



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

Executive summary



World Health
Organization

Global status report on the public health response to dementia: executive summary

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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.

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

Berrie Holtzhausen,
Namibia

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.

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.



55.2
million
people worldwide
living with dementia

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.

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

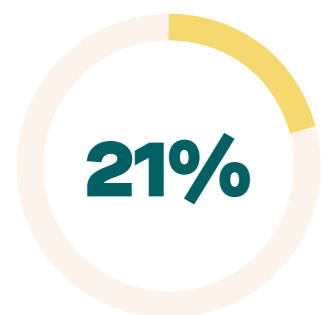
campaign on dementia and 50% of countries with at least one dementia-friendly initiative (DFI) to foster a dementia-inclusive society.

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.



26%

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



21%
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.

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,

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

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.

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.



Only 29

GDO countries can report on dementia diagnostic rate

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.

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

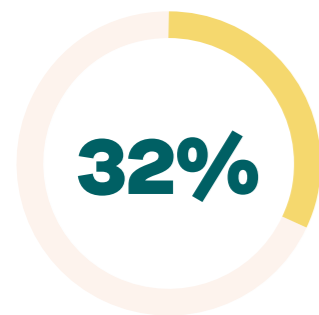
Developing new prioritization strategies and implementing innovative health technologies is paramount to advancing capabilities for prevention, risk reduction, early diagnosis, therapies and care for people with dementia. Social and medical priorities must be identified for dementia research to increase 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.



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



Other NCDs
have up to
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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.

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