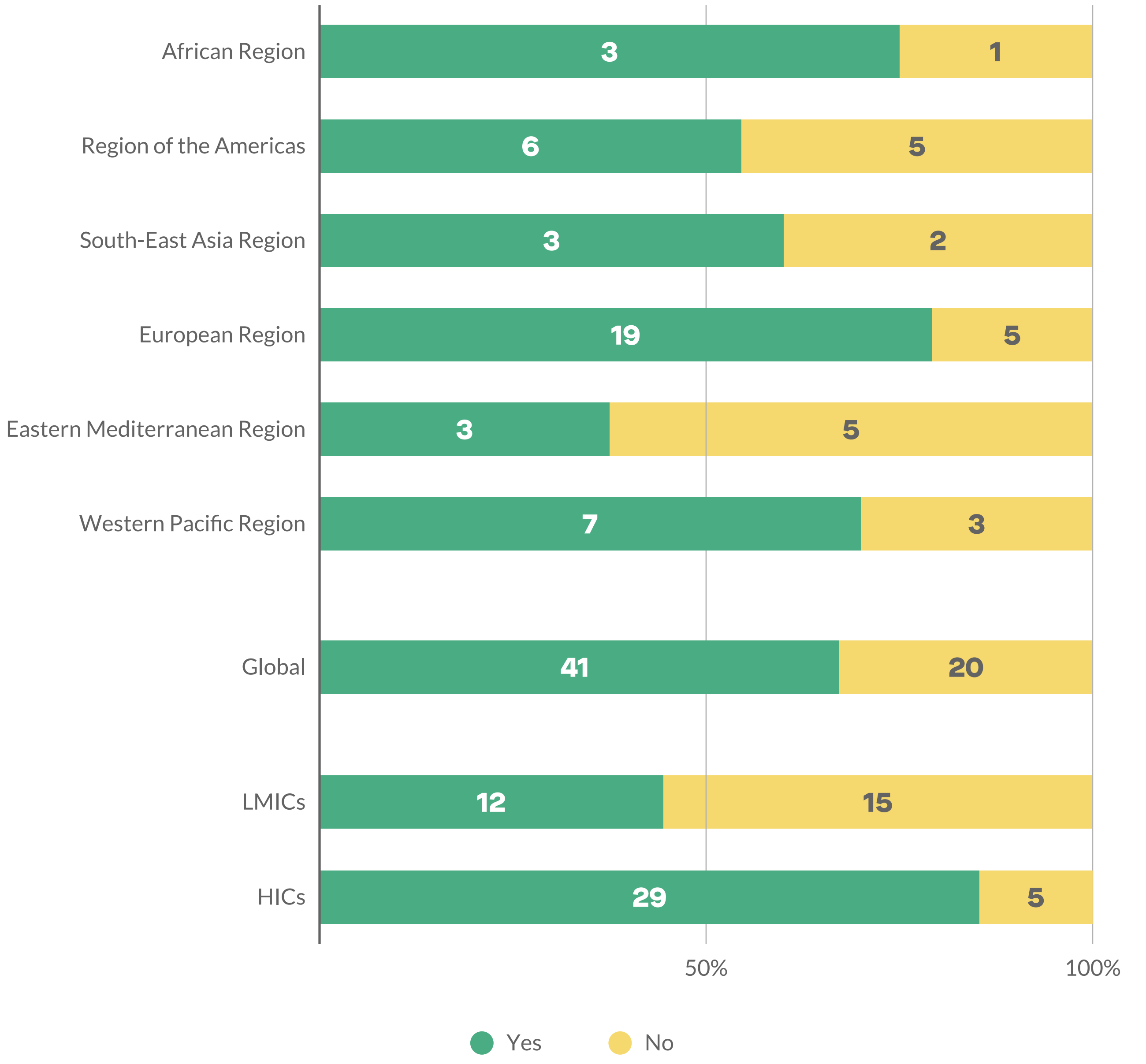
Dementia friendliness and awareness in Poland

Dementia friendliness and awareness are topics that are gradually gaining ground in Poland. Although there is still much to be done, it is possible to point to many initiatives that can be treated as potentially valuable in the hope that the coming years will bring progress in creating favourable environments for people living with dementia and those supporting them. For this reason, it is important to recognize every initiative – even grassroots efforts such as local support groups, Alzheimer's cafés, workshops, online forums etc.

All these initiatives exist in Poland but they are usually isolated local efforts that are often run by activists – usually people who are directly or indirectly affected by the suboptimal way in which dementia care is organized nationally. Their persistence and determination constitute a potent and vital foundation which, with top–down institutional support, could develop into nationwide programmes for coherent care and support. An important factor empowering and facilitating the dissemination of information about such activities are the contributions of researchers. One example is the establishment of Meeting Centres operating within the European MeetingDem network and spearheaded by the research team from Wroclaw Medical University. Although these are not large-scale activities and their availability is limited, even small and gradual changes in local, community-based dementia care significantly improve lives. The best hope for integrating these good practices throughout Poland is the introduction of a national dementia strategy that has already been developed but has not yet been authorized or implemented. Moreover, as friendliness stems from understanding, the everyday reality of people and their families living with dementia should be made public in order to stimulate reflection and spark empathy. Making dementia care a common cause and taming stigma may be building blocks to create an environment that is open to dementia-related issues on many levels – social, organizational, architectural – as well as to research and policy-making.

FIGURE 17

Number of countries providing training and education on dementia to populations outside the health and social sector



Note: LMICs = Low- and middle-income countries; HICs = High-income countries.

There are many examples of successful training initiatives from around the world. They are primarily run by civil society and contribute to raising awareness and understanding of dementia and promoting dementia inclusiveness globally (see **Box 9** for examples).

BOX 9

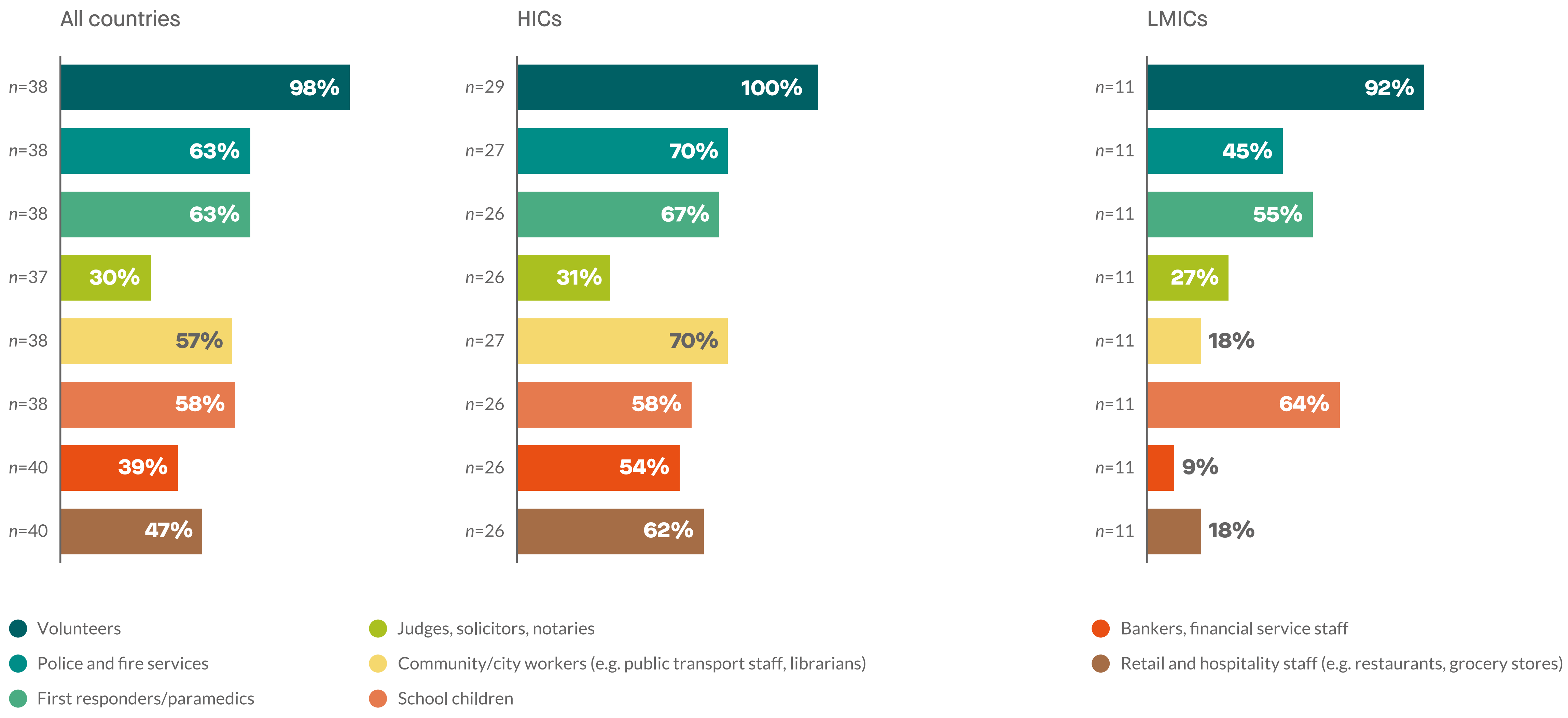
Promoting a dementia-inclusive world – examples from three countries

- Initially launched by Alzheimer's Society UK, the **Dementia Friends** programme aims to transform the way people think, act and talk about dementia. There are currently 67 Dementia Friends programmes launched or in development in 56 countries, with nearly 19 million Dementia Friends worldwide. One study at Bemidji State University in Minnesota, USA, examined whether Dementia Friends could affect attitudes toward people with dementia. The study used the Dementia Attitudes Scale to measure participants' attitudes before and after participating in a one-hour Dementia Friends session. Of the 80 people who participated, overall scores showed a statistically significant improvement in attitudes toward dementia after taking part in training. Participants also reported a statistically significant increase in dementia knowledge as well as a statistically significant increase in social comfort around people with dementia *(9)*.
- In Bangalore, India, the local branch of the Alzheimer's & Related Disorders Society of India (ARDSI) partnered with Nightingale's Medical Trust, a local service provider, to drive forward several DFIs. In September 2019, ARDSI started a pilot programme called "Creating a Dementia-Friendly Generation" to increase awareness. On the first day, they signed up nearly 1500 persons with the aim of increasing that to 10 000 new dementia friends in the first year. Another initiative was the Bengaluru race, in which 600 participants engaged in an innovative treasure hunt that was created to reduce stigma and increase awareness across the city as people participated *(10)*.
- Finally, Alzheimer's New Zealand has developed a "Dementia-friendly recognition programme" to help expand the number of dementia-friendly businesses. An important component of the programme is a toolkit that enables private companies to "self-evaluate" their practices in order to gauge their own level of dementia awareness. The programme then helps the company to establish a more dementia-friendly model *(11)*.

Figure 18 shows population groups that received training and education on dementia by countries globally and by World Bank income classification. Of the countries that reported on this sub-indicator, most countries trained volunteers (98%), followed by police and fire services (63%), and first responders/paramedics (63%). GDO data further suggest that HICs and LMICs put the least emphasis on training of judges, solicitors and notaries (30%) and bankers and financial service staff (39%).

FIGURE 18

Populations outside the health and social sector who receive training and education on dementia (% of countries)



*n reflects the number of countries that replied to the respective indicator.
Bars show the percentage of 'n' where training is provided.
Note: LMICs = Low- and middle-income countries; HICs = High-income countries.

Volunteers were the most common population group to receive training, with 92% trained in LMICs and 100% in HICs. Significant differences can be seen for training of community and city workers. While 70% of HICs report training this population group, only 18% of LIMCs do so. Similarly, while 62% of HICs provide training to hospitality staff, only 18% of LMICs reported doing so.

BOX 10

Awareness raising efforts and innovative responses to the COVID-19 pandemic by civil society partners

Response type	Country/civil society examples
Information/ guidelines	Alzheimer's Indonesia (ALZI) developed an infographic on COVID-19 key messages for people with dementia, older adults and family carers which was translated into English by HelpAge International Asia Pacific Region and has been disseminated in Indonesia and in the Asia Pacific Region.
Awareness-raising	Iran Dementia & Alzheimer's Association (IDAA) translated information and key messaging from ADI and WHO into Farsi, producing videos on COVID-19, and posting on their website, Instagram and the Telegram channel.
	Madagascar Alzheimer ran short radio programmes twice weekly providing tips and advice around COVID-19 for older persons, especially those living with dementia and their carers.
	The Alzheimer Society of Ireland engaged in an extensive advocacy programme highlighting concerns about the impact of COVID-19 on people living with dementia and their family carer.
Practical tips	The US Alzheimer's Association developed Tips for Dementia Caregivers at Home to support carers to help people with dementia remember important hygiene practices.
	Regional Alzheimer's societies in Germany developed materials (e.g. documents, podcasts and videos) to support people living with dementia and their family carers during the pandemic.
Virtual support	Alzheimer Indonesia (ALZI) produced a "dementia care tips and tricks" video and provided music therapy, Poco-Poco traditional dancing, yoga and brain gym exercise sessions online as well as online webinars to support people with dementia and their carers. Families were supported with educational sessions, online counselling and talk shows.
	The Alzheimer Society in the United Kingdom provided "Singing for the Brain" sessions online.
	Dementia Alliance International (DAI) provided peer-to-peer support for people living with dementia.
	Fundación Alzheimer de Venezuela provided online carers' groups and personal zoom calls to people living with dementia.
	Alzheimer's and Related Disorders Society of India (ARDSI) provided support to carers via telephone, video-conferencing and social media platforms.

The way forward

There is an ongoing need to raise public awareness and improve the understanding of dementia by engaging communities and helping them assume ownership of this endeavour. This is the first step in combating stigma. Well-resourced public awareness campaigns – implemented in partnership with civil society, people with dementia, their carers and other relevant stakeholders – represent an important actionable step towards achieving the targets outlined in this chapter.

There may also be strategic opportunities to integrate dementia into existing awareness-raising campaigns such as those for NCDs, ageing, neurological disorders or disability. These actions are aligned with the 2019 G20 Health Ministers' Declaration *(31)*, which committed to promoting "age-friendly and dementia-inclusive environments by raising awareness to enable better understanding of dementia and prevent and overcome stigma" and empowering "families and carers to support persons with dementia".

Achieving the global targets for dementia awareness and friendliness also involves creating strategic links to existing commitments – such as the *Decade of Healthy Ageing 2021–2030* – in order to integrate dementia into existing initiatives – such as through WHO's Global Network for Age-friendly Cities and Communities – and build community-level capacity on dementia. Additionally, combating ageism may be key to improving care and support for older persons with dementia. In March 2021 WHO issued a global report on agism *(41)*.

Figure 19 outlines the actions included in the Global dementia action plan, key barriers to implementing these actions, and strategies to overcome the barriers through accelerators for action.

> **"Combating ageism may be key to improving care and support for older persons with dementia."**

FIGURE 19

Proposed actions for Member States, identified barriers and opportunity to accelerate actions

PROPOSED ACTIONS

- Implement public awareness campaignS
- Foster dementia-friendly environments
- Provide dementia training to non-health and social care professionals/sections of the population

BARRIERS

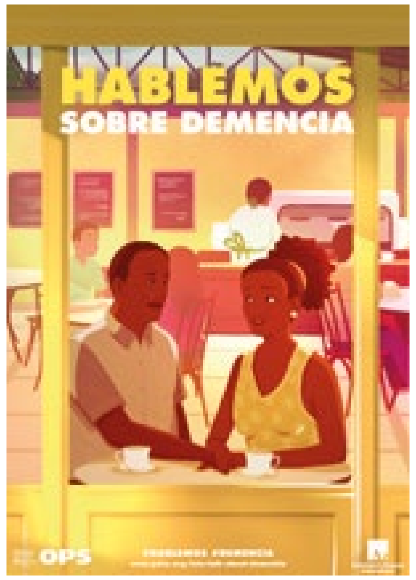
- Lack of guidance, awareness and knowledge
- Stigma and misconceptions
- Reliance on NGOs to run campaigns/initiatives

OPPORTUNITIES TO ACCELERATE ACTION

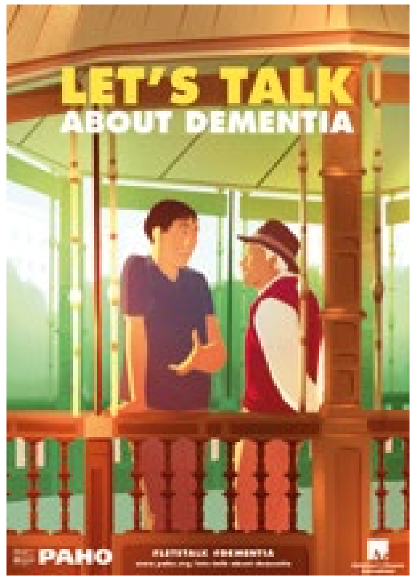
- Partner with civil society, WHO and other relevant stakeholders to implement, replicate and/or scale up regional awareness-raising campaigns such as the joint ADI/PAHO *Let's Talk Dementia* campaign.
- Leverage strategic commitments such as the Decade of Healthy Ageing 2021–2030 to integrate dementia into existing initiatives such as WHO's Global Network for Age-friendly Cities and Communities.
- Implement WHO's *Towards a dementia-inclusive society: WHO toolkit for dementia-friendly initiatives* to train and build capacity of non-health and social care professionals on dementia.

Learning from experience: ADI/PAHO "Let's Talk About Dementia" campaign

Regional awareness-raising campaigns implemented in partnership with civil society, WHO and other stakeholders have the potential to increase the understanding of dementia significantly and to reduce stigma. One example is the regional PAHO "Let's Talk About Dementia" campaign which started in September 2019 and ran alongside the global World Alzheimer's Month campaign in partnership with ADI. Although each campaign had the same theme, the PAHO campaign had a unique design that was tailored to be regionally and culturally relevant. The PAHO campaign was implemented as part of *PAHO's Regional Strategy and Plan of Action on Dementias in Older Persons (2015–2019)*, which aimed to promote UHC and access to quality interventions for people with, or at risk of, dementia. The campaign sought to de-mystify dementia through conversation and contribute to better planning and support for people living with dementia and their carers.



Campaign materials, including posters and social media cards, were made available in Dutch, English, French, Portuguese and Spanish. They not only highlighted the importance of talking about dementia, but also explained its warning signs and ways to reduce risk factors for the disease. Social media (particularly via Facebook, Twitter and Instagram) was the main tool used by PAHO country offices to implement the campaign. Campaign data show that the 237 social media posts disseminated through the campaign reached almost 800 000 people in the Region. PAHO´s website hosted the campaign pages as well as a press release announcing it. Overall, the campaign webpages registered nearly 30 000 visits. Additionally, it received press coverage across the Region.



The campaign brought increasing awareness about the need to better understand dementia and how discussions could improve care for older adults in the Americas. There were multiple requests to adapt the materials to country contexts and, as a result, the campaign was extended from the initial month of September to include October and November too. Additionally, the campaign enhanced multisectoral collaboration between civil society, ministries of health and PAHO country offices – a model that can be recreated in other regional contexts.

Given the long period required to monitor behavioural and attitudinal change, it will take years to realize the full impact of the campaign. However, a promising example mentioned earlier in this report is provided by the Dominican Republic, where multisectoral collaboration was particularly successful and accelerated the launch of the country's national dementia plan in July 2020.

Leveraging existing global commitments: the Decade of Healthy Ageing 2021–2030 & WHO's Global Network for Age-friendly Cities and Communities

In August 2020, the Seventy-third World Health Assembly endorsed the UN Decade of Healthy Ageing 2021–2030. The Decade represents an opportunity over the next ten years to bring together partners – including governments, civil society, international agencies, academic institutions, health and social care professionals and the private sector – to improve the lives of older people, including persons with dementia, their families and communities. As demographics rapidly change, a decade of concerted global action on healthy ageing is needed. To date, there are more than 1 billion people aged 60 years or older, most of them living in LMICs *(42)*. Many do not have access to basic resources and face multiple barriers that fail to respect their dignity and prevent their full participation in society.

The Decade of Healthy Ageing refers to healthy ageing as the process of developing and maintaining the functional ability that enables well-being in older age *(12)*. The Decade of Healthy Ageing shares similar principles to those of the Global dementia action plan, including a focus on inclusion, equity, multistakeholder partnerships and sustained global action. The focus is on changing how people think, feel and act towards age and ageing, and ensuring that communities foster the abilities of older people, which are particularly relevant to dementia awareness and friendliness. This includes conducting campaigns to increase public knowledge and understanding of healthy ageing, taking action against ageism, stigma and discrimination, and developing programmes on age-friendly cities and communities *(12)*.

Established in 2010, WHO's Global Network for Age-friendly Cities and Communities is particularly relevant. The network supports cities' efforts to become more age-friendly by improving their responses to the needs of ageing populations and involving older people in urban planning *(43)*. The network promotes the exchange of experience and mutual learning between cities and communities worldwide that are committed to promoting healthy and active ageing. Age-friendly environments share many goals that are similar to those envisioned by dementia-inclusive societies and DFIs. These include: 1) the creation of environments that are free from physical and social barriers; and 2) the promotion of health, physical and mental capacity, and independent living. Both also aim to empower older people and those with dementia to make decisions and participate in society. The Decade of Health Ageing 2020–2030 and the Global Network for Age-friendly Cities and Communities represent opportunities to leverage important international commitments to achieve impact at national and local levels.

Implementing existing tools to build capacity on dementia. Towards a dementia inclusive-society: WHO toolkit for dementia-friendly initiatives

Tools such as *Towards a dementia-inclusive society: WHO toolkit for DFIs* provide actionable means of fostering dementia-friendly environments and building an understanding of dementia at community level, both among the general population and among non-health and social care professionals.

The toolkit supports individuals, communities and countries in empowering people with dementia to remain in their community and be a significant part of it. Through a person-centered, rights-based approach, it is grounded in international commitments such as the CRPD, the 2030 Agenda for Sustainable Development and its SDGs and UHC.

The toolkit supports persons working in communities with little or no experience in programme planning, implementation, management and/or evaluation, nor of creating a dementia-inclusive society. The toolkit has two parts. The first part contains introductory information on dementia and a conceptual framework, while the second part includes four modules, each featuring a series of practical steps and exercises. The modules focus on: 1) starting a new DFI; 2) integrating dementia into an existing initiative; 3) monitoring and evaluating a DFI; and 4) scaling up a DFI. The modules can be used together or separately and can be adapted to suit local needs and settings.

BOX 11

Inclusion begins at home: supporting dementia-inclusive communities through strategic communication

To support the implementation of the Global dementia action plan, WHO's Western Pacific Region launched a strategic communication tool developed for community leaders and organizers, programme managers, mental health advocates, and specialists in health promotion, education and communication. The toolkit contains essential information about dementia, case studies of similar initiatives, and a full range of multimedia materials that are applicable across different communication channels. The toolkit also gives guidance on organizing various activities that are designed to:

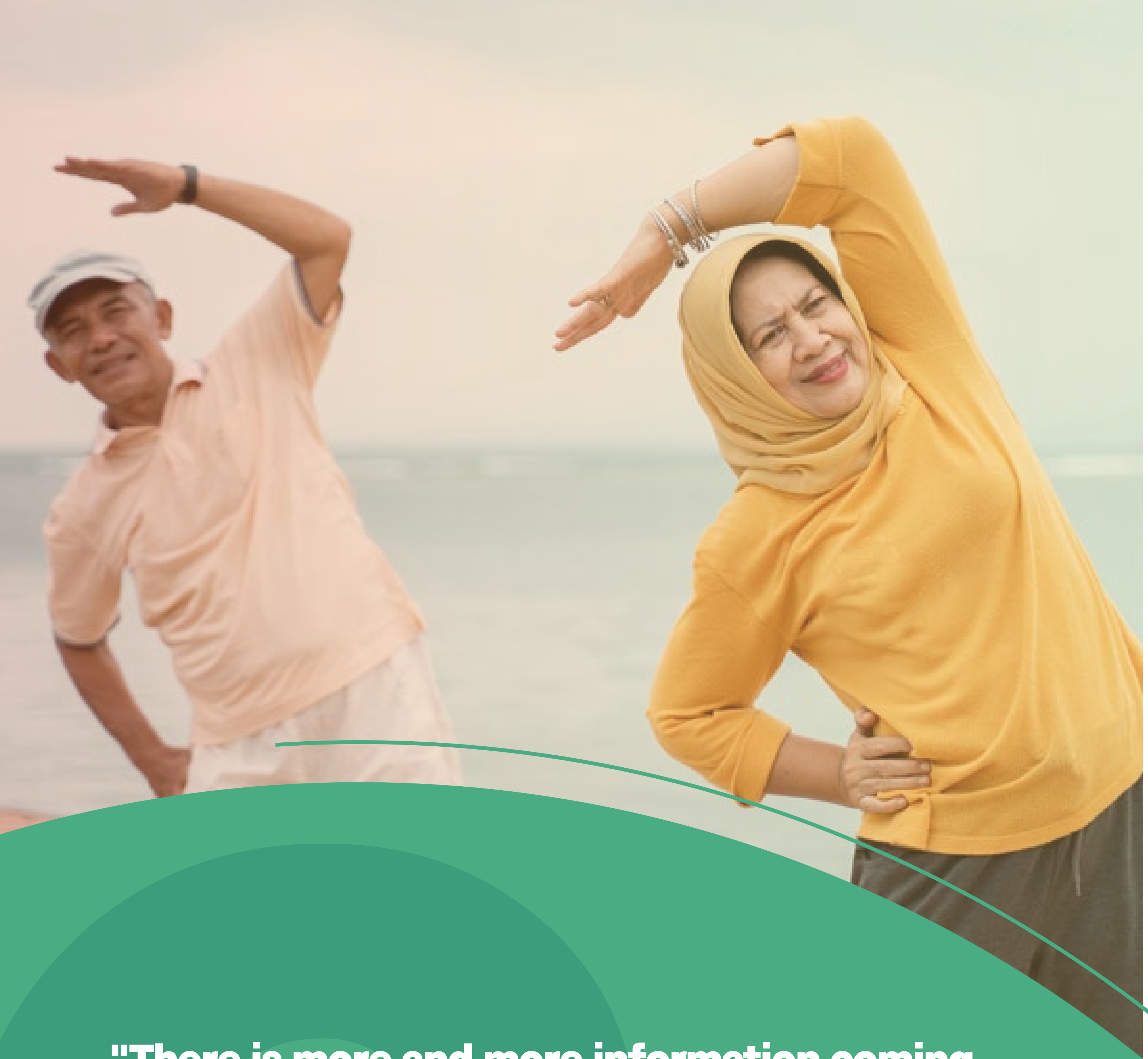
- ✓ Improve the accuracy of the general public's knowledge about dementia;
- ✓ Reduce stigma;
- ✓ Dispel myths and misconceptions;
- ✓ Promote early diagnosis; and
- ✓ Emphasize the need for appropriate services for people living with dementia.

The centrepiece of the toolkit is a strategic communication framework to help communities to L.I.V.E. (learn, identify, value, empower) with dementia. A monitoring and evaluation framework is also provided to facilitate proper planning and implementation.

The tool was launched online during World Alzheimer's Month in September 2020, to be followed by its progressive implementation through government and development partners across the Western Pacific Region over subsequent months.

Concluding remarks

While progress is being made in establishing dementia awareness campaigns and DFIs, more concerted action is required, particularly in LMICs where the majority of people with dementia live. Guidance on how to implement, evaluate and scale up these activities is also needed. In many countries, stigma and discrimination against people with dementia, as well as their families and carers, remain high. However, much can be done to enhance public understanding and knowledge of dementia at all levels of the general population. Efforts are needed to ensure that the key principles included in the CRPD are implemented at national level by fostering dementia-inclusive societies as well as implementing, evaluating and scaling up DFIs.



"There is more and more information coming out, telling us what to do to reduce our risk of dementia. But many people feel that dementia won't happen to them. Risk reduction should start in primary school, geared to their level of understanding as they move up, and this will also benefit their general health."

James McKillop,
United Kingdom

6. Dementia risk reduction

Context

Up to 40%
of dementia cases can potentially be prevented

While age is the strongest known risk factor for cognitive decline, dementia is not an inevitable consequence of ageing. A growing evidence base demonstrates that there are clear risk and protective factors that affect the cognitive health of adults. Potentially modifiable risk factors include physical inactivity, unhealthy diets, tobacco use and the harmful use of alcohol. Protective factors include access to formal education, employment and other opportunities for cognitive stimulation, physical activity and social connection. Moreover, a number of NCDs are also associated with the risk of cognitive impairment and dementia – including depression, hypertension, diabetes, hearing impairments and mid-life hypercholesterolemia and obesity. Additionally, environmental risk factors such as exposure to ambient and indoor air pollution and the impact of traumatic brain injuries are increasingly being recognized. All these factors together account for up to 40% of dementia risk, as detailed by the 2020 Lancet commission on dementia prevention, intervention and care *(44)*.[3] Importantly, these risk factors may cluster together across the life course especially in marginalized populations, thus increasing the risk at earlier ages and for whole communities.

---

[3] Alzheimer's Disease International developed an infographic highlighting the 12 modifiable risk factors for dementia detailed in the 2020 Lancet Commission on dementia prevention, intervention and care, which included the following: physical inactivity, smoking, alcohol consumption, air pollution, head injuries, infrequent social contact, less education, obesity, hypertension, diabetes, depression, and hearing impairment. See: https://www.alzint.org/resource/dementia-risk-factors-infographic/ (accessed 6 July 2021).

The COVID-19 pandemic has heightened risk factors for dementia globally and continues to do so. In addition to concerns about the long-term sequelae and impacts of SARS-CoV-2 infection on the central nervous system, the broader consequences of the pandemic – including disruption of essential health services, access to emergency services, routine care and supply chains for medications – have prevented the diagnosis and management of numerous NCDs known to be risk factors for dementia. See **Box 12** for more information. Moreover, public health measures designed to control the pandemic, such as repeated lockdowns, have led to increased social isolation in countless older adults which in turn accounts for 4% of dementia-attributable risk *(44)*.

BOX 12

Disruption of essential health services due to COVID-19 pandemic (WHO Pulse surveys)

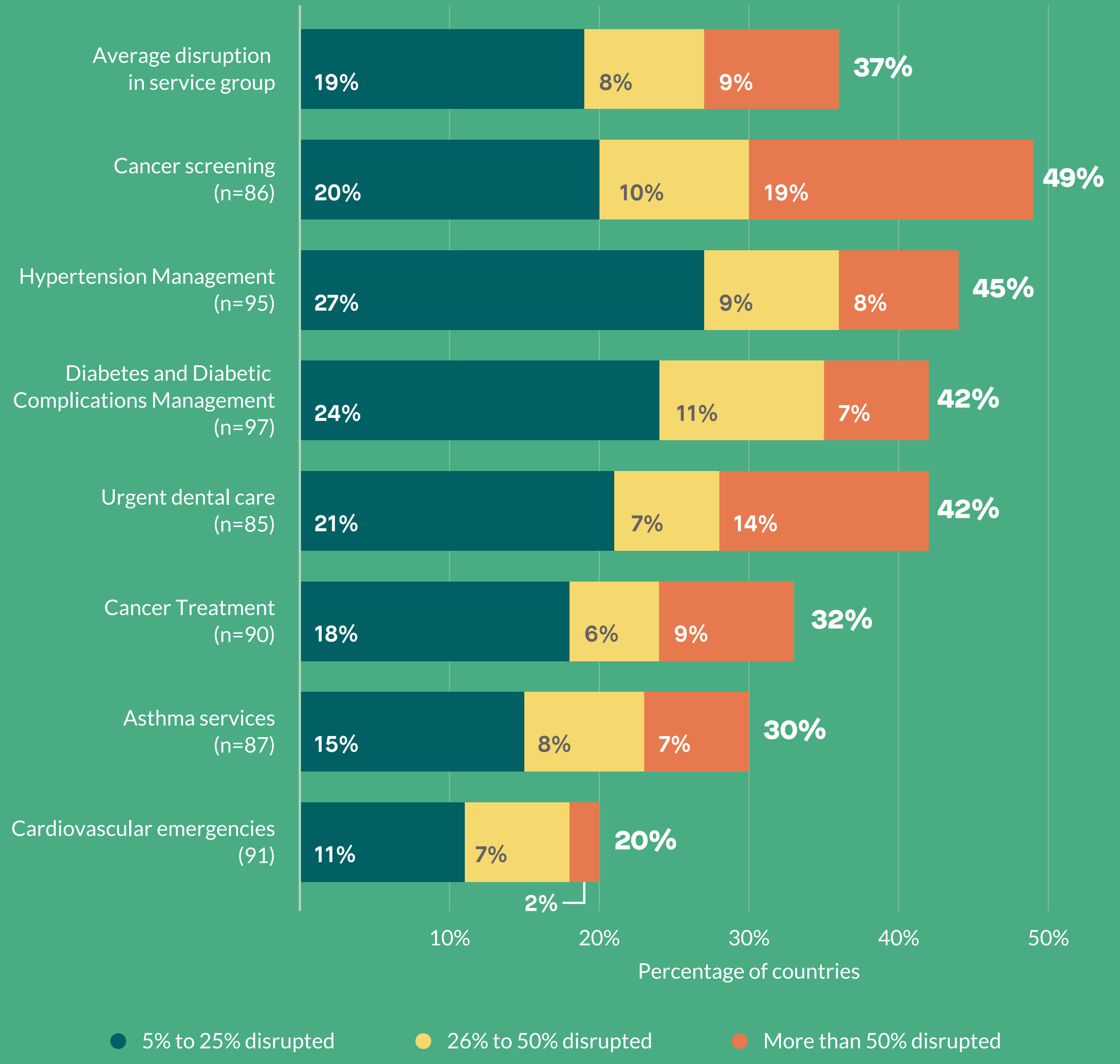
WHO's Pulse survey on the continuity of essential health services during the COVID-19 pandemic, released in August 2020, revealed that 48% of 105 countries surveyed reported at least partial disruptions in all services for NCDs and mental health (7). Further, 69% of countries reported disruptions in services for diagnosis and treatment of NCDs, with 5% of countries reporting severe disruptions.

As a complement to the Pulse survey, WHO also carried out a rapid assessment specifically focused on NCD resources and services in the context of COVID-19 in May 2020. This survey found that both human and financial resources were by necessity being reallocated away from NCDs during this time. In the majority of countries surveyed (94% of 163), all or some NCD focal points within ministries of health were focusing on COVID-19 efforts either full-time or alongside routine NCD activities, and 20% of countries reported that public funds previously allotted to NCDs were shifted to non-NCD services. Over one third (37%) of countries reported suspension of mass communication campaigns related to NCDs. Over half (53%) of countries reported disruptions to hypertension management services, and close to half (49%) reported disruptions to diabetes and diabetic complication management services. Close to one third of countries reported disruptions to services for cardiovascular emergencies (31%), with differences across income brackets, with 50% and 17% of LICs and HICs, respectively, reporting these disruptions.

WHO's second Pulse survey on the continuity of essential health services during the COVID-19 pandemic, released in April 2021, demonstrated some improvements over 2020 but noted persistent disruptions to NCD services (45). Roughly half of countries surveyed reported disruptions to one or more essential NCD services, with 45% reporting disruptions to hypertension management, 42% reporting disruptions to diabetes management and 20% reporting disruptions to services for cardiovascular emergencies (see **Figure 20**).

FIGURE 20

Prevalence of countries reporting disruptions in NCD services



A public health approach to dementia risk reduction is needed now more than ever and requires an interdisciplinary, cross-sectoral perspective across the life course, as outlined in the Global dementia action plan. Studies have shown that risk factors are cumulative in their impact on the risk of dementia. There is increasing support for addressing more than one risk factor simultaneously to obtain the best outcomes. Importantly, reducing dementia risk factors necessitates addressing socioeconomic inequalities across the life course and improving the environments in which people live. Evidence-based, effective interventions and strategies for dementia risk reduction are required, especially in LMICs, and should be appropriately designed for vulnerable populations (see **Box 13**).

> **"Reducing dementia risk requires addressing socioeconomic inequalities across the life course and improving environments in which people live."**

Reducing the risk of dementia globally supports WHO's Triple Billion targets, and specifically the target of one billion more people enjoying better health and well-being, as well as SDG target 3.4 on reducing mortality from NCDs and promoting mental health. A global commitment to address the risk factors of dementia is also reflected in the Okayama Declaration of the G20 Health Ministers in October 2019 *(31)*. Relevant WHO and UN initiatives to support this endeavour are summarized in Annex 2.

To reflect the inherent links between dementia and other NCDs, the Global dementia action plan links the attainment of Global target 3 to the targets defined in the Global action plan for prevention and control of NCDs 2013–2020. After all, addressing NCDs will ultimately help reduce the risk of dementia.

This chapter provides an overview of global progress made to date in achieving the global target and recommended risk reduction actions of the Global dementia action plan. It begins by assessing country-driven progress based on data collected through WHO's Global Coordination Mechanism (GCM) on the Prevention and Control of NCDs and WHO's GDO, and identifies barriers to achieving further progress. The chapter additionally outlines opportunities to accelerate action and presents country case studies in the area of dementia risk reduction.

BOX 13

Boosting dementia risk reduction evidence in low- and middle-income countries (LMIC)

The International Research Network on Dementia Prevention (IRNDP) was established in 2017 with support from the Australian Dementia Centre for Research Collaboration. It has a mission to "link researchers globally to foster new research and accelerate knowledge translation that will delay or prevent dementia worldwide".

IRNDP's vision is for "global delay and prevention of dementia". The IRNDP aims to increase dementia risk reduction messaging worldwide, and to develop targeted research to answer questions about the impact of known and emerging risk factors in dementia.

This has particular relevance in LMICs because the exposure to lifestyle and clinical risk factors is becoming more common as LMIC economies grow. This is the only collaborative network of researchers to focus global attention on prevention and on LMICs.

The IRNDP has facilitated the open access publication of articles on dementia risk reduction and has supported international webinars, an early career group and a conference focusing solely on dementia prevention.

Australian researchers have also developed a risk index for Alzheimer's disease that is freely available online[4] and can be completed by self-report. It was designed to be accessible to the general public and has been shown to be effective in assessing risk in cohorts from LMICs.

For more information, see:

- ✓ Anstey KJ, Peters R. Dementia, risk, risk reduction, and translation into practice: An International Research Network for Dementia Prevention (IRNDP) Special Issue. J Alzheimers Dis. 2019;70(s1): S1–3. doi.org/10.3233/JAD-190506.

- ✓ Stephan BCM, Pakpahan E, Siervo M, Licher S, Muniz-Terrera G, Mohan D et al. Prediction of dementia risk in low-income and middle-income countries (the 10/66 Study): an independent external validation of existing models. Lancet Glob Health. 2020;8(4):e524–35.

---

[4] Available here: https://anuadri.anu.edu.au/take-the-assessment.html?view=adri (accessed 21 July 2021)

Progress to date

The Global dementia action plan recommends countries to link dementia with other programmes, policies and campaigns on NCD risk reduction and health promotion across relevant sectors, as well as developing and delivering evidence-based risk reduction training to health professionals. International, regional and national partners can support these recommendations by promoting population health strategies to foster a socially active lifestyle that is physically and mentally healthy for all, taking specific actions to reduce the risk of dementia (particularly during mid-life) and supporting national efforts for the prevention and control of NCDs in general and dementia in particular.

As WHO data show, these recommendations still stand and require urgent action. The Global Coordinating Mechanism on the Prevention and Control of NCDs monitors NCD-related indicators, including the number of countries which have set voluntary NCD targets, as well as proxy outcome indicators which contribute to the eventual reduction of dementia incidence in the long term. Additionally, the GDO provides insights into the number of countries that include dementia risk reduction in their national health or national dementia plans, countries that have guidelines for dementia risk reduction, and the number of countries that have carried out dementia risk campaigns.

> **"It is crucial to link dementia with programmes, policies and campaigns on NCD risk reduction and health promotion."**

Global progress on NCD indicators

The Global dementia action plan identified indicators from the Global action plan for the prevention and control of NCDs 2013–2020 that reflect the link between NCDs and dementia risk reduction. These are:

- ✓ a 25% relative reduction in overall mortality from cardiovascular diseases, cancer, diabetes or chronic respiratory diseases;
- ✓ a 30% relative reduction in prevalence of current tobacco use in persons aged 15 years or older;
- ✓ at least a 10% relative reduction in the harmful use of alcohol, as appropriate, within the national context;
- ✓ a 25% relative reduction in the prevalence of raised blood pressure or contain the prevalence of raised blood pressure according to national circumstances;
- ✓ a 10% relative reduction in prevalence of insufficient physical activity;
- ✓ a halt in the rise in diabetes and obesity.

WHO reports on the progress of NCD risk reduction at regular intervals. **Table 14**, which is derived from a report to the Seventy-second World Health Assembly in 2019, presents data from 2010 to 2016 *(46)*. There has been incremental improvement in overall mortality from cardiovascular diseases, cancer, diabetes and chronic respiratory diseases (4% reduction globally). Additionally, there has been a roughly 2% decrease in both tobacco smoking and heavy episodic drinking amongst people 15 years of age or older, and a 1% reduction in the age-standardized prevalence of high blood pressure. While these changes are encouraging, they fail to meet global targets. Additionally, the levels of physical inactivity in adults remain unchanged and the rates of overweight and obesity in adults 18 years or older has increased by 3%. See **Table 14** for more information.

Overall, these figures suggest that urgent action is required, to both advance prevention and control of NCDs, as well as to see concurrent benefits for dementia risk reduction. As mentioned above, unfortunately widespread disruption of essential health services due to the COVID-19 pandemic has negatively impacted the prevention and management of NCDs (see **Box 12**).

TABLE 14

Progress towards the targets of the Global action plan for the prevention and control of noncommunicable diseases 2013–2020

Target for 2025	Indicator	2010	2014	2016
A 25% relative reduction in the overall mortality from cardiovascular diseases, cancer, diabetes, or chronic respiratory diseases	Unconditional probability of dying between ages of 30 and 70 years from cardiovascular diseases, cancer, diabetes or chronic respiratory diseases	22%	19%	18%
At least 10% relative reduction in the harmful use of alcohol	Total alcohol per capita (aged ≥15 years old) consumption within a calendar year in litres of pure alcohol	6.4 litres	No data	6.4 litres
	Age-standardized prevalence of heavy episodic drinking:			
	• among adolescents (15–19 years old)	15.6%	No data	13.6%
	• among adults (≥15 years old)	20.6%		18.5%
	Age-standardized prevalence of alcohol use disorders (as a percentage of population ≥15 years old)	5.1%	No data	5.1%
A 10% relative reduction in prevalence of insufficient physical activity	Prevalence of insufficiently physically active adolescents	82%	81%	81%
	Age-standardized prevalence of insufficiently physically active persons aged ≥18 years	28%	28%	28%
A 30% relative reduction in prevalence of current tobacco use in persons aged ≥15 years	Prevalence of cigarette smoking in 13–15-year-olds	No data	No data	6.8% (2017)
	Age-standardized prevalence of tobacco smoking among adults aged ≥15 years	22.1%	20.6%	19.9%
A 25% relative reduction in the prevalence of raised blood pressure or contain the prevalence of raised blood pressure	Age-standardized prevalence of raised blood pressure among persons aged ≥18 years and mean systolic blood pressure	23%	22%	22% (2015)
Halt the rise in diabetes and obesity	Age-standardized prevalence of raised blood glucose/diabetes among persons aged ≥18 years	7.9%	8.5%	No data
	Prevalence of overweight and obesity in adolescents	14%	16%	17%
	Age-standardized prevalence of overweight and obesity in persons aged ≥18 years	36%	38%	39%

Risk reduction in dementia or other health plans

A critical first step towards prioritizing dementia risk reduction nationally is to include it within dementia plans or other health plans. According to GDO data, out of 62 countries, 35 countries (56%) reported having dementia risk reduction included in their dementia plan or other health plans.

Of these 35 countries, over 70% are HICs (see **Figure 21 and Table 15**). There are also regional differences, with a higher percentage of reporting countries in the WHO European and Western Pacific regions covering risk reduction in their policies compared with countries in other regions (see **Table 15**).

FIGURE 21

Countries with dementia risk reduction in their dementia or health plans by World Bank income level

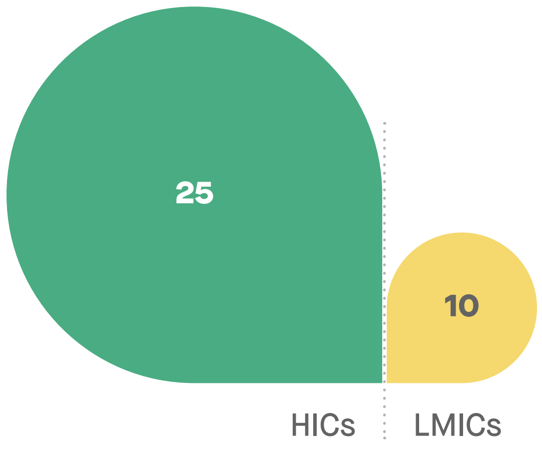


TABLE 15

GDO countries including risk reduction in dementia or other health plans, by WHO region and World Bank income classification

Region	GDO countries with dementia plan	GDO countries with dementia risk reduction included in dementia or health plan	% of GDO countries with dementia risk reduction included in dementia or health plan, by income category or region
Global	43	35	81%
WHO region			
African Region	1	1	100%
Region of the Americas	7	4	57%
South-East Asia Region	3	2	66%
European Region	19	16	84%
Eastern Mediterranean Region	5	5	100%
Western Pacific Region	8	7	88%
Income level			
Low- and middle-income	14	10	71%
High income	29	25	86%

BOX 14

Promoting brain health in Finland

The population of Finland is ageing, and the number of people living with dementia and cognitive impairment is increasing. Approximately 200 000 people in Finland have some form of cognitive impairment and approximately 14 500 new cases of dementia are diagnosed each year.

In order to meet the increasing demand for services and costs, actions are needed to promote brain health, to prevent dementia and to detect neurodegenerative diseases as early as possible. Observational studies and trials show that memory disorders could be prevented by a healthy lifestyle. One aim of the Finnish social and health-care policy is to promote health and functional capacity.

The **Elderly care act (980/2012)** states that local authorities must draw up a plan for measures to support the well-being, health, functional capacity and independent living of the older population.

Quality recommendations by the Ministry of Social Affairs and Health and the Association of Finnish Local and Regional Authorities include nutrition and physical exercises as one area of recommendations for health promotion.

Current care guidelines contain, for instance, guidelines for physical activity and exercise training for adults with and without diseases, and guidelines for dementia.

The **FINGER model**, the Finnish Geriatric Intervention Study to Prevent Cognitive Impairment and Disability (2009–2024), includes a multidomain intervention programme that includes management of metabolic and vascular risk factors, guidance on healthy diet and exercise and brain training. The intervention consists of regular meetings over two years with various health professionals.

The FINGER programme has so far shown that it is effective in preventing cognitive decline among older people, that it reduces the risk of disability and multimorbidity, and that it has positive effects on health-related quality of life.

The Finger model will continue to be implemented in social and health-care reform.

Moreover, the model includes guidance and recommendations for physical activities and nutrition for older people and the population of working age.

Dementia risk reduction in clinical guidelines

The availability of guidelines on dementia risk reduction is a vital step to integrating risk reduction into clinical practice. In 2019, WHO released guidelines on the risk reduction of cognitive decline and dementia (see **Box 15**).

BOX 15

WHO guidelines on risk reduction of cognitive decline and dementia (2019)

Physical activity interventions

- Physical activity should be recommended to adults with normal cognition to reduce the risk of cognitive decline.
- Physical activity may be recommended to adults with mild cognitive impairment to reduce the risk of cognitive decline.

Tobacco cessation interventions

- Interventions for tobacco cessation should be offered to adults who use tobacco since they may reduce the risk of cognitive decline and dementia in addition to other health benefits.

Nutritional interventions

- The Mediterranean-like diet may be recommended to adults with normal cognition and mild cognitive impairment to reduce the risk of cognitive decline and/or dementia.
- A healthy, balanced diet should be recommended to all adults on the basis of WHO's recommendations on healthy diet.
- Vitamins B and E, polyunsaturated fatty acids and multi-complex supplementation should not be recommended to reduce the risk of cognitive decline and/or dementia.

Interventions for alcohol use disorders

- Interventions aimed at reducing or ceasing hazardous and harmful drinking should be offered to adults with normal cognition and mild cognitive impairment to reduce the risk of cognitive decline and/or dementia in addition to other health benefits.

Cognitive interventions

- Cognitive training may be offered to older adults with normal cognition and with mild cognitive impairment to reduce the risk of cognitive decline and/or dementia.

Social activity

- There is insufficient evidence for social activity and the reduction of risk of cognitive decline/dementia.
- Social participation and social support are strongly connected to good health and well-being throughout life and social inclusion should be supported over the life course.

Weight management

- Interventions for mid-life overweight and/or obesity may be offered to reduce the risk of cognitive decline and/or dementia.

Management of hypertension

- Management of hypertension should be offered to adults with hypertension according to existing WHO guidelines.
- Management of hypertension may be offered to adults with hypertension to reduce the risk of cognitive decline and/or dementia.

Management of diabetes mellitus

- The management of diabetes in the form of medications and/or lifestyle interventions should be offered to adults with diabetes according to existing WHO guidelines.
- The management of diabetes may be offered to adults with diabetes to reduce the risk of cognitive decline and/or dementia.

Management of dyslipidaemia

- Management of dyslipidaemia at mid-life may be offered to reduce the risk of cognitive decline and dementia.

Management of depression

- There is currently insufficient evidence to recommend the use of antidepressant medicines for reducing the risk of cognitive decline and/or dementia.
- The management of depression in the form of antidepressants and/or psychological interventions should be provided to adults with depression according to existing WHO mhGAP guidelines.

Management of hearing loss

- There is insufficient evidence to recommend the use of hearing aids to reduce the risk of cognitive decline and/or dementia.
- Screening followed by provision of hearing aids should be offered to older people for timely identification and management of hearing loss as recommended in the WHO ICOPE guidelines.

According to GDO data, of the 36 countries that report having clinical guidelines for dementia, 21 report including a specific focus on dementia risk reduction. Most of these risk reduction-specific guidelines (16 of the 21 or 76%) come from HICs, with 5 of the 21 (or 24%) reported from LMICs. Around 62% of the guidelines (13 of the 21) come from the European region alone (see **Table 16**). These data must be interpreted in view of the limitations of lower rates of reporting on this question in some regions, and it may not reflect the overall regional situation.

TABLE 16

GDO countries with risk reduction included in dementia guidelines, by WHO region and World Bank income classification

Region	GDO countries that report having a dementia guideline	GDO countries with dementia risk reduction included in dementia guidelines	% within region or income group
Global	36	21	58%
WHO region			
African Region	1	1	100%
Region of the Americas	4	2	50%
South-East Asia Region	2	1	50%
European Region	20	13	65%
Eastern Mediterranean Region	3	1	33%
Western Pacific Region	6	3	50%
Income level			
LMICs	8	5	62%
HICs	28	16	57%

Existence of dementia risk reduction campaigns

Globally, population awareness of the possibility of dementia risk reduction is limited. Given the interrelatedness of NCD risk factors and those for dementia, it should be noted that awareness-raising campaigns focused on health promotion but that are not dementia-specific may also bring gains in terms of dementia risk reduction. Nevertheless, running nationwide campaigns for dementia risk reduction can help raise population awareness and educate people about known risk and protective factors. Twenty-eight GDO countries reported having run dementia risk reduction campaigns. Importantly, the majority of these countries are HICs, with just 8 LMICs reporting risk reduction campaigns. There are also regional differences (see **Table 17**). However, this data must be interpreted in view of the limitations of lower rates of reporting for this question in some regions.

TABLE 17

GDO countries reporting risk reduction campaigns

Region	GDO countries reporting risk reduction campaigns (Yes)	% within region or income group
Global (*n*=62)	28	45%
WHO region		
African Region (*n*=4)	1	25%
Region of the Americas (*n*=11)	3	27%
South-East Asia Region (*n*=5)	3	60%
European Region (*n*=24)	11	46%
Eastern Mediterranean Region (*n*=8)	4	50%
Western Pacific Region (*n*=1)	6	60%
Income level		
Low- and middle-income (*n*=27)	8	29%
High-income (*n*=34)	20	59%

28 of 62

GDO countries report running risk reduction campaigns; most frequently using print media, television and radio to deliver messages

Of the 28 GDO countries reporting risk reduction campaigns, the majority organized campaigns at the national level (19; 68%), over half reported dedicated funding for the campaign (16; 57%), and 18 (64%) documented evidence as to whether certain milestones were reached. Most campaigns were run by government (20; 71%), while seven countries reported campaigns that were run by NGOs and four reported campaigns run by the private sector. In terms of target audience, 18 campaigns (64%) addressed the general population while six campaigns had a specific target audience. The most commonly used delivery channels for risk reduction campaigns (not mutually exclusive) were print media (20 countries), television (17 countries), radio (16 countries), social media (11 countries) and billboards (10 countries). See **Box 16** for an example of a dementia risk reduction campaign from the Western Pacific Region.

Training of health-care workers in dementia risk reduction

Overall, the training of health-care workers in dementia is grossly insufficient. Refer to Chapter 7 for analyses of GDO data on dementia-specific training reported by countries for different cadre of health-care workers. No specific data are available on the training of health-care workers in dementia risk reduction.

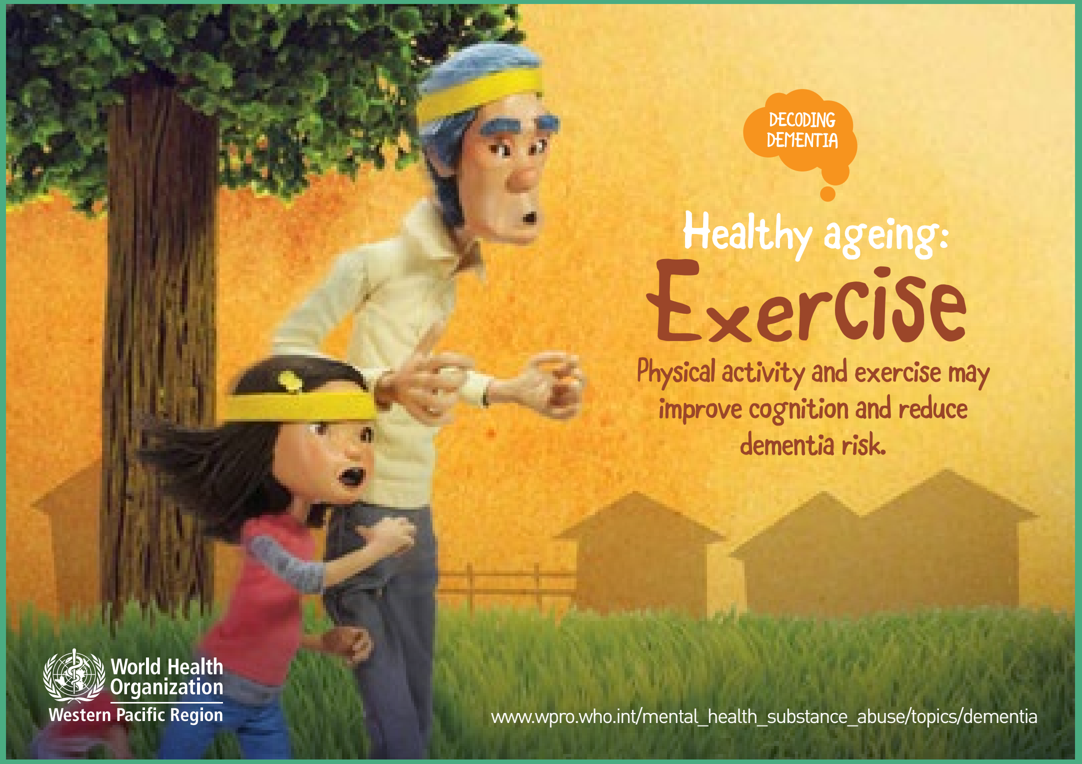
BOX 16

Dementia campaigns include risk reduction in the Western Pacific Region

In 2018, WHO's Western Pacific Region launched a dementia awareness campaign with posters that were shared widely over social media. These posters included several specific areas of focus on dementia risk reduction, including:

1. the importance of mental stimulation, physical activity and exercise;
2. healthy balanced diets;
3. stopping tobacco and harmful use of alcohol; and
4. addressing cardiovascular risk factors, including weight, blood pressure, sugar and cholesterol. The following image is from one such poster which stressed the importance of physical activity and exercise. All other social media posters from this campaign are available at the following link:

   https://iris.wpro.who.int/handle/10665.1/14005



The way forward

Numerous barriers serve as bottlenecks that impede progress in dementia risk reduction. Such barriers include the lack of public awareness of the importance of risk reduction, lack of financial resources for dementia risk reduction programmes, inequitable distribution of services, human resource limitations (including lack of health workforce and lack of training in this area), and lack of coordination between sectors both nationally and locally – all of which are exacerbated by ongoing disruptions in essential NCD services by the COVID-19 pandemic.

Additionally, stigma is another impediment to dementia risk reduction. The 2019 *World Alzheimer Report* presented results of a global survey on attitudes towards dementia. A quarter of respondents felt nothing could be done to prevent dementia and only a little over half felt that lifestyle factors increased risk for dementia *(47)*.

"Accelerating action will require population level health education on dementia risk reduction, increased awareness of the interrelatedness of dementia risk with that of other neurological, mental health and substance use conditions as well as other NCDs, and the need for integration of care."

Accelerating action will require population-level health education on dementia risk reduction, increased awareness of the interrelatedness of dementia risk with that of other neurological, mental health and substance use conditions as well as other NCDs, and the need for integration of care. It will also require increased financial resources in order to develop, deliver and promote evidence-based risk reduction interventions in primary care and conduct the necessary workforce training.

A critical aspect of integrating dementia risk reduction programmes into primary care will be the creation of national guidelines on dementia risk reduction and the adaptation of evidence-based risk reduction interventions tailored for the local context (see **Box 17**). Risk reduction interventions should be integrated into national UHC packages, and health-care workers should be routinely trained to address modifiable risk factors such as those associated with NCDs (including weight management, tobacco cessation and reduction of harmful use of alcohol) in addition to promoting healthy lifestyles (including healthy diets and physical activity).

BOX 17

Multidomain interventions to promote healthier lives and reduce dementia risk

The World-Wide FINGERS (WW-FINGERS) network was launched in 2017 as the first global network of multidomain lifestyle intervention trials for dementia risk reduction and prevention. The Nordic-UK Brain Network runs the Scientific Helpdesk of WW-FINGERS, with support from and in collaboration with several organizations and stakeholders, including WHO, the Alzheimer's Association (AA), and Alzheimer's Disease Data Initiative (ADDI), among others.

The multifactorial and heterogeneous nature of late-onset dementia, including Alzheimer's disease, indicates that multidomain interventions and the targeting of several modifiable risk factors simultaneously can have a potential impact on optimal risk reduction. The positive results of such an approach are supported by the landmark multidomain Finnish Geriatric Intervention Study to Prevent Cognitive Impairment and Disability (FINGER). The overall scope of WW-FINGERS is to adapt, test and optimize the FINGER multidomain model for dementia risk reduction across the spectrum of cognitive decline – from at-risk asymptomatic states to early symptomatic stages – in different geographical, cultural and economic settings and contexts.

The WW-FINGERS network currently includes 30-plus countries (including LMICs) across all continents. The network provides a unique forum to harmonize and adapt multidomain interventions across various countries and settings and to facilitate data-sharing and analysis across studies. It promotes international joint initiatives to identify effective and feasible risk reduction strategies that can be implemented globally.

For more information, see:

- ✓ Ngandu T, Lehtisalo J, Solomon A, Levälahti E, Ahtiluoto S, Antikainen R et al. A 2 year multidomain intervention of diet, exercise, cognitive training, and vascular risk monitoring versus control to prevent cognitive decline in at-risk elderly people (FINGER): a randomised controlled trial. Lancet. 2015;385(9984):2255–63. doi:10.1016/S0140-6736(15)60461-5.
- ✓ Kivipelto M, Mangialasche F, Snyder HM, Allegri R, Andrieu S, Arai H et al. World-Wide FINGERS Network: a global approach to risk reduction and prevention of dementia. Alzheimer's & Dementia. 2020;17(7):1078–94. doi:10.1002/alz.12123.

Dementia risk reduction should be included in both pre-service training for health care workers and as a mandatory aspect of continuing medical education. Unfortunately, GDO data cannot currently capture risk-reduction-specific training of the workforce. More detailed information will be needed in the future. There additionally needs to be increased investment in research on dementia risk and protective factors to ensure that interventions are based on the best available evidence, particularly pertaining to social, environmental and dietary risk factors.

Figure 22 presents ongoing opportunities to accelerate action, beginning with the implementation of WHO's Global action plan for the prevention and control of noncommunicable diseases 2013–2020. Progress of the action plan is tracked by the Global Coordinating Mechanism on the Prevention and Control of NCDs (48). WHO has developed several guidelines, technical packages and tools relating to the prevention and control of NCDs which, if implemented globally, can advance dementia risk reduction. WHO's Package of Essential Noncommunicable (PEN) Disease Interventions for Primary Care, WHO's training package on building capacity for tobacco control and the WHO HEARTS technical package are three such examples (49,50). Additionally, WHO's dementia risk reduction guidelines provide up-to-date guidelines on evidence-based interventions for reducing dementia risk (52). As a complement to these guidelines, WHO released a module on dementia prevention in the mDementia Handbook in order to provide countries with easy mHealth-based implementation options (see **Box 18**) (53).

BOX 18

mDementia

mDementia is an mHealth intervention developed by WHO's Mental Health and Substance Use Department and Be He@lthy Be Mobile (BHBM), a joint initiative between WHO and the International Telecommunications Union. mDementia provides guidance on implementing messaging programmes for dementia risk reduction (mDementiaPrevention) and support for carers of people with dementia (mDementiaSupport).

mDementiaPrevention content specifically aims to encourage persons of middle age or above to manage modifiable risk factors in order to delay or slow the onset or progression of dementia. According to WHO's *Guidelines on risk reduction of cognitive decline and dementia*, these risk factors include low physical activity, tobacco use, unhealthy diets and harmful use of alcohol. Certain medical conditions – including hypertension, diabetes, dyslipidaemia, obesity and depression – are also associated with an increased risk of dementia. For this reason, mDementia offers a comprehensive brain and physical health promotion package.

FIGURE 22

Proposed actions, identified barriers, and opportunities to accelerate action in the area of risk reduction

PROPOSED ACTIONS

- Link dementia risk reduction with other programmes, policies and campaigns on NCDs
- Develop, deliver and promote evidence-based risk reduction interventions in primary care
- Workforce training and education on dementia risk reduction

BARRIERS

- Inequitable distribution of services (e.g. urban vs. rural, income level)
- Human resource limitations (lack of workforce, lack of training)
- Lack of services
- Dementia risk reduction not routinely included in clinical curricula

OPPORTUNITIES TO ACCELERATE ACTION

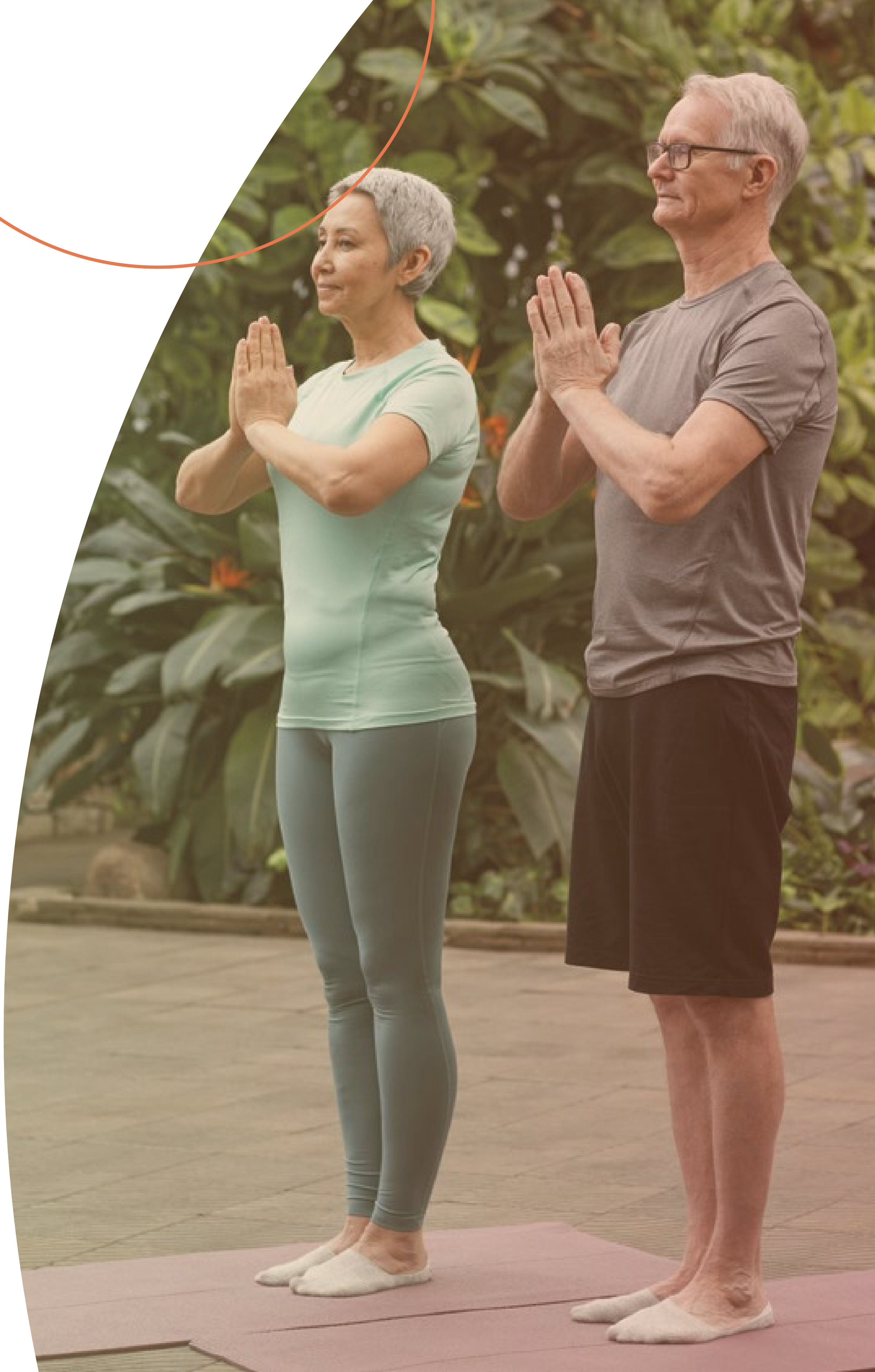
- Develop national and local dementia risk reduction guidelines, relying on established guidelines such as WHO's *Guidelines on risk reduction of cognitive decline and dementia.*
- Include dementia risk reduction interventions in country-level UHC packages, modelled after the WHO UHC compendium.
- Implement and/or scale up programmes that increase health workforce knowledge and training in risk reduction of NCDs through WHO's PEN package, HEARTS technical package and tobacco training package.
- Increase awareness of dementia risk reduction through campaigns such as the Western Pacific Region's dementia campaign.
- Implement digital health solutions to increase population-level access to dementia risk reduction strategies through WHO's mDementia (Prevention) programme.
- Leverage synergies with the SDGs, the WHO Global Coordinating Mechanism on NCDs, and the forthcoming Intersectoral global action plan on epilepsy and other neurological disorders (World Health Assembly Resolution WHA 73.10).

Concluding remarks

The risk of developing dementia can be reduced or its progression delayed by improving the capacity of health and social care professionals to provide evidence-based, multisectoral gender- and culturally-appropriate interventions to the general population, and by educating about and proactively managing modifiable risk factors for dementia that are shared with other NCDs. Dementia risk reduction requires addressing risk factors for other NCDs. The Global dementia action plan recognizes the inherent links between dementia and other NCDs by outlining a global target linked to the targets defined in the Global action plan for prevention and control of NCDs 2013–2020. While there has been incremental improvement in overall mortality from cardiovascular diseases, cancer, diabetes and chronic respiratory diseases (4% reduction globally), these changes fall short of global NCD targets.

Additionally, WHO's GDO provides important data on country-driven progress on process indicators related to reduction of dementia risk. GDO data provide insights into countries that include dementia risk reduction in their dementia plans or other health plans, as well as within clinical guidelines. Over half of all GDO countries include dementia risk reduction in a dementia plan, though most of these countries are HICs. Similarly, over a third of GDO countries report including a focus on dementia risk reduction in dementia clinical guidelines, but most of these countries too are HICs. GDO data also highlights the existence and types of dementia risk reduction campaigns globally, the majority of which were organized in HICs at the national level, were government-run and addressed the general population.

Barriers impeding progress in the area of dementia risk reduction include the lack of public awareness of the importance of risk reduction, lack of financial resources available for dementia risk reduction programmes, inequitable distribution of services, human resource limitations (including lack of health workforce and lack of training in this area), and lack of coordination between sectors nationally and locally, all of which are exacerbated by ongoing disruptions in essential NCD services because of the COVID-19 pandemic. Stigma is another barrier for dementia risk reduction. Addressing these barriers requires action in multiple disciplines and sectors. First, dementia risk reduction should be linked with other programmes, policies and campaigns on NCDs. Second, evidence-based risk reduction interventions should be developed, delivered and promoted within primary care settings. Both actions will require the widespread availability of training and education on dementia risk reduction for the health workforce.



“When you are diagnosed, you only think, I'll never do anything again - like drive, cook dinner, or go on holidays. It would be nice to be informed of how we can continue to live and do the things that we did before being diagnosed, and what you really want is for your clinician to give you that information.”

Helen Rochford-Brennan,
Ireland

7. Dementia diagnosis, treatment and care

Context

In line with the principle of UHC, the Global dementia action plan emphasizes that people with dementia should have access to person-centred, rights-based health and social services when and where they need it, without financial hardship.

Dementia is associated with complex care needs and high levels of dependency and morbidity in its later stages. Thus, dementia requires a range of services from both within and outside the health sector – such as primary health care, specialist medical care, community-based services, rehabilitation, long-term care, and palliative care. Diagnosis is the entry point to accessing any dementia care and support. The critical importance of early diagnosis is reflected in target 4 of the Global dementia action plan (i.e., that in at least 50% of countries, the diagnostic rate for dementia is at least 50%).

With respect to post-diagnostic support, evidence suggests that multidisciplinary and multi-component care models for dementia are effective when integrated within primary care. A recent systematic review of 10 trials examined post-diagnostic dementia care models delivered by primary care in four countries (Germany, Netherlands, Singapore, the United States) and found that primary care provider (PCP)–case management partnerships for people living with dementia and their carers improved several important outcomes, including neuropsychiatric symptoms experienced by people living with dementia, as well as carer burden and costs associated with the health system (54). PCP-led care also yielded better outcomes, including decreased hospital and memory clinic costs and improved carer mental health.

WHO hosted a session on dementia care pathways as part of the 2018 WHO mental health gap action programme (mhGAP) Forum. During the session, key stakeholders in the field of dementia discussed essential components of dementia care pathways and mapped across them existing tools and identified gaps that need future work (see **Box 19**). As a result, a working model of integrated dementia care pathways was developed (see **Figure 23**). WHO has developed, and continues to develop, guidance and tools to assist countries in developing components of integrated care pathways.

BOX 19

WHO session on dementia care pathways – "Leaving no one behind"

In 2018, WHO hosted the annual mhGAP Forum which had the theme "Accelerating country action on mental health". As part of the forum, WHO organized a parallel session dedicated to dementia care pathways. In line with the vision and goals of the Global dementia action plan, this small group session discussed stakeholder needs across the continuum of dementia care, service availability and implementation mechanisms at country level and mapped these against existing WHO tools and guidelines on dementia, healthy ageing, human rights and rehabilitation in order to identify gaps and further needs for WHO guidance.

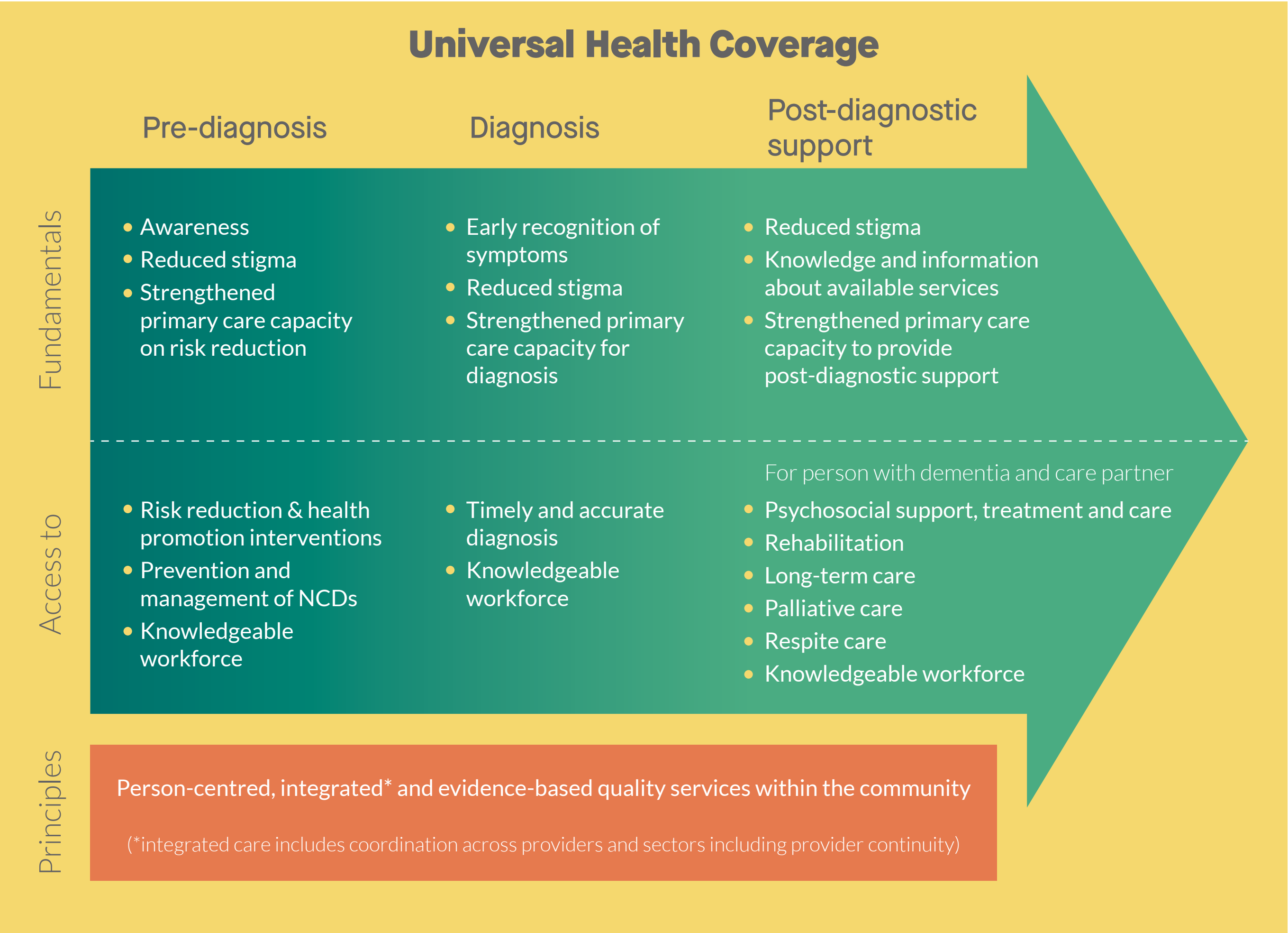
The session was attended by over 30 representatives from Member States, non-State actors, WHO colleagues at all three levels of the organization and professionals of multiple disciplines – including experts in public health, psychiatry, geriatrics, neuropsychology, occupational therapy, neuroimaging and health economics, as well as people with lived experience of dementia. During this session, partners and stakeholders shared their views on dementia care pathways, and their statements emphasized the need for early diagnosis followed by holistic and *integrated* care and management that can be adapted to different cultural settings and are based on human rights, equity, evidence and sustainability. Participants highlighted the importance of empowering people with dementia to maintain their intrinsic/functional capacity for as long as possible. It was agreed that a positive approach focusing on abilities rather than disabilities would enable people with dementia and reduce stigma.

Statements were followed by an interactive group exercise, during which participants mapped out the foundation and requirements for an integrated dementia care pathway along the continuum of a person's dementia (i.e. from before symptom onset to the end of life). Participants were encouraged to work creatively on this continuum, add their own ideas to reflect personal needs or professional experiences and engage in discussions with each other. The outcome of this exchange of ideas was summarized in a large mind map (see photo below):

Participants of the dementia care pathways session of 2018 WHO mhGAP Forum

FIGURE 23

Model for integrated dementia care



Each step on the dementia care pathway should be rooted in a human rights-based approach in line with key principles of the CRPD, including dignity, choice and autonomy. The needs and preferences of people living with dementia must be met and their autonomy from diagnosis to the end of life must be respected through integrated, culturally appropriate, person-centred, community-based health, psychosocial, long-term care and support and, where appropriate, the inputs of families and carers.

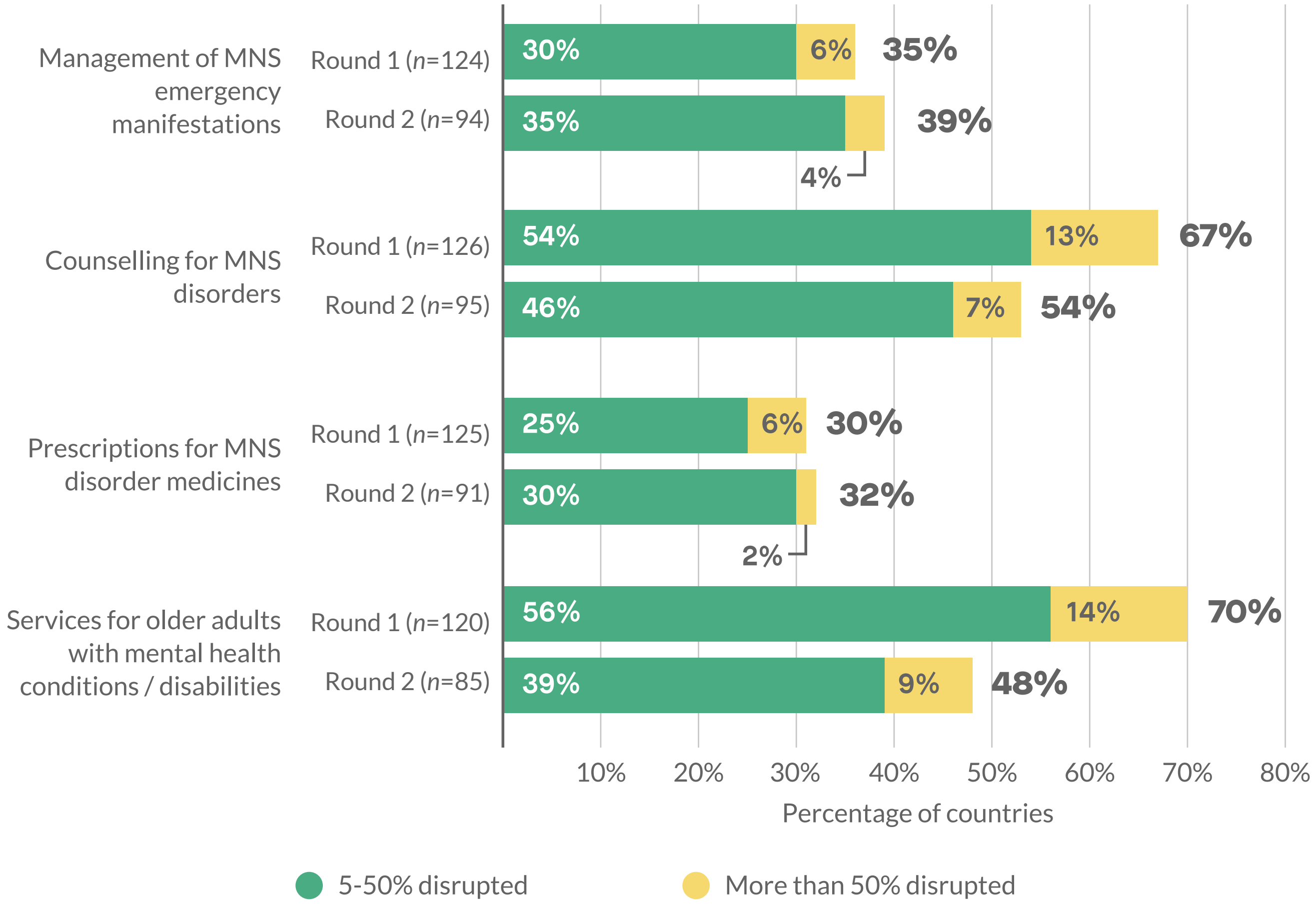
COVID-19 and dementia care

The ongoing COVID-19 pandemic has disrupted health care systems globally and these disruptions threaten to reduce access to timely dementia diagnosis and entry to care pathways. WHO's *Pulse survey on the continuity of essential health services during the COVID-19 pandemic*, released in August 2020, revealed that 48% of 105 countries surveyed reported at least partial disruptions in all services for NCDs and mental health (7). Importantly, three out of four countries reported disruptions in 2020 in services for older adults with mental health conditions or disabilities, including dementia.

WHO's second round of the national Pulse survey on continuity of essential health services during the COVID-19 pandemic found that, while there have been some improvements during the second year of the pandemic, disruptions to essential mental, neurological and substance use services persist (45) (see **Figure 24**). When specifically considering services for older adults with mental health conditions or disabilities, the percentage of countries reporting ongoing disruptions in 2021 approached 50% (of 58 countries).

FIGURE 24

Pulse survey Rounds 1 and 2 comparison of disruptions in services for mental, neurological and substance use disorders



This chapter provides an overview of global progress made to date in improving dementia care pathways by assessing country-driven progress based on GDO data. The chapter discusses the diagnostic gap and ways to improve diagnostic rates, reviews the availability of community-based services, discusses health and social workforce training and education, and care coordination. The chapter additionally outlines spotlight activities, country case studies and key accelerators for action in this area, showing links to WHO's normative work in this area, including mhGAP, ICOPE, the forthcoming Package of Interventions for Rehabilitation (PIR) for dementia and WHO's guidance package on good practice community-based services for mental health and dementia.

Progress to date

In line with the Global dementia action plan, the GDO monitors global, regional and country-level progress concerning diagnostic rates for dementia; the availability and accessibility of community-based dementia services; the existence of care pathways for dementia; and health and social workforce training and education for dementia. Progress in each of these areas is outlined below.

Dementia diagnostic rate

Receiving an accurate diagnosis of dementia is a prerequisite for accessing any kind of services. Globally, we are far from achieving the target of 50% of countries reporting at least 50% of dementia being diagnosed. According to GDO data, fewer than half the countries (29/62 or 47%) were able to report on dementia diagnostic rates, by providing either a nationally calculated rate or the total number of people diagnosed with dementia, from which the diagnostic rate could be calculated. As such, not even for GDO countries that are likely biased towards being more "dementia-ready", we are meeting the first condition of the global target.

Moreover, there is considerable variability in reported diagnostic rates on the basis of country income, with the median diagnostic rate for HICs being 58% compared with 21% for LMICs (see **Table 18**). The large variation observed in the range for diagnostic rates demonstrates the need for quality data on dementia diagnosis and prevalence estimates. Increased capacity-building efforts are needed to enable countries to be able to track, monitor and report information. More specifically, accurate recording of diagnostic rates will require standardized diagnostic criteria and processes for recording new diagnoses, ideally by establishing centralized registries and/or electronic health records. Additional information can be surveyed via prescription records, insurance or other health utilization data, but reliance on these sources runs the risk of incompleteness or redundancy.

Furthermore, while the GDO asks countries to report on diagnostic rates, these data do not provide insight into the timeliness of diagnoses or waiting times. Greater granularity of data – including the severity of dementia at time of diagnosis and, specifically, the incidence and prevalence rates of mild dementia versus moderate/severe dementia over time – may provide some insight into waiting times. It may be expected that an increase in mild dementia diagnoses is indicative of people being diagnosed earlier, whereas an increase in moderate-to-severe dementia may signal the opposite.

TABLE 18

Dementia diagnostic rates by WHO region and World Bank income level

Region	Dementia diagnostic rate Median	Range
Global (*n* = 29)	48%	0.08% - 95%
WHO region		
African Region (*n* = 1)	--	0.4%
Region of the Americas (*n* = 2)	--	23% - 73%
South-East Asia Region (*n* = 2)	--	0.08% - 8%
European Region (*n* = 16)	60%	3% - 95%
Eastern Mediterranean Region (*n* = 4)	19%	17% - 56%
Western Pacific Region (*n* = 4)	27%	0.3% - 96%
Income level		
Low- and middle-income (*n* = 10)	21%	0.08–96%
High-income (*n* = 19)	58%	3–95%

Availability of community-based services

Within the context of UHC, broad access to quality evidence-based person-centred services for everyone is essential. GDO data provide insight into the existence of various types of community-based dementia services within a country and additionally the availability of these services in urban as compared to rural areas within countries. The majority of GDO countries (89%) report provision of community-based services for dementia, but there are significant variations based on income level – e.g. 97% of HICs report community-based services, compared with 78% of LMICs. Of the countries reporting community-based services, over 90% report providing community-level diagnostic services, psychosocial services and rehabilitation, assessment and management of behavioural and psychological symptoms of dementia (BPSD), and social and financial protection (see **Figure 25** and **Table 19**). HICs reporting on community-based services report greater availability of all services listed in **Table 19** compared with LMICs. Notably, all HICs with community-based services report having social and financial protection, compared with 75% of LMICs.

Geographical coverage of community-based dementia services in urban versus rural areas can serve as a proxy indicator of equitable access. There is a significant gap between the availability of community-based services in HICs and LMICs (see **Table 20**). For all types of community-based dementia services, there is 37–51% higher coverage in rural areas in HICs as opposed to LMICs. LMICs report considerably higher coverage in the capital and main cities than in rural areas. For diagnostic services, HICs report 41% more coverage in rural areas than LMICs do. This is a critical bottleneck since timely and accurate diagnosis is the entry point to accessing post-diagnostic services. Addressing these inequities will be essential for increasing the availability of dementia services globally.

Up to 51%
higher coverage of community-based dementia services in rural areas for HICs compared to LMICs

FIGURE 25

Number of countries providing community-based dementia services, by World Bank income classification

Note: LMICs = Low- and middle-income countries; HICs = High-income countries. ADL = Activities of Daily Living.
BPSD = Behavioural and psychosocial symptoms of dementia.

TABLE 19

Availability of community-based services by type of service

	Countries with any community-based services	Types of community-based services						
		Diagnostic services	Assessment and management of BPSD		Psychosocial services and rehabilitation	ADL support	Palliative care	Social and financial protection
	% of GDO countries	% of GDO countries with any community-based services	% of GDO countries with any community-based services		% of GDO countries with any community-based services	% of GDO countries with any community-based services	% of GDO countries with any community-based services	% of GDO countries with any community-based services
Global (*n* = 62)	**55** (89%)	51 (93%)	53 (96%)		51 (93%)	47 (85%)	43 (78%)	50 (91%)
Number of countries reporting community-based services by region								
African Region (*n* = 4)	4	3	3		4	3	3	3
Region of the Americas (*n* = 11)	8	8	8		7	6	6	8
South-East Asia Region (*n* = 5)	3	2	3		3	3	3	3
European Region (*n* = 24)	23	22	22		21	23	21	23
Eastern Mediterranean Region (*n* = 8)	7	6	7		6	4	3	4
Western Pacific Region (*n* = 10)	10	10	10		10	8	7	9
Number and % of countries reporting community-based services by income classification								
Low- and middle-income (*n* = 27)	21 (78%)	18 (86%)	20 (95%)		20 (95%)	16 (76%)	14 (67%)	16 (76%)
High-income (*n* = 34)	**33** (97%)	32 (97%)	32 (97%)		30 (91%)	31 (94%)	29 (88%)	33 (100%)

Note that numbers reported by region and/or World Bank income classification do not necessarily add up to 100%, as some information was missing. ADL = Activities of daily living. BPSD = Behavioural and psychosocial symptoms of dementia.

TABLE 20

Urban versus rural availability of community-based dementia services

Availability of community-based dementia services	HICs	% of GDO HICs (*n*=34)	LMICs	% of GDO LMICs (*n*=27)
Diagnostic services				
Urban only	7	21%	10	37%
Urban and rural	23	67%	7	26%
Assessment and management of BPSD				
Urban only	10	29%	13	48%
Urban and rural	20	59%	6	22%
Psychosocial services and rehabilitation				
Urban only	7	21%	16	59%
Urban and rural	21	62%	3	11%
Support for ADL				
Urban only	5	15%	10	37%
Urban and rural	24	71%	7	26%
Palliative and end-of-life care services				
Urban only	7	21%	9	33%
Urban and rural	19	56%	4	15%
Social and financial protection				
Urban only	1	3%	1	4%
Urban and rural	29	85%	13	48%

Note: LMICs = Low- and middle-income countries; HICs = High-income countries; GDO = Global Dementia Observatory; BPSD = Behavioural and psychosocial symptoms of dementia; ADL = Activities of daily living. Note that numbers reported by region and/or World Bank income classification do not necessarily add up to 100%, as some information was missing.

Equitable access to essential community-based dementia services encompasses not only availability, but also affordability. GDO data can provide insights into geographical coverage, as discussed above, and affordability when considering social and financial protection schemes and majority providers as proxy indicators. Importantly, the availability of community-based social and financial protection schemes in rural areas is available in nearly 40% more HICs than LMCIs in HICs (see **Table 20**). Social and financial protection schemes are paramount to accessing services. Additionally, services in the public sector are generally less costly than those in the private sector which may require out-of-pocket payments. Understanding the majority provider in a country offers insight into the costs of dementia care to the end-user. See Box 20 for an illustrative example of an Indian family's dementia journey, including the struggles of receiving a diagnosis and accessing services.

> **"40% higher availability of social and financial protection schemes in rural areas of HICs than in LMICs."**

BOX 20

Case vignette from STRiDE, India

The STRiDE (Strengthening responses to dementia in countries) Project, supported by the United Kingdom's Research and Innovation Global Challenges Research Fund, has developed case vignettes to represent the many challenges in accessing care for dementia. The case vignette below is from India.

About five years ago Mrs C started to become forgetful. Now, at 75 years of age, Mrs C hardly ever leaves her room in her daughter's house – located in a metropolitan city – to which she was moved when it became clear that she could no longer look after herself. The daughter and her granddaughter help her with dressing, eating, washing and going to the bathroom. The domestic help also provides additional support with caregiving. The family has to make sure that food is not too chunky as Mrs C has difficulty swallowing. It is difficult for the daughter's family to go away together for the day as someone always needs to be around to look after her. Mrs C's other children visit during holidays but they find it difficult as she cannot always remember who they are. Mrs C has also started displaying some very strange behaviour.

Mrs C's granddaughter suggested that her mother (Mrs C's daughter) take Mrs C to a psychiatrist. Mrs C's daughter was initially reluctant to do so, as she was worried what the neighbours would think if they found out that she was taking her mother to see a psychiatrist. On the insistence of her daughter, she decides to visit a psychiatrist at a public hospital. The next day, Mrs C and her daughter visit the outpatient department of a public hospital 30–40 minutes' journey from their house. They find that the psychiatric outpatient department appointments are finished for the day, so they have to come back another day.

They come back a few days later, but the waiting time is very long and they end up waiting for almost six hours before they can see the doctor. During this time Mrs C gets increasingly agitated and the daughter almost considers going back home. Finally they manage to see a psychiatrist. The psychiatrist informs Mrs C's daughter that they need to do some tests, including an MRI and a neuropsychological assessment, but the waiting time to get these tests done are 1 month and 3 months respectively. The consult and the tests are are only partly subsidized and paid for out-of-pocket.

The family provides care as usual as they wait for the test to be conducted. When they eventually get the tests done and receive the reports, Mrs C's daughter takes her mother to see the psychiatrist again for a follow-up.

During the follow-up, the psychiatrist informs the daughter that her mother has Alzheimer's disease. He does not go into much detail but prescribes some medications and refers them to a social worker at the hospital, who can provide them with further guidance. The social worker explains the diagnosis and advises the daughter to take Mrs C to a day care centre located 15 kilometres away (about 1 hour by auto-rickhsaw (three-wheeler public transport) from their house.

The daughter has a discussion with her husband, and they agree to take Mrs C to the day care center as the psychiatrist suggested, as it is run by an NGO and the services are affordable. However, the daughter is unable to take Mrs C to the center daily due to her own responsibilities at home. She manages to take Mrs C to the centre only once or twice a week.

The daughter begins to attend a few carer support meetings at the centre whenever possible. As Mrs C's symptoms progress, the burden of caregiving falls heavily on the daughter, who spends a minimum of 8–10 hours each day providing care. The granddaughter also helps when possible and spends around 2 hours per day providing care to Mrs C. The need to provide constant care in addition to her own family responsibilities has placed a major strain on the daughter's marriage and her health, as she also suffers from health problems.

Availability of health and social care facilities

In addition to the availability of community-based dementia services, GDO countries report on the availability of different types of health and social care facilities. There is significant variance in the availability of certain types of health and social care facilities across country income brackets (see **Table 21**). While all or most countries report the availability of tertiary care facilities (i.e., hospitals) and outpatient health centres, all other facilities are considerably more available in HICs as opposed to LMICs, with 22% more HICs reporting the availability of residential and long-term care facilities, almost 30% more HICs reporting the availability of hospice centres and adult day centres, and nearly 50% more HICs reporting the availability of outpatient community/social care centres. These inequities must be addressed in order to ensure access to care along the full care spectrum from diagnosis and treatment through rehabilitation and palliative care when needed. This necessitates increased financial investment in health facilities that provide essential services for all people living with dementia.

TABLE 21

Availability of health and social care facilities, by World Bank income classification

Availability of health and social care facilities	HICs	% of GDO HICs (*n*= 34)	LMICs	% of GDO LMICs (*n*= 27)
Hospitals	34	100%	27	100%
Residential and long-term care facilities	31	91%	19	70%
Hospice centres	25	74%	12	44%
Adult day centres	32	94%	18	67%
Outpatient health centres	33	97%	24	89%
Outpatient community/social care centres	31	91%	11	41%

Note: LMICs = Low- and middle-income countries; HICs = High-income countries; GDO = Global Dementia Observatory. Note that numbers reported by region and/or World Bank income classification do not necessarily add up to 100%, as some information was missing.

The number of facilities and associated beds or places, standardized per population, can provide insights as to availability of dementia services in a country and, when combined with numbers of admissions related to dementia, can help us understand utilization rates. If analysed further in light of estimated numbers of people with dementia in the country, service coverage can be estimated. GDO countries are asked to provide quantitative information regarding specific availability of health and social care facilities (i.e., hospitals, residential long-term care facilities, hospice centres, adult day-care centres and outpatient centres) including number of beds/places (non-specific, dementia-specific and geriatric-specific). However, the majority of countries participating in the GDO are not able to report such numbers. Possessing such data is vital in order to identify gaps in the health and social care services provided to people with dementia, as well as evaluate the progress overtime in the efforts to fill these gaps.

Availability of dementia-related medication and care products

In addition to the availability of community-based services, as well as health and social care facilities and their utilization rates, access to dementia care also necessitates affordable access to medicines and other care products. GDO countries provide data on the availability and affordability of dementia-related medicines, adult hygiene products, equipment or assistive technology and housing adjustments. **Table 22** provides GDO data on the availability of anti-dementia medicines.

TABLE 22

Availability of anti-dementia medicines

	Any anti-dementia medicine n (%) approved	Generic version available	Reimbursement of anti-dementia medicine for on-label use		
	number of countries (%)	number of countries (%)	Full	Partial	No
Global (*n* = 62)	54 (87%)	45 (71%)	33 (53%)	9 (15%)	11 (18%)
LMICs (*n* = 27)	21 (78%)	16 (59%)	7 (26%)	5 (19%)	8 (30%)
HICs (*n* = 34)	33 (97%)	29 (85%)	26 (76%)	4 (12%)	3 (9%)

LMICs = Low- and middle-income countries; HICs = High-income countries. Note that numbers reported by World Bank income classification do not necessarily add up to 100%, as some information was missing.

While anti-dementia medicines developed to date have limited efficacy and are primarily labelled for Alzheimer's disease, these medicines are inequitably available around the world. More studies are needed in order to establish robust evidence on the cost-effectiveness of anti-dementia medicines, though it is clear that increasing access to early diagnosis and thereby to treatment, will improve the likelihood of such treatments being cost-effective(55). That is, the cost effectiveness of anti-dementia medicines is highly dependent on the delay to access treatment and the overall population coverage(55-57). Social inequalities, combined with high costs of medication and lack of financial support and reimbursement programmes, not only limit the accurate representation of cost-effectiveness studies, but also impose barriers into improving the quality of life of people living with dementia.

In each country the access to medicines begins with national regulatory approval. Upon approval, access to a medicine is expedited by the availability of generic versions and the presence of reimbursement schemes to reduce out-of-pocket expenses. Unfortunately, according to GDO data, anti-dementia medicines for on-label use remain far more available and affordable in HICs than in LMICs. Anti-dementia medicines for on-label use (again, primarily for Alzheimer's disease) are almost universally approved in HICs (97%) compared with LMICs (78% approved) (see **Table 22**). Generic versions of anti-dementia medicines are available in the majority of HICs (85%) compared with less than 60% of LMICs. Furthermore, at least one anti-dementia medicine is fully reimbursable in more than 3 out of 4 HICs, compared with just over 1 in 3 LMICs. Closing the global equity gap in access to anti-dementia medicines necessitates increased regulatory approvals in-country, widespread availability of generic versions, and increased provision of reimbursement schemes to lower the financial burden on people living with dementia and their families.

Medications intended to control or treat common conditions that may be comorbid with dementia – including diabetes, hypertension or elevated cholesterol – are also essential *(7, 58)*. These medications were already out of reach for many people in low-resource settings prior to the COVID-19 pandemic, and with ongoing disruptions to supply chains and essential services, have been even more inaccessible. In the Region of the Americas, PAHO disseminated a flyer with key considerations for improving access to medications for NCDs in 2020 – including implementing policies that facilitate access to a 90-day supply of medication, facilitating physical access to medication supplies (including home deliveries), and establishing strong monitoring with planning for potential stock-outs *(59)*.

It should be noted that psychiatric medications are sometimes used to alleviate BPSD, and in doing so the benefits of these medications should be weighed against any risks to the individual. Persons living with dementia, and their carers if appropriate, should be fully informed of the risks and benefits, and treatment choices should be made in accordance with the person's wishes and preferences. The off-label use of atypical antipsychotic medications can be particularly problematic as multiple studies have linked these medicines to increased risk of death in people with dementia. As a result, the United States Food and Drug Administration (FDA) issued a black box warning in 2005 regarding atypical antipsychotic medications and dementia *(60)*. Similarly, guidance from the United Kingdom's National Institute for Health and Care Excellence (NICE) also calls for caution and the assessment of the risks versus limited benefits when using these medications in people with dementia *(61)*. Chapter 9 discusses country-reported monitoring of antipsychotic prescriptions for people with dementia.

Additionally, when examining GDO data on adult hygiene products, assistive technologies and housing adjustments, a similar pattern emerges between HICs and LMICs. First, these products and services are more available in HICs compared with LMICs. Moreover, these products are more likely to be reimbursable in HICs than in LMICs (27–51% more countries reporting affirmatively), making these products much more likely to incur out-of-pocket expenses for people living with dementia and their families residing in LMICs (see **Table 23**).

Health and social workforce training and education

In order to provide timely and adequate person-centred care rooted in a human-rights based approach, the training and education of health and social care workers in basic dementia competencies (including diagnosis, care and ethics, among other components) is essential. Globally, the number of health-care providers for dementia in countries remains limited with large variability between HICs and LMICs. Additionally, GDO data demonstrate that the extent to which they are trained in dementia is also limited. With the exception of few LMICs, mainly HICs provide routine dementia training to all professionals (e.g. doctors, specialists and nurses) but not necessarily to all relevant cadres (e.g. pharmaceutical personnel). The majority of countries only train some health professionals (see Figure 22). That leaves a significant proportion of the workforce potentially ill-prepared to provide quality dementia care. It is crucial that basic dementia competencies are included in the pre-service training of all cadres of the health and social workforce in order to ensure that those who are meant to serve people living with dementia and their carers are equipped with the knowledge they need.

It is also important to note that, in many countries, formally trained and paid carers working in nursing or long-term care facilities are stigmatized and their work is not adequately recognized by society. This inadequate consideration may present barriers to policy development. While these carers perform physically and emotionally demanding work, they are typically low-paid, are not offered ongoing quality training, supervision or psychological support, and their career development is not promoted. As a result, high turnover is common, which has a significant impact on the availability and quality of care.

TABLE 23

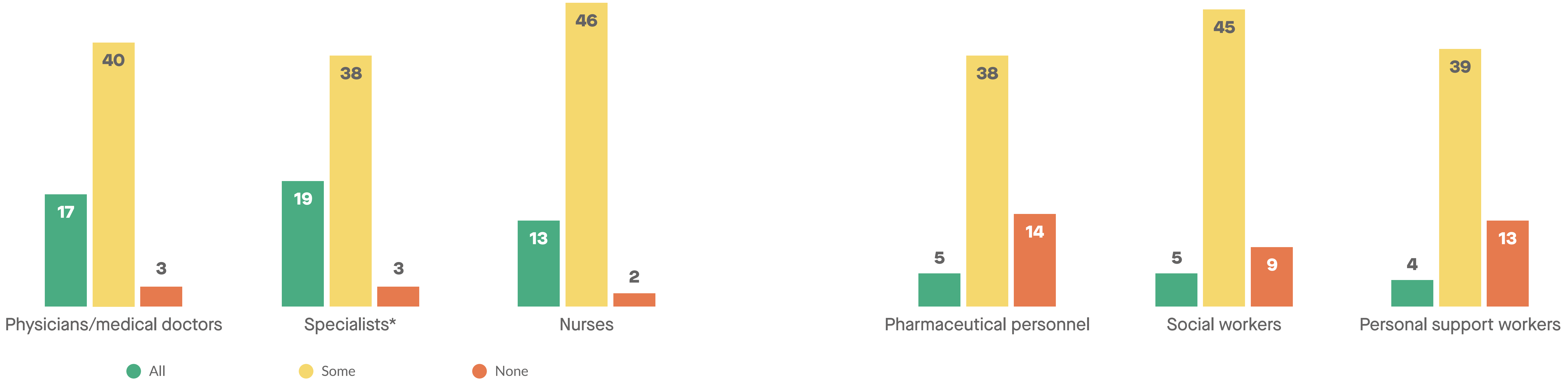
Availability of adult hygiene products, assistive technology and housing adjustments (% GDO countries), by WHO region and World Bank income classification

	Adult hygiene products			Assistive technology			Housing adjustments		
	Unavailable	Reimbursable	Out-of-pocket	Unavailable	Reimbursable	Out-of-pocket	Unavailable	Reimbursable	Out-of-pocket
Global (*n* = 62)	4 (6%)	34 (55%)	22 (35%)	4 (6%)	36 (58%)	12 (31%)	13 (21%)	24 (39%)	22 (35%)
LMICs (*n* = 27)	3 (11%)	9 (33%)	15 (56%)	3 (11%)	12 (44%)	12 (44%)	11 (41%)	3 (11%)	12 (44%)
HICs (*n* = 34)	1 (3%)	25 (74%)	6 (18%)	1 (3%)	24 (71%)	7 (21%)	2 (6%)	21 (62%)	9 (26%)

LMICs = Low- and middle-income countries; HICs = High-income countries. Note that numbers reported by region or World Bank income classification do not necessarily add up to 100%, as some information was missing.

FIGURE 26

Number of countries providing routine dementia training to (all, some, or none) health professionals of relevant cadres



* Geriatricians, psychogeriatricians, old-age psychiatrists as well as psychiatrists and neurologists who can diagnose dementia and provide treatment for individuals with dementia.

BOX 21

Strengthening dementia capacity in Slovenia

In 2016, Slovenia adopted the Dementia Management Strategy until 2020. The strategy summarizes the essential elements and commitments contained in the documents adopted by the EU, UN and WHO. The purpose of the strategy is to ensure preventive measures, early detection of the disease and an appropriate standard of health and social protection and health care for people with dementia.

In order to successfully implement the national strategy, suitably qualified staff and an informed professional and lay public are of key importance. The Ministry of Health, in accordance with the guidelines of the national strategy in 2017, conducted a Call for tender to co-finance education and awareness programs with the following key objectives:

- strengthening the capacities and competencies of professionals in the care chain for people with dementia in different settings;
- raising awareness of individual occupational and other target groups in the local environment to create a dementia-friendly environment;
- reducing differences between individual Slovenian regions.

In order to apply for programs an intention had been established to form a consortium of at least three partners from the psychiatric, neurological and social care professions.

Over 350 lectures were conducted, attended by more than 10 000 participants in all regions.

UKC Ljubljana, the Neurological Clinic, the University Psychiatric Clinic Ljubljana, the Social Chamber of Slovenia and Spominčica-Alzheimer Slovenije have the most credit for exceeding the objectives of the tender.

Dementia-specific clinical guidelines, standards and protocols

Nationally recognized guidelines, standards and protocols are critically important prerequisites for implementing dementia care pathways. Topics covered should include prevention and risk reduction, diagnosis, management, carer support, advance care directives, palliative and end-of-life care, care in nursing and residential facilities, and care in hospitals. In the absence of such nationally recognized guidelines and standards, components of the dementia care pathway may be missing, under-recognized or under-resourced. Only 36 GDO countries report having dementia-specific guidelines, standards and protocols, and most of these countries are HIC (82% of HIC report affirmatively versus 33% of LMIC). Globally, dementia diagnosis and management are prioritized within guidelines, standards and protocols over other areas (see **Table 24**). It is essential to close these gaps in order to better ensure person-centred, human rights-oriented service coverage, particularly in caring for advanced dementia through to end-of-life care.

58%
of GDO countries report having dementia-specific clinical guidelines, standards and protocols

TABLE 24

Standards, guidelines and protocols for dementia and topics covered

	Are there standards, guidelines or protocols for dementia?	Topics covered within standards, guidelines and protocols								
		Prevention/risk reduction	Diagnosis	Management		Support for carers	Advance care directives	Palliative and end-of-life care	Care in nursing/ residential care facilities	Care in hospitals
	(Yes, % of GDO countries)	(Yes, % of GDO countries with standards, guidelines or protocols)	(Yes, % of GDO countries with standards, guidelines or protocols)	(Yes, % of GDO countries with standards, guidelines or protocols)		(Yes, % of GDO countries with standards, guidelines or protocols)	(Yes, % of GDO countries with standards, guidelines or protocols)	(Yes, % of GDO countries with standards, guidelines or protocols)	(Yes, % of GDO countries with standards, guidelines or protocols)	(Yes, % of GDO countries with standards, guidelines or protocols)
Global (*n* = 62)	**36** (62%)	21 (58%)	35 (56%)	33 (92%)		22 (62%)	19 (53%)	20 (56%)	22 (62%)	23 (64%)
LMICs (*n* = 27)	**9** (33%)	6 (67%)	9 (100%)	9 (100%)		4 (44%)	2 (22%)	3 (33%)	3 (33%)	4 (44%)
HICs (*n* = 34)	**28** (82%)	16 (57%)	27 (96%)	25 (89%)		19 (68%)	17 (61%)	17 (61%)	19 (68%)	19 (68%)

LMICs = Low- and middle-income countries; HICs = High-income countries. Note that numbers reported by World Bank income classification do not necessarily add up to 100%, as some information was missing.

Care coordination at national and subnational levels

Coordination across sectors is paramount in order to achieve integrated and multidisciplinary care for people living with dementia. Just over half of GDO countries (32 countries, 52%) report having a mechanism to coordinate care for people with dementia across sectors in government, while fewer than one third of GDO countries report having a formal agreement for such a mechanism (19 countries, 31%). HICs are more likely to have a coordination mechanism and a formal agreement than LMICs. Globally, national implementation of dementia care coordination is far more commonly reported than subnational implementation. The sectors that are most commonly included in care coordination are the health and social sectors (100% and 97%, respectively), followed by the private, justice, civil society and housing sectors. Less than one third of countries that have a coordination mechanism include the education or employment sectors (see **Table 25**).

In the delivery of dementia services, components of care coordination reported by countries also vary (see **Table 26**). Components of care coordination reported through the GDO include the use of multidisciplinary or interdisciplinary teams, task-shifting, responsive referral pathways, continuity of care (including both continuity of information and provider continuity), and a community-based approach.

TABLE 25

Care coordination mechanisms, level of implementation and sectors involved

	Is there a mechanism to coordinate care across sectors?	Level of implementation		Sectors involved in care coordination							
		National	Subnational	Health	Social	Education	Employment	Justice	Housing	Civil society	Private sector
	(Yes, % of GDO countries)	(Yes, % of GDO countries reporting coordination mechanisms)	(Yes, % of GDO countries reporting coordination mechanisms)	(Yes, % of GDO countries reporting coordination mechanisms)	(Yes, % of GDO countries reporting coordination mechanisms)	(Yes, % of GDO countries reporting coordination mechanisms)	(Yes, % of GDO countries reporting coordination mechanisms)	(Yes, % of GDO countries reporting coordination mechanisms)	(Yes, % of GDO countries reporting coordination mechanisms)	(Yes, % of GDO countries reporting coordination mechanisms)	(Yes, % of GDO countries reporting coordination mechanisms)
Global (*n* = 62)	**32** (52%)	23 (72%)	9 (28%)	32 (100%)	31 (97%)	10 (31%)	9 (28%)	16 (50%)	13 (41%)	14 (44%)	17 (53%)
LMICs (*n* = 27)	10 (37%)	8 (80%)	2 (20%)	10 (100%)	10 (100%)	3 (30%)	1 (10%)	3 (30%)	2 (20%)	4 (40%)	6 (60%)
HICs (*n* = 34)	**22** (65%)	15 (68%)	7 (32%)	22 (100%)	21 (95%)	7 (32%)	8 (36%)	13 (59%)	11 (50%)	10 (45%)	11 (50%)

LMICs = Low- and middle-income countries; HICs = High-income countries. Note that numbers reported by World Bank income classification do not necessarily add up to 100%, as some information was missing.

TABLE 26

Components of care coordination

	Components of care coordination reported					
	Multidisciplinary or interdisciplinary teams	Task-shifting	Responsive referral pathways	Continuity of information	Provider continuity	Community-based approach
	(Yes, % of GDO countries reporting coordination mechanisms)	(Yes, % of GDO countries reporting coordination mechanisms)	(Yes, % of GDO countries reporting coordination mechanisms)	(Yes, % of GDO countries reporting coordination mechanisms)	(Yes, % of GDO countries reporting coordination mechanisms)	(Yes, % of GDO countries reporting coordination mechanisms)
Global (*n* = 62)	33 (53%)	24 (39%)	23 (38%)	23 (38%)	22 (36%)	27 (44%)
LMICs (*n* = 27)	9 (33%)	9 (33%)	7 (26%)	5 (19%)	7 (26%)	8 (30%)
HICs (*n* = 34)	24 (71%)	15 (44%)	16 (47%)	18 (53%)	15 (44%)	19 (56%)

Note that numbers reported by region or World Bank income classification do not necessarily add up to 100%, as some information was missing.

Dementia-specific nongovernmental organizations

In many countries, NGOs provide essential dementia services to the public and to people living with dementia and their carers. **Table 27** shows GDO data on the availability of dementia-specific NGOs and areas of focus for these organizations. There is some variability between income brackets as to availability: 94% HICs report the presence of dementia-specific NGOs in their country, compared with 77% of LMICs. However, there are similar areas of focus of NGOs within HICs and LMICs, with almost all reporting involvement in awareness-raising, 51% involved in home health and social care services, and over 80% involved in carer training. While NGOs can and do provide various services along dementia care pathways, increased resources are needed to ensure uniform availability of public-sector services across regions (and urban versus rural areas) as well as assurance of adequate oversight, quality, standards, monitoring and reporting.

> **"In many countries, NGOs provide essential dementia services to the public and to people living with dementia and their carers."**

TABLE 27

Availability of dementia-specific NGOs and areas of focus

	Are dementia-specific NGOs available?	Areas of focus of dementia-specific NGOs		
		Awareness-raising	Home health and social care services	Carer training
	(Yes, % of GDO countries)	(Yes, % of countries with NGOs)	(Yes, % of countries with NGOs)	(Yes, % of countries with NGOs)
Global (*n* = 62)	53 (85%)	53 (100%)	27 (51%)	46 (87%)
WHO region				
African Region (*n* = 4)	3 (75%)	3 (100%)	1 (33%)	2 (67%)
Region of the Americas (*n* = 11)	9 (82%)	9 (100%)	3 (33%)	8 (89%)
South-East Asia Region (*n* = 5)	4 (80%)	4 (100%)	3 (75%)	4 (100%)
European Region (*n* = 24)	23 (96%)	23 (100%)	12 (52%)	20 (87%
Eastern Mediterranean Region (n = 8)	6 (75%)	6 (100%)	3 (50%)	5 (83%)
Western Pacific Region (n = 10)	8 (80%)	8 (100%)	5 (63%)	7 (88%)
Income level				
LMICs (*n* = 27)	21 (78%)	21 (100%)	11 (52%)	18 (86%)
HICs (*n* = 34)	32 (94%)	32 (94%)	16 (47%)	28 (82%)

Note: LMICs = Low- and middle-income countries; HICs = High-income countries. Note that numbers reported by region or World Bank income classification do not necessarily add up to 100%, as some information was missing.

Involvement of carers in the care planning

The Global dementia action plan recommends that countries involve carers in care planning, with attention being given to the wishes and preferences of people living with dementia. However, despite global efforts in the last few years, informal carers continue to be excluded from treatment decisions and care planning affecting people living with dementia. At present, the GDO is not able to measure to what extent informal carers are involved in the care planning at country level. In addition, research on carer participation in care planning is also scarce (17). There is currently no common understanding as to what participation entails, and no common agreement on how to assess whether and how carers can participate in care and policy decision-making, as well as what the outcomes of this participation should be (62).

Carer involvement is key at any stage of the care pathway and can help extend the participation of persons living with dementia when otherwise they are no longer able to participate. However, there are many barriers to carers' participation in care planning, including health and social care staff perceptions of legal and ethical care responsibilities, stigma, a perception that health-care professionals are the only care experts, and the high health and social care staff workload (63).

Carer participation in care planning has important ethical and practical implications, particularly with respect to end-of-life care. For this reason, some countries have started recognizing carers' rights within health and social care systems, as well as their role as care partners through legislation and guidance. For instance, the Swedish law Sveriges Kommuner och Landsting Patientmedverkan (64) (2014–2015, updated 2018) ensures that people living with dementia and their carers can participate in care-related decisions. In England, the National Health Service has issued guidance to support the involvement of carers in care planning (65). Many countries, especially HICs, also have legal provisions that enable advance care planning through legal guardianship and advance care directives. However, little information is available regarding how legal frameworks and guidelines for carer involvement are implemented in different contexts.

The way forward

Numerous barriers, including financial limitations, serve as bottlenecks that impede progress in the area of dementia care pathways, as evidenced by variations in the availability of community-based services and training by country income level and urban versus rural inequities. Such barriers relate to: the affordability of services for the end-user; a lack of national standards, guidelines and protocols on dementia; human resource limitations with a limited workforce and limited dementia-specific training; a lack of coordination between sectors at the national and subnational levels; a lack of public awareness about dementia; and pervasive stigma. During the COVID-19 pandemic, the disruption of access to essential services for all NCDs, as well as disruption to services for older persons with mental health conditions and/or disabilities, have further exacerbated these barriers.

Accelerating action in the area of dementia diagnosis, treatment and care will require: increased investment across regions and countries; development of dementia-specific national standards, guidelines and protocols (which will ultimately support dementia-specific training for all health workers); and the provision of evidence-based interventions. Dementia-specific training should be included as a mandatory element in pre-service training and continuing medical education. Additionally, community-based health and social services should be prioritized over hospital-based services; legislation supporting community-based care and earmarked funding can facilitate these efforts. Ongoing coordination mechanisms and regular meetings within sectors both nationally and locally can ensure there are efficient coordinated care pathways. The inclusion of dementia services in national UHC packages for financial risk protection will also help to increase the scaling-up of necessary services and will reduce out-of-pocket costs to people with dementia and their carers. Importantly, stigma reduction campaigns can normalize help-seeking, increase utilization of services, and improve the well-being of people with dementia and their carers.

"Community-based health and social services should be prioritized over hospital-based services; legislation supporting community-based care and earmarked funding can facilitate these efforts."

See **Figure 27** for a summary of proposed actions, barriers, and opportunities to accelerate action in the area of dementia diagnosis, treatment and care.

FIGURE 27

Proposed actions, barriers, and opportunities to accelerate action in the area of dementia diagnosis, treatment and care

PROPOSED ACTIONS

- Increase diagnostic rate for dementia
- Ensure availability of community-based services
- Improve access to services and supports
- Efficient coordinated care pathways
- Workforce training and education

BARRIERS IDENTIFIED

- Lack of availability of services, lack of affordability of services
- Inequitable distribution of services (e.g. urban vs. rural and income level)
- Human resource limitations (lack of workforce, lack of training)
- Dementia-related training not routinely included in clinical curricula
- Lack of coordination between sectors nationally and locally
- Stigma

OPPORTUNITIES TO ACCELERATE ACTION

- Develop national and local clinical guidelines for dementia, relying on established guidelines such as WHO’s mhGAP guidelines.
- Include dementia services in country-level UHC packages, modelled after WHO's UHC Compendium.
- Enhancing the promotion of human rights in all dementia services by implementing WHO’s guidance package on good practice community-based dementia services.
- Scale up integration of dementia services within primary care by implementing WHO’s mhGAP, including through the mhGAP guidelines, Intervention guide, Community toolkit and mhGAP e-learning.
- Scale up integration of dementia services within the long-term care sector by referring to ICOPE and ICARE, and include a focus on rehabilitation utilizing the forthcoming Package of interventions for rehabilitation.
- Implement digital health solutions to increase population-level access to dementia care and support through WHO’s mDementia programme.
- Leverage synergies with the SDGs, WHO’s Global coordinating mechanism on NCDs, and the forthcoming Intersectoral global action plan on epilepsy and other neurological disorders (World Health Assembly Resolution WHA 73.10).[5]

---

[5] Requested by the Seventy-third World Health Assembly in November 2020.

WHO guidelines, tools and packages to accelerate action

WHO has developed several guidelines, tools and packages which can be used to accelerate action, beginning with WHO's *mental health Gap Action Programme (mhGAP) guidelines, the mhGAP Intervention guide* and *mhGAP Training manual*, which contain guidelines, training modules and implementation considerations specific to dementia diagnosis and care for use by non-specialist health-care workers globally *(66)*. Moreover, based on WHO's existing dementia guidelines, WHO's UHC Compendium of interventions released in December 2020 contains 22 actions related to dementia risk reduction, diagnosis and management *(67)*. Other WHO products and tools include:

✓ WHO's guidance package on good practice community-based dementia care services (68, 69)

WHO has recently developed a guidance package on good practice community-based mental health services that promote human rights and person-centred recovery approaches. The WHO guidance describes different services around the world that promote legal capacity (informed consent and the right to decide), that implement a policy of non-coercive practices, promote participation in the design and delivery of the service, facilitate community inclusion, and adopt person-centred approaches. During the course of developing this document WHO received many requests to develop similar guidance in the area of dementia services (see **Box 22**).

BOX 22

WHO's good practices on community-based dementia care services

WHO's good practices on community-based dementia care services will provide international guidance on community-based good practice services in the health and social care sectors that promote a person-centered human rights-based approach to dementia across the care continuum. A similar methodology will be followed to that used to develop WHO's guidance package on good practice community-based mental health services.

Specifically, WHO's good practices community-based dementia care services guidance package will include:

- ✓ a clear articulation of human rights in relation to dementia care with reference to the CRPD and related international policy and legal standards, and WHO standards and criteria for good practice services in dementia care;
- ✓ a description and evaluation of good practice services across WHO's six regions illustrating a wide range of examples from high-, middle- and low-income countries in both urban and rural settings, with an emphasis on their ability to provide person-centred care and support human rights; description of the services will include costs, outcomes, and sustainability and transferability to different socioeconomic and country contexts;
- ✓ a description and evaluation of good practice multisectoral service networks, including multisectoral housing, education, employment, social benefits, transport, advocacy, research highlighting how they support human rights; and
- ✓ guidance on how to develop good practice services for dementia as part of an integrated care pathway and on how to integrate and scale up good practice services in health and social care systems through policy, law, community service models, financing, information systems, and advocacy among other areas.

The guidance package will inform policy-makers and decision-makers, as well as programme and service managers, in developing, supporting and scaling up rights-based, person-centred services for dementia as part of integrated care pathways for dementia within the context of broader efforts to strengthen health systems.

WHO's integrated care for older people (ICOPE)

WHO's *Guidelines on integrated care for older people* (ICOPE) were released in 2017 and provide guidance on community-level interventions to prevent, slow or reverse declines in the physical and mental capacities of older people *(70)*.

ICOPE reflects a continuum of care that will help to reorient health and social services towards a more person-centred and coordinated model of care that supports optimizing intrinsic capacity (physical and mental capacity) and functional ability for older people. Several WHO ICOPE guidelines and tools are available to support ICOPE implementation, namely:

- ICOPE Guidelines *(70)* provide evidence-based recommendations on what works to prevent, slow or reverse declines in the physical and mental capacities of older people.
- ICOPE implementation framework *(71)* assists policy-makers and programme managers concretely to assess and monitor the capacity of services and systems to deliver integrated care and develop action plans.
- ICOPE handbook and application, which are intended for health and care workers in the community and primary care, describe practical care pathways to detect declines in intrinsic capacity and to develop a personalized care plan.

These tools facilitate the implementation of the Decade of Healthy Ageing (2021–2030) in order to deliver integrated care and primary health services that are responsive to older people.

WHO package of interventions for rehabilitation

WHO is also currently developing a Package of interventions for rehabilitation (PIR), which will provide a set of evidence-based interventions for rehabilitation including for people with dementia (see **Box 23**).

BOX 23

Package of interventions for rehabilitation

This package consists of a set of interventions designed to optimize functioning and reduce disability in interaction with the environment for people with health conditions. With rising prevalence of NCDs and chronic diseases, ageing populations and more people surviving injuries thanks to improved access to health care, global rehabilitation needs are high and are expected to rise. Rehabilitation is essential in people with dementia as it can help them to achieve and maintain optimal levels of functioning by: 1) providing preventive, promotive, restorative and compensatory approaches that are tailored to an individual's needs and capacities; and 2) optimizing the individual's physical and social environment. Despite the benefit of rehabilitation in people with dementia, the gap between the existing rehabilitation needs and access to rehabilitation is evident, particularly in contexts with limited resources.

To address the lack of access to rehabilitation for people with dementia and other health conditions, WHO is currently developing the *Package of interventions for rehabilitation* (PIR). The PIR will provide a set of evidence-based interventions for rehabilitation that are essential to people with a health condition since they target aspects of functioning that are frequently impaired or limited but are amenable to rehabilitation. The interventions are effective, and the cost–benefit ratio favours the benefit. Specific consideration for the selection of interventions to be included in the PIR is given to the low- and medium-resource context. For all the interventions included in the PIR, information on the requirements for materials (assistive products, equipment, consumables) and human resources (workforce, time) will be available, and recommendations on the availability at service delivery platforms will complete the PIR.

The information available with the PIR will support ministries of health in planning, budgeting and integrating rehabilitation interventions both into all service delivery platforms and along the continuum of care, according to national needs and available resources. The PIR will also be useful for service planners, researchers, academics and service providers.

Concluding remarks

Action area 4 of the Global dementia action plan calls for countries to develop efficient, coordinated dementia care pathways that are person-centered and fully integrated into the health and social care system. Integrated dementia care pathways span the full care spectrum from dementia diagnosis and post-diagnostic support, through care and treatments, to rehabilitation and palliative care. The GDO monitors global, regional and country-level progress on diagnostic rates for dementia, the availability of community-based dementia services, access to dementia services, levels of coordinated care, and training and education of the health and social workforce for dementia.

Diagnosis is the first step to accessing dementia care pathways, and currently fewer than one-third of GDO countries are able to report dementia diagnostic rates, which falls far short of the global target of 50% of GDO countries reporting diagnostic rates. Additionally, there is a large variation observed between the diagnostic rates reported by countries of different income levels, with HICs on average reporting 50% diagnostic rates versus 29% for LMICs. With regard to the availability of community-based services, the majority of GDO countries report providing community-based services for dementia, although overall 20% more HICs than LMICs report providing these services. There is also a wide gap between country income categories with respect to urban versus rural inequities in terms of service availability. Community-based dementia services, including social and financial protection schemes, are more likely to be available in rural areas in HICs than in LMICs. A similar pattern is observed for health and social care facilities; while all or most countries report the availability of tertiary care facilities and outpatient health centres, all other facilities are more available in HICs than in LMICs.

Dementia-related health products are more available and more likely to be reimbursable in HICs than in LMICs, which has implications for the out-of-pocket costs to people living with dementia. Moreover, health and social workforce training remains inadequate in the area of dementia. While the majority of health service cadres receive some training globally, there are still significant proportions of the workforce that are not routinely trained in basic dementia competencies. Dementia-specific clinical guidelines, standards and protocols are essential for making health and social workforce training a reality but less than two thirds of GDO countries (58%) report having them. Additionally, just over half of GDO countries report having a mechanism to coordinate care across sectors for dementia.

Accelerating action in the area of dementia diagnosis, treatment and care necessitates increased global investments. Urgent action is needed to scale up evidence-based community interventions for dementia with adequate health and social workforce training and education, to close urban–rural inequities, and with adequate social and financial protections to reduce out-of-pocket costs to people with dementia and their carers.

“The quality of life of persons with dementia lies also in their carer’s hands. That’s why we need to support carers and enable them to provide good care to persons with dementia.”

Peach Wattanavitukul,
Thailand

8. Support for carers of people living with dementia

Context

"Support services for carers of people living with dementia should be considered an investment and not a cost."

Most people with dementia are cared for by family members or other unpaid carers without any additional support, especially in LMICs where the majority of people with dementia live. Carers often face numerous financial, social and psychological stressors, all of which may have been heightened due to the COVID-19 pandemic and can have a significant impact on their physical and mental health. This, in turn, can lead to a breakdown of informal home-based care for persons with dementia and affect their ability to live in the community for longer and age in place. An anticipated consequence of this can be the use of residential facilities. As such, support services for carers of people living with dementia should be considered as an investment and not as a cost *(74)*. The return on these investments translates into improved health and well-being of people with dementia and carers themselves and are associated with cost savings resulting from decreased health-care utilization over time. These services also generate important benefits to society through increased participation, consumption and social cohesion.

Carer policies, programmes and services currently remain underfunded and underdeveloped due to an overreliance on informal caregiving, which may in turn affect the likelihood that carers seek support. As identified in **Table 28**, caregiving also disproportionately affects women, who contribute roughly 70% of the global hours of informal care, with the highest proportion in LMICs. Although perceived social and gender norms vary across societies and countries, in many settings the general expectation that families have the obligation to provide care can represent a structural barrier to improving care policies.

TABLE 28

Female proportion of hours of informal care, by WHO region and World Bank income classification, 2019

	Female million hours (all ADLs)	Female % (all ADLs)	Female million hours (ADLs + supervision)	Female % (ADLs + supervision)
WHO region				
African Region	4 618	79.6	6 861	79.5
Region of the Americas	9 291	76.4	17 121	76.8
South-East Asia Region	9 616	77.2	13 657	77.6
European Region	14 339	68.2	20 043	67.6
Eastern Mediterranean Region	3 875	74.2	6 144	74.1
Western Pacific Region	19 745	60.4	28 678	61.3
Total hours	61 484	68.8	92 505	69.4
Income level				
Low-income countries	2 977	76.9	4 379	77.1
Lower-middle-income countries	14 202	76.0	19 696	76.0
Upper-middle income countries	26 122	63.9	37 702	65.3
Low- and middle-income countries	43 301	68.3	61 778	69.1
High-income countries	18 183	70.1	30 727	70.0
Total hours	61 484	68.8	92 505	69.4

Globally, there is a need for increased care and services integrated into, and funded by, national/subnational health and social systems – as well as social and financial support for carers of people living with dementia. Action area 5 of the Global dementia action plan focuses on delivering multisectoral care, support and services for carers. Carer supports and services are to focus on preventing decline in mental and physical health and improving social well-being in line with carers' needs. The global target associated with this action area is that *75% of countries will provide support and training programmes for carers and families of people with dementia by 2025*.

Achieving the global target requires providing accessible and evidence-based information, training programmes and respite services tailored to the needs of carers, as well as social and financial benefits. Concerted efforts by government in close partnership with civil society are also required to protect carers from stigma and discrimination, including through the implementation of policies, legislation and awareness-raising efforts. It also necessitates capacity-building of the health and social care workforce in order to identify and reduce carer stress and burn-out, and to promote the meaningful involvement of carers in care planning, policy and research.

> **"Concerted efforts by government in close partnership with civil society are also required to protect carers from stigma and discrimination, including through the implementation of policies, legislation and awareness-raising efforts."**

This chapter addresses each of these issues in turn by providing an overview of global progress made to date on the basis of available GDO data and complementary evidence-based examples and information. The chapter also addresses the impact of COVID-19 on carers' mental health, outlining spotlight activities carried out by WHO's secretariat to assist countries in supporting carers of people with dementia and also featuring country case studies. It should be noted that the chapter does not represent a comprehensive literature review. Rather, the goal is to provide a global overview of the current status in the area of support for dementia carers on the basis of GDO data, complemented by illustrative examples and information from peer-reviewed and grey literature.

Progress to date

Information, services and supports for carers

38%

higher provision of carer support services in HICs

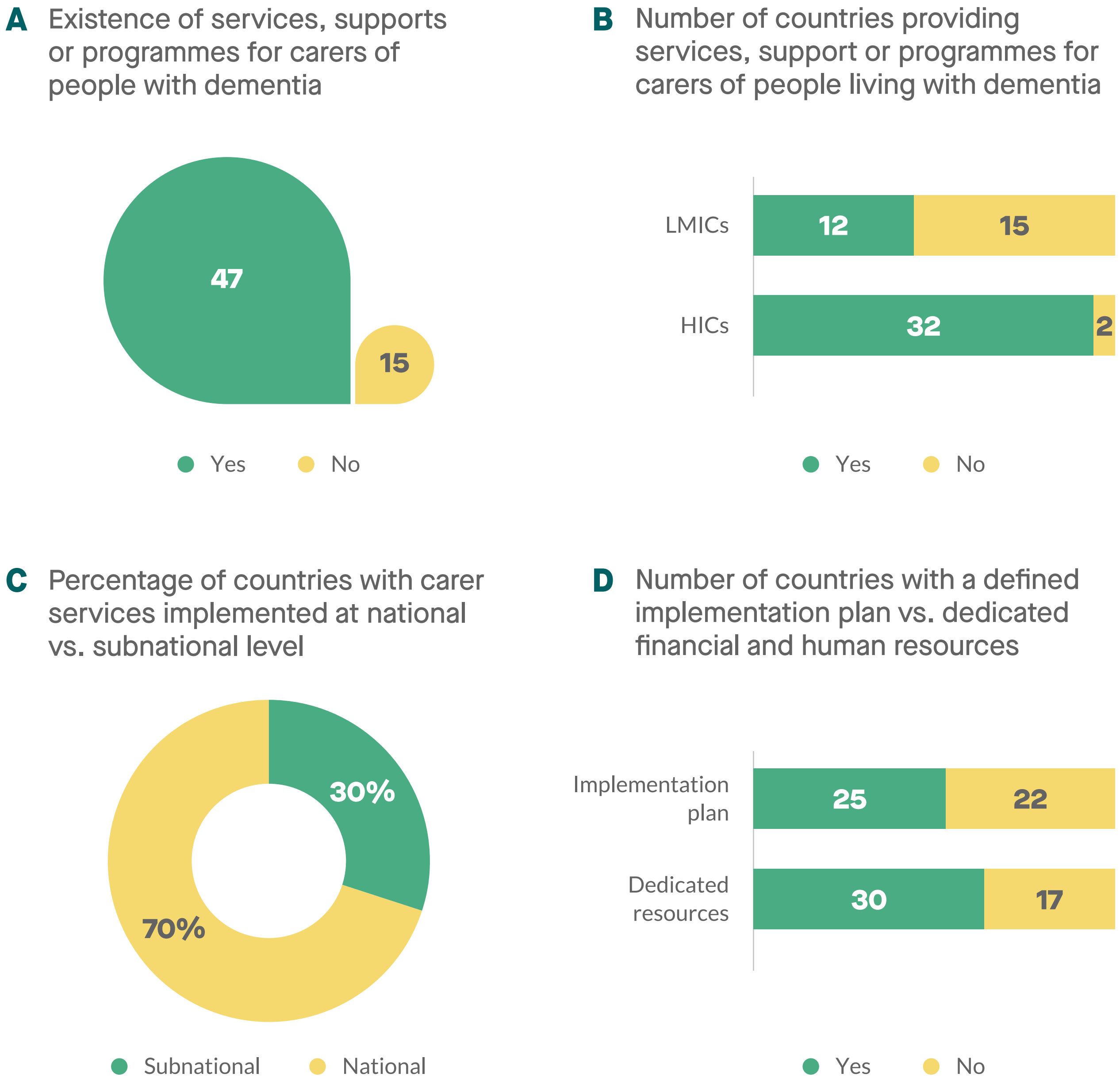
It is important that carers have access to supports and services tailored to their needs so that they may effectively respond to, and manage, the physical, mental and social demands of their caregiving role. The Global dementia action plan recommends that countries provide accessible and evidence-based information, training programmes, respite services and other resources tailored to the needs of carers. This support is important for improving knowledge and caregiving skills, such as coping with behaviour changes related to dementia to enable people living with dementia to live in the community for longer and to prevent stress and health problems for carers.

Of the 62 GDO countries, 47 offer services, supports or programmes for carers of people living with dementia (see **Figure 28a**). Of these 47 countries, more HICs provide carer services and supports compared to LMICs (see Figure 28b). Within the same subset of 47 countries, 70% have implemented carer services and supports at national level and 30% at subnational level (see **Figure 28c**). Moreover, **Figure 28d** shows that 63% (or 30 countries) of these countries have dedicated financial and human resources and 52% (or 25 countries) have a defined implementation plan for these services.

It should be noted that GDO country data, although encouraging, captures information from Member States with a relatively high level of dementia readiness. As such, this information should be interpreted with caution as data from additional countries (not currently part of the GDO) are likely to influence these findings significantly.

FIGURE 28

Existence, types, allocated funding and implementation status of carer services, supports and programmes



A Existence of services, supports or programmes for carers of people with dementia

B Number of countries providing services, support or programmes for carers of people living with dementia

C Percentage of countries with carer services implemented at national vs. subnational level

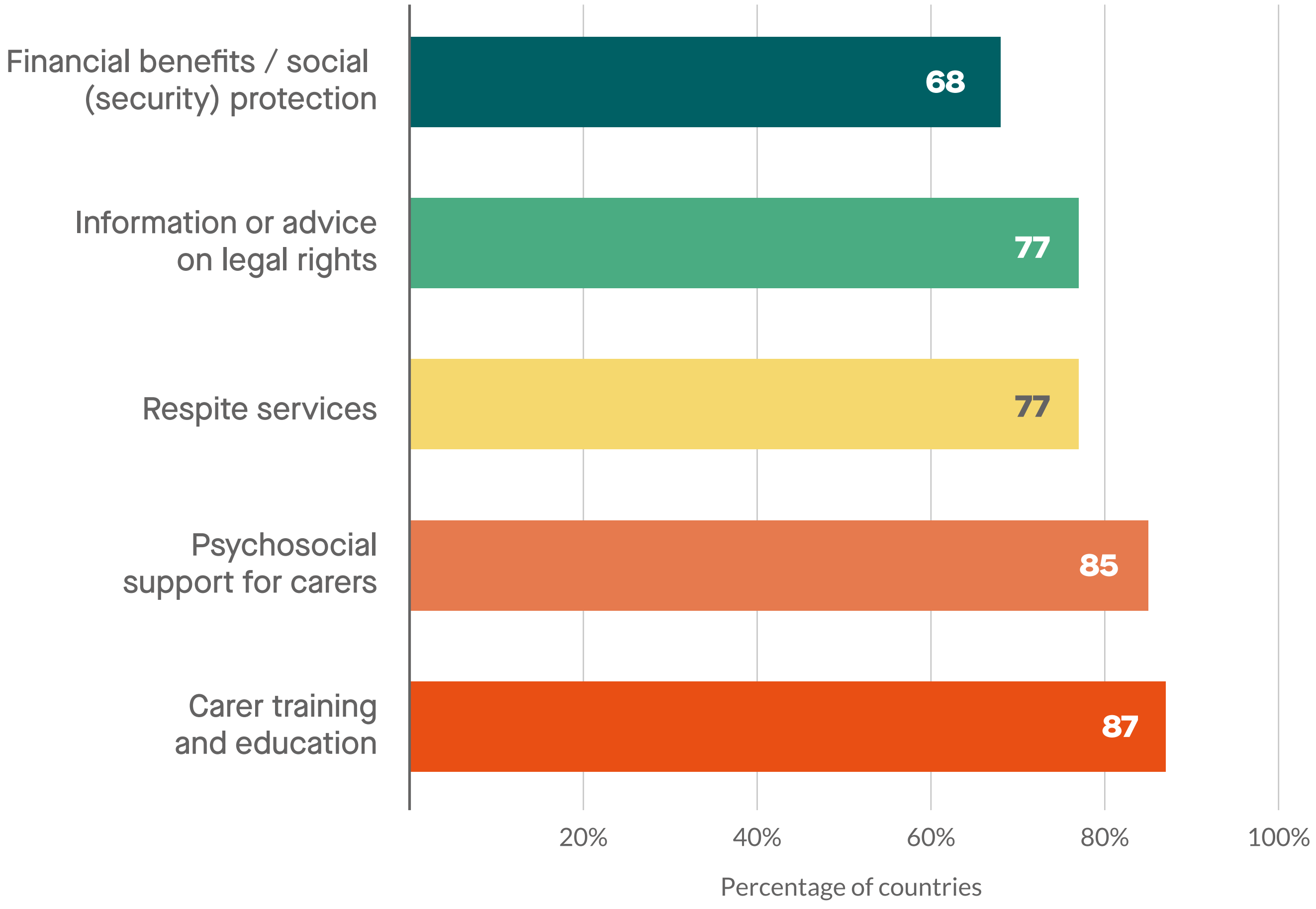
D Number of countries with a defined implementation plan vs. dedicated financial and human resources

Types of carer services and supports

Carer services and supports cover a broad range of programmes. **Figure 29** shows that, out of 47 countries that identified specific types of carer services and supports through the GDO, over 87% include carer training and education on dementia management, 85% include psychosocial support for carers, 77% include respite services, as well as information or advice on legal rights. However, only 68% report providing financial benefits/social (security) protection.

FIGURE 29

Types of carer services and support across countries



There are multiple recent noteworthy examples of carer programmes implemented by countries (also see **Box 24**). For example, Australia created the "Carer Gateway" in 2019 to connect carers to support services; the Danish Committee for Health initiated a national education programme for informal carers in 2018; Finland started to provide coaching on caregiving in 2018; and Malta implemented a national "Respite at Home" service in 2017 *(75)*. Some countries – including Germany, Japan and the United Kingdom – have promoted an overarching vision of dementia care. For example, legislation such as the United Kingdom's Care Act (2014) *(76)* recognizes carers as both partners in care planning/delivery and clients of health and social support services. As part of this legislation, carers receive assessment and support throughout the caregiving trajectory and following the death of the person living with dementia. Recently, some countries have also initiated or reinforced mechanisms for the financial support of carers. For instance, with the approval of the carer statute (Law no. 100/2019) in Portugal, an allowance for primary carers became available at subnational level. In 2017, the Irish Government extended carers' financial allowance for 12 weeks after the death of the person in care or his/her entry into long-term institutional care.

Additionally, a recent systematic review and meta-analysis found that multi-component interventions for carers of people living with dementia can have broad-ranging impacts on quality of life for people living with dementia, depressive symptoms and on BPSD, and also impacts on carers *(77)*.

However, ongoing gaps in carer services and supports remain, particularly in LMICs. A number of countries still lack training and information services for carers. When carer services and supports are available, many remain underutilized due to a lack of knowledge about them *(78)*. Carer support is also frequently fragmented across sectors and is not person-centred *(79)*.

"Ongoing gaps in carer services and supports remain, particularly in LMICs. A number of countries still lack training and information services for carers. When carer services and supports are available, many remain underutilized due to a lack of knowledge about them."

BOX 24

Dementia Intervention Team – responding to community carer needs in Malta

In response to the growing challenge that dementia is posing on the Maltese society at large, in 2015 Malta launched its first national dementia plan entitled *Empowering Change: A National Strategy for Dementia in the Maltese Islands (2015–2023)* with the objective of enhancing the quality of life of persons with dementia, their carers and family members. Among the various intervention streams highlighted in the strategy document, community-based dementia management, care and support were considered priorities in need of urgent attention. In view of this, a specialized team of multidisciplinary health and social care professionals (the Dementia Intervention Team) was developed with the aim of providing support to individuals with dementia and their informal carers in their home environment. Even though this service was initially launched as a pilot project manned by two health-care professionals, it soon gathered momentum.

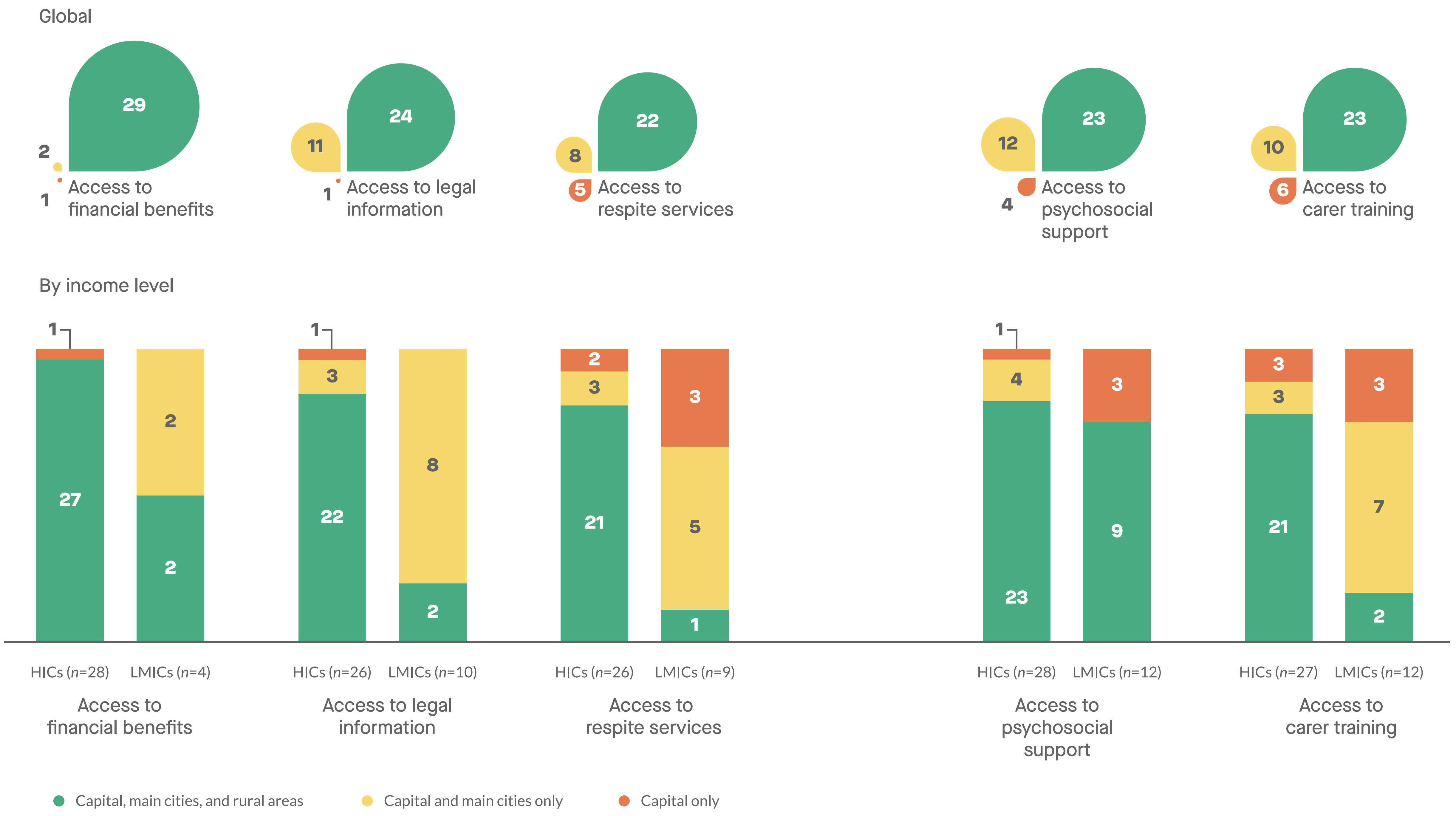
Currently, the service boasts six highly skilled professionals who visit more than 600 community-dwelling individuals with dementia and their carers per year. Through a dedicated landline, the team is in constant contact with carers who require advice on various issues related to dementia care. In collaboration with the National Dementia Helpline and working closely with community-based clinicians and geriatric specialists, the team identifies and intervenes in cases that need urgent intervention. It also acts as a main body of advice for carers on other support services that are available and, as a member of the National Dementia Working Group, is involved in shaping dementia policy. The importance of such a service was highlighted during the COVID-19 pandemic in which the team played a central role in ensuring that persons with dementia obtain the right information pertaining to the effects of the pandemic on their well-being.

Availability of carer services and supports

The GDO measures the geographical distribution of carer services and supports – i.e. whether these are available across: 1) the capital, main cities and rural areas; 2) the capital and main cities; or 3) the capital. **Figure 30** shows that, of the countries that responded to this indicator, most provide all types of carer services, supports or programmes across urban and rural settings. More specifically, while the majority of HICs provide all carer services and supports across urban and rural settings, these programmes tend to be concentrated in urban settings only for LMICs. Making it difficult if not impossible for carers in rural areas to access services. Moreover, financial and social protection is more frequently provided in HICs as compared to LMICs (**Figure 30**). Importantly, while availability of services is a prerequisite of access, it says very little about service coverage and utilization. Although the GDO attempts to measure service utilization, countries at large are not able to provide that information due to a lack of available data.

FIGURE 30

Accessibility of carer services and supports



> **"Importantly, while service availability is a prerequisite of access, it says very little about service coverage and utilization. The GDO attempts to measure service utilization, but countries at large are not able to provide that information due to lacking data."**

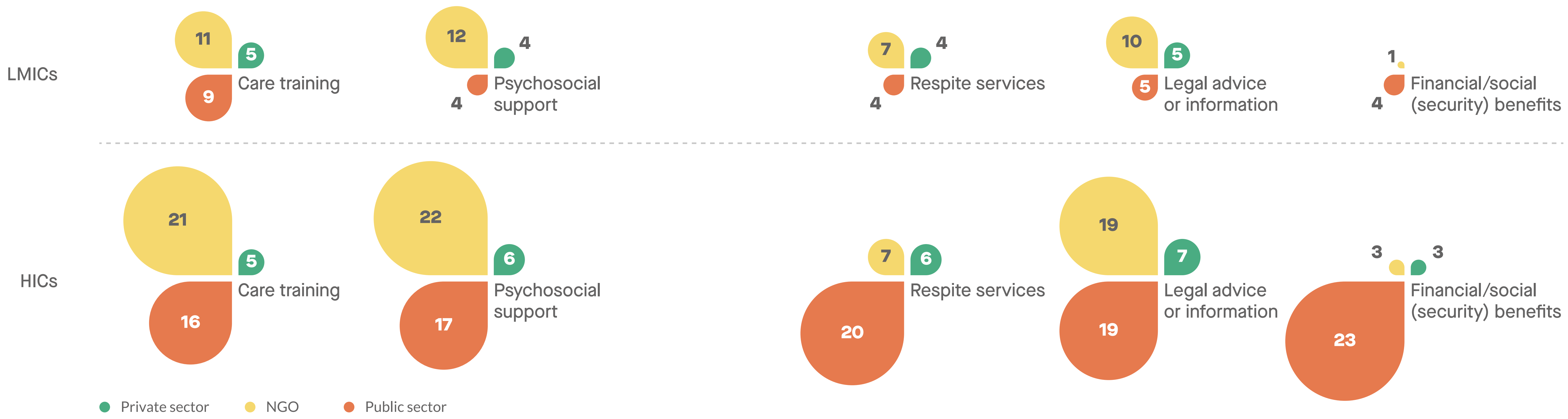
The GDO also measures who the majority service provider of carer supports is – i.e. whether the supports are offered by the public sector, private sector or a nongovernmental provider. **Figure 31** shows that, across countries, NGOs are the majority providers of legal advice or information, psychosocial support and carer training. In contrast, the private sector is the majority provider of respite services and financial benefits/social (security) protection. The data disaggregated by income level show that NGOs are the majority providers for all carer services and supports in LMICs – except financial benefits/social (security) protection which is provided mainly by the public sector. In HICs, the public sector represents the majority provider for respite services and financial benefits/social (security) protection, while NGOs are the main providers of carer training and education as well as psychosocial support. Legal information or advice is provided equally by NGOs and the public sector in HICs, according to GDO data.

The reliance on NGOs and civil society organizations for providing carer support services, however, comes at the risk of being short-lived and lacking coordination *(80)*.

Monitoring service availability and use is key to understanding which services benefit carers, at what time and in which context. Understanding the effectiveness of carer services and supports in both clinical and community settings and how such findings are incorporated into health and social systems is also important. Another important issue relates to determining whether under-represented carer groups receive appropriate support, such as older carers with specific physical and mental health needs *(81)*, or carers who are illiterate, have low levels of health literacy, live in rural areas, or who are migrants *(82)*, refugees or from other vulnerable groups. Strengthening health and social information systems to collect and report on equity measures is particularly important in this regard, especially in low-resource settings. In this regard, gaps in health information systems and infrastructure limit comprehensive reporting by countries on all GDO indicators related to dementia carer support.

FIGURE 31

Majority provider of carer services, programmes and support



BOX 25

Carer schools in Norway: information and training for relatives and carers of people living with dementia

The Norwegian Dementia Plan aims to promote the development of good, flexible and tailored municipal health and care services that focus on prevention, timely diagnosis, post-diagnostic follow-up, daily activity, housing and education. People with dementia and their families need information about dementia, support and access to arenas where they can meet others in the same situation. Therefore, grants were established that all municipalities can apply for to participate in an educational programme of "Carer schools" and support groups. A manual for establishing the measure in the municipalities was developed and implemented nationally through the grants. The municipalities receive material for information and guidance. Some 66% of the municipalities participated in the programme and arranged the courses in 2018–2019.

Regional measures have also been established. "Meeting for coping" provides courses for people with early onset dementia together with their partners, and "Time to be young" provides information and an arena for the children of people with dementia. A national summer camp is arranged for the youngest children together with the parent who does not have dementia.

Courses tailored to carers from ethnical minority groups and the Sami people, and for people with intellectual disabilities, have been developed and implemented, including through e-learning. Carers can also attend courses to receive guidance on how to tell their stories to support other carers.

The experiences of family members who have followed the educational programmes and the different courses are systematically evaluated and responses have in general been very positive. Examples of common statements from participants are: *"I feel better prepared to meet the future"* (person with dementia); *"We travel back feeling richer both individually and as a couple"* (carer); and *"I am more motivated to be open both towards my family and friends, and to seek help when necessary"* (young carer).

Carer protection

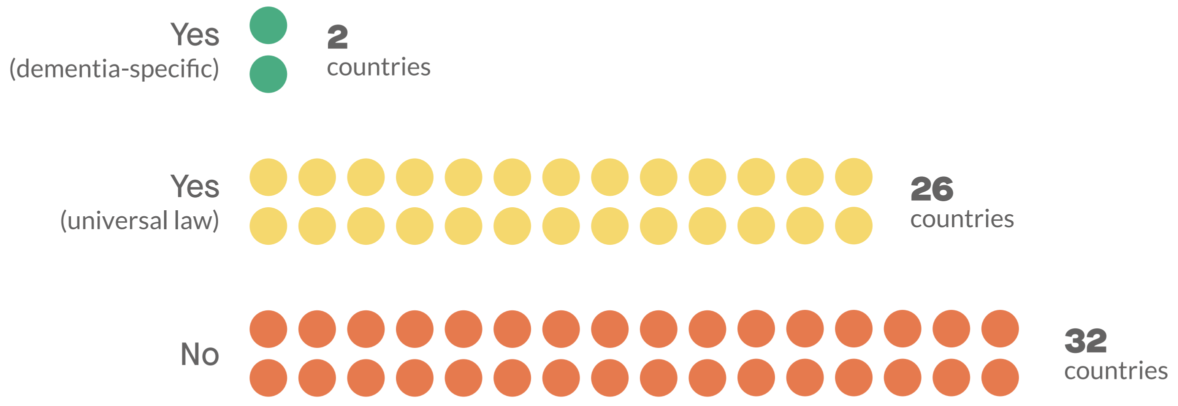
Globally, people living with dementia and their carers continue to suffer from stigma, discrimination and human rights violations, in part due to limited public awareness of the caregiving role and carer needs *(83-85)*. Stigma and discrimination result in delayed diagnosis, increased carer burden, depression and social isolation, as well as reduced help-seeking behaviours and capacity to provide care to the person living with dementia over the long term *(86)*. Public awareness and education campaigns, co-designed with carers, are promising approaches for addressing stigma and enhancing the recognition of the carer's role by employer and society *(39, 87)*. Recent examples of such initiatives include the celebration of national "carer days/weeks/months" (e.g. in Canada and the United States of America), media campaigns (e.g. in Sweden *(87)*) and caregiving conferences and events (e.g. in Slovenia *(75)*). Global movements, such as the "Embracing Carers" campaign, have also begun to emerge in an effort to promote greater visibility and awareness of carer challenges, to support increased policy attention and action, and to create innovative opportunities for integration into the health-care system.

Stigma and discrimination are multilevel social phenomena involving structural, intrapersonal and interpersonal issues *(88)*. Structural stigma can be tackled at policy and service level by, for instance, proposing anti-stigma actions that are feasible and measurable, using nondiscriminatory language (e.g. avoid calling dementia "a burden to society"), and reporting on equity indicators related to service access and use, stratified by different population groups. To address stigma against carers of people living with dementia, the Global dementia action plan recommends that countries develop or strengthen the protection of carers, including through policies and legislation against discrimination, and support them beyond their caregiving roles in all settings.

Of the 43 GDO countries with stand-alone, integrated or subnational dementia plans, 37 included carer support as an action area. National dementia plans represent important first steps in protecting carers and responding to their multiple needs. Fewer than half the countries (26 or 44%) indicated having legal provisions that aim to end discrimination against family carers included in universal laws, while only 2 indicated including these in dementia-specific legislation (see **Figure 32**).

FIGURE 32

Countries with legal provisions to end discrimination against carers of people with dementia



In some countries, carers' responsibilities are protected under equal opportunity and anti-discrimination legislation (i.e. universal laws), especially concerning the workplace *(89)*. A recent example in this area is the introduction of new federal legislation – the Protecting Family Carers from Discrimination Act (2020) – in the United States of America. A few countries also protect family carers from "discrimination by association" – i.e. discrimination against someone associated with a person living with dementia – as in the Equality Act in the United Kingdom (2010). Other countries have developed specific legislation to recognize and support carers' roles. For example, in 2019 France adopted a legislation to promote the recognition of carers, secure their social rights and provide them with information and support *(75)*. Other similar initiatives are seen, for instance, in Belgium (2019), Italy (2019) and Portugal (2019) *(75)*. Some countries have also dedicated new budget allocations to operationalize legislative measures on caregiving. While promising, complicated bureaucratic processes that do not take into account the accessibility needs of carers (e.g. literacy) may prevent the formal recognition of carers and hinder their access to financial and social support, particularly among carers with lower education or socioeconomic status (80).

Health and social care worker training

The Global dementia action plan recommends that health and social workers are trained to identify and reduce carer stress and burn-out. GDO data reveal that efforts to train the health and social care workforce in dementia core competencies, including assessment and treatment of carer distress, remain insufficient. As noted in Chapter 7, out of 59 countries reporting on this GDO indicator, no more than 5% across all WHO regions have trained *all* health and social care workers in core dementia competencies. Additionally, while 37 GDO countries report including carer support in a dementia plan, only 37% all countries (23 of 62) report having standards, guidelines or protocols for carer treatment and support.

Indeed, critical gaps in education and training for the health and social care workforce, including a lack of knowledge related to the assessment and treatment of carer distress, continue to be identified by stakeholders in the dementia field *(90)*. One promising example is England's national Dementia Training Standards Framework which includes educational content and learning outcomes for health and social care staff focused on carers' support needs (2015, updated in 2018) *(91)*. Health and social care workers need to understand carers' roles and be able to effectively communicate with them, foster their mental and physical resilience, empower them, and guide them through accessing services and resources *(92)*. This is particularly important for carers who have low levels of literacy or education, and who are from vulnerable or lower socioeconomic groups (e.g. migrants, refugees, cultural or religious minorities) *(62)*.

37%
of GDO countries have guidelines on carer support

Impact of COVID-19 on dementia carers

The COVID-19 outbreak brought new challenges to informal carers. Lockdowns limited the range of services offered to people living with dementia, resulting in delayed access to diagnostic and post-diagnostic care and a significant impact on cognitive health *(93-95)*. Carer support programmes such as respite services offered through day centres were also frequently discontinued (96). The disruption of formal services has resulted in increased social isolation and a more intensive care burden, having an impact on carers' physical and mental health – potentially over the long term (96, 97). According to *WHO's rapid assessment of the impact of COVID-19 on mental, neurological and substance use services* more than 20% of surveyed WHO Member States reported that services for carers of people with mental, neurological and substance use disorders were completely disrupted due to the pandemic (4). Additionally, as outlined in *WHO's updated infection prevention and control guidance for long-term care facilities in the context of COVID-19 (98)*, it is important to consider the impact of visitation restrictions on the health and well-being of people with dementia who live in institutional or hospital settings and their family members, and the need to recognize carers as core partners of the care team. While limiting face-to-face interactions represents an important step in controlling the spread of infection in nursing and long-term care facilities, these procedures have resulted in the increased isolation of people with dementia and significant worry among health-care staff concerning residents' well-being *(39)*.

While many countries included paid leave policies and special allowances for childcare in their national COVID-19 response, social and financial benefits for carers of older relatives were rarely included *(99)*. This policy gap may expose carers of people living with dementia to a double burden of caregiving while working from home full-time *(100)*. Together these factors are likely to contribute to a decreased capacity to provide care over the long term, which is associated with premature institutionalization of the person living with dementia (101).

To address some of these issues, digital interventions have gained momentum in facilitating carer access to training and support. Evidence shows that Internet-based interventions can be beneficial in reducing symptoms of anxiety and depression, diminishing subjective burden and improving the quality of life among carers of people living with dementia, including during COVID-19 lockdowns *(102-104)*. However, increased demands and stress resulting from COVID-19 measures may result in carers having less time to use online interventions. In addition, older, less educated and socioeconomically disadvantaged carers may not have access to new technologies *(105)*. As a result, further efforts are needed to develop online solutions that respond to carers' cultural, accessibility and socioeconomic needs, and to help overcome the technology gap. More generally, additional evidence is required to better understand the design, benefits and outcomes of digital interventions for carers.

The way forward

While wide variations exist between countries, access to and availability of carer services remain particularly limited in LMICs, where the majority of people with dementia are cared for at home in the community. Achieving the global target requires establishing appropriate services, support and training that are accessible to carers in their communities, in partnership with civil society and international partners. Effective training programmes represent an important element in building carers' capacity to protect their mental and physical health and well-being and enabling them to continue providing care over the long term. Ensuring that health and social workers are appropriately trained to identify and manage carer stress and burn-out is also key to supporting carers in the community. Digital health programmes – such as WHO's iSupport, mDementia and e-mental health Gap Action Programme (e-mhGAP) – represent opportunities to overcome barriers related to access and cost as well as service discontinuation due to COVID-19.

Due attention should be given to addressing stigma, discrimination and competing responsibilities (e.g. childcare, work obligations), which constitute important barriers to carers in seeking available support. Carer protection – in the form of social, financial and disability benefits, policies and legislation against discrimination – is an important prerequisite to supporting carers beyond their caregiving role and enhancing service demand. The forthcoming Intersectoral global action plan on epilepsy and other neurological disorders represents a significant opportunity to strengthen legislation and embed carers in the care continuum within the broader context of neurological disorders. **Figure 33** outlines the actions included in the Global dementia action plan, key barriers to implementing these and strategies to overcome them through accelerators for action. Key accelerators are subsequently reviewed.

> **"Effective training programmes represent an important element in building carers' capacity to protect their mental and physical health and well-being and enabling them to continue providing care over the long term."**

FIGURE 33

Proposed actions, identified barriers and opportunities to accelerate action to support dementia carers

PROPOSED ACTIONS

- Implement carer training and education programmes
- Train health and social care workers to identify and reduce carer stress and burn-out
- Develop/strengthen protection for carers
- Empower carers, including participation in care planning

BARRIERS

- Lack of appropriate and accessible training and education
- Service disruption due to COVID-19
- Lack of training on dementia core competencies
- Lack of legislation to end discrimination and ensure carers' financial protection
- Carers not perceived as core members of the care team

OPPORTUNITIES TO ACCELERATE ACTION

- Implement digital health solutions to increase carer access to training and address service discontinuation, including through WHO's iSupport, iSupport Lite and mDementia (Support) programmes
- Implement and/or scale up WHO's mental health mhGAP, including through the mhGAP Intervention Guide, guidelines, community toolkit and mhGAP e-learning
- Leverage synergies with the forthcoming Intersectoral global action plan on epilepsy and other neurological disorders (World Health Assembly resolution WHA 73.10)

Digital health solutions to support carers of people with dementia

iSupport

In 2017, WHO launched iSupport[6], an online knowledge and skills training programme for carers of people with dementia, to support Member States in achieving the global target that *75% of countries will provide support and training programmes for carers and families of people with dementia by 2025*. iSupport is a self-help tool and aims to prevent and/or decrease mental and physical health problems associated with caregiving, and to improve the quality of life of those caring for people with dementia. iSupport includes five modules and accompanying exercises, namely: 1) Introduction to dementia; 2) Being a carer; 3) Caring for me; 4) Providing everyday care; and 5) Dealing with behaviour changes. iSupport is available both as an online programme and as a manual that can be printed and used offline, allowing for a broad reach of the programme, particularly in regions of the world with low Internet bandwidth and/or connectivity.

iSupport can be adapted to national or local contexts and needs. Once adapted, carers can choose to work through all modules and lessons consecutively or select the lessons that are most relevant to their everyday lives. All lessons consist of brief readings, descriptive examples, and several exercises. Carers receive feedback as they work through each exercise.

iSupport is currently being adapted in over 20 countries, including Australia, Brazil, China, Czechia, France, Greece, Indonesia, Ireland, Japan, Malta, Mexico, Netherlands, New Zealand, Nigeria, Portugal, Qatar, Spain, Switzerland, Tunisia, the United Kingdom and Viet Nam and Wales. Lessons learned thus far from country implementation include the importance of conducting multistakeholder user-testing and focus groups in order to appropriately tailor the programme to local needs, the need to align iSupport with emerging technological developments and trends, and the usefulness of building on other countries' experiences.

Multiple studies of the feasibility and effectiveness of iSupport in improving carer health outcomes are underway. Preliminary findings to date indicate that: 1) carers identified iSupport as an online platform that can meet their educational and care management needs; and 2) health and social care providers can play an important role in promoting the programme *(106)*. For instance, among Portuguese carers, most of the themes reported as training needs are covered by iSupport *(63)*. The programme has also shown potential in fostering among carers positive and person-centered attitudes towards people living with dementia. In Brazil, preliminary research data show that iSupport

---

[6] See: https://www.who.int/publications/i/item/isupport-for-dementia (accessed 11 July 2021).

is easy to understand and is culturally relevant *(107)*. iSupport can also be integrated into the continuum of services and programmes offered to carers at national level *(64)*.

iSupport Lite

In 2020, the COVID-19 pandemic and resulting breakdown of community-based services for people with dementia and their carers emphasized the importance of providing carers with accessible public health messages to reduce carer stress and improve their mental health and well-being. Therefore, WHO launched iSupport Lite,[7] consisting of a set of short, practical support messages for carers of people with dementia extracted from iSupport. iSupport Lite offers tips for carers of people with dementia in the form of a video, posters, and questions and answers.

Practical tips for carers of people with dementia

Reach out for support

Caring for someone with dementia can be overwhelming. Ask for help when you need it – from family members, local associations or health and social services.

WHO's **iSupport programme** may also help you.

World Health Organization

Practical tips for carers of people with dementia

Reaching out to others for help

You are not alone
Caring for someone with dementia can be overwhelming and does not need to be a lonely experience.

Ask for help
Describe your problem and what kind of help you need. Be flexible – maybe you will not get exactly what you asked for, but it is a start and it will be helpful.

Use available support services
Services, such as self-care guidance, caregiver training, respite, or informal support groups may be available within your community, or online.

Consider different types of help
You may wish to ask for practical help such as housecleaning, or preparing a meal; help doing pleasant activities with the person with dementia such as asking family members to read to the person; emotional support; or collecting information on dementia.

For more information
iSupport Module 2 "Being a caregiver" Lesson 1 "Involving others"

Check your local Alzheimer's Association's website or call your doctor's office to find out more information.

iSupport For Dementia

World Health Organization

---

[7] See: www.isupportfordementia.org (accessed 11 July 2021).

mDementiaSupport

mDementiaSupport is part of WHO's mHealth dementia programme (53). Its content is based on WHO's iSupport programme which aims to improve the quality of life of carers of people living with dementia and prevent and/or decrease mental and physical health problems associated with caregiving. It extracts key messages from each of the five modules included in iSupport, which can be disseminated through one- and two-way SMS messaging. mDementiaSupport is particularly relevant in reducing carers' social isolation and overcoming the caregiving burden associated with disruption of home and community service due to COVID-19.

Concluding remarks

While progress is being made to support carers of people living with dementia, there continue to be wide variations both between and within countries with respect to the types of services, supports and programmes accessible to carers. Where these services and supports are available, significant disruptions to due to COVID-19 restrictions have been reported within the context of home and community care, resulting in increased carer burden and stress.

From a legislative and policy standpoint, much can be done to better protect carers from stigma and discrimination in communities, care settings and workplaces, and to ensure that they are supported through financial and social security benefits.

Finally, increased investments in the scale-up of dementia care services and building the capacity of the health and social care workforce are necessary in order to identify and manage carer stress and burn-out more effectively, to involve carers as core members of care teams, to promote their health and well-being and provide training and education.

9. Dementia health information systems and monitoring

> **“The development and implementation of a dementia action plan becomes a whole lot more difficult when there is little or no key dementia data recorded. A plan is reliant on systematic monitoring of a core set of dementia indicators to guide evidence-based actions for the services and standards required and measures for the implementation.”**
>
> **Alister Robertson,**
> New Zealand

Context

Action area 6 of the Global dementia action plan focuses on health information systems for dementia. The collection and analysis of data are used to inform the trends of several indicators – including the burden of dementia, prevalence of risk factors, disease mortality and service provision. Effective and routine monitoring of dementia-related indicators is essential to support the formulation and implementation of evidence-based policy, service planning and delivery, and to track progress at national and subnational levels. Establishing health information systems for dementia is also aligned with objective 4 of the Mental health action plan (to strengthen information systems, evidence and research for mental health). Moreover, it contributes to tracking progress towards achieving SDG 3 (good health) and targets 3.8 (UHC), 3b (Support research, development and universal access to affordable vaccines and medicines) and 3c (Increase health financing and support health workforce in developing countries).

Based on available GDO data, this chapter focuses on demonstrating the existence of health information systems and identifying gaps and opportunities associated with monitoring dementia data across countries.

The Global dementia action plan sets a global target of having 50% of countries routinely collecting a core set of dementia indicators through their national health and social information systems every two years by 2025.

Progress to date

Global monitoring of core dementia indicators

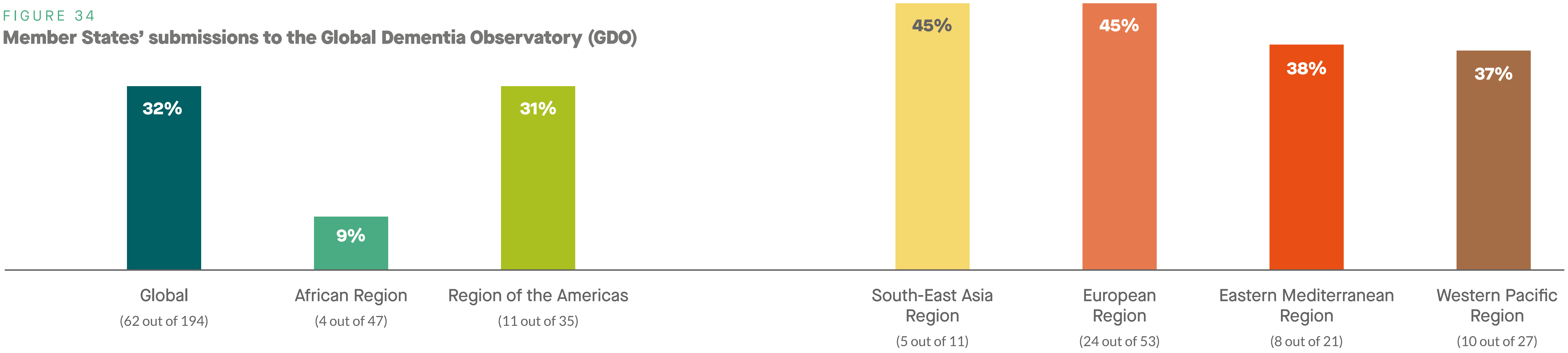
To date, 62 Member States have submitted GDO data (32% of all WHO Member States), with significant regional/geographical variation (**Figure 34**). Of the countries that have submitted data to the GDO, 56% are HICs, while 44% are LMICs. Together, countries participating in the GDO account for 65.5% of the global population and 76% of the population aged 60 years or older. Countries' response rates can be used as a proxy measure to assess their ability to report on dementia data. Moreover, the shortage of responses originating from low-income countries demonstrates that it is imperative to support countries in strengthening their health systems and health infrastructure, and in building capacity to enable effective health information systems, especially where resources are limited.

Although data completion for GDO indicators was overall satisfactory – especially for those indicators relating to dementia law and policy, service availability and training – the response rate was particularly low for other indicators that required the quantification of users receiving a service and physical installations that provided the services. Notably, on average 93% of countries were not able to report on the quantification of services provided to carers (e.g. proportion of carers receiving a particular service), and approximately 80% of countries could not provide complete data related to the availability of health and social care facilities. Overall, countries encountered major challenges in reporting indicators that reflected the quantitative availability of services/personnel/health infrastructure as well as the number of people providing/receiving such services.

Indeed, according to the countries participating in the GDO, only 31% routinely monitor people with dementia and, among those, 79% report having electronic records of these data. The lower response rate in these indicators is a reflection of the scarcity and difficulty that countries often encounter in obtaining and providing data at national level.

FIGURE 34

Member States' submissions to the Global Dementia Observatory (GDO)



National reports on dementia

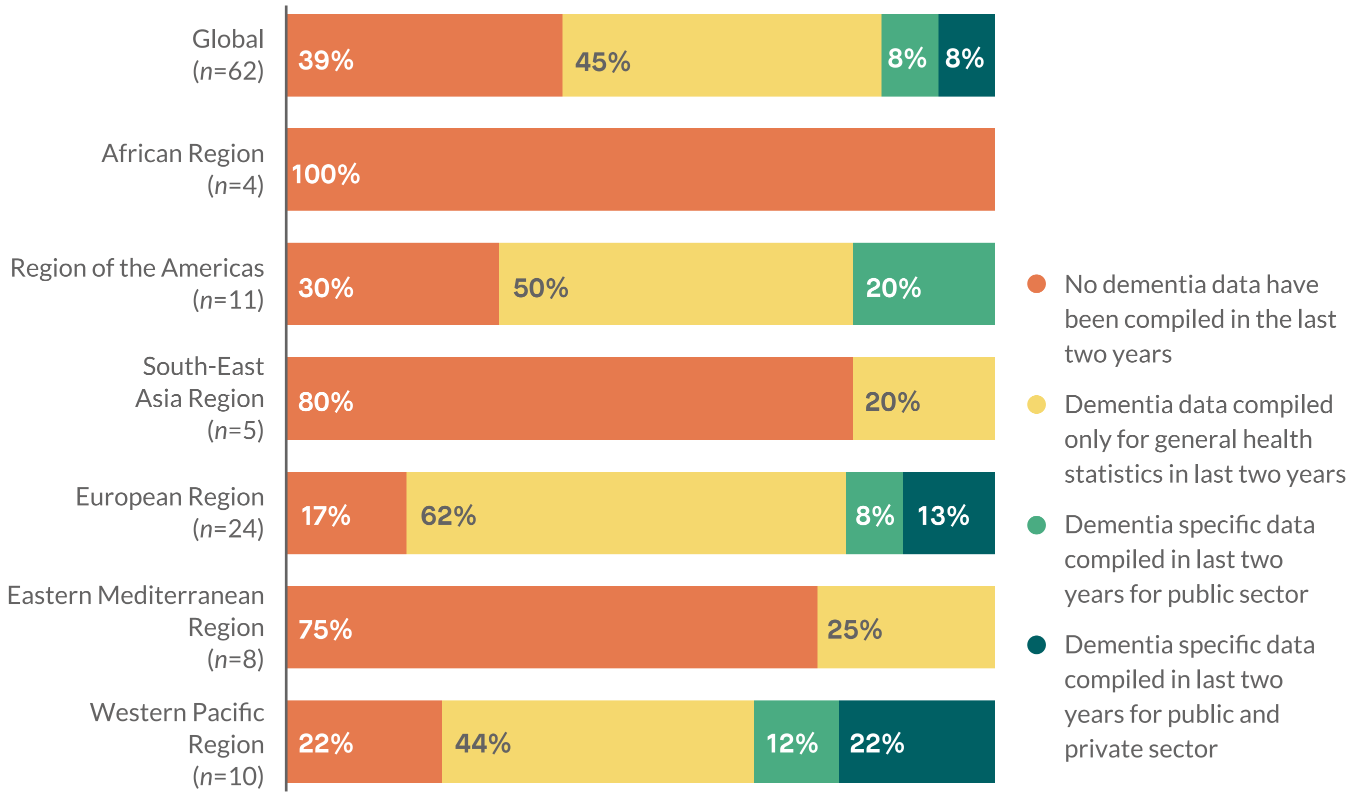
Systematic, routine population-level monitoring of dementia indicators is essential to guide evidence-based actions to improve services and to measure progress towards implementing national dementia policies. Moreover, the evaluation of health and social care data can help to identify gaps in service delivery, improve accessibility to, and coordination of, care for people with dementia, and allow a better understanding and detection of population-level changes and trends. By building and/or strengthening information systems for dementia, the functional trajectories of people with dementia, their carers and families can be improved.

It is noteworthy that specific reports on dementia can raise the profile of dementia and effectively support the policy-making process.

Globally, fewer than 1 in 5 countries collected public- and/or private-sector dementia information and compiled it in a dementia-specific report. Some 45% of GDO countries, at least, compiled dementia data (in either the public system, or the private system, or both) for general health statistics but not in a specific report, while 37% of the countries affirmed that no dementia data have been compiled in a report for policy, planning or management purposes (**Figure 35**).

FIGURE 35

Extent of dementia monitoring and reporting in GDO countries by WHO region



The low number of specific reports, or even the lack of general reports including dementia, show that it is still necessary to raise awareness of the importance of having monitoring systems for dementia.

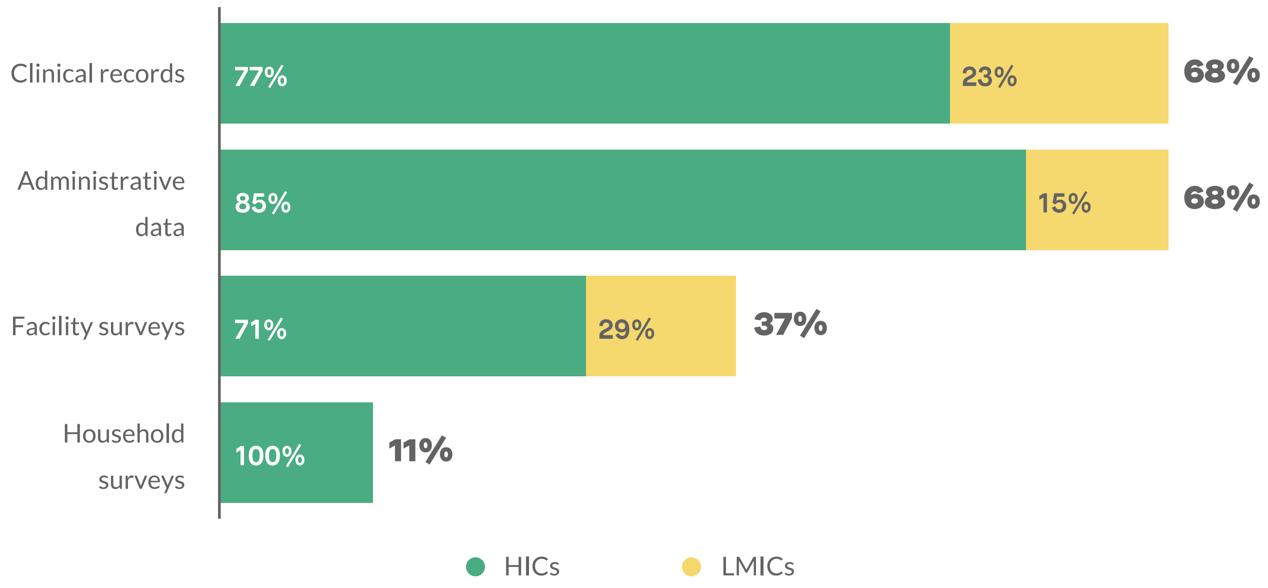
Data sources to monitor people living with dementia

National surveillance and monitoring systems are important assets for improving the availability of high-quality and multisectoral data on dementia. Thus, implementing dementia registers that are fully integrated with existing national health information systems can be a powerful tool to ensure access to health and social care data, and to monitor resource implementation at national and regional levels. At the policy level, out of 43 GDO countries that indicated having any kind of dementia plan, 34 include the promotion of monitoring and information systems for dementia. However, of these 34, only 14 report routinely monitoring people with dementia, showing that further action is needed to translate the goals outlined in the dementia plans into reality.

In total, 19 GDO countries report routinely monitoring people with dementia. Among these, a range of different sources are being used to collect the data, with 68% collecting data from clinical records (77% HICs, 23% LMICs) or administrative data (85% HICs, 15% LMICs), 37% from facility surveys (71% HICs and 29% LMICs) and 11% from household surveys (100% HICs) (**Figure 36**).

FIGURE 36

Sources of data used in monitoring people with dementia



In line with the Global dementia action plan's cross-cutting principle of equity, an important issue remains the collection of appropriately disaggregated data in relevant dimensions addressing, for instance, common health inequities and, in turn, the use of those data to design valuable interventions and increase the rate of successful implementation. In this context, 84% of the 19 GDO countries that routinely monitor people with dementia indicate being able to disaggregate the numbers of people with dementia (e.g. by sex, age, type of dementia). However, since only 31% of GDO countries are routinely monitoring people with dementia, the share of countries that possess these types of data represents just 26% of the total. Moreover, although 84% of GDO countries that routinely monitor people with dementia are able to disaggregate data, almost all (14 out of 16) are HICs.

Monitoring of health services

The establishment of monitoring systems is paramount to identifying gaps in service provision, ensuring appropriate funding allocation and developing evidence-based policies. Moreover, such surveillance systems are indispensable tools for the evaluation of services that are already in place or that were recently implemented. Together with the monitoring of health-care services, the monitoring of social care services can provide quality surveillance and support a comprehensive reporting of care services. Moreover, better links between hospital and long-term settings can improve communication and the flow of data across the care network and help to: 1) break silos of some settings; 2) provide the means for better quality controls; and 3) facilitate the continuation of care.

BOX 26

Germany's national dementia strategy as an example to monitor country-level action

Germany's national strategy on dementia was developed between 2019 and 2020.

It builds on previous initiatives of the federal government such as the so-called "Alliance for people with dementia", on existing measures of the long-term care insurance and health insurance systems, as well as on activities of the federal states (Länder) and non-governmental organisations. In addition, dementia plans and guidelines of other countries and international organisations were taken into consideration.

Governmental actors of different policy areas and administrative levels, as well as over 50 relevant organisations and interest groups were involved in the drafting process. The strategy identifies four priority fields of action:

1. building dementia-inclusive communities,
2. improving support for persons living with dementia and their family caregivers,
3. improving medical care, nursing care and long-term care for people with dementia, and
4. promoting research on dementia.

All involved actors agreed on 27 goals and 162 measures to substantially improve the situation and living conditions of persons with dementia and their families. Many measures thus focus on enhancing the quality of everyday life of people living with dementia and the quality of care in various care settings. Examples of such measures are increasing the number of local dementia networks, conducting coordinated campaigns on dementia-awareness, more training on dementia for different target groups, promoting dementia-friendliness in hospitals and long-term care facilities, and fostering research and better transfer of research results into practice.

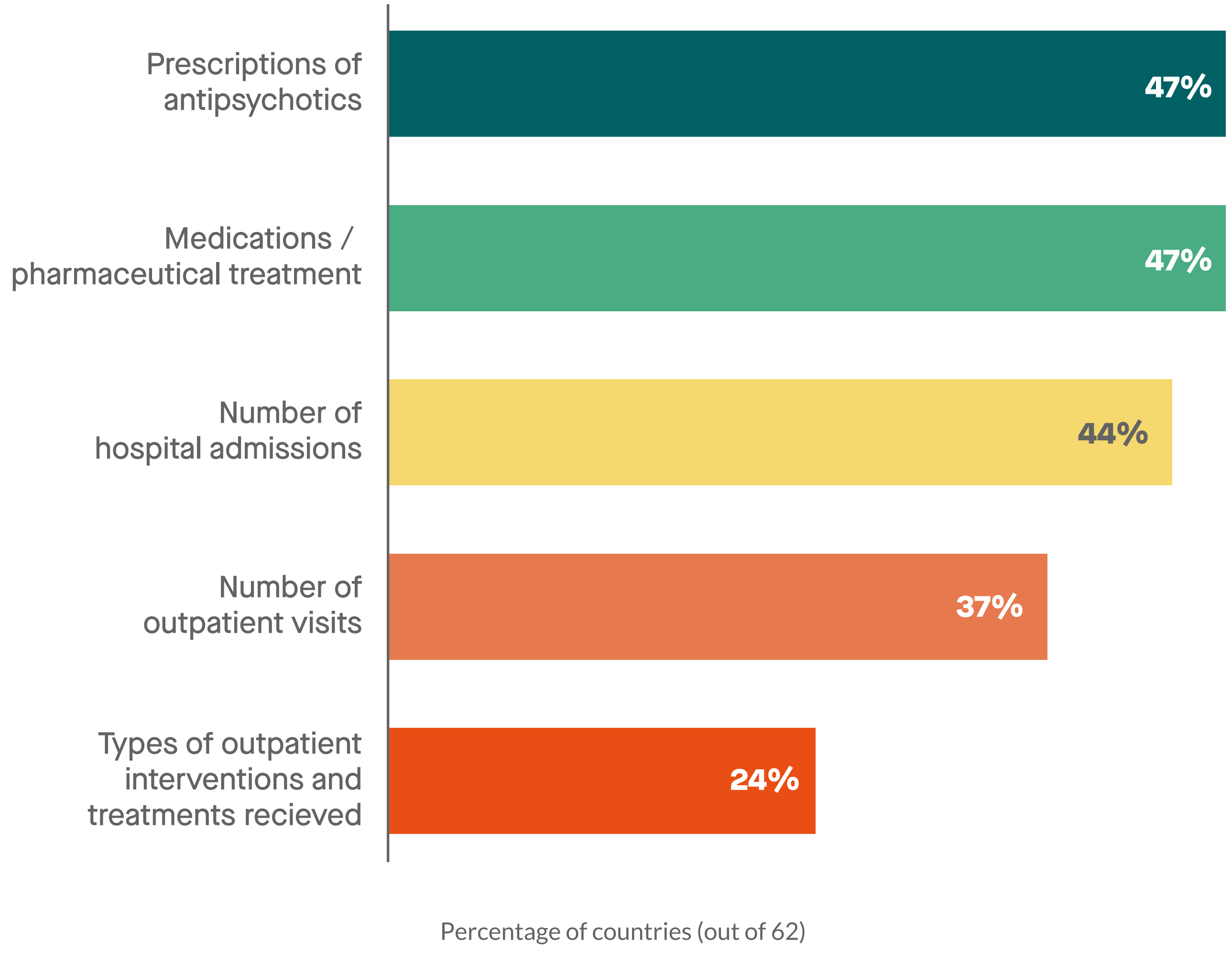
The implementation of the strategy will be regularly monitored to ensure sustainable improvements and to allow necessary adaptations to new challenges such as the current COVID-19 pandemic. The strategy's goals are interlinked with other governmental strategies such as the so-called "Concerted Action on Care" ("Konzertierte Aktion Pflege") which was signed in 2019 to improve training and working conditions for professional care workers in Germany.

The strategy in its entirety and further information can be found at: https://www.nationale-demenzstrategie.de/

Several indicators can be used to inform the provision of health services for people living with dementia. Of the 62 GDO countries, 47% monitor medications/pharmaceutical treatment and the prescriptions of antipsychotics, while 44% monitor the number of hospital admissions, 37% monitor the number of outpatient visits, and 24% monitor the types of outpatient interventions and treatments received (**Figure 37**).

FIGURE 37

Monitoring of services for people with dementia



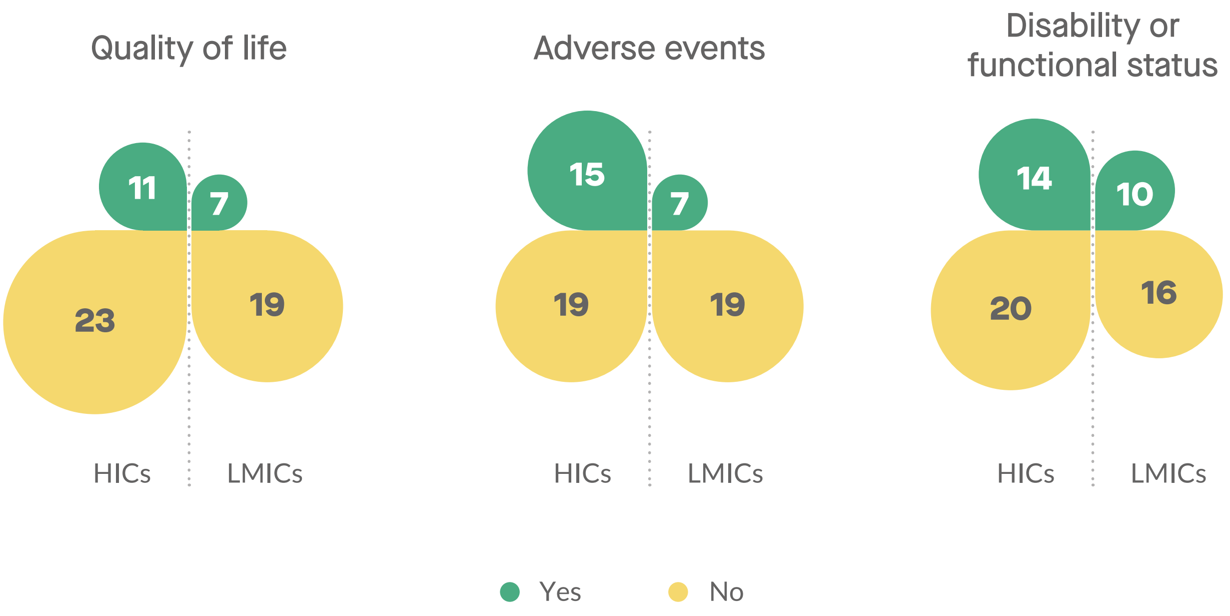
Monitoring the prescriptions of antipsychotic medication in people with dementia is a powerful indicator of dementia care quality. As noted in Chapter 7, the FDA and NICE in the United Kingdom have issued warnings and cautions about the use of antipsychotic medications in people with dementia due to increased risks of death in this population. Studies suggest that drug advisory warnings such as that issued by the FDA can be effective in changing prescribing patterns. Thus, systematic monitoring of prescription utilization serves to evaluate prescriber practice and is an essential element of ensuring that people with dementia receive evidence-based medicine and care.

Monitoring of patient-level data

Systematic monitoring of indicators that can inform the quality of care for people living with dementia is important to ensure that 'to ensure that their human rights are respected. The indicators can also serve as parameters for designing new strategies for improvement in accessibility and care coordination. Moreover, this monitoring also provides information on whether people have access to quality and timely care in an equitable manner across the country (**Figure 38**). Over 50% of countries that provided data to the GDO, including both HICs and LMICs, do not monitor clinical indicators such as quality of life, adverse events and disability or functional status.

FIGURE 38

Routine monitoring of patient-level data (number of countries by World Bank income level)



The way forward

Several barriers have been identified to strengthening health monitoring systems for dementia. First, a scarcity of resources and infrastructure limits countries' ability to collect dementia-related data across different sectors. Additionally, lacking digital infrastructure can impede the integration of data and implementation of national surveillance systems, especially in low-income settings. Moreover, current health information systems are unable to disaggregate data by common equity measures such as age, gender, income, educational level and geographical area (rural versus urban).

Accelerating action in the area of health monitoring systems for dementia will necessitate the integration of national surveillance and monitoring systems into existing health information systems in order to improve access to high-quality, multisectoral data on dementia. There should be access to health and social care data at national and regional levels in order to improve service delivery and coverage across the care continuum. Additionally, policies or legislation pertaining to the measurement, collection and sharing of data on health and social care for dementia should be created and updated, where relevant. Importantly, the collection of data on epidemiology, care and resources relating to dementia should be used to evaluate the implementation of dementia policies and plans. Importantly, collecting and analyzing country-level data is not only crucial to identify the magnitude of gaps throughout the entire dementia care pathway, but also to unravel the reasons why such gaps persist and how they can be better addressed.

WHO has developed several guidelines and tools that can be used to accelerate action in the area of monitoring systems for dementia, beginning with the GDO to support countries in measuring progress in implementing the Global dementia action plan (**Box 27**). Secondly, the implementation of WHO's SCORE technical package can assist countries in strengthening health data and information systems. Additionally, countries can implement health inequity monitoring by utilizing tools and resources from WHO's Health Equity Monitor, which will allow countries to disaggregate and analyse data across different population subgroups in order to identify and close gaps in care and realize health equity. **Figure 39** summarizes proposed actions, identified barriers and accelerators to support monitoring systems for dementia.

FIGURE 39

Proposed actions, identified barriers and opportunities to accelerate actions to support monitoring systems for dementia

PROPOSED ACTIONS

- ✓ Integrate national surveillance and monitoring systems (e.g. registers) into existing health information systems to improve access to high-quality, multisectoral data on dementia
- ✓ Enable access to health and social care data at national and regional levels to improve service delivery and coverage across the care continuum
- ✓ Update or create supportive policy or legislation pertaining to the measurement, collection and sharing of data on health and social care for dementia
- ✓ Collect and use necessary data on epidemiology, care and resources relating to dementia to implement relevant policies and plans

BARRIERS

- ⊗ Scarcity of resources and infrastructure to conduct data collection across different sectors
- ⊗ Lack of equity monitoring to understand the health needs of subgroups within populations
- ⊗ Lack of adequate digital infrastructure to facilitate the integration of data and implementation of national surveillance systems, especially in low-income settings

OPPORTUNITIES TO ACCELERATE ACTION

- » Monitoring of dementia-related indicators through WHO's Global Dementia Observatory
- » Implementation of WHO's SCORE technical package[8] to strengthen health data and information systems
- » Implement health inequity monitoring with resources from WHO's Health Equity Monitor[9]

---

[8] See: https://www.who.int/data/data-collection-tools/score (accessed 11 July 2021).

[9] See: https://www.who.int/data/gho/health-equity (accessed 11 July 2021).

BOX27

The Global Dementia Observatory

The Global Dementia Observatory (GDO) is a data and knowledge exchange platform that offers easy access to key dementia data from WHO Member States across the following three domains: policies, service delivery, and information and research. The GDO supports countries in measuring progress on dementia actions outlined in the Global dementia action plan and assists them in strengthening policies, service planning and health and social care systems for dementia.

Through data collection and monitoring of progress, the GDO supports countries in identifying gaps and challenges where actions are needed to address dementia.

To support countries' responses, WHO recently launched the GDO Knowledge Exchange (KE) Platform (www.globaldementia.org) which contains key resources to support the implementation of the Global action plan and its seven action areas. The GDO KE Platform provides a space to share resources (e.g., policies, guidelines, case studies and examples of good practice) and to facilitate mutual learning and knowledge exchange. Resources included are available at no cost and are reviewed by the WHO secretariat, a panel of peer reviewers who are experts in the field of dementia, as well as a Focus Group of people with lived experience of dementia.

Concluding remarks

It is evident that action must be taken to develop and strengthen monitoring systems for dementia worldwide. As of August 2021, 62 WHO Member States participated in the GDO. That is 32% and falls short of Global target 6 of the Global dementia action plan.

The dearth of resources that are currently available for the development of appropriate monitoring systems hinders the implementation of evidence-based strategies to improve the lives of people with dementia, their carers and families and ease the burden on national health and social systems. Building a comprehensive national surveillance system is a means to strengthening the response to dementia worldwide, enhancing countries' capacities to address gaps in care provision and ultimately improving the lives of people with dementia.

The COVID-19 pandemic and its disproportionate effect on the lives of people with dementia has demonstrated the importance of establishing robust mechanisms to gather appropriate data and provide timely and effective responses to health emergencies.

32%
of WHO Member States participate in the GDO

"The dearth of resources that are currently available for the development of appropriate monitoring systems hinders the implementation of evidence-based strategies to improve the lives of people with dementia, their carers and families and ease the burden on national health and social care systems."

> **“It is important for people living with dementia to be involved in research from the beginning to the end, to ensure that research is appropriate for their needs and that the research topics undertaken are relevant.”**
>
> **Howard Gordon,**
> United Kingdom

10. Dementia research and innovation

Context

As the number of people with dementia rises, investing in research and innovation is ever more important in order to minimize the impact of the disease and improve the lives of people with dementia and their carers *(110)* in line with the vision of the Global dementia action plan. Developing new prioritization strategies and implementing innovative health technologies is paramount in advancing capabilities for prevention, risk reduction, early diagnosis, disease-modifying therapies and care for people with dementia. Action area 7 of the Global dementia action plan sets a target of doubling dementia-related research output between 2017 and 2025. Strengthening dementia research and innovation is also aligned with objective 4 of the Mental health action plan (to strengthen information systems, evidence and research for mental health). Importantly, in order to guarantee that any increase in dementia research is successfully implemented with translatable impact, social and medical priorities must be identified to guide Member States, which will ultimately increase the likelihood of effectiveness and progress.

In 2018, a report by the World Dementia Council emphasized the need for all G7 countries to live up to the collective commitment of significantly increasing the amount of funding for dementia research *(111)*. In 2019, G20 health ministers pledged to promote research and development for healthy ageing, including for risk reduction, early detection, diagnosis and treatment of dementia.

Based on data submitted to the GDO, WHO's Global Observatory of Health Research and Development and data centrally collected by the WHO secretariat, this chapter provides an overview of country-driven progress in the implementation and funding of dementia research programmes, as well as the current status of research towards the achievement of the global target for Action area 7. It also analyses the participation of people with dementia and their carers in the research process and identifies gaps and opportunities for improvement. Finally, this chapter features country case studies, accelerators for action and a spotlight on current activities being developed by WHO.

Progress to date

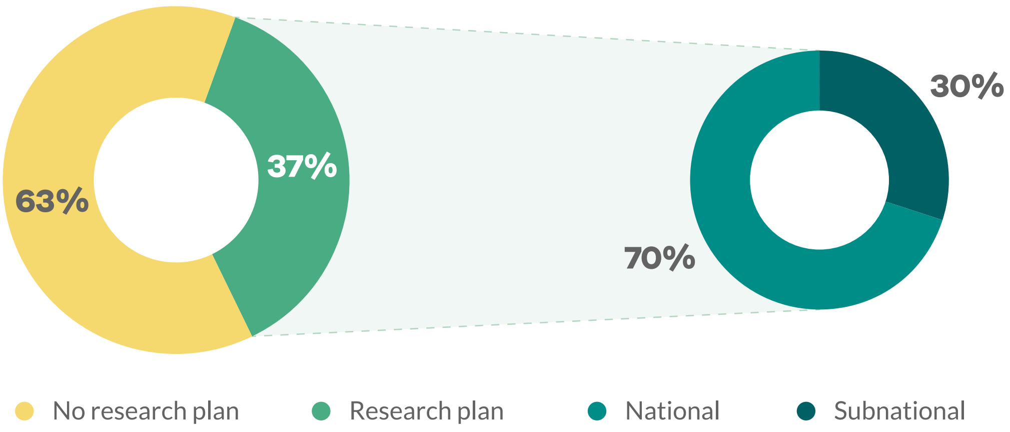
In 2013, during the G8 dementia summit, countries committed to finding a cure or disease-modifying therapy for dementia by 2025, and to increasing significantly the amount of funding as a means to achieve that goal *(112)*. Available data show that between 2011 and 2016 the overall research funding in six out of the eight countries formerly part of the G8 has in fact increased, albeit with considerable variation between them *(113)*.

Existence of a dementia research agenda

The extent of prioritization of dementia research can be measured by the existence of research agendas or plans specifically designed for dementia. Worldwide, based on data submitted by 62 GDO countries, 37% of countries have dementia research plans, of which 70% are national and 30% are subnational research plans (**Figure 40**).

FIGURE 40

Existence of national or subnational research plans

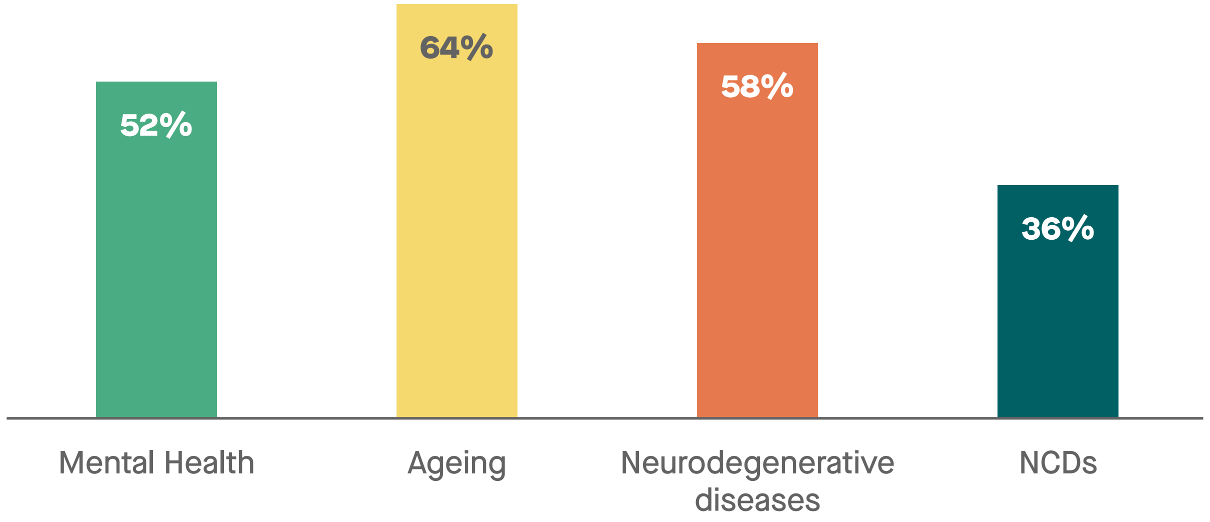


Whether a country has a research plan in place appears to be intimately tied to the country's income level, as no low-income or lower-middle-income countries reported having a dementia research plan. This is in contrast to countries of higher wealth, where 31% of upper-middle-income countries and 50% of HICs reported having national or subnational research plans.

Dementia research plans can also exist as part of a larger national research agenda on a range of different disease topics. Of 62 GDO countries, 33 have a dementia research plan included into another research plan, of which 52% are integrated into mental health, 64% into ageing, 58% into neurodegenerative diseases and 36% into NCDs (**Figure 41**).

FIGURE 41

Dementia research plan integrated into other research agendas



Enabling the research environment and funding

The implementation of research plans needs to be accompanied by the allocation of appropriate funding and infrastructure to enable scientific breakthroughs and innovative interventions, and to have their impact effectively translated into benefits to society. Currently, 37% of GDO countries have allocated funding specifically for dementia research. Notably, the existence of any kind of dementia plan, dedicated or integrated, is associated with an increase in funding allocation for dementia research. Specifically, 47% of countries that have a dementia plan possess dedicated funds for dementia research, whereas only 16% of countries that do not have a dementia plan have a dementia-specific research funding allocation.

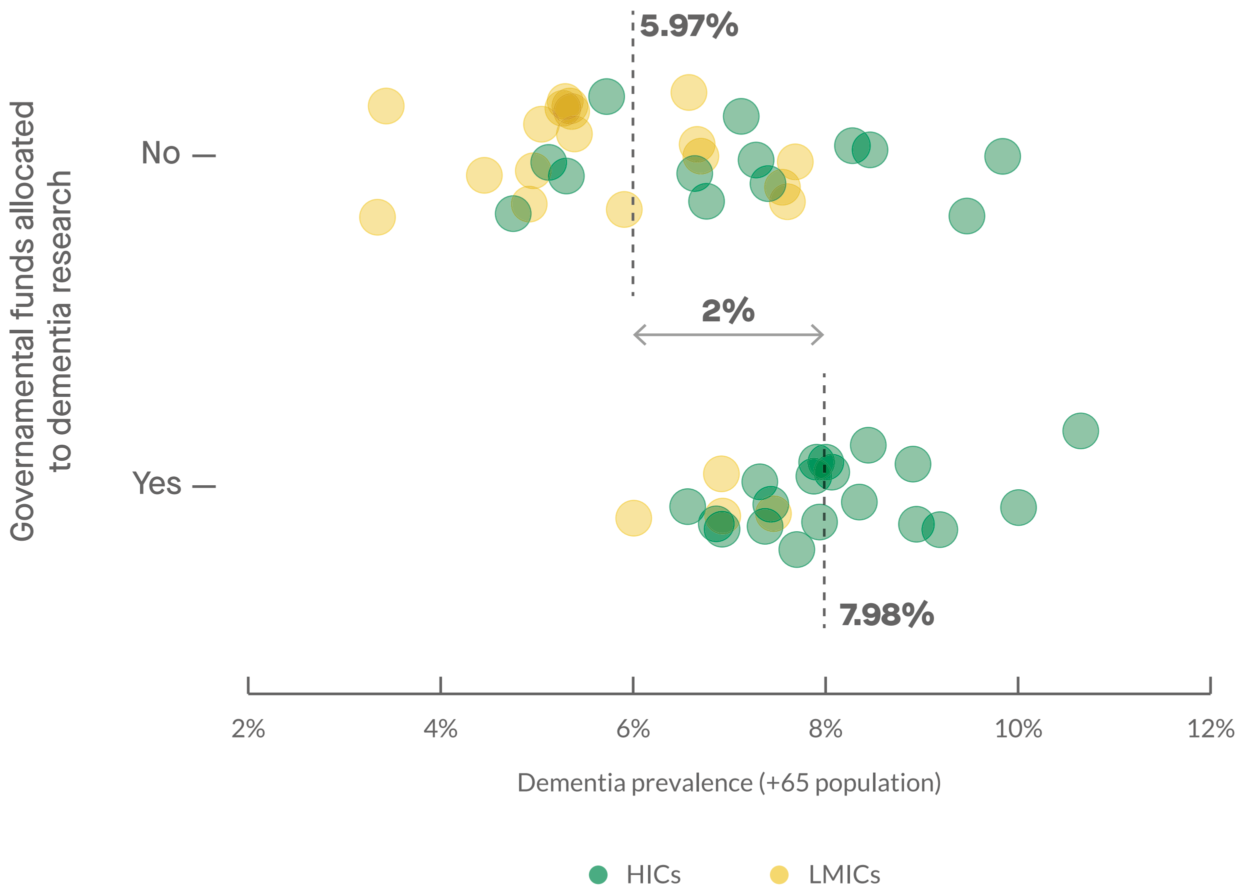
37%
of GDO countries have allocated funding specifically for dementia research

The staggering socioeconomic impact of dementia and other brain disorders on society has not translated into financial support that pushes forward care and therapeutic research *(114)*. The COVID-19 pandemic has exacerbated an already existing disproportionate lack of funding for neurological disorders worldwide. With recent reports of funding cuts to brain research, the dire consequences of the pandemic are likely to slow down progress in research and innovation for dementia *(115)*.

Investments in research are also needed in the areas of social science, public health and implementation science. Epidemiological studies are crucial to provide adequate data that will ultimately help to evaluate the readiness of a country and its national health system in caring for people with dementia. These studies are also needed to track prevalence and incidence of dementia, understand risk and protective factors, and to observe the impacts of public health measures. GDO data show that countries that allocate funds to dementia research have, on average, 2% higher dementia prevalence (**Figure 42**). Another trend that can be observed is the lower proportion of LMICs allocating funds for dementia research as compared to HICs. Although LMICs show an overall lower dementia prevalence, it is worth noting that the prevalence of dementia is expected to increase at much higher rates in LMICs as compared to HICs, warranting an increased focus on and investment in dementia research, innovation and related areas, especially in LMICs.

FIGURE 42

Dementia research investment relative to dementia prevalence



An increase in investment in dementia research is imperative to drive progress in several research areas. In particular, the Global dementia action plan recommends a focus on budget allocations that will promote national and international research collaboration, encourage data-sharing and open access research to reduce redundancies, and support the retention of a dementia research workforce. Further, interdisciplinary research collaboration is essential to ensure that the knowledge of basic research is transferred into preclinical and clinical research, and ultimately that it will promote effective changes in the lives of people with dementia, their families and their carers.

WHO's Global Observatory on Health Research and Development[10] is a data platform that reports on a number of indicators for health research, including funding distribution and research collaboration resulting from grants for health research by major funders. Data available from 2019 show that, although funding allocation for Alzheimer's disease and other dementias has increased, it is primarily restricted to HICs such as Canada, theUnited Kingdom and the United States of America. Accordingly, out of the 50 organizations/institutions that received the largest number of grants for Alzheimer's and other dementias for that year, 41 were from the United States of America, six from the United Kingdom and three from Canada. This discrepancy also influences with whom the institutions establish research collaboration – out 178 direct research grants, 100% were offered to high-income country institutions. These 178 grants have led to the establishment of 540 instances of research collaboration, of which 527 were with institutions in other high-income countries, 11 in upper-middle-income countries and only three in lower-middle-income countries. No collaboration with low-income countries was reported in this data set.

Only 2.6%
of research collaborations with LMICs

Collaboration and data sharing

To address the above challenges and to cultivate an equitable and collaborative environment, several initiatives worldwide have the goal of increasing data-sharing activities by creating platforms that will make data more accessible and will connect dementia researchers. In these efforts, WHO strongly supports the establishment of cross-regional collaboration with emphasis on the inclusion of LMICs, acknowledging country-specific needs and moving towards the equitable co-design and co-production of science. An encouraging example is the Alzheimer's Disease Data Initiative (ADDI), that aims to empower and increase the capacity of dementia researchers by facilitating access to resources and enabling data-sharing (see **Box 28**). Such collaboration has the untapped potential of filling scientific gaps, promoting inclusion and equity, and building research capacity in LMICs.

---

[10] See: https://www.who.int/observatories/global-observatory-on-health-research-and-development (accessed 11 July 2021).

BOX 28

Data – the key to unlocking answers for Alzheimer's disease

The Alzheimer's Disease Data Initiative (ADDI) is a new global effort that aims to advance innovation for Alzheimer's disease (AD) and related dementias. Led by Bill Gates and a coalition of partners, the initiative connects researchers with the data needed to generate insights and inform the development of improved treatments and diagnostic tools.

In November 2020, Gates announced ADDI on Gates Notes and unveiled its AD Workbench which is a data-sharing and analytics platform that empowers researchers around the world to share data, resources and tools to achieve the ADDI vision of accelerating research into Alzheimer's disease. With AD Workbench, researchers will have the ability to work with multiple interoperable data sets from different sources, allowing them to securely add, access and transfer data from other platforms. This ability to access and share data and collaborate with other scientists and researchers will increase the speed of discoveries and innovations for Alzheimer's Disease and related dementias. Additionally, the AD Workbench provides a space for open access models, applications and algorithms that will expand the Workbench's existing analytics for the benefits of advancing dementia research.

Investments from the private sector and the establishment of research coalitions are needed to keep dementia research progressing. Several national and international efforts exist to address key challenges in the field; these efforts aim to foster research collaboration, support health-care system preparedness, and accelerate the development of innovative interventions while decreasing the cost of research. The European Union's Joint Programme for Neurodegenerative Disease Research (JPND) is one such initiatives that brings together leading researchers, scientific evidence and national funding bodies to establish a collaborative research environment, accelerate the discovery of treatments and enable early diagnosis. Similarly, the Davos Alzheimer's Collaborative brings together key actors from the private sector, government leaders, NGOs and academics to link current research efforts, scale up successful models and create new initiatives to tackle unaddressed challenges in several areas. Finally, the Strengthening responses to dementia in developing countries (STRiDE) project aims to build capacity to conduct research in LMICs and to turn that research, using evidence, advocacy, and stakeholder engagement, into actual policy change that will have a positive impact on the lives of people affected by dementia. The project works with local teams made up of senior and early-career researchers and Alzheimer associations in seven countries: Brazil, India, Indonesia, Jamaica, Kenya, Mexico, and South Africa.

Despite these recent successful efforts, there is still a need for higher government investment and coordination of dementia research. This is especially evident in lower-income regions. GDO data show that no low-income or lower-middle-income countries specifically allocates money for dementia research, whereas 25% of upper-middle-income countries and 56% of HICs report the direct allocation of funds for dementia research. Recent efforts have been made in the United States of America towards the allocation of funding for dementia research, leading to the strengthening of existing initiatives and the establishment of new programmes and partnerships and the sponsorship of clinical trials (**Box 29**).

BOX 29

The United States' response to deliver on Action area 7 – Research and Innovation

Fighting Alzheimer's disease and related dementias (AD/ADRD) is a national priority in the United States. Heightened interest in AD/ADRD resulted in passage of the National Alzheimer's Project Act in 2011 and unprecedented increases in research funding targeting AD/ADRD in recent years.

Overall, the National Institutes of Health (NIH) annual investment in AD/ADRD research has increased from US$ 631 million in the 2015 financial year to an estimated US$ 2.8 billion in the 2020 financial year, or an increase of US$ 2.2 billion over the last five years. This tremendous public investment in research has enabled enormous advances in our understanding of the complexities of AD/ADRD. The funding has been applied to a broad, multidisciplinary programme in which research moves through a pipeline from studies of basic mechanisms to application in clinical trials and studies, as well as research on care and caregiving.

Recent boosts in funding have enabled:

- ✓ Basic studies of the biology of AD/ADRD, including genetics, in order to better understand what causes the pathology and which interventions may protect against it.
- ✓ Translational studies that are yielding an increasing number of new therapeutic targets that address treatment and prevention. For example, investigators with the Accelerated Medicines Partnership have identified over 500 potential new drug targets for AD/ADRD.
- ✓ Discovery and development of biomarkers, such as imaging and blood tests, to track the course of disease and test the effectiveness of new therapies.
- ✓ Support of programmes and infrastructure to make data, knowledge and research tools widely available to all researchers to address key challenges in therapy development.
- ✓ Clinical trials to test a range of potential therapies. NIH currently sponsors some 230 active trials of interventions (both pharmacological and non-pharmacological) to enhance cognitive health in older adults and to prevent, treat or manage AD/ADRD.
- ✓ Research to support improved quality of life for people living with dementia and their carers/care partners.

Dementia research output

Over the past decades, the repeatedly unsuccessful clinical trials in the field, combined with high costs for research and development, resulted in dementia research being deprioritized by various stakeholders, including within the private sector. Indexed peer-reviewed publications on life sciences and the biomedical databases (e.g. PubMed) can be used to track the research output pertaining to different disease areas and serve as a proxy for the amount of research being conducted. These data show that the research output on other NCDs such as cancer, heart conditions, kidney disease, diabetes and depression is substantially higher than the output on dementia (**Figure 43**).

If the target of doubling dementia research output by 2025, as set by the Global dementia action plan, is to be achieved, urgent action is needed to support dementia research and create an environment where this research is prioritized. Yet, due to the lack of dementia awareness in all spheres of society, accompanied by a challenging research environment and consequent decreased interest, dementia research output accounts for less than 1.5% of the total health research output across all WHO regions (**Figures 44 and 45**).

FIGURE 44

Volume of dementia research as % of total research by WHO region

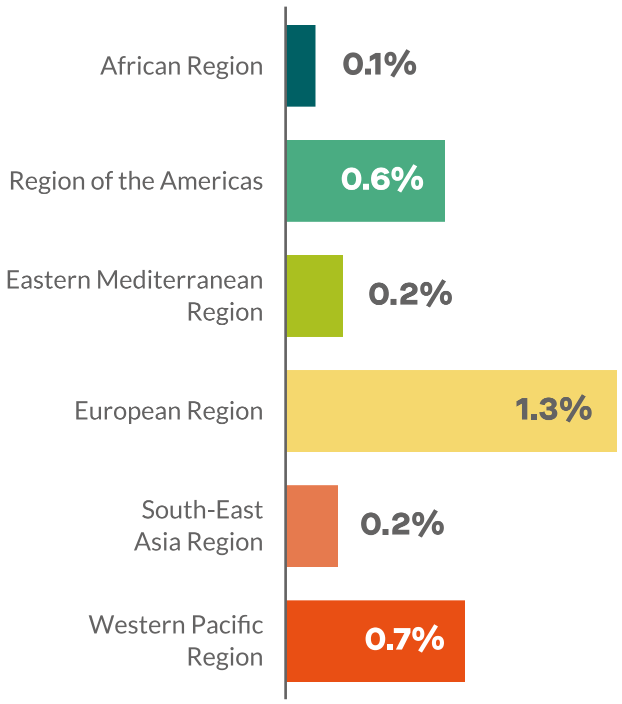


FIGURE 45

Volume of dementia research by income level as % of total research

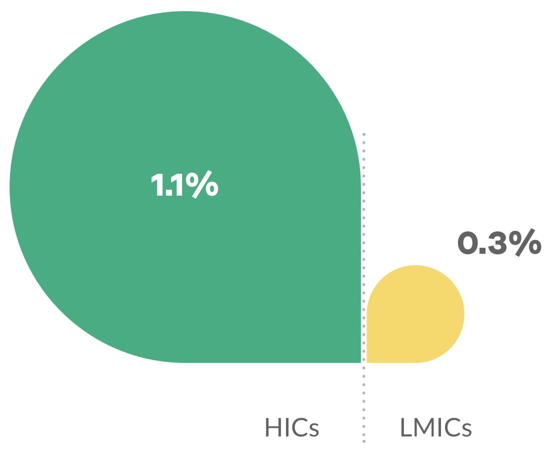
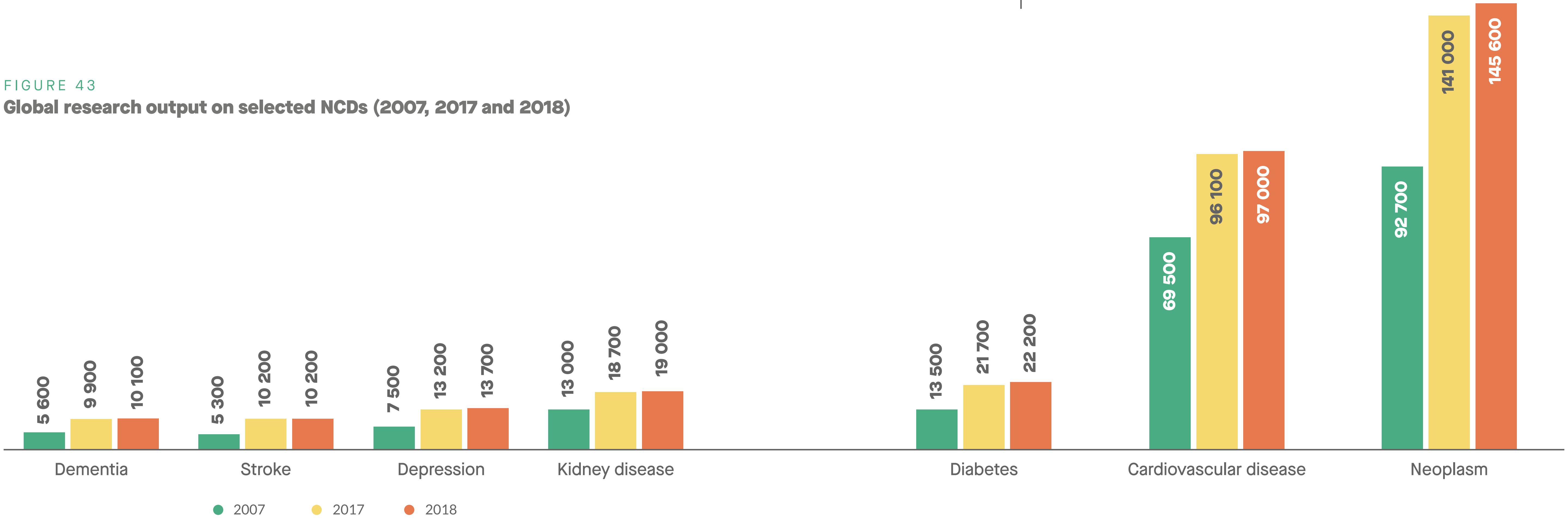


FIGURE 43

Global research output on selected NCDs (2007, 2017 and 2018)



Innovation and novel technologies for dementia

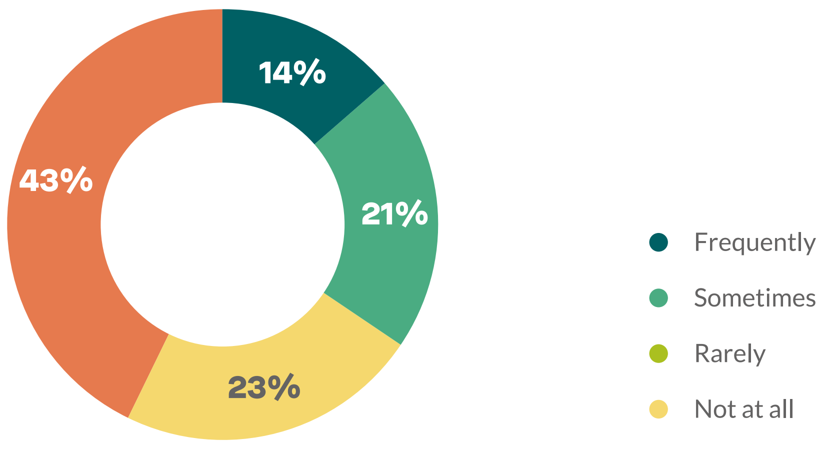
Multiple fields within the health and social care sector are beginning to utilize and implement innovative technologies such as robotics, artificial intelligence and telemedicine to provide support and manage long-distance treatment, diagnosis, and many other services, especially in the context of the COVID-19 pandemic. There is growing interest in, and demand for, the use of innovative health technologies at all stages of the dementia care pathway. Innovations aim to enhance knowledge, skills and coping mechanisms in order to improve and support the daily lives of people with dementia and their carers. In particular, innovations should meet identified needs in an evidence-based and age-, gender- and culturally sensitive manner.

43%
of GDO countries do not involve people with dementia in research development process

Dementia research participation, engagement and involvement

In March 2015, during the first WHO Ministerial Conference on Global Action against Dementia(11), participants reinforced the need to empower people with dementia and support their full and active engagement in society. Similarly, Action area 7 calls for more inclusiveness of people with dementia, their carers and families, in all areas of research. GDO data show that only 14% of countries frequently involve people with dementia in the research process; in 21% of countries there is occasional involvement, in 23% of countries there is rare involvement, and 43% of countries report that people with dementia are not at all involved in the research development process (**Figure 47**).

FIGURE 47
Extent of involvement in the research process by people living with dementia as reported by countries



Although some progress has been made in including people with dementia, carers and families in the research process and monitoring their participation, greater efforts should be made to ensure the involvement of people with lived experience in the research process. If progress is to be realized and the lives of people with dementia are to be improved, they must be seen as key stakeholders from research conceptualization to its implementation. Moreover, in order to ensure that the results of research are generalizable and strategies implementable across different regions, the diversity of backgrounds – including socioeconomic and ethnic – within countries and across income levels must be reflected.

The way forward

In 2013, the former G8 countries collectively committed to increase their coordination for greater innovation and to increase structured funding for dementia research by setting an ambitious goal of identifying a cure or disease-modifying therapy by 2025. Similarly, in 2017, all 194 WHO Member States adopted the Global dementia action plan and committed to strengthen their response to dementia, support people with dementia and their families and achieve the targets set by the action plan. This commitment was further reinforced by the G20 countries in 2019 when they recognized the impact of dementia and urged countries to develop ambitious national responses and adopt integrated approaches in line with the Global dementia action plan.

However, while progress has been made in some areas, research and innovation in the dementia field has yet to receive more attention and support. The actions proposed in the Global dementia action plan are key to creating an enabling research environment in which dementia research is seen as a priority and a constant stream of investments will allow for scientific breakthroughs and sustainable research. **Figure 48** outlines proposed actions, identified actions and opportunities to accelerate dementia research.

The lack of dementia awareness, insufficient funding and a fragmented research landscape together present major barriers to effective research development and implementation. Moreover, the under-representation of LMICs due to scarce funding and insufficient research capacity, together with the exclusion of people with dementia and carers from the research development, hinders inclusiveness which is a vitally necessary approach in dementia research. In order to support worldwide innovation in dementia, and to address the gaps and barriers that stand in the way of effective actions, several initiatives aim to increase research collaboration and data-sharing in order to fast-track innovation in the field. WHO is developing the Dementia Research Blueprint (**Box 30**) as a global coordination mechanism to enable and facilitate policy in the area of dementia research.

FIGURE 48

Proposed actions, identified barriers and opportunities to accelerate dementia research

PROPOSED ACTIONS

- ✓ Develop, implement and monitor the establishment of a national research agenda on prevention, diagnosis, treatment and care of people with dementia
- ✓ Increase investment in dementia research and innovative research governance
- ✓ Foster the development of technological innovations
- ✓ Promote equitable opportunities and access for people with dementia and their carers to be part of clinical and social research that concerns them

BARRIERS

- ⊗ Lack of dementia awareness at all levels of society, leading to decreased interest and support for research
- ⊗ Insufficient funding for dementia research and its implementation - aggravated by the COVID-19 pandemic
- ⊗ Fragmented research landscape with scarce data-sharing initiatives and open access resources
- ⊗ Insuffcent research capacity in the field, with under-representation of LMICs at the forefront of dementia research
- ⊗ Exclusion of people with dementia and carers from research development

OPPORTUNITIES TO ACCELERATE ACTION

- » WHO Dementia Research Blueprint to guide:
    - » research prioritization exercises
    - » establishment of collaboration and data-sharing initiatives
    - » promotion of the availability of open access data
    - » equitable access to research funding
    - » institution of co-research environments with the inclusion of patients and carers in the research development process
- » Targeted actions based on evidence collected through WHO's Global Dementia Observatory and GDO Knowledge Exchange Platform

BOX 30

Dementia Research Blueprint

Global research prioritization is necessary to ensure that ongoing research efforts cover critical areas within the full care pathway (including prevention, treatment, cure and implementation science), in ways that harmonize investigative approaches and reduce redundancies. Moreover, research efforts must be rooted in equity, diversity, and inclusiveness, be person-centred and family inclusive. This necessitates building greater research capacity in all income settings, as well as developing mechanisms to ensure inclusion of people with dementia and their carers in all research activities.

To this end – and building on the successful WHO R&D blueprints for infectious diseases (116) – WHO is developing the *WHO's Dementia Research Blueprint*. Being the first in the context of NCDs, the Blueprint aims to accelerate global dementia research and innovation and make research more productive and efficient, as well as promote research capacity-building in low-resource settings and ensure inclusiveness at all stages from generation to implementation.

Being developed with active contributions from a diverse group of stakeholders, the Blueprint will catalyze processes for increased investment in dementia research and innovation, increase capacity-building in all income settings, and foster uptake and equitable dissemination of effective interventions in both policy and programme planning. By leading such a coordination mechanism for dementia research, *WHO's Dementia Research Blueprint* can provide direction to funders for research investment, increase the profile of dementia research and innovation in the global agenda and ultimately enable and facilitate policy-making for dementia research.

Concluding remarks

While different initiatives have been put in place to push dementia research forward and address long-standing gaps, the COVID-19 pandemic has created additional barriers that must be overcome. With reports of funding disruption and dementia research being deprioritized, it has never been so important to find synergies and avoid duplication in research efforts.

Given the complexity of the disease, dementia cannot be solved by working in silos. If we are comprehensively and meaningfully to improve the lives of people living with dementia, their carers and families, we must reach beyond our traditional ways of doing research and find better strategies to coordinate between sectors and stakeholders, including governments, multilateral organizations, academic institutions, civil society, people living with dementia and the private sector. Finally, promoting equitable inclusion and research capacity-building in lower-income settings, as well as ensuring the meaningful participation of people with dementia, their families and carers in research, will foster an environment where scientific discoveries are translatable and deliver higher impact.

> **"If we are comprehensively and meaningfully to improve the lives of people living with dementia, their carers and families, we must reach beyond our traditional ways of doing research and find better strategies to coordinate between sectors and stakeholders."**

References

1. Global health estimates. Geneva: World Health Organization (https://www.who.int/data/global-health-estimates, accessed 28 June 2021).
2. Global action plan on the public health response to dementia 2017–2025. Geneva: World Health Organization; 2017 (https://apps.who.int/iris/bitstream/handle/10665/259615/9789241513487-eng.pdf, accessed 11 July 2021).
3. World Health Organization. Neurology and COVID-19. Geneva: WHO; 2021.
4. The impact of COVID-19 on mental, neurological and substance use services: results of a rapid assessment. Geneva: World Health Organization; 2020 (https://www.who.int/publications/i/item/978924012455, accessed 11 July 2021).
5. Suárez-González A, Livingston G, Low L-F, Cahill S, Hennelly N, Dawson WD et al. Impact and mortality of COVID-19 on people living with dementia: cross-country report. London: Long-term Care Policy Network; 2020 (https://ltccovid.org/2020/08/19/impact-and-mortality-of-covid-19-on-people-living-with-dementia-cross-country-report/, accessed 11 July 2021).
6. Devlin H. Extra 10,000 dementia deaths in England and Wales in April. The Guardian; 2020 (https://www.theguardian.com/world/2020/jun/05/covid-19-causing-10000-dementia-deaths-beyond-infections-research-says, accessed 28 June 2021).
7. Pulse survey on continuity of essential health services during the COVID-19 pandemic: interim report, 27 August 2020. Geneva: World Health Organization; 2020 (https://www.who.int/publications/i/item/WHO-2019-nCoV-EHS_continuity-survey-2020.1, accessed 11 July 2021).
8. Sharma M, Lioutas VA, Madsen T, Clark J, O'Sullivan J, Elkind MSV et al. Decline in stroke alerts and hospitalisations during the COVID-19 pandemic. Stroke Vasc Neurol. 2020;5:403–5. doi: 10.1136/svn-2020-000441.
9. Suárez-González A, Rajagopalan J, Livingston G, Alladi S. The effect of Covid-19 isolation measures on the cognition and mental health of people living with dementia: a rapid systematic review of one year of evidence. medRxiv. 2021. doi:10.1101/2021.03.17.21253805.
10. García-Azorín D, Seeher KM, Newton CR, Okubadejo NU, Pilotto A, Saylor D et al. Disruptions of neurological services, its causes and mitigation strategies during COVID-19: a global review. J Neurol. 2021. doi:10.1007/s00415-021-10588-5.
11. First WHO ministerial conference on global action against dementia: meeting report, WHO Headquarters, Geneva, Switzerland, 16–17 March 2015. Geneva: World Health Organization; 2015 (https://apps.who.int/iris/bitstream/handle/10665/179537/9789241509114_eng.pdf, accessed 11 July 2021).
12. UN Decade of Healthy Ageing 2021–2030. Geneva: World Health Organization.
13. GBD 2019 Diseases and Injuries Collaborators. Global burden of 369 diseases and injuries in 204 countries and territories, 1990–2019: a systematic analysis for the Global Burden of Disease Study 2019. Lancet. 2020;396:1204–22. doi:10.1016/S0140-6736(20)30925-9.
14. World population prospects 2019. New York (NY): United Nations; 2019 (https://www.un-ilibrary.org/content/books/9789210046428, accessed 11 July 2021).
15. Dementia: a public health priority (Infographic). Geneva: World Health Organization (https://www.who.int/images/default-source/infographics/dementia-symptoms.png?sfvrsn=fa92aa99_2, accessed 28 June 2021).
16. Andrew MK, Tierney MC. The puzzle of sex, gender and Alzheimer's disease. Why are women more often affected than men? Women's Health. 2018;14. doi:10.1177/1745506518817995.
17. The epidemiology and impact of dementia: current state and future trends. Document WHO/MSD/MER/15.3. Geneva: World Health Organization; 2015.
18. The Global Health Observatory: disability-adjusted life years (DALYs). Geneva: World Health Organization (https://www.who.int/data/gho/indicator-metadata-registry/imr-details/158, accessed 28 June 2021).
19. Chong SA, Abdin E, Vaingankar J, Ng LL, Subramaniam M. Diagnosis of dementia by medical practitioners: a national study among older adults in Singapore. Aging Ment Health. 2016;20:1271–6. doi:10.1080/13607863.2015.1074160.
20. Olafsdóttir M, Skoog I, Marcusson J. Detection of dementia in primary care: the Linköping study. Dement Geriatr Cogn Disord. 2000;11:223–9. doi:10.1159/000017241.
21. OECD, Eurostat, WHO (2011), A System of Health Accounts, OECD Publishing. DOI: http://dx.doi.org/10.1787
22. World Economic Outlook Update, January 2021. Washington (DC): International Monerary Fund, 2021 (https://www.imf.org/en/Publications/WEO/weo-database/2020/October, accessed 28 June 2021).
23. Prince M, Ferri CP, Acosta D, Albanese E, Arizaga R, Dewey M et al. The protocols for the 10/66 dementia research group population-based research programme. BMC Public Health. 2007;7:165. doi:10.1186/1471-2458-7-165.

24. STRIDE. Strengthening the responses to dementia in developing countries (website) (https://stride-dementia.org, accessed 28 June 2021).

25. Care work and care jobs for the future of decent work. Geneva: International Labour Organization; 2018.

26. Nygaard HA, Ruths S. Missing the diagnosis: senile dementia in patients admitted to nursing homes. Scand J Prim Health Care. 2003;21:148–52. doi:10.1080/02813430310001798.

27. Sternberg SA, Wolfson C, Baumgarten M. Undetected dementia in community-dwelling older people: the Canadian Study of Health and Aging. J Am Geriatr Soc. 2000;48:1430–4. doi:10.1111/j.1532-5415.2000.tb02633.x.

28. Towards a dementia plan: a WHO guide. Geneva: World Health Organization; 2018 (https://apps.who.int/iris/bitstream/handle/10665/272642/9789241514132-eng.pdf, accessed 11 July 2021).

29. Cahill S. WHO's global action plan on the public health response to dementia: some challenges and opportunities. Aging Ment Health. 2020;24:197–9. doi:10.1080/13607863.2018.1544213.

30. From plan to impact 2018: progress towards targets of the Global action plan on dementia. London: Alzheimer's Disease International; 2018.

31. Okayama Declarations of the G20 Health Ministers, 19–20 October 2019 (https://www.mhlw.go.jp/seisakunitsuite/bunya/hokabunya/kokusai/g20/health/img/G20Okayama_HM_EN.pdf, accessed 11 July 2021).

32. From plan to impact III: maintaining dementia as a priority in unprecedented times. London: Alzheimer's Disease International; 2020.

33. Wright T, O'Connor S. Reviewing challenges and gaps in European and global dementia policy. J Public Ment Health. 2018;17:157–67. doi:10.1108/JPMH-02-2018-0012.

34. From plan to impact II: the urgent need for action. London: Alzheimer's Disease International; 2019.

35. Mukadam N, Waugh A, Cooper C, Livingston G. What would encourage help-seeking for memory problems among UK-based South Asians? A qualitative study. BMJ Open. 2015;5. doi:10.1136/bmjopen-2015-007990.

36. Schmachtenberg T, Monsees J, Hoffmann W, Van Den Berg N, Stentzel U, Thyrian JR. Comparing national dementia plans and strategies in Europe – Is there a focus of care for people with dementia from a migration background? BMC Public Health. 2020;20:1–10. doi:10.1186/s12889-020-08938-5.

37. World Migration Report 2020. Geneva: International Organization for Migration; 2020.

38. Hulko W. Decolonizing dementia care: a grounded theory of memory loss and memory care for Secwepemc nation elders, Alzheimer's Disease International Conference, Toronto, 27 March 2011 (Four First Nations' Perspectives on Dementia). Slide show (https://slideplayer.com/slide/6670384, accessed 11 July 2021).

39. World Alzheimer's Report 2019: attitudes to dementia. London: Alzheimer's Disease International; 2019.

40. World Alzheimer's Report 2020: Design Dignity Dementia: dementia-related design and the built environment. London: Alzheimer's Disease International; 2020.

41. Global report on ageism. Geneva: World Health Organization; 2021 (https://www.who.int/publications/i/item/9789240016866, accessed 11 July 2021).

42. What is the decade of healthy ageing? Geneva: World Health Organization. (https://www.who.int/initiatives/decade-of-healthy-ageing, accessed 21 July 2021).

43. The Global Network for Age-friendly Cities and Communities. Looking back over the last decade, looking forward to the next. Geneva: World Health Organization; 2018 (https://www.who.int/publications/i/item/WHO-FWC-ALC-18.4, accessed 11 July 2021).

44. Livingston G, Huntley J, Sommerlad A, Ames D, Ballard C, Banerjee S et al. Dementia prevention, intervention, and care: 2020 report of the Lancet Commission. Lancet. 2020;396:413–46. doi:10.1016/S0140-6736(20)30367-6.

45. Second round of the national pulse survey on continuity of essential health services during the COVID-19 pandemic. Geneva: World Health Organization; 2021 (https://www.who.int/publications/i/item/WHO-2019-nCoV-EHS-continuity-survey-2021.1, accessed 11 July 2021).

46. Seventy-second World Health Assembly, Geneva, 20–28 May 2019. Agenda item A72/19: Follow-up to the high-level meetings of the United Nations General Assembly on health-related issues. Prevention and control of noncommunicable diseases. Report by the Director-General. Geneva: World Health Organization; 2019 (https://apps.who.int/gb/ebwha/pdf_files/WHA72/A72_19-en.pdf, accessed 11 July 2021).

47. Lynch C. World Alzheimer Report 2019: attitudes to dementia, a global survey. Alzheimers Dement. 2020;16. doi:10.1002/alz.038255.

48. Global Coordination Mechanism on the Prevention and Control of NCDs (website). Geneva: World Health Organization (https://www.who.int/groups/gcm, accessed 28 June 2021).

49. WHO package of essential noncommunicable (PEN) disease interventions for primary health care. Geneva: World Health Organization; 2020 (https://www.who.int/publications/i/item/who-package-of-essential-noncommunicable-(pen)-disease-interventions-for-primary-health-care, accessed 11 July 2021).

50. Hearts: technical package for cardiovascular disease management in primary health care. Geneva: World Health Organization; 2016 (https://apps.who.int/iris/handle/10665/252661, accessed 11 July 2021).

51. Building capacity for tobacco control: training package. Geneva: World Health Organization; 2011 (https://www.who.int/publications/i/item/9789241501354, accessed 11 July 2021).

52. Risk reduction of cognitive decline and dementia: WHO guidelines. Geneva: World Health Organization; 2019 (https://apps.who.int/iris/handle/10665/312180, accessed 11 July 2021).

53. Be He@lthy, Be Mobile: a handbook on how to implement mDementia. Geneva: World Health Organization and International Telecommunication Union, 2021. Licence: CC BY-NC-SA 3.0 IGO.

54. Frost R, Walters K, Wilcock J, Rait G, Aw S, Brunskill G et al. Effectiveness of different post-diagnostic dementia care models delivered by primary care: a systematic review. Br J Gen Pract; 2020;70: e434–41 (https://bjgp.org/content/70/695/e434, accessed 11 July 2021).

55. Zala D, Chan D, McCrone P. The cost-effectiveness implications of suboptimal treatment for different severities of Alzheimer's disease in the UK. Int J Geriatr Psychiatry. 2018;33:307-15. doi: 10.1002/gps.4745.

56. Knapp M, King D, Romeo R, Adams J, Baldwin A, Ballard C et al. Cost-effectiveness of donepezil and memantine in moderate to severe Alzheimer's disease (the DOMINO-AD trial). Int J Geriatr Psychiatry. 2017;32:1205-16. doi: 10.1002/gps.4583.

57. da Silva LR, Vianna CMM, Mosegui GBG, Peregrino AAF, Marinho V, Laks J. Cost-effectiveness analysis of the treatment of mild and moderate Alzheimer's disease in Brazil. Braz J Psychiatry. 2019;41:218-24. doi: 10.1590/1516-4446-2017-0021.

58. Essential medicines and basic health technologies for noncommunicable disease: towards a set of actions to improve equitable access in Member States. Geneva: World Health Organization; 2015 (https://www.who.int/nmh/ncd-tools/targets/Final_medicines_and_technologies_02_07_2015.pdf, accessed 11 July 2021).

59. Access to essential medicines for noncommunicable diseases during the COVID-19 pandemic. Washington (DC): Pan American Health Organization; 2020 (https://iris.paho.org/bitstream/handle/10665.2/52477/PAHONMHNVCOVID-19200029_eng.pdf, acvcessed 11 July 2021).

60. Lenzer J. FDA warns about using antipsychotic drugs for dementia. BMJ. 2005;330:922. doi:10.1136/bmj.330.7497.922-c.

61. Antipsychotics in people living with dementia. London: National Institute for Health Care and Excellence; 2015 (https://www.nice.org.uk/advice/ktt7/chapter/Key-points, accessed 28 June 2021).

62. Egan KJ, Pot AM. Encouraging innovation for assistive health technologies in dementia: barriers, enablers and next steps to be taken. J Am Med Dir Assoc. 2016;17:357–63. doi:10.1016/j.jamda.2016.01.010.

63. Bee P, Price O, Baker J, Lovell K. Systematic synthesis of barriers and facilitators to service user-led care planning. Br J Psychiatry. 2015;207:104–14. doi:10.1192/bjp.bp.114.152447.

64. Garcia-Ptacek S, Dahlrup B, Edlund AK, Wijk H, Eriksdotter M. The caregiving phenomenon and caregiver participation in dementia. Scand J Caring Sci. 2019;33:255–65. doi:10.1111/scs.12627.

65. Personalised care and support planning handbook. The journey to person-centred care: core information. London: NHS England; 2016 (https://www.england.nhs.uk/wp-content/uploads/2016/04/core-info-care-support-planning-1.pdf, accessed 11 July 2021).

66. mhGAP Intervention Guide – Version 2.0. Geneva: World Health Organization; 2019 (https://www.who.int/publications/i/item/mhgap-intervention-guide---version-2.0, accessed 11 July 2021).

67. UHC Compendium: health interventions for universal health coverage (website). Geneva: World Health Organization (https://www.who.int/universal-health-coverage/compendium, accessed 11 July 2021).

68. Guidance on community mental health services: promoting person-centred and rights-based approaches. Geneva: World Health Organization; 2021

69. Guidance and technical packages on community mental health services: promoting person-centred and rights-based approaches. See: https://www.who.int/publications/i/item/guidance-and-technical-packages-on-community-mental-health-services (accessed 7 July 2021).

70. Integrated care for older people: guidelines on community-level interventions to manage declines in intrinsic capacity (ICOPE). Geneva: World Health Organization; 2017 (https://apps.who.int/iris/handle/10665/258981, accessed 11 July 2021).

71. Integrated care for older people (ICOPE) implementation framework: guidance for systems and services. Geneva: World Health Organization; 2019 (https://www.who.int/publications/i/item/9789241515993, accessed 21 July 2021).

72. Towards long-term care systems in sub-Saharan Africa – WHO series on long-term care. Geneva: World Health Organization; 2017 (https://www.who.int/ageing/long-term-care/WHO-LTC-series-subsaharan-africa.pdf, accessed 11 July 2021).

73. Ibanez A, Parra MA, Butler C, Latin America and the Caribbean Consortium on Dementia. The Latin America and the Caribbean Consortium on Dementia (LAC-CD): from networking to research to implementation science. J Alzheimers Dis. 2021;82:S379–94. doi:10.3233/JAD-201384.

74. Misconceptions on ageing and health. Geneva: World Health Organization; 2015 (https://www.who.int/news-room/photo-story/photo-story-detail/ageing-and-life-course, accessed 28 June).

75. Eurocarers. Towards carer-friendly societies: Eurocarers country profiles (website). Brussels: Eurocarers (https://eurocarers.org/country-profiles/, accessed 28 June 2021).

76. Care Act 2014. London: Government of the United Kingdom; 2014. (https://www.legislation.gov.uk/ukpga/2014/23/contents/enacted, accessed 28 June 2021).

77. Laver K, Milte R, Dyer S, Crotty M. A systematic review and meta-analysis comparing carer focused and dyadic multicomponent interventions for carers of people with dementia. J Aging Health. 2017;29:1308–49. doi:10.1177/0898264316660414.

78. Teles S, Paúl C, Sosa Napolskij M, Ferreira A. Dementia caregivers training needs and preferences for online interventions: a mixed-methods study. J Clin Nurs. 2020:1–19. doi:10.1111/jocn.15445.

79. Martin A, O'Connor S, Jackson C. A scoping review of gaps and priorities in dementia care in Europe. Dementia. 2020;19:2135–51. doi:10.1177/1471301218816250.

80. The challenging roles of informal carers. Policy brief. Geneva: United Nations Economic Commission for Europe; 2019 (https://unece.org/DAM/pau/age/Policy_briefs/ECE_WG1_31.pdf, accessed 11 July 2021).

81. Oliveira D, Vass C, Aubeeluck A. Quality of life on the views of older family carers of people with dementia. Dementia. 2019;18:990–1009. doi:10.1177/1471301217700741.

82. Sagbakken M, Spilker RS, Ingebretsen R. Dementia and migration: family care patterns merging with public care services. Qual Health Res. 2018;28:16–29. doi:10.1177/1049732317730818.

83. Oliveira D, Figueredo Da Mata FA, Mateus E, Musyimi CW, Farina N, Ferri CP et al. Experiences of stigma and discrimination among people living with dementia and family carers in Brazil: qualitative study. Ageing Soc. 2021:1–22. doi:10.1017/S0144686X21000660.

84. Nguyen T, Li X. Understanding public-stigma and self-stigma in the context of dementia: a systematic review of the global literature. Dementia. 2020;19:148–81. doi:10.1177/1471301218800122.

85. Musyimi CW, Ndetei DM, Evans-Lacko S, Oliveira D, Mutunga E, Farina N. Perceptions and experiences of dementia and its care in rural Kenya. Dementia. 2021. doi:10.1177/14713012211014800.

86. Werner P, Mittelman MS, Goldstein D, Heinik J. Family stigma and caregiver burden in Alzheimer's disease. Gerontologist. 2012;52(1):89–97. doi:10.1093/geront/gnr117.

87. White CL, Overbaugh KJ, Pickering CEZ, Piernik-Yoder B, James D, Patel DI et al. Advancing care for family caregivers of persons with dementia through caregiver and community partnerships. Res Involv Engagem. 2018;4:1. doi:10.1186/s40900-018-0084-4.

88. Cook JE, Purdie-Vaughns V, Meyer IH, Busch JTA. Intervening within and across levels: a multilevel approach to stigma and public health. Soc Sci Med. 2014;103:101–9. doi:10.1016/j.socscimed.2013.09.023.

89. A comparative analysis of non-discrimination law in Europe 2019. Luxembourg: European Union; 2020 (https://op.europa.eu/en/publication-detail/-/publication/a88ed4a7-7879-11ea-a07e-01aa75ed71a1, accessed 28 June 2021).

90. Weiss J, Tumosa N, Perweiler E, Forciea MA, Miles T, Blackwell E et al. Critical workforce gaps in dementia education and training. J Am Geriatr Soc. 2020;68:625–9. doi:10.1111/jgs.16341.

91. Dementia Training Standards Framework. Bristol: Skills for Health; 2018 (https://skillsforhealth.org.uk/info-hub/dementia-2015-updated-2018/, accessed 28 June 2021).

92. Fisher R, Parmar J, Duggleby W, Tian PGJ, Janzen W, Anderson S et al. Health-care workforce training to effectively support family caregivers of seniors in care. Can Geriatr J. 2020;23:160–71. doi:10.5770/cgj.23.384.

93. Greenberg NE, Wallick A, Brown LM. Impact of COVID-19 pandemic restrictions on community-dwelling caregivers and persons with dementia. Psychol Trauma. 2020;12:S220-1. doi:10.1037/tra0000793.

94. Armitage R, Nellums LB. COVID-19 and the consequences of isolating the elderly. Lancet Public Health. 2020;5:e256. doi:10.1016/S2468-2667(20)30061-X.

95. Palmer K, Monaco A, Kivipelto M, Onder G, Maggi S, Michel JP et al. The potential long-term impact of the COVID-19 outbreak on patients with non-communicable diseases in Europe: consequences for healthy ageing. Aging Clin Exp Res. 2020;32:1189–94. doi:10.1007/s40520-020-01601-4.

96. Vaitheswaran S, Lakshminarayanan M, Ramanujam V, Sargunan S, Venkatesan S. Experiences and needs of caregivers of persons with dementia in India during the COVID-19 pandemic – a qualitative study. Am J Geriatr Psychiatry. 2020;28:1185–94. doi:10.1016/j.jagp.2020.06.026.

97. Cohen G, Russo MJ, Campos JA, Allegri RF. Living with dementia: increased level of caregiver stress in times of COVID-19. Int Psychogeriatr. 2020;32:1377-81. doi: 10.1017/S1041610220001593.

98. Infection prevention and control guidance for long-term care facilities in the context of COVID-19 update: interim guidance. Geneva: World Health Organization; 2021 (https://www.who.int/publications/i/item/WHO-2019-nCoV-IPC_long_term_care-2021.1, accessed 11 July 2021).

99. Koslowski A, Blum S, Dobrotić I, Kaufman G, Moss P. International review of leave policies and related research 2020. International Network on Leave Policies & Research; 2020 (https://www.leavenetwork.org/annual-review-reports/review-2020/, accessed 11 July 2021).

100. Committee on Family Caregiving for Older Adults; Board on Health Care Services; Health and Medicine Division; National Academies of Sciences, Engineering, and Medicine. Families caring for an aging America. Schulz R, Eden J, editors. Washington (DC): National Academies Press; 2016.

101. Afram B, Stephan A, Verbeek H, Bleijlevens MH, Suhonen R, Sutcliffe C et al. Reasons for institutionalization of people with dementia: informal caregiver reports from 8 European countries. J Am Med Dir Assoc. 2014;15:108–16. doi:10.1016/j.jamda.2013.09.012.

102. Hopwood J, Walker N, McDonagh L, Rait G, Walters K, Iliffe S et al. Internet-based interventions aimed at supporting family caregivers of people with dementia: systematic review. J Med Internet Res. 2018;20:e216. doi:10.2196/jmir.9548.

103. Egan KJ, Pinto-Bruno Á, Bighelli I, Berg-Weger M, van Straten A, Albanese E et al. Online training and support programs designed to improve mental health and reduce burden among caregivers of people with dementia: a systematic review. J Am Med Dir Assoc. 2018;19:200–6.e1. doi:10.1016/j.jamda.2017.10.023.

104. Lai FH, Yan EW, Yu KK, Tsui WS, Chan DT, Yee BK. The protective impact of telemedicine on persons with dementia and their caregivers during the COVID-19 pandemic. Am J Geriatr Psychiatry. 2020;28:1175–84. doi:10.1016/j.jagp.2020.07.019.

105. Goldfarb A, Prince J. Internet adoption and usage patterns are different: implications for the digital divide. Inf Econ Policy. 2008;20(1):2–15. doi:https://doi.org/10.1016/j.infoecopol.2007.05.001.

106. Garvelink M, Ngangue P, Adekpedjou R, Diouf N, Goh L, Blair L et al. A synthesis of knowledge about caregiver decision making finds gaps in support for those who care for aging loved ones. Health Aff (Millwood). 2016;35:619–26.

107. Oliveira D, Ferrari Jacinto A, Martins Gratao AC, Ottaviani AC, Ferreira CR, Quirino Monteiro D et al. Translation and cultural adaptation of iSupport in Brazil. Alzheimers Dement. 2020;16(57). doi.10.1002/alz.038917.

108. Dorsey ER, Rabbani A, Gallagher SA, Conti RM, Alexander GC. Impact of FDA black box advisory on antipsychotic medication use. Arch Intern Med. 2010;170:96–103. doi:10.1001/archinternmed.2009.456.

109. Desai VC, Heaton PC, Kelton CM. Impact of the Food and Drug Administration's antipsychotic black box warning on psychotropic drug prescribing in elderly patients with dementia in outpatient and office-based settings. Alzheimers Dement. 2012;8:453–7. doi:10.1016/j.jalz.2011.08.004.

110. Prince M, Wimo A, Guerchet M, Ali G-C, Wu Y-T, Prina M. World Alzheimer Report 2015. The global impact of dementia – an analysis of prevalence, incidence, cost and trends. London: Alzheimer's Disease International; 2015.

111. Defeating dementia: the road to 2025. London: World Dementia Council; 2018.

112. G8 summit declaration, December 2013 (https://www.gov.uk/government/publications/g8-dementia-summit-agreements/g8-dementia-summit-declaration, accessed 28 June 2021).

113. Pickett J, Brayne C. The scale and profile of global dementia research funding. Lancet. 2019;394:1888–9. doi:10.1016/S0140-6736(19)32599-1.

114. Aerts L, Lauwers E, De Strooper B. Dementia and COVID-19: a health and research funding crisis. Lancet Neurology. 2021;20:90. doi:10.1016/S1474-4422(21)00002-8.

115. Neglect during a crisis: the stark reality. Lancet Neurol. 2020;19:879. doi:10.1016/S1474-4422(20)30361-6.

116. An R&D Blueprint for Action to Prevent Epidemics. Geneva: World Health Organization; 2016 (https://www.who.int/publications/m/item/an-r-d-blueprint-for-action-to-prevent-epidemics, accessed 21 July 2021).

Annexes

Annex 1 Making dementia a public health priority – the Global dementia action plan

The World Health Organization (WHO) published its first report on dementia *Dementia: a public health priority*, prepared in collaboration with Alzheimer's Disease International (ADI), in 2012. That report summarized the challenges that countries and societies – but first and foremost people with dementia and their carers across the world – were facing and continue to face.

To address these global challenges, a number of international efforts have been undertaken in recent years (see Box 31), leading to the adoption of the Global action plan on the public health response to dementia 2017–2025 *(2)*.

BOX 31

International efforts to address dementia

2012	WHO launched the report *Dementia: a public health priority* in collaboration with Alzheimer's Disease International (ADI)
2013	The United Kingdom hosts G8[11] summit on dementia followed by G7[12] legacy events
2014/15	G7 legacy events on dementia in Canada, Japan, the United Kingdom and the United States of America
2015	First Ministerial Conference on Global Action Against Dementia
2017	Global action plan on the public health response to dementia 2017–2025 Launch of WHO's Global Dementia Observatory (GDO)
2019	G20[13] Osaka Leaders' declaration committing to a "comprehensive set of policies to address dementia, including promoting risk reduction and sustainable provision of long-term care as well as inclusive societies aiming to improve quality of lives of people with dementia and carers".

---

[11] The G8 dementia summit was held in London on 11 December 2013, together with government ministers, researchers, pharmaceutical companies and charities. In 2013, the following countries took part in the meeting: Canada, France, Germany, Italy, Japan, Russia, United Kingdom and United States of America.

[12] The G7 (Group of seven) is an intergovernmental political forum involving Canada, France, Germany, Italy, Japan, United Kingdom and United States of America.

[13] The G20 is the international forum that brings together the world's major economies. Its members are Argentina, Australia, Brazil, Canada, China, France, Germany, India, Indonesia, Italy, Japan, Republic of Korea, Mexico, Russia, Saudi Arabia, South Africa, Turkey, United Kingdom, United States of America and the European Union.

The vision of the Global dementia action plan is "a world in which dementia is prevented, and people with dementia and their carers live well and receive the care and support they need to fulfil their potential with dignity, respect, autonomy and equality". Concretely, the plan aims to improve the lives of people with dementia, their families and the people who care for them, while decreasing the impact of dementia on communities and countries. Areas for action include:

- making dementia a public health priority through policy and legislation;
- raising dementia awareness and inclusion;
- reducing the risk of dementia;
- improving dementia diagnosis, treatment and care;
- developing support and services for dementia carers;
- strengthening health information systems for dementia; and
- fostering research and innovative technologies.

The Global dementia action plan is deeply grounded in principles such as human rights, empowerment and the engagement of people with dementia and their carers, evidence-based practice for dementia risk reduction and care, multisectoral collaboration, universal and social health coverage for dementia, equity, and appropriate attention to dementia prevention, disease modification, cure and care.

Specifically, preventing dementia for those at risk represents an important component of achieving population health for all and is required to ensure that more people enjoy better health and well-being. Similarly, timely and affordable access to quality diagnosis, treatment, care, rehabilitation and palliative care for people with dementia, their carers and families is central to ensuring universal health coverage (UHC) for all. Finally, ensuring that the needs of people with dementia are met within the context of the ongoing COVID-19 pandemic, and also in humanitarian crises and the aftermaths of natural disasters, represents an integral part of addressing health emergencies. Additionally, socioeconomic inequities increase risk factors and reduce protective factors for whole communities; thus need to be addressed using a whole-of-society approach at both international and national levels, with specific focus on vulnerable or marginalized populations who may be at increased risk. The Global dementia action plan also supports numerous other global action plans and strategies, decisions and resolutions adopted as international commitments, including the forthcoming Intersectoral global action plan on epilepsy and other neurological disorders.[14]

Reaching the targets included in the Global dementia action plan is intimately connected to the achievement of other high-level commitments such as the 2030 Agenda for Sustainable Development and the Sustainable Development Goals (SDGs), the United Nations (UN) Convention on the Rights of Persons with Disability (CRPD), the Political Declaration of the High-level Meeting of the General Assembly on the Prevention and Control of Non-communicable Diseases (2018), the UN Decade of Healthy Ageing 2021–2030, commitments to UHC and the Declaration of Astana on strengthening primary health care (2018), and the 2019 Okayama Declaration of the G20 Health Ministers*(31)*.

Annex 2 WHO & UN initiatives relevant for dementia risk reduction

- **2005**: FCTC Framework Convention on Tobacco Control: https://www.who.int/fctc/en/
- **2010**: Global Strategy to reduce the harmful use of alcohol: https://apps.who.int/iris/handle/10665/44395
- **2010**: WHO Package of essential noncommunicable (PEN) disease interventions for primary health care in low-resource settings. Geneva: WHO; 2010. https://apps.who.int/iris/handle/10665/334186
- Global recommendations on physical activity for health. Geneva: WHO; 2010. http://www.who.int/dietphysicalactivity/publications/9789241599979/en/
- **2011**, **2014**, **2018**: UN High-level meetings on noncommunicable diseases:
  - https://www.un.org/en/ga/ncdmeeting2011/
  - https://undocs.org/en/A/66/L.1

---

[14] These include: the Strategy for Healthier Populations 2020–2030; the Decade of Healthy Ageing 2020–2030; the WHO Global Disability Action Plan 2014–2021; WHO's Global Action Plan for the Prevention and Control of Noncommunicable Diseases 2013–2020; the Comprehensive Mental Health Action Plan 2013–2020; World Health Assembly Resolution WHA67.22 (2014) on Access to Essential Medicines; and the WHO Guideline: Recommendations on Digital Interventions for Health System Strengthening.

- Political declaration of the High-level Meeting of the General Assembly on the Prevention and Control of Non-communicable Diseases, 2011
    - https://www.who.int/nmh/events/2014/a-res-68-300.pdf?ua=1 (Resolution adopted by the General Assembly on 10 July 2014)
- **2013**: Global action plan for prevention and control of noncommunicable diseases (2013-2020): https://www.who.int/nmh/events/ncd_action_plan/en/
- Strengthening health systems for treating tobacco dependence in primary care. Geneva: WHO, 2013. https://apps.who.int/iris/handle/10665/84388
- Prevention and control of noncommunicable diseases: guidelines for primary health care in low-resource settings. Geneva: WHO; 2012. http://apps.who.int/iris/bitstream/10665/76173/1/9789241548397_eng.pdf
- **2013**: WHO Comprehensive mental health action plan https://www.who.int/publications/i/item/9789241506021
- **2015**: WHO First Ministerial Conference on Global Action against Dementia https://apps.who.int/iris/handle/10665/179537
- **2016**: Integrated care for older people (ICOPE): Recommendations on interventions to improve physical and mental capacities of older people at community level. https://apps.who.int/iris/handle/10665/258981
- **2017**: WHO Global action plan on the public health response to dementia 2017–2025 https://apps.who.int/iris/handle/10665/259615
- **2018**: HEARTS Technical package for cardiovascular disease management in primary health care: evidence-based treatment protocols. https://apps.who.int/iris/handle/10665/260421
- **2019**: WHO Guidelines on risk reduction of cognitive decline and dementia: https://apps.who.int/iris/bitstream/handle/10665/312180/9789241550543-eng.pdf?ua=1
- **2019**: Recommendations on healthy diet. http://www.who.int/en/news-room/fact-sheets/detail/healthy-diet
- **2020**: WHO guidelines on physical activity and sedentary behavior https://apps.who.int/iris/handle/10665/336656

Web annex Methodology for estimating dementia cost

The methodology for estimating dementia cost can be accessed via the following link: https://apps.who.int/iris/bitstream/handle/10665/344479/9789240033269-eng.pdf

For more information, please contact:
Department of Mental Health and Substance Use
World Health Organization
Avenue Appia 20
CH-1211 Geneva 27
Switzerland

Email: whodementia@who.int
Website: https://www.who.int/health-topics/dementia

9789240033245
9 789240 033245