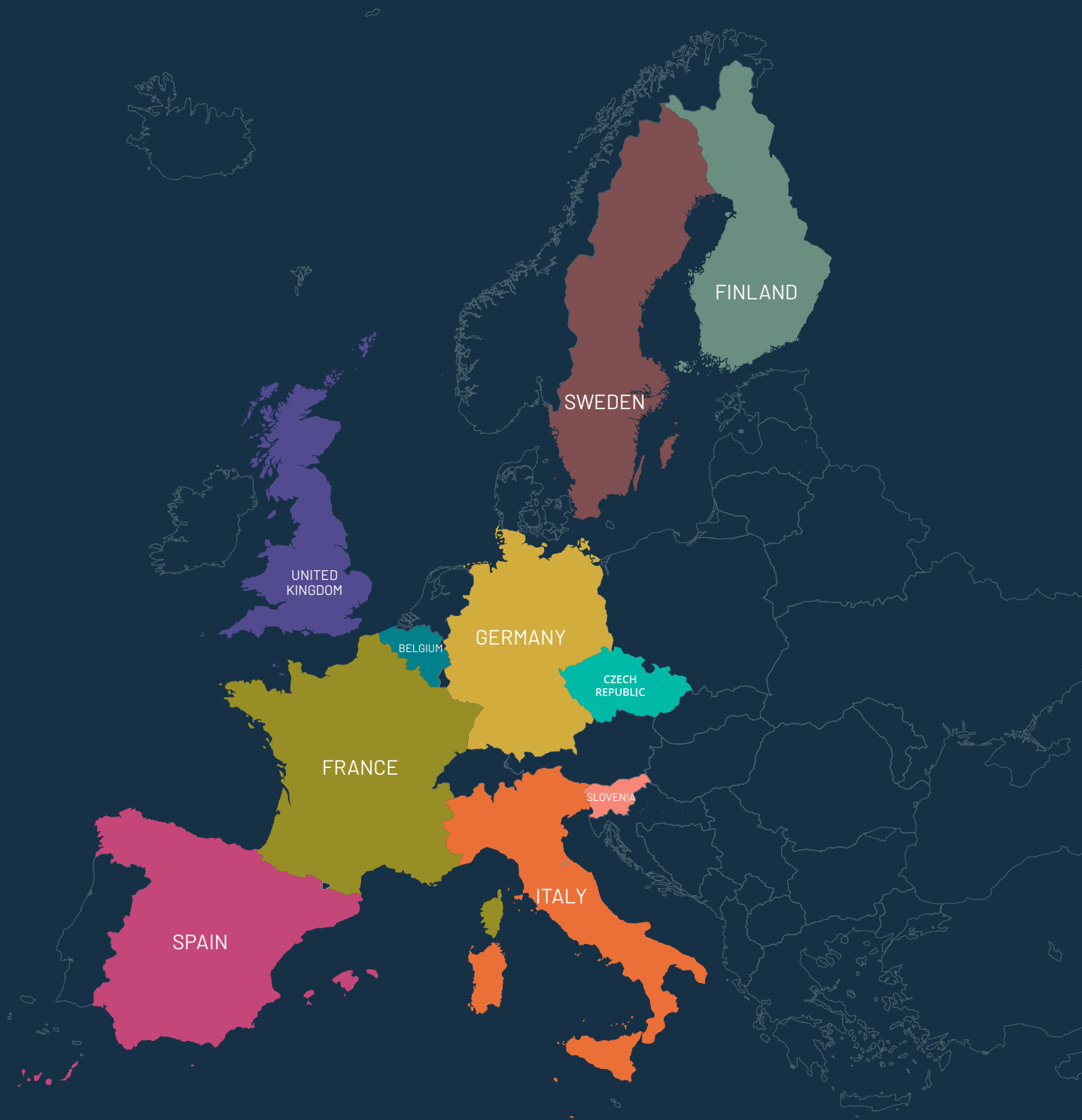




2021 Alzheimer's Innovation Readiness Index

The development costs of the 2021 edition of the *Alzheimer's Innovation Readiness Index (AIRI)* were funded by Biogen.
The 2021 AIRI was created in partnership with GCOA and ADI.





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Introductory Letter

As European governments continue making progress in combating COVID-19, decision makers will need to pay closer attention to health issues that took a backseat over the past year, including the diagnosis, treatment, and management of Alzheimer's disease. While many governments successfully implemented foundational aspects of their dementia and Alzheimer's national action plans before the pandemic, initiatives in several countries have since been stalled, disrupted, or delayed. In the coming decades, European governments will face immense pressure to bolster Alzheimer's disease and dementia strategies as the number of people impacted is projected to nearly double from about 10 million to 20 million by 2030.¹ Furthermore, the WHO estimates that global costs of dementia are set to rise dramatically, from \$1.3 trillion in 2019 to about \$2.8 trillion by 2030, accounting for increased care costs.²

As the global population ages and the number of people living with Alzheimer's disease grows, society's burden continues to expand. Informal caregivers are shouldering a huge proportion of the care burden in many countries, accounting for about half of the global cost of dementia.³ In fact, Alzheimer's Disease International estimates that globally over 65 million people will be full-time informal carers for those living with dementia by 2030.⁴ The growing demand for Alzheimer's disease services means governments must do more to address these challenges.

We believe European governments have a unique opportunity to meet the moment by fully funding national initiatives to combat Alzheimer's disease and other dementias. But changes are needed:

- First, countries must pass or renew national plans that articulate concrete, attainable measures to address the growing needs of this population and their caregivers.
- Second, governments must move beyond simply constructing well-organized plans by securing the necessary funding to implement key initiatives.
- Third, a new era of advocacy is needed, driven by regional and national political champions committed to sustaining efforts to combat Alzheimer's disease and other dementias.

All these goals are achievable. But they will not come about on their own.

Fully funding national plans will require a greater level of political commitment. National plans will need to be more detailed and include the seven key actions areas and indicators of the WHO Global Action Plan (GAP) on dementia. Governments will also need to make firmer commitments to funding Alzheimer's and dementia programs and be more transparent in the budgetary process. All strategies must be drafted and enacted with an eye to the human rights of people living with dementia, which sadly have often been overlooked or forgotten.

The consequences of inaction could be dire. As the pandemic has demonstrated, our healthcare infrastructure is vulnerable to systemic challenges and not equipped to handle significant increases in demand. Recent studies demonstrate that across European nations, people living with dementia have been hard hit by COVID-19, not only in terms of mortality and morbidity, but also longer term effects of COVID-19 that are still being investigated.⁵ Those living with Alzheimer's disease and dementia have faced challenges finding support during the pandemic, leading many to call for greater attention to their wellbeing and rights, as well as those of their caregivers.⁶ Researchers are

also investigating whether COVID-19 increases the risk of Alzheimer's disease, particularly early-onset.⁷

To help decision makers rethink their approach to Alzheimer's disease and other dementias, we have assembled the *2021 Alzheimer's Innovation Readiness Index (AIRI)*, a comprehensive, comparative examination of country-level progress across 10 European nations.

This *Index*, which was funded by Biogen, is the fourth collaboration between Alzheimer's Disease International (ADI) and the Global Coalition on Aging (GCOA). It builds on two previous reports measuring the readiness of G7, select G20, and large cities to integrate innovative dementia solutions into their healthcare systems. We hope this report will inform decision makers and encourage them to implement policies to support those living with Alzheimer's disease and other dementias. As Europe rapidly ages, more families are impacted, and the burden of Alzheimer's disease continues to rise. It is imperative that governments make investments now to ensure we can properly diagnose, holistically treat, and care for individuals in the coming decades.

Paola Barbarino
CEO, Alzheimer's Disease
International

Michael Hodin, PhD
CEO, Global Coalition on Aging

Acronyms

ACER	Addenbrooke's Cognitive Examination Revised	EAA	European Alzheimer's Alliance	LMICs	Low- and middle-income countries
AD	Alzheimer's disease	EFNA	European Federation of Neurological Associations	MCI	Mild cognitive impairment
ADI	Alzheimer's Disease International	EFPIA	European Federation of Pharmaceutical Industries and Associations	MEPs	Members of European Parliament
AIRI	Alzheimer's Innovation Readiness Index	EMA	European Medicines Agency	MMSE	Mini-Mental State Exam
ALCOVE	Alzheimer Cooperative Valuation in Europe	EPAD	European Prevention of Alzheimer's Dementia Consortium	MOPEAD	Models of Patient Engagement for Alzheimer's disease
ALD	French long-term illness policy	FAE	Fundación Alzheimer España	MRI	Magnetic resonance imaging
AMYPAD	Amyloid imaging to prevent Alzheimer's disease initiative	FINGER	Finnish Geriatric Intervention Study to Prevent Cognitive Impairment and Disability	NAP	National action plan
BMBF	German Federal Ministry of Education and Research	GA	German memory clinic	PET	Positron emission tomography
BMFSFJ	German Federal Ministry for Family Affairs, Senior Citizens, Women and Youth	GAP	Global Action Plan	RBC	Relationship-based care
BNA	French National Alzheimer database	GCOA	Global Coalition on Aging	SveDem	Swedish national registry for dementia
ČALS	Czech Alzheimer Society	GPs	General Practitioners	WHO	World Health Organization
CEAFA	Confederación Española de Familiares de Enfermos de Alzheimer	HICs	High-income countries		
CMBD	Basic minimum data set	HSE	Irish Health Service Executive		
CSF	Cerebrospinal Fluid	IMI	Innovative Medicines Initiative		
DEM2	The EU's 2nd Joint Action on Dementia	JPND	EU Joint Programme –Neurodegenerative Disease Research		
DPUK	Dementias Platform UK				

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Chair of the European
Working Group of People
with Dementia, Alzheimer's
Europe

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			EU
			Tadeusz Hawrot European Federation of Neurological Associations
			Frédéric Destrebecq European Brain Council

Executive Summary

As the number of people in Europe living with Alzheimer's disease and other dementias grows significantly in the coming decades, regional action will be critical in ensuring these individuals receive the diagnosis, treatment, and care they deserve. This comprehensive Alzheimer's disease index has been created to help raise awareness and guide decision makers. The *Index* examines country-level progress across five categories critical to boosting initiatives at the national level, while also providing a brief overview of EU initiatives and efforts. Our goals are to help decision makers better understand the impact of these diseases, stimulate discussion about the best approaches to dealing with this crisis, and help secure and sustain funding to implement effective programs and initiatives related to Alzheimer's disease and other dementias.

This *Index* builds on previous calls for greater innovation in tackling the disease at the local, regional, national, and global levels. In this report, we evaluate the progress of 10 European countries across five categories critical to assessing national performance: Strategy & Commitment, Early Detection & Diagnosis, Access to Care (Medical), Awareness & Monitoring, and Care Standards & Settings.

The information in this report is divided into two main sections. The first section provides high-level findings for each category, reflecting insights gleaned from experts surveyed and interviewed across Europe. The second section is comprised of detailed country profiles, including national Alzheimer's disease landscapes and updates on country-specific performance across the five core categories.

By distilling and analyzing a wealth of information, we hope stakeholders, particularly those less familiar with the topic, will be able to identify opportunities and gaps more easily within their countries. Stakeholders can also benefit by reviewing progress in other countries, both to identify best practices worth replicating and understand how their policies stack up against their peers. Additionally, the pan-European case studies included in this *Index*, led by the EU or by national governments themselves, also should serve as a source of ideas and inspiration for decision makers.

Although the majority of countries featured in this report are high-income countries (HICs) that have progressed in developing national dementia plans, highlighting their efforts can help build momentum elsewhere. As the 2019 Okayama Declaration and the 2021 Rome Declaration of the G20 Health Ministers clearly outline the need for

member states to lead by example, it is vital that these countries adequately fund national plans, which is not always the case.⁸

Throughout the report, the terms “persons living with dementia” or “people living with dementia” are used interchangeably. This term is meant to connote nothing further than a person or persons living with Alzheimer’s

disease or dementia. The terms “carers,” “caregivers,” and “care partners” are also used interchangeably. In certain instances, we use the terms “formal caregivers” and “informal caregivers” to address issues specific to these segments.

The following key findings will be explored in more detail in the report’s respective sections:

-
- Countries must move beyond developing plans to securing funding for implementation
-
- Early diagnosis and detection efforts remain insufficient
-
- Stigma is a primary barrier to timely diagnosis and care
-
- Variation within countries has created a “postcode lottery” for treatment access

-
- Government investments in awareness campaigns to combat stigma and in research are not commensurate with the need
-
- Care systems in most countries are in desperate need of reform
-
- Training for caregivers, both informal and formal, is insufficient across almost all countries

Methodology

Framework

This *Index* was created to evaluate the commitments made by governments to address Alzheimer's disease and other dementias in 10 European countries and to assess their progress in Alzheimer's disease innovation—defined as applied tools/solutions, resources, methods and approaches, technologies, services, interventions, best practices, existing or under development, that would impact the prevention, treatment, or care of people with Alzheimer's disease and other dementias. These 10 European countries were chosen due to upcoming EU Presidencies and roles as G7 and G20 hosts, making these governments key players in future policy discussions about Alzheimer's disease and other dementias. We believe the results provided here offer a benchmark for nations to measure their progress and determine where they need to do more. In analyzing the landscape, we attempted to answer several key questions:

- Have countries made political commitments to improving Alzheimer's disease and other dementias prevention, care, and treatment?
- Are there concerted efforts to increase diagnosis rates? To improve how and when diagnoses are made?
- Do persons living with Alzheimer's disease or dementia have sufficient access to requisite diagnosis and treatment?
- Are national governments investing in prevention and risk reduction?
- Is care for Alzheimer's disease and other dementias accessible, high-quality, and innovative?

Categories and Indicators

To answer these questions and provide a view of the disease landscape, we developed a series of categories to direct our research. These categories were chosen after a thorough investigation of the global Alzheimer's disease and other dementias ecosystem that included a comprehensive review of the existing literature; scores of conversations with country-level and pan-European experts and stakeholders; and insights gained from several key reports—Alzheimer's Europe's *Dementia Monitor*, ADI's *From Plan to Impact*, and the WHO's *Global Dementia Observatory* reports.

Strategy & Commitment

Captures the high-level policies, political commitments, and investments that national governments have undertaken to address Alzheimer's disease and other dementias.

Early Detection & Diagnosis

Investigates government-driven efforts to increase rates of early detection and improve diagnosis for those living with Alzheimer's disease and dementia.

Access to Care (Medical)

Measures the level of access within a country to the appropriate and necessary medical care.

Awareness & Monitoring

Judges how seriously governments have committed to efforts that can reduce the risk of developing Alzheimer's disease or dementia.

Care Standards & Settings

Assesses the level of access, innovation, and government commitment to national care standards and care settings.

Scoring

The *Index* incorporates both qualitative and quantitative data across five categories, subdivided into 23 component areas, and over 120 distinct metrics. The full list of metrics, indicators, evaluation criteria, and specific metric scores can be found in the appendices.

All metrics were scored on a 100-point scale. Numerical metrics were converted to a 100-point scale and relatively scored based on the determined best score scenario. Binary and qualitative data were converted to a simple banded 100-point scale (e.g., Yes= 100, No=0). Metrics were then grouped based on theme and equally weighted to form 23 component areas. In turn, these component areas were grouped and equally weighted to compose the five categories. These category scores were then equally weighted to produce the final index score.

Assumptions and Limitations

Alzheimer's disease and other dementias have rarely received the necessary attention from national governments. People living with dementia and their families often experience stigma, isolation, hopelessness, and suffering. Without treatments to alter the course of the disease, the Alzheimer's disease and dementia community has often been dismissed and neglected, inhibiting innovation within the field. Rather than provide an

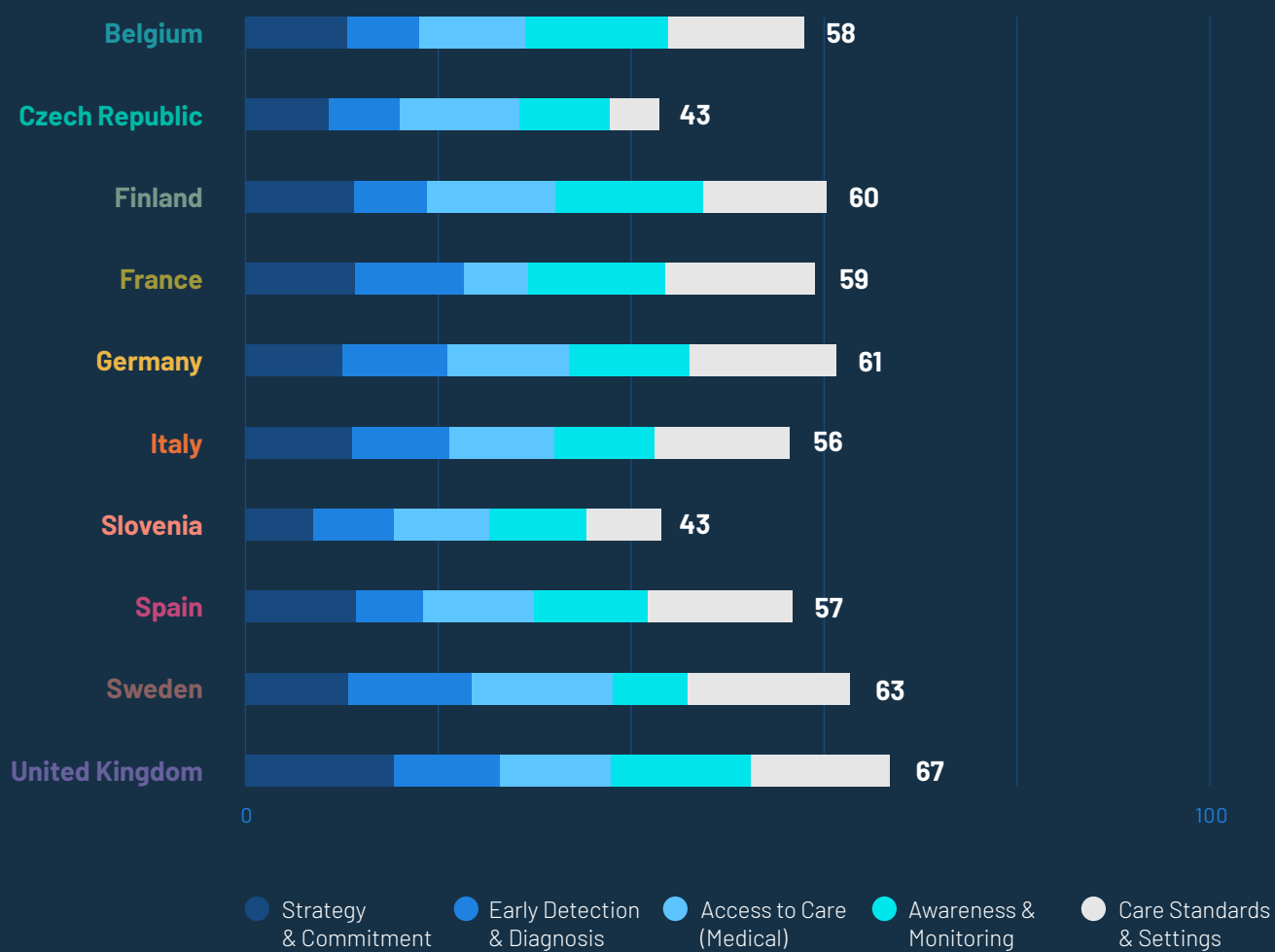
exhaustive map of Alzheimer's disease and dementia efforts, this report seeks to highlight the key areas where research suggests that action and inaction will disproportionately determine levels of national progress.

Global efforts to increase early detection and diagnosis for Alzheimer's disease and other dementias have been extremely limited. Thus, many of the figures regarding estimations of prevalence and diagnosis rates within countries are inherently flawed. This is a crucial shortcoming in the countries assessed; without the infrastructure to diagnose and detect these diseases at an early stage, the effectiveness of interventions is reduced.

Many of the insights here were derived from conversations with expert Alzheimer's disease and dementia stakeholders, and the scores assume the reliability of these contributors. The surveys and interviews were conducted in English, from January 2021 to May 2021. The results in this report represent language-limited insights from a snapshot in time.

Overall Scores

Overall Scores with Category Contributions



Category Level Insights



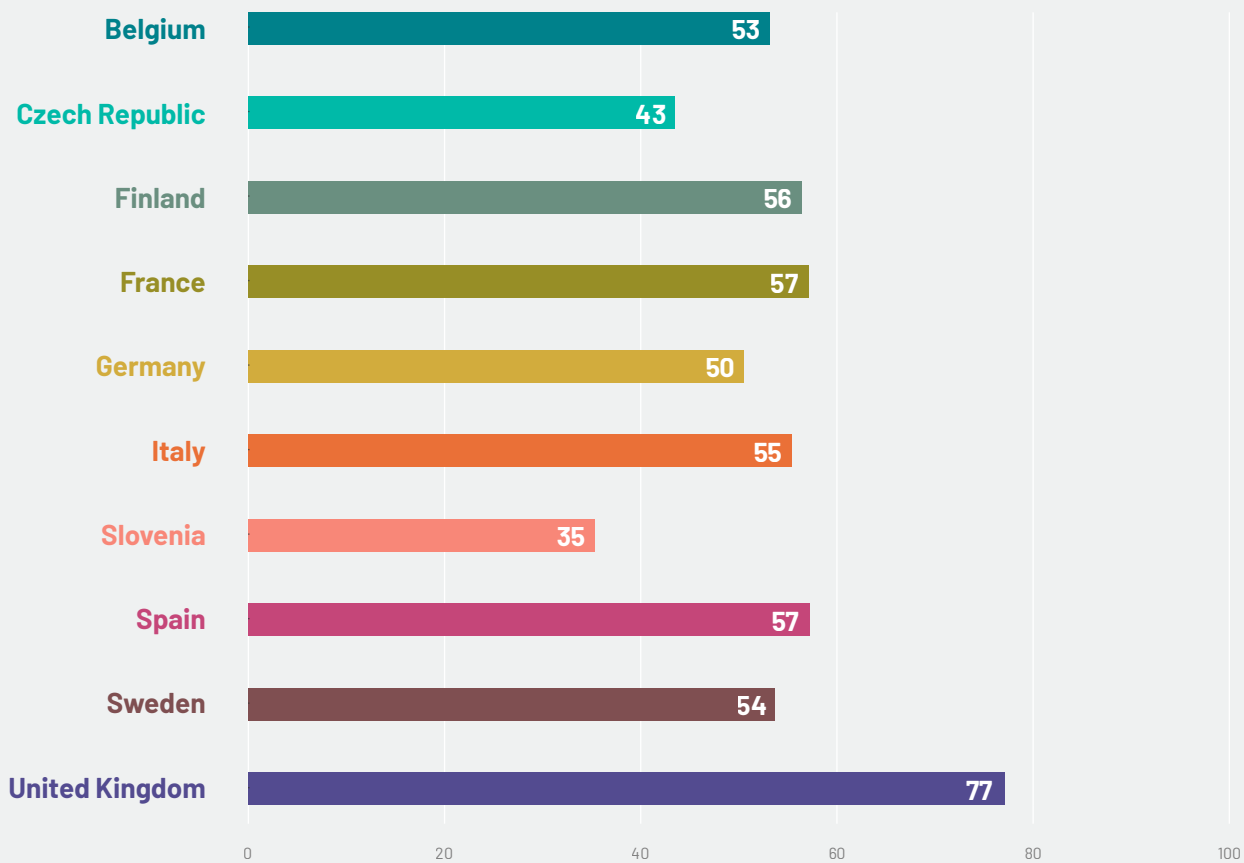


Strategy & Commitment

Scoring Insights

While the UK performs well due to the comprehensiveness of its plans, greater stakeholder engagement in developing strategies and stronger mechanisms for monitoring and implementation are needed. Slovenia lags behind largely due to weak implementation, poor monitoring, and inadequate political leadership on the issue. Nevertheless, ADI and the national association are currently advocating for the reinstatement of a standalone national plan. The WHO reports that even though half of total member state dementia plans are found in Europe, many have expired, are expiring, or require renewed government commitments.⁹

Strategy & Commitment Country Comparison



Captures the high-level policies, political commitments, and investments that national governments have undertaken to address Alzheimer's disease and other dementias.



Key Findings

Most countries are not fully funding implementation of Alzheimer's disease and other dementias plans

Experts in many countries expressed optimism that the latest editions of their national plans better address the specific needs of those living with dementia, care-givers, and professionals. Though most national plans are aligned with the World Health Organization (WHO) and other global recommendations and reflect input from a range of stakeholders, securing full funding for implementation remains a challenge.¹⁰ Many experts worry that legislators and ministries will not provide the funding needed to implement integral programs in the coming years.

COVID-19 has disrupted implementation, renewal, and funding of national plans

The COVID-19 pandemic has substantially impacted national action plans in every country examined.¹¹ In spite of continued cross-party commitments to fund programs and initiatives, the pandemic has pushed Alzheimer's disease and other dementias down the list of policymaker priorities. In some countries, the pandemic has created a state of limbo, with experts uncertain about the status of national action plans. In France, experts suggest the challenges in securing support for a national plan predated the pandemic and that COVID-19 merely compounded these difficulties.¹² Nevertheless, there has been an evaluation of the previous French plan and release of a new Neurodegenerative Disease Roadmap 2021-2022.¹³ Experts in Finland believe the scheduled update to the 2012-2020 plan for memory disorders had been delayed due to COVID-19.¹⁴ The pandemic has also made experts in many countries, including Belgium and the Czech Republic, wary of the funding environment for Alzheimer's disease and other dementias.¹⁵

Driven by third-party organizations and advocacy groups, political support for Alzheimer's disease and other dementias is slowly growing, though political champions remain rare

Experts in several countries indicated that decision-maker awareness of Alzheimer's disease and dementias was steadily increasing. In France, a national parliamentary group on Alzheimer's disease and other dementias has been revitalized, after lying dormant for years. In the latest count, 11 of the 79 French Members of European Parliament (MEPs) have joined the European Alzheimer's Alliance. In the UK, former Prime Minister David Cameron helped champion a series of national dementia initiatives aimed at increasing awareness and funding much needed research initiatives.¹⁶ In Sweden, Queen Silvia has long been an active proponent for improving training for caregivers and other medical providers, while extending her influence as an ADI Global Ambassador.¹⁷

Much of the increased attention to Alzheimer's disease and other dementias is thanks to national associations and other third-party organizations, which have sought to raise awareness, provide services to those living with dementia and their families, and push for greater political commitment. National associations are often the strongest drivers of change, with the greatest ability to influence the development or expansion of a national plan. For example, in Slovenia, Spominčica has led public awareness efforts and raised political attention to the issue through targeted campaigns and initiatives. Likewise, the Czech Alzheimer's Society (ČALS) has conducted media campaigns to increase awareness and political attention, while also providing free testing to encourage early detection and diagnosis.

Alzheimer's disease and other dementias are often relegated to the "second-tier" of issues, making funding more difficult to secure

Stakeholders in many countries expressed concern that advocates for greater funding for Alzheimer's disease and dementia programs must compete with efforts to lobby decision makers to spend on other disease initiatives. Specifically, experts noted that unlike cancer or HIV, Alzheimer's disease and other dementias have yet to "break through," relegating them to secondary status in terms of decision-maker attention and funding. While innovative financing mechanisms and greater private funding can help, the primary responsibility for funding national programs remains with central governments. In Spain, parliamentarians have avoided firm commitments to specific disease areas for fear of alienating other constituency groups, making it nearly impossible to secure standalone grants or allocations for Alzheimer's disease and other dementias.¹⁸ Additionally, many decision makers do not appreciate the need for sustained funding, leading to a de-prioritization of the issue.¹⁹ The French national government drastically reduced spending for Alzheimer's disease and other dementias after the completion of President Sarkozy's bold and well-funded initiative ended in 2012. Experts stated that many policymakers believed the program had run its course and achieved stated objectives, therefore funding was no longer necessary.

Devolved administration of health systems undermines national efforts to streamline Alzheimer's disease and other dementia programs

Experts in several countries flagged decentralized governing structures as a major barrier to effectively implementing prevention, diagnosis, treatment, and care programs. Decentralized systems inhibit the integration of national-level policies and programs, making

it harder to standardize services. In Spain, experts noted substantial differences in program quality across regions, where local leaders and governments retain autonomy. In Belgium, there are stark differences between the level of government involvement in programs in the north compared to the Francophone south (Wallonia). Italy's Alzheimer's disease and other dementias infrastructure is similarly segmented along regional lines, with disparities in financial support and implementation of regional programs. Despite recent NHS restructuring, local councils in the UK are still the primary facilitator of Alzheimer's disease and other dementia provisions, creating substantial variation in the quality of care that people living with dementia receive.²⁰

Data consolidation is a large gap, with countries struggling to establish or develop systems to collect data across the care pathway (diagnosis, treatment, management)

The Alzheimer's disease data landscape remains fragmented in most countries. While Alzheimer's Europe has produced a list of recommendations to improve the collection and usage of Alzheimer's disease and other dementias' data,²¹ many countries are not heeding this guidance. Although some have partial databases, regional variation, lack of coordination between levels of government and an absence of accurate standards makes it challenging to get a clear disease snapshot in each country. To address this serious gap, several countries examined in this *Index* are undertaking efforts to help streamline data collection related to Alzheimer's disease and other dementias. In Sweden and the UK, the SveDem and Dementia Platform have been used to collect and provide access to national dementia data while aiming to improve data robustness and breadth.



European governments continue to underfund Alzheimer's disease and other dementias research

Experts warned that European governments are not allocating sufficient funding for research into Alzheimer's disease and other dementias. In France, funding and allocations for Alzheimer's disease and other dementias research projects have dropped precipitously since their peak during the 2008 Sarkozy initiative. Specifically, experts note that the number of funded research opportunities is limited compared to the number of interested researchers, forcing many to go abroad to gain the experience needed to sustain a career in the field. Across Europe, a greater commitment to clinical trials is also imperative. In their *2020 Dementia Monitor*, Alzheimer's Europe found that only half of the 36 countries included had ongoing or open trials.²²

Calls to Action

Governments must commit the requisite resources to fully implement national plans

There is a strong consensus that national level funding for these Alzheimer's disease and other dementias plans is insufficient.²³ Though countries should be commended for soliciting input from a wide range of stakeholders when crafting actionable plans, progress will be limited without a renewed commitment of financial resources from national policymakers.

Governments should develop a streamlined and centralized approach to Alzheimer's disease and other dementias policy

In several countries, regional governments have too much control over Alzheimer's disease and dementia policy, leading to significant differences in the quality of healthcare services available. Devolved government structures can lead to an uneven distribution of resources and inhibit the successful implementation of national initiatives for improving Alzheimer's disease and other dementias prevention, treatment, and care. To address these challenges, governments should empower federal officials to implement policies with more authority. More attention should also be directed to person-centered care and the rights of those living with dementia. For example, Ireland's approach to tie almost all national strategy goals and values to personhood represents a refreshingly human strategy that is focused on inclusion and respect.²⁴

Governments must conduct a regular national census for Alzheimer's disease and other dementias data

In nearly every country assessed, data was fragmented, incomplete, and/or siloed. No country has a database that accurately tracks all types of data needed, including prevention, diagnosis/prevalence, referrals, reimbursements, medication usage, long-term care usage, in-home care usage, etc. European governments should make it a national priority to establish a transparent, reliable, and accurate database for managing this information. This would improve outcomes, optimize the allocation of resources, and help policymakers better understand the scope of the problem.



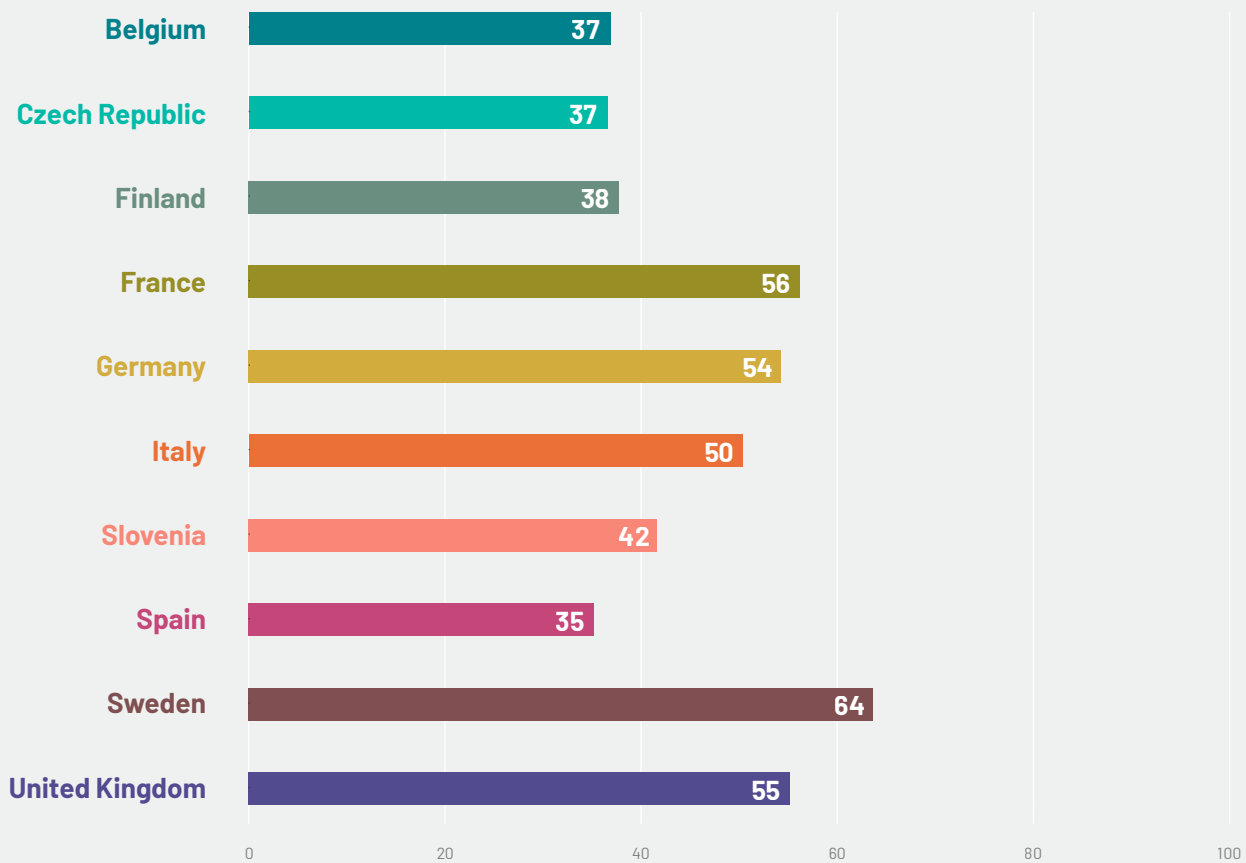
Early Detection & Diagnosis

Scoring Insights

Sweden performed marginally better due to higher numbers of memory clinics and early onset AD clinics per capita. Spain generally scored poorly due to lack of training for healthcare professionals and weaker efforts to increase early screening and detection in primary care.

N.B., as referenced in the methodology, the lack of early detection and diagnosis screening efforts makes it difficult to quantifiably ascertain just how poorly countries are performing in this area and estimates of Alzheimer's disease and other dementia prevalence are currently inherently unreliable.

Early Detection & Diagnosis Country Comparison



Investigates government-driven efforts to increase rates of early detection and improve diagnosis for those living with Alzheimer's disease and dementia.

Key Findings

Stigma remains a huge barrier in many countries, making people wary of seeking diagnosis

In nearly every European country examined, stigma remains the primary barrier to early and effective diagnosis for Alzheimer's disease and other dementias. In a 2019 World Alzheimer's Report survey, about one in four Europeans said they would hide their symptoms from others if diagnosed.²⁵ Public attitudes towards people living with Alzheimer's disease and other dementias have a substantial impact on the likelihood people will visit a general practitioner (GP) for an early diagnosis.²⁶ Awareness campaigns have been insufficient in size and scope to eliminate stigma and reduce the fear of entering the diagnostic pathway.²⁷

GPs still lack adequate diagnostic tools and competency

Despite being the first point of medical contact for most people living with Alzheimer's disease and other dementias, GPs across Europe lack access to the tools needed to make an initial diagnosis. Most people living with Alzheimer's disease and dementia are still diagnosed using basic screening tools, which have high false positive and false negative rates.²⁸ Some GPs may have access to basic screening tools but lack access to the more advanced diagnostics needed to move persons along the diagnostic pathway. Others lack the time to effectively screen people²⁹ or express

reluctance to refer people for formal diagnosis. Since GPs are the gatekeepers on the care pathway, they play a critical role in ensuring early and accurate diagnosis. Yet many GPs fail to refer symptomatic persons to specialists out of concern that the lack of a disease-modifying therapy negates the value of diagnosis—so called “therapeutic nihilism.”³⁰ Though formal Alzheimer's disease and other dementias training is included in basic medical education, many GPs are not trained well enough to facilitate diagnosis, identify early symptoms, and differentiate these symptoms from other disorders.³¹

Timeliness remains an issue for Alzheimer's disease and other dementias diagnosis

In many countries, persons living with dementia can wait for up to three to four years for a proper and formal diagnosis. In some cases, GPs are fulfilling their responsibilities to refer people to specialists, only to see diagnosis take as long as three years due to a lack of available specialists. Experts in several countries flagged chronic shortages of geriatricians, neurologists, psychiatrists, and other cognitive experts³² who are crucial in diagnosing Alzheimer's disease and other dementias.³³



Calls to Action

Governments must invest in GP training to improve diagnosis and ensure timely diagnosis

As health system gatekeepers, GPs must be trained to effectively identify and screen for symptoms of Alzheimer's disease and other dementias. Few countries have invested in or required this kind of specialized training for GPs. National governments should make it a priority for GPs to receive specialized diagnostic training on an annual basis. Further investments must be made to train GPs to recognize early warning signs, such as mild cognitive impairment (MCI), to improve early diagnosis rates and treat people more successfully.³⁴ In France, Fondation Vaincre Alzheimer has been attempting to improve GP knowledge, though experts claim they are only able to reach 10% of French GPs,³⁵ demonstrating the need for government to better fund and support this program to expand its reach.

Governments must provide GPs and specialists with the tools they need to accelerate diagnosis and expedite interventions

Governments must make it a priority to ensure that GPs and specialists have access to the latest and most accurate diagnostic tools—from CSF and PET scans to digital- and blood-based biomarkers. Countries must also ensure GPs can readily utilize preliminary screening tools to reduce the number of unscreened persons sent to receive costlier diagnosis tools like PET scans. By investing in improving access to first tier tools, governments can help create greater efficiencies

within the diagnostic pathway and enable earlier, more effective medical interventions. Early diagnosis is key in allowing those living with the disease to effectively plan for the future, access social care, pursue lifestyle interventions and brain health promoting activities, and enter clinical trials.

Increase funding for medical schools to expand the pipeline of specialists, including geriatricians, psychiatrists, neurologists, neuropsychiatrists, and others who can formally diagnose Alzheimer's disease and other dementias

There is already a huge shortage of specialists in Europe. As the number of persons living with dementia increases over the next several decades, demand for specialist services will explode.³⁶ Without enough trained specialists, many countries will face a diagnostic bottleneck.³⁷ Governments must increase funding for medical schools and focus on producing more specialists with the skills needed to effectively diagnose Alzheimer's disease and other dementias. Governments should also support efforts by medical institutions to make the study of neurology (and other relevant disciplines) more appealing to medical students.³⁸ Within the European Union, national stakeholders should aim to move towards "a learning society"³⁹ so the EU can meet the challenge of Alzheimer's disease and other dementias with enough healthcare professionals.

Commit to national awareness campaigns to combat stigma

Action Area 2 of the WHO Global Action Plan on dementia calls on all national governments to run awareness campaigns to combat stigma. All countries in this report unanimously adopted this plan.⁴⁰ Yet, national associations, not governments, are still the main drivers of stigma eradication efforts. Despite their best efforts, these associations and other third-party organizations lack sufficient resources to engage in the sustained campaigns needed to combat stigma associated with Alzheimer's disease and other dementias. Governments should allocate the funds needed to run these anti-stigma campaigns or provide adequate funding for advocacy groups to execute them. Governments should also closely engage with national associations through the likes of ADI's World Alzheimer's Month campaign, allowing for a concerted effort towards the action area objectives and encouraging further involvement in fighting stigma.⁴¹

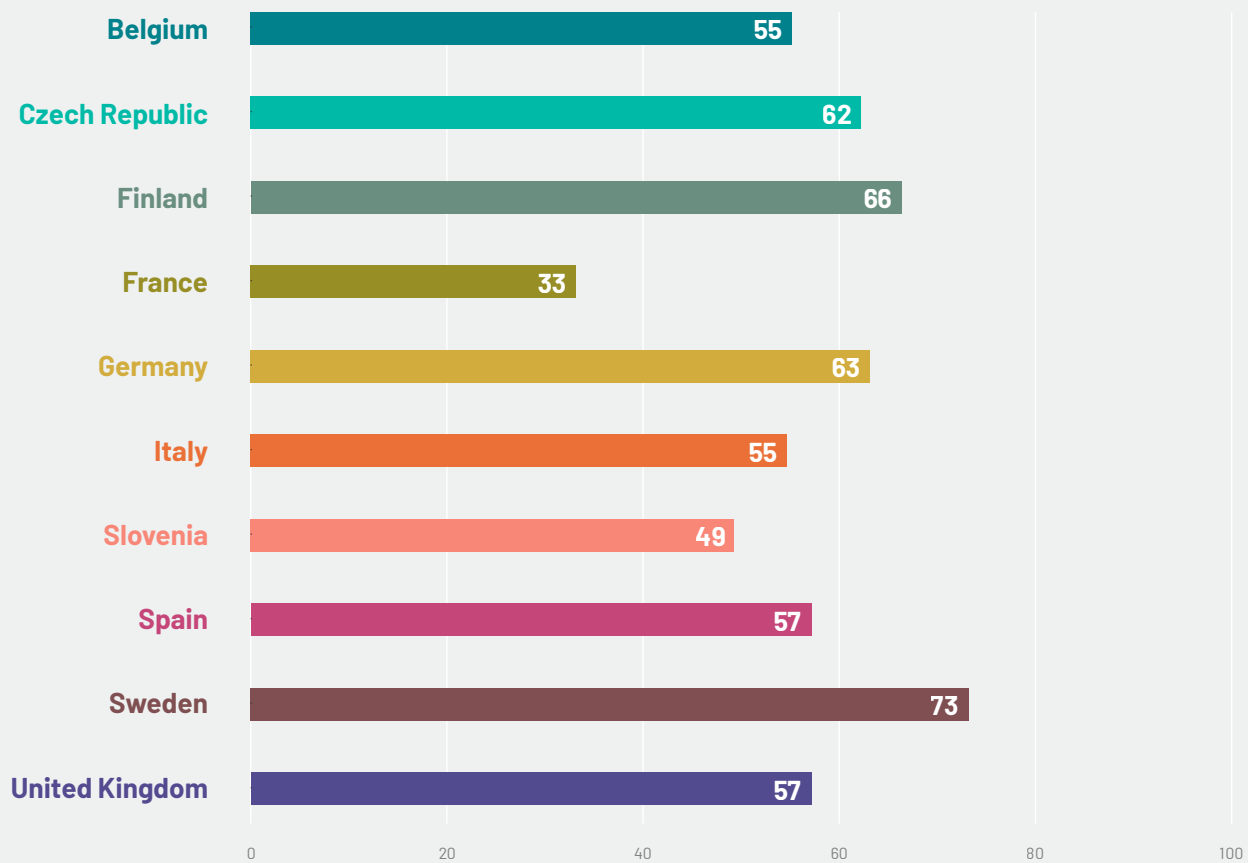


Access to Care (Medical)

Scoring Insights

Germany has very strong reimbursement for therapies while also providing greater access to post-diagnostic support than most other countries. France, on the other hand, scored lower due to its recent decision to stop the reimbursement of Alzheimer's disease-related drug therapies.

Access to Care Country Comparison



Measures the level of access within a country to the appropriate and necessary medical care.



Key Findings

In most countries, reimbursement does not pose a barrier for medications and some treatments, though other services are not fully covered

Reimbursement systems for Alzheimer's disease and other dementias in most countries ensure that out-of-pocket costs for consumers remain relatively low. Medical costs, like diagnostic tests, post-diagnostic consultations, or specialist visits, are covered by most national health systems. Medications for Alzheimer's disease are generally fully reimbursed or heavily subsidized. In France, however, the national government has recently stopped the reimbursement of Alzheimer's disease drugs, leading to a steep decline in prescriptions and use.⁴² The percentage of treatment and care costs subsidized by governments, however, varies. In general, costs for home care services or other types of private care are split between persons and governments, with some countries covering less than half of the costs.⁴³

Widespread variation within countries creates a "postcode lottery" with geography influencing care access and quality

Where a person lives, even within a country, can substantially influence access to treatment and care. In Spain, Catalonia provides high-quality care and access to advanced diagnostic tools, while other regions lack the resources and organization to provide these needs. Proximity to specialist centers also impact accessibility. In Sweden, people in the Stockholm area are often able to receive a formal diagnosis in a matter of weeks, while taking months to complete in other regions. Yet, some countries struggle to provide access even in more densely populated urban centers. Even in large cities like Helsinki, where residents generally have better access to specialist services and dedicated memory centers, residents can still face access challenges. In Belgium, residents of the French-speaking Wallonia region having significantly less access to services compared to their counterparts in Flanders.



Calls to Action

Governments must improve equity and access across geographies and economic groups

National governments must take a more proactive role in ensuring that all citizens can access care and services reliably and equitably. In particular, decision makers must identify gaps and drivers of poor coverage and allocate resources accordingly. Governments must also engage with local, municipal, regional, and state authorities as well as other stakeholders to standardize care service offerings.

Governments must work to improve affordability and coverage

In light of growing demand for services, governments must develop innovative ways to keep out-of-pocket consumer costs low. The acceleration of digital health and telemedicine during the COVID-19 pandemic creates opportunities to identify cost-savings and improve efficiencies. Strategic investments in early detection and risk reduction initiatives can also help yield long-term savings. To the extent possible, national governments should also streamline management of healthcare systems to reduce redundancies and generate additional savings.

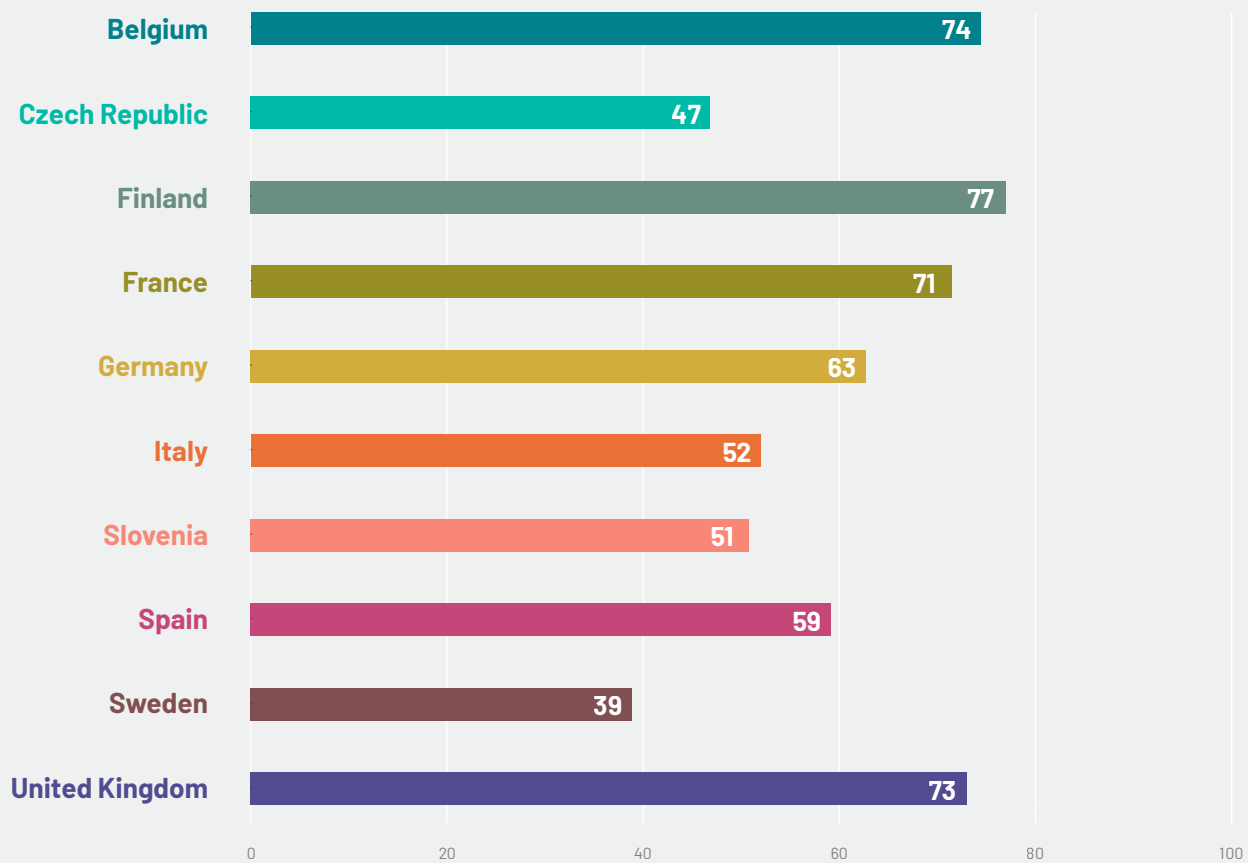


Awareness & Monitoring

Scoring Insights

National associations and other third-party organizations, not governments, are the main driver of awareness campaigns in most countries. Additionally, all countries continue to struggle with effectively tracking and monitoring dementia.

Awareness & Monitoring Country Comparison



Judges how seriously governments have committed to efforts that can reduce the risk of developing Alzheimer's disease or dementia.

Key Findings

Most governments do not have sustained campaigns to educate the public about the risks associated with Alzheimer's disease and other dementias

While a number of governments have funded or supported one-off public education campaigns, there is little evidence of ongoing support for initiatives focused on encouraging healthier behaviors and other strategies to reduce the risk of Alzheimer's disease and other dementias.⁴⁴ There is a growing body of evidence on the benefits of risk reduction efforts, yet a broad lack of understanding among the general public about behaviors to slow or reduce the risk of developing dementia.⁴⁵ While almost all national plans call for risk factor campaigns, few countries have translated this into meaningful actions to raise overall awareness. In a few instances, third-party organizations have sought to fill the gap left by governments, such as the work done by ADI to develop and disseminate materials related to risk.⁴⁶ In Flanders (Belgium), the Expertisecentrum Dementie Vlaanderen (Flanders Dementia Expert Center) pursued a study and campaign alongside other European partners to highlight risk reduction methods for dementia.⁴⁷ The SaniMemorix initiative also provides online awareness tools for people in participating countries.⁴⁸

Governments are not investing enough in research related to identifying modifiable risk factors

As rates of Alzheimer's and other dementias rise and costs of care and treatment skyrocket, governments have a clear incentive to better understand the underlying risk factors of these diseases. Yet, many governments continue to chronically underfund research programs dedicated to identifying these drivers. As a result, governments are forced to spend more resources on care and treatment after the disease develops and progresses.

Calls to Action

Governments must fund national campaigns to address risk factors associated with Alzheimer's disease and other dementias

Though broad awareness campaigns to combat stigma are critical, governments must also invest in educating citizens about the underlying health and lifestyle factors that contribute to Alzheimer's disease, including obesity, inactivity, and heart disease. National-level surveys demonstrate little public understanding of the relationship between underlying conditions and Alzheimer's disease and other dementias. In a review of these surveys, Cations et al. (2018) found almost half of respondents believe dementia was not preventable; less than half believe dementia is associated with other factors like high cholesterol, hypertension, drug consumption, air pollution, emotional trauma, and psychiatric illness.⁴⁹

Awareness campaigns should also seek to target those with MCI due to Alzheimer's disease or dementias, so that those living with earlier stages of these diseases can understand ways to possibly mitigate its progression. To address these challenges and reduce long-term disease burden, governments should directly fund campaigns promoting multi-domain lifestyle interventions as a means of reducing associated dementia and Alzheimer's risk factors.

Governments must invest more in research to better understand the risks associated with Alzheimer's disease and other dementias

Investing in research to better understand the factors contributing to Alzheimer's and other dementias can help individuals avoid or delay future diagnoses, thereby reducing overall health system costs while increasing productivity and quality of life. While this requires more government investment upfront, the long-term benefits are clear.

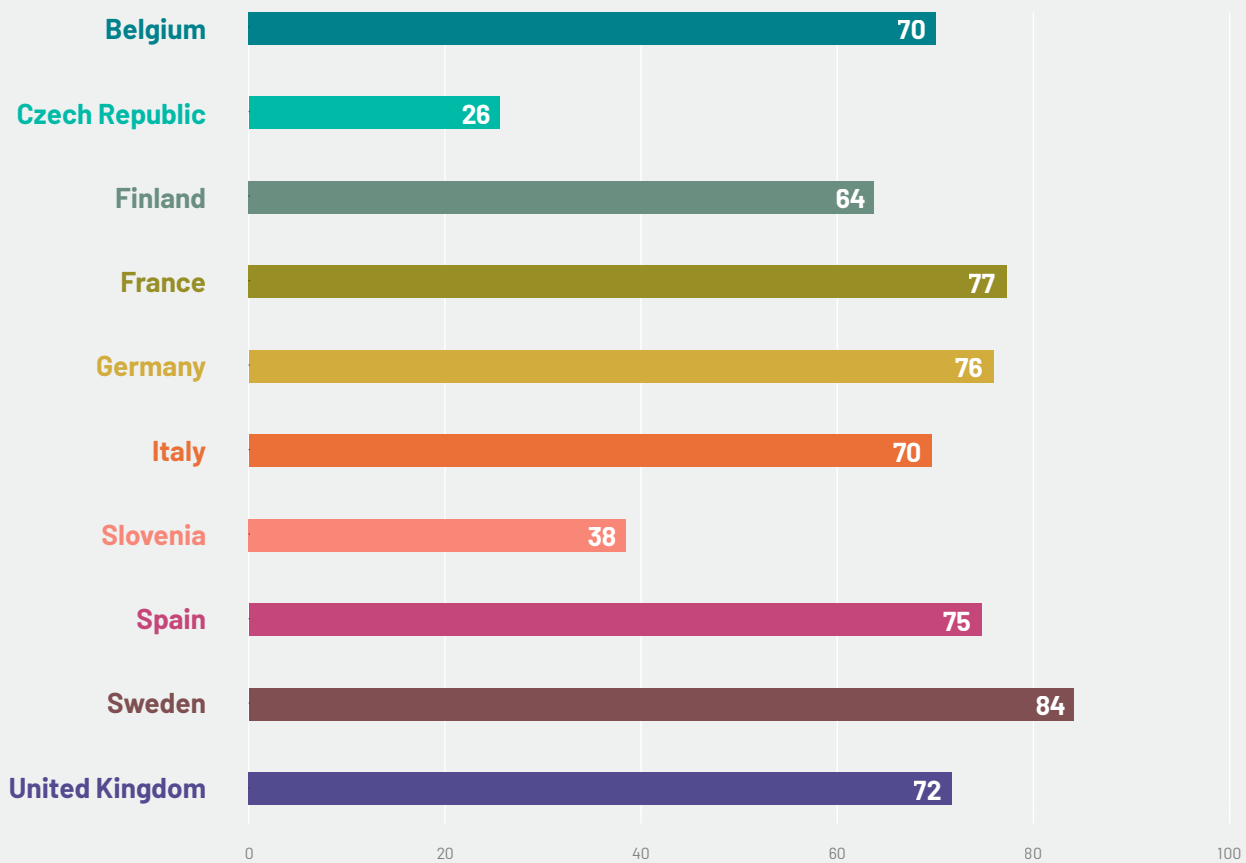


Care Standards & Settings

Scoring Insights

Sweden has shown a commitment to integrating care innovations into the health system and helping to ensure services are available and accessible. In the Czech Republic, poor scores are a result of insufficient support for informal caregivers, lack of quality-of-care standards, and inadequate case coordination and management.

Care Standards & Settings Country Comparison



Assesses the level of access, innovation, and government commitment to national care standards and care settings.

Key Findings

Care pathways remain difficult to navigate for people living with dementia, caregivers, and healthcare professionals

In almost every country, experts report that people continue to face difficulties navigating complex care pathways. There are few initiatives that make the process easier for those living with dementia and their loved ones. Experts express concern that for most people, the journey from recognizing initial symptoms to formal diagnosis remains complicated and burdensome. National associations and other third-party organizations can help alleviate some of these concerns, but most living with dementia still rely on informal caregivers to shepherd them through the process. As the number of persons aging alone grows, many lack the support needed to access and navigate the post-diagnostic treatment and care landscape.

Few countries have sought to develop care regimes and pathways specific for persons living with Alzheimer's disease and other dementias

Though several global organizations have called on countries to revamp the pathway from diagnosis to treatment and care, only a handful of European countries have acted. Alzheimer's Europe's *2020 Dementia Monitor* cites only two governments featured in this report: Flanders (Belgian region) and Sweden, as providing sufficient case management and care coordination.⁵⁰

Informal caregivers continue to shoulder the brunt of caregiving responsibilities

As Europe's population continues to age, informal caregivers are bearing greater responsibility for Alzheimer's disease and other dementias care. As state-subsidized care systems face greater cost pressures and challenges in meeting demand,⁵¹ it will become increasingly difficult for informal caregivers to shift responsibilities to professional caregivers. The waiting times for long-term care facilities continue to increase, while access to subsidized home care services is also becoming more constrained. The private care sector, which can alleviate some of these pressure points, is still in its infancy in some countries. Costs also remain a barrier since many families cannot afford to pay for their loved ones' care out of pocket. Furthermore, in some countries, governments do not offer reimbursements or tax credits for informal caregivers, who often must miss or forgo their own work to provide care.⁵² This translates in poorer health and economic stability for informal caregivers—often referred to as the “invisible” or “second” patient.

These pressures are acutely felt by women, who provide most of the informal care in the EU that constitutes 80% of total care for dementia.⁵³ In the UK, women are 2.5 times more likely to provide 24-hour dementia care than men.⁵⁴ This gender disparity can destabilize or threaten careers, with many women reducing their hours or altogether quitting their jobs in order to provide for loved ones.⁵⁵



People living with dementia face challenges in accessing both home care and long-term care, though financial costs are generally not as big an issue—for now

While many care services are currently subsidized by governments, availability can be limited. In a 2020 review of 36 European countries, Alzheimer's Europe found that less than half had sufficient availability of homecare, home help, respite care, and other vital services.⁵⁶ Wait times for long-term care facilities can be lengthy, with some people waiting two to three years to secure a place. In many instances, people living with dementia experience significant cognitive decline between the time they first apply for long-term care and are finally admitted. Some countries have exemptions to fast track high-risk or high-needs persons, but this approach is not universal. While European governments, with their robust national health programs, have either fully or mostly covered these services to date, cost pressures continue to increase, jeopardizing the sustainability of care. Driven by increased demand, staffing shortages, high turnover, and increased longevity, many governments are being forced to rethink how long-term care is financed. Despite projected increases in public health expenditures,⁵⁷ financing reforms will likely lead to greater out-of-pocket costs and service reductions.

Caregiver training is lacking and inaccessible in many countries

Most countries do not have systems in place to provide comprehensive training for formal or informal caregivers. Though there are some training programs for formal caregivers, there are huge discrepancies across countries in terms of standards and qualifications for providing care, with many having none at all.⁵⁸ Training

programs for informal caregivers are even more rare,⁵⁹ with third-party organizations and advocacy groups often filling the gap to provide families with training and educational resources. The reach of these groups, however, is understandably limited relative to the need.

Caregiving standards vary greatly by region and often are not specific to disease areas

Only a handful of countries have national care standards for dementia or other cognitive diseases. Where standards do exist, there is huge variability even within national borders.⁶⁰ Lack of standards and uniformity is a particularly acute problem in countries with decentralized models for managing Alzheimer's and other dementias. In these countries, some regions have robust standards, while others have limited standards or none at all.

Advocacy organizations play a key role in providing support for the families and caregivers of people living with dementia

Alzheimer's and dementia organizations provide essential services in many countries, ensuring those living with dementia, their families, and caregivers are supported throughout the disease journey. In some countries, Alzheimer's associations run Alzheimer's Cafes to provide practical and emotional support. Advocacy organizations in many countries also play a leading role in ensuring these diseases remain a priority for policymakers. Associations directly engage in lobbying efforts on the national and regional levels, advocating for the rights of people living with dementia and caregivers, government support for informal caregivers, and increased funding for disease initiatives. These organizations also run their own campaigns to raise awareness, combat stigma, and promote risk-reduction

measures. In most countries examined, national associations are also the main drivers of advocacy efforts to establish national dementia plans.

Calls to Action

Governments must work to simplify pathways for people living with Alzheimer's disease and other dementias

Governments can play a key role in ensuring that those living with dementia can access services and support across the complex care continuum. To make this process easier, governments should issue clear guidelines for public and private sector healthcare providers to help people living with dementia and their caregivers more effectively receive treatment and care. Countries should look to their peers with more defined care pathways for best practices. Furthermore, countries should move beyond the baseline aspects of care and into the more innovative practices highlighted in this paper that help restore and safeguard quality of life, such as the social prescribing approach,⁶¹ adopted in the UK, which seeks to eliminate the challenges brought on by dementia in all aspects of life.

Governments must commit more to support and train informal caregivers

Governments must be more proactive about recognizing the rights of caregivers; implementing national programs to provide education, awareness, and training to informal carers; and helping offset income losses they experience by taking on caregiving responsibilities.

Specifically, governments should include allocations for informal caregiving training in national plans and broader healthcare budgets. Governments should consider expanding economic relief—in the form of tax credits, government aid, etc.—to lessen the financial burden on these individuals.⁶²

Governments must work to improve access to and quality of long-term care

Looking ahead, governments must ensure comprehensive long-term care reforms that align with national Alzheimer's disease and dementias plans, while providing more direct relief to ensure people can adequately access the care they need. Specifically, governments should pass measures that encourage the growth of the private care sector, work to build more community-based and institutional care facilities and invest in supporting a more robust care workforce.

Governments must commit more to helping support and train formal caregivers

To combat high turnover and burn out, governments must take an active role in developing a robust and sustainable care workforce. This includes making investments in training and certification programs, engaging a wide range of stakeholders in plan development and implementation, and potentially subsidizing some of the costs associated with care. Governments must also work with private agencies to ensure the ratio of caregivers to people living with dementia remains high enough to meet demand and that prospective caregivers have a clear, well-defined career pathway.⁶³



Governments must work with a range of stakeholders to establish and clarify care standards

Governments must ensure that all people living with Alzheimer's disease and dementia are treated in a manner consistent with the highest professional standards. To improve the overall quality of care, governments must work with third-party organizations to establish local and regional guidelines, including labor standards for caregivers, policies for the rights of those living with dementia, and uniform audits for quality of care.⁶⁴

Governments must allocate funds to spur innovation

National health budgets and Alzheimer's and other dementias plans must have dedicated funding to spur innovation across the care continuum. Specifically, governments must set aside funds that innovators can access to develop better diagnostic tools, design new technologies to support monitoring and adherence, create assistive technologies to help manage daily activities, and construct residential and social environments better suited for those living with Alzheimer's disease and other dementias.

Country Profiles





Belgium

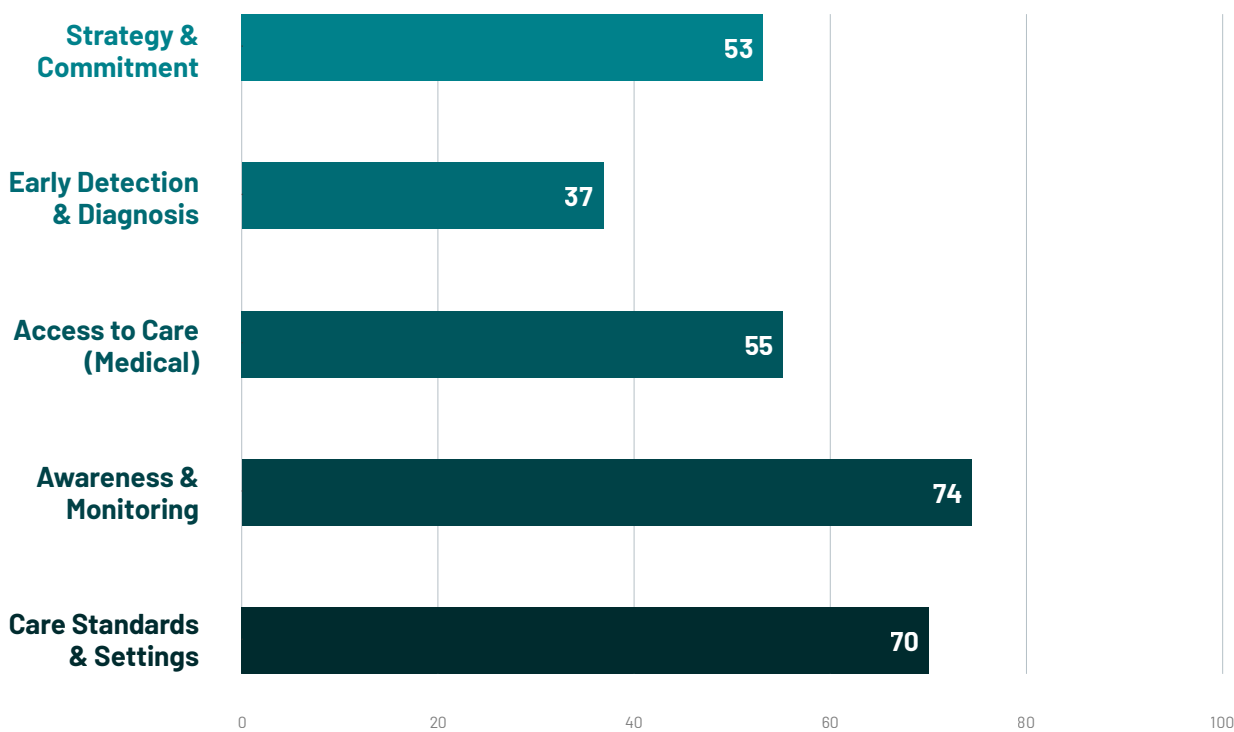
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Overview

Alzheimer's disease initiatives in Belgium are separately administered by the country's two regional governments: the Flanders government in the Flemish-speaking north and the Walloon government in the Francophone south. While Flanders is traditionally recognized for having greater commitment to Alzheimer's, Wallonia is the only regional government in Europe that has dementia-friendly communities, dementia-friends programs, and working groups for those living with dementia and caregivers.⁶⁵ Alzheimer Liga Vlaanderen, a leading nonprofit organization in Flanders, organizes regional groups (such as the Dementia and Young Dementia Family Groups), leads social initiatives, raises local awareness, and publishes information to assist those living with dementia in accessing services.⁶⁶

Belgium Category Assessments



Country	Belgium
AD or Dementia plan	Flanders —Concluded: Regional Dementia Plan, (2016–2019) Wallonia —No
Number of people living with Alzheimer’s and other dementia (est.)	192,926 / (1.69%) / (2019) ⁶⁷
Awareness raising	Yes: Limited Government Engagement (General dementia stigma & risk reduction, lifestyle, and Alzheimer’s-specific campaigns)
Total Annual Costs	€23.9 billion (Total Cost of Illness, 2008) €201.2 million (Informal Care, 2008) ⁶⁸ €1.14 – 2.42 billion (MCI & Mild AD)

Similar activities and initiatives are led by Ligue Alzheimer in Wallonia.⁶⁹ A number of cities (46) in both regions have demonstrated their commitment and support by signing on Dementia Friendly City Charter.⁷⁰

Category Assessments

Strategy & Commitment

Flanders has issued two dementia plans to date. The first ran from 2010 to 2014; the second, an extension of the first, from 2016 to 2019. The next dementia plan, currently being developed, will have distinct programs addressing Alzheimer’s disease and will encourage greater government action to combat the disease. Specifically, experts are focusing on ways to identify and engage new stakeholders, establishing key performance indicators to help evaluate progress, and allocating funding to implement programs.⁷¹ Experts also hope the upcoming plan will address the effects of COVID-19 on those living with Alzheimer’s disease and other dementias. Despite Flanders having more robust infrastructure for Alzheimer’s and dementia than Wallonia, underfunding remains a challenge in both regions, with organizations continuously having to seek funds to finance research, awareness campaigns and other efforts.

Wallonia does not have a separate plan for Alzheimer’s disease or dementia, but instead folds relevant initiatives into its broader aging strategy. An Alzheimer’s disease plan was initiated in 2011,⁷² but it was not effectively implemented, and efforts to develop another Alzheimer’s-specific plan under the current government have proven difficult. Without a regional plan in place, people living with dementia and caregivers have more difficulty accessing information about the disease. There are several promising projects underway run by third-party organizations. These include Ligue Alzheimer’s support for Agent Proximité Dénée (Prox-idem), a program which appoints and trains agents in dementia friendly communities, and the Polidem project, an effort that addresses safety concerns related to dementia patients.⁷³ The overall third-party landscape, however, is less comprehensive in comparison to Flanders.

While Alzheimer associations in Belgium have received some government support, the country’s overall engagement on this issue at the international level is lacking. Belgium did not participate in the EU’s 2nd Joint Action on Dementia (DEM2) and only three Belgian policymakers signed the Glasgow Declaration.⁷⁴ While a handful of politicians remain interested in the fight against Alzheimer’s, according to experts, the country lacks political champions.

Early Detection & Diagnosis

Flanders had no guidelines for medical professionals to diagnose Alzheimer's and other dementias until the Flanders Dementia Expert Center developed guidelines for primary care settings, which were integrated into the 2016–2019 dementia plan. The organization is also working to provide screening tools in home care settings as part of a pilot initiative to determine their efficiency and efficacy. Unfortunately, general practitioners have generally been following more informal strategies, wherein GPs wait for symptoms to become more acute and obvious before sending patients onto diagnosis. Experts note that when a biomarker is detected early, the person living with dementia seldomly returns for follow-up exams.⁷⁵

In Wallonia, experts said increased awareness of Alzheimer's disease among clinicians has led to a clear process for obtaining a diagnosis for people between 50 and 80 years. On the other hand, experts commented that some GPs have been less inclined to refer persons aged 80 years and older for a diagnosis due to a perceived lack of effective treatment, beyond symptomatic therapies. Though practitioners have demonstrated a desire to improve early diagnosis through the use of biomarkers, access to these tools remains limited. A study of Belgian experts revealed that 57% would use biological biomarkers for MCI *if* they were accessible.⁷⁶

Access to Care (Medical)

In Belgium drug reimbursement decisions are made at a federal level. All Alzheimer's disease therapeutics are reimbursed with low out-of-pocket costs, which are further reduced if the person belongs to a vulnerable group.⁷⁷ Yet, many GPs rarely recommend symptomatic

therapies and these drugs were almost taken off reimbursement lists in 2019.⁷⁸ While people living with Alzheimer's may receive a prescription immediately following a diagnosis, GPs often discontinue treatment when they enter a care home setting.⁷⁹

Awareness & Monitoring

Belgium does not have a national register for Alzheimer's disease or dementia.⁸⁰ Some dementia data, including drug reimbursement figures, can be accessed by practitioners, though this information reflects only those individuals who receive treatment.⁸¹

Regional associations and third-party organizations in Wallonia and Flanders, as well as a smaller organization created to support the German-speaking population of Belgium (Patienten Raat en Treff), provide general information to those living with dementia, caregivers, and the general public. The Flanders Dementia Expert Center ran a joint campaign focused on risk reduction with Norway, Germany, Luxembourg, and the Netherlands. The Expert Center's campaign includes the online SaniMemorix informational video and several other informational articles on the Center's site.⁸² Due to funding constraints, Ligue Alzheimer (Wallonia) does not run awareness or stigma eradication campaigns, nor does the local government support such activities.

Care Standards & Settings

In recent decades, the Dementia Expert Center in Flanders has trained dementia reference persons (nurses who can coordinate care and provide dementia-specific expertise within care homes)⁸³ in an attempt to enhance the quality-of-care people receive. As part of this program, trainees undergo a 60-hour program that concludes with a final exam. Trainees who pass the

exam receive a certificate and are required to complete 8 hours of additional training each year to maintain their status. This effort is accredited and funded by the regional government.

In Wallonia, several measures are in place to care for individuals living with dementia. Though the public sector is not directly involved with in-home Alzheimer's disease care, public funding is available for caretakers to work in the homes of people living with dementia. Civil unions and associations for professional nurses and caretakers help ensure that caregivers receive the necessary training to provide effective care. Organizations such as Baluchon Alzheimer even coordinate a volunteer system which provides informal caretakers a break from their duties.⁸⁴ Dementia-friendly areas and Alzheimer's Cafes have also been established in the region.

Calls to Action

Develop an Alzheimer's disease and other dementias plan for Wallonia

While there are several cross-sector initiatives in Wallonia, the government, unlike its Flanders counterpart, has not recently developed an Alzheimer's disease and other dementias plan. Decision makers should prioritize crafting and approving a plan to guide regional efforts, with a focus on consolidating program administration, improving service offerings for patients and their loved ones and better integrating initiatives across the care continuum.

Allocate sufficient resources to help regions implement initiatives

Both regions in Belgium struggle to guarantee sufficient funding for Alzheimer's disease and dementia initiatives. The two regional governments and the national government must allocate funding with specific actionable goals in order for critical initiatives to be fully implemented.

Invest in mass-media awareness campaigns focused on combating stigma

Due to lack of public and third-party funding, Belgium has no major awareness campaigns to combat the stigma associated with Alzheimer's disease. The government must make investments to run large-scale anti-stigma campaigns directly or provide third-party organizations the resources to do so. Campaigns to combat stigma will help encourage those living with MCI or those who may be living with undiagnosed Alzheimer's disease to enter the diagnostic process and can reduce the marginalization and discrimination people living with dementia and their loved one's face.



RANKING

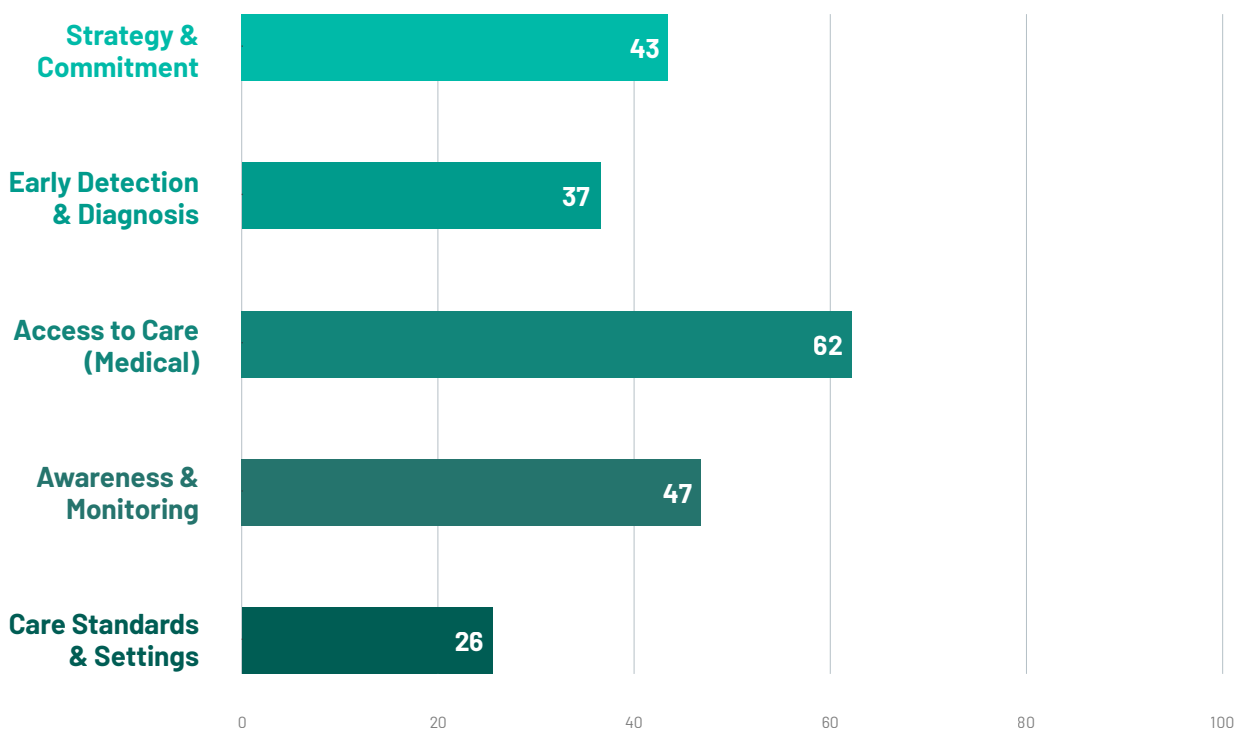
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Czech Republic

Overview

Since the 1990s, the prevalence of dementia has doubled in the Czech Republic,⁸⁵ and many patients living with Alzheimer's disease and other dementias struggle with securing needed assistance. Over 150,000 people are living with dementia in the Czech Republic, yet only 21,000 beds in care homes for treatment are available.⁸⁶ The problem is exacerbated by poor education and awareness among the general public and low availability of informal caregiver education programs.⁸⁷ The WHO Global Dementia Observatory reports 72% of persons living with Alzheimer's disease and other dementias in the Czech Republic have been diagnosed formally.⁸⁸ However, a significant proportion of these diagnoses happen at a later stage, which suggests that people with pre-dementia MCI and early onset Alzheimer's and other dementias are being missed.⁸⁹

Czech Republic Category Assessments



Country	Czech Republic
AD or Dementia plan	Yes: National Action Plan for Alzheimer's Disease and Similar Diseases, (2020-2030)
Number of people living with Alzheimer's and other dementia (est.)	149,633 / (1.41%) / (2019) ⁹⁰
Awareness raising	Yes: Limited Government Engagement (General dementia stigma & risk reduction and lifestyle campaigns)
Total Annual Costs	€1.01 billion (Total Cost of Illness, 2008) €588 million (Informal Care, 2008) ⁹¹ CZK 21.5 billion (€0.84 billion) (MCI & Mild AD, 2020) ⁹²
Annual Treatment & Care Cost per Person	€13,080

Category Assessments

Strategy & Commitment

The Czech government recently approved an Alzheimer's disease and other dementias plan (2020-2030), which is now awaiting implementation.⁹³ Experts note that the first plan, which ran from 2016 to 2019, was not comprehensive and lacked sufficient stakeholder involvement.⁹⁴ Experts say the second plan, modeled after the WHO framework, incorporates more stakeholder feedback and is more comprehensive.⁹⁵ Concerns remain that the COVID-19 pandemic could hamper implementation, limit funding allocation, and reduce political attention to the issue. Likewise, experts stated a dedicated budgetary allocation for Alzheimer's disease and other dementias was still critically needed.⁹⁶

The forthcoming 2020-2030 plan seeks to improve care coordination and better delineate the care pathway, including medical care, social work, specialist centers, and research centers.⁹⁷ The goal is to develop national guidelines and frameworks for care, enable greater collaboration between social and medical sectors, and more clearly define priorities. The new plan must overcome poor coordination and fragmentation of initiatives

nationwide. Some experts suggested that there are efforts underway to include funding specifically for program implementation and the appointment of individuals to oversee key action items for the 2020-2030 plan.⁹⁸

Early Detection & Diagnosis

Diagnostic infrastructure remains inadequate nationwide, a challenge that is compounded by high levels of stigma associated with the disease. In January of 2019, GPs began screening people using a mini-cog test to help determine whether a specialist referral for formal diagnosis is necessary.⁹⁹ To combat low diagnosis rates, the Czech Alzheimer's Society (ČALS) provides free testing with the Addenbrooke's Cognitive Examination Revised (ACER), advertising this service through annual media and radio campaigns.¹⁰⁰ Many who seek out this test believing that the GP-administered mini-cog test is inaccurate, and that their GP did not investigate further after they passed the easier, more flawed test. Furthermore, the country also has no detailed national guidelines for interventions.¹⁰¹

Access to Care

In the Czech Republic, most Alzheimer's disease-related therapies are reimbursed at 100%, though at least one is not fully reimbursed.¹⁰² Despite these favorable reimbursement policies, there is little to no post-diagnostic support in place.¹⁰³ Further, the ratio of GPs to the general population is inadequate, placing physicians under great stress, contributing to the emigration of younger doctors from the Czech Republic to other countries.¹⁰⁴ This likely causes the reported shorter consultation times,¹⁰⁵ which inhibits efforts by GPs to explain processes and perform assessments.¹⁰⁶

Awareness & Monitoring

ČALS is the largest and most visible actor in raising awareness for Alzheimer's disease in the Czech Republic. The organization runs an awareness week for the general public, convenes open conferences on Alzheimer's disease, and also provides informational resources to people living with dementia and caregivers on its website.¹⁰⁷ While the government has called for general awareness campaigns for Alzheimer's disease,¹⁰⁸ there have been no large-scale Alzheimer's-specific, or stigma and risk reduction campaigns at the national level.

Additionally, consistent, reliable, national Alzheimer's data is unavailable in the Czech Republic.¹⁰⁹ Stakeholders hope that, with new Alzheimer's disease plan funding, resources will be available to establish and sustain a more robust surveillance infrastructure.

Care Standards & Settings

In the Czech Republic, care work is divided between social care and healthcare providers. Nurses are directed by GPs and paid under the public healthcare model; a choice model exists for social care, based on a care allowance system.¹¹⁰ Though the government does provide support for the care of those living with Alzheimer's disease or dementia, many individuals rely on ČALS and similar third-party organizations for free appointments, consultations, and practical help with in-home care.

Calls to Action

Increase funding for the 2020-2030 plan to ensure that programs are fully implemented

With a new plan in the final stages of development, Czech policymakers must guarantee that funding is available to finance all programs within the plan. Despite the COVID-19 pandemic, decision makers must allocate funding to specific initiatives in a coordinated fashion to ensure the plan is actionable and impactful.

Create comprehensive data surveillance and monitoring infrastructure

With no consistent data collection system in place, the Czech Republic must commit to establishing standardized collection protocols and developing an effective monitoring infrastructure. This will enable policymakers and stakeholders to better track the needs of the population and the effectiveness of key aspects of the soon-to-be implemented national plan.



Expand training programs and screening tool access for GPs, with a focus on improving early diagnosis

A lack of training and effective screening tools for GPs has forced people to seek testing for Alzheimer's and other dementias through third-party organizations to attain more reliable results. Governments must improve access to more accurate screening tools and mandate a stronger Alzheimer's disease and dementia training curriculum for GPs to enable them to engage in early detection and diagnosis efforts.



Finland

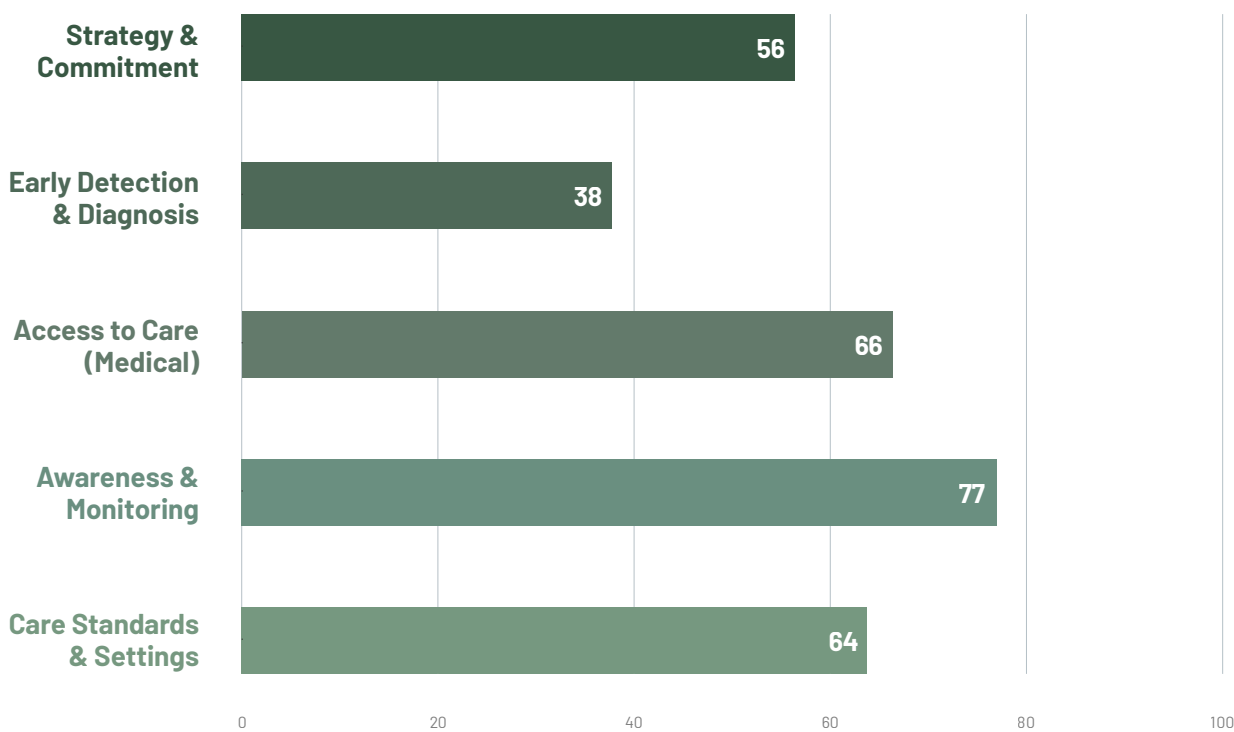
RANKING

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Overview

As the number of deaths from dementia has nearly doubled over the past 10 years, Finland now has one of the highest dementia mortality rates among EU countries.¹¹¹ Nearly 190,000–200,000 people in Finland are living with memory disorders;¹¹² nearly half of these are living with Alzheimer’s disease and an additional 7,000–10,000 working age individuals have early onset AD.¹¹³ In 2012, the Finnish Ministry of Social Affairs and Health, partnering with the Alzheimer Society of Finland, launched a national dementia plan called the National Memory Programme 2012–2020, which aims to create a “memory-friendly Finland.”¹¹⁴

Finland Category Assessments



Country	Finland
AD or Dementia plan	Concluded (replaced by aging plan): National Memory Programme, (2012-2020)
Number of people living with Alzheimer's and other dementia (est.)	95,836 / (1.74%) / (2019) ¹¹⁵
Awareness raising	Yes: Limited Government Engagement (General dementia stigma & risk reduction and lifestyle campaigns)
Total Annual Costs	€1.50 – 2.50 billion (Total Cost of Illness, 2018) ¹¹⁶ €609.2 million (Informal Care, 2008) ¹¹⁷
Annual Nursing Home Care Cost per Person	€46,000 (2012) ¹¹⁸

Finland has a robust Alzheimer's research environment, including prominent projects like the FINGER study. Launched in 2009, FINGER (Finnish Geriatric Intervention Study to Prevent Cognitive Impairment and Disability) was a pioneering randomized clinical trial that utilized a multidomain approach to reduce the risk of cognitive decline in at-risk older adults.¹¹⁹ The FINGER study demonstrated that a 2-year lifestyle intervention, consisting of nutritional guidance, exercise, cognitive training, and control of vascular risk factors benefited cognition in seniors at increased risk of dementia.¹²⁰ To broaden understanding of these diseases, the World-Wide FINGERS network was created, the first global network of clinical trials for risk reduction of dementia and Alzheimer's through multi-domain interventions.¹²¹

Category Assessments

Strategy & Commitment

Finland's national plan addressing memory-disabling diseases expired in 2020. The government is currently reevaluating this plan, with a goal of developing an updated plan with more consistent program implementation. Unfortunately, this effort has been delayed due

to COVID-19. A broader plan for aging is in place, which remains a government priority.¹²² However, this less specific approach has disappointed many stakeholders, including non-government organizations seeking more targeted Alzheimer's disease-specific initiatives. Experts fear that many Alzheimer's-specific challenges will be lost in the shuffle as dementia diseases are folded into the broader aging policy framework. Special programs and targets for Alzheimer's disease have already been dropped—for example, the decision to no longer support specialized geriatric nurses embedded within emergency rooms.¹²³

Though experts confirm politicians want to improve early diagnosis and facilitate risk reduction interventions, some funding for these initiatives is being redirected to COVID-19. Within the Finnish government, Alzheimer's disease champions, including Chair of Muistiliitto Merja Mäkilä-Ropponen, MP and Deputy Chair Sirpa Pietikäinen, MEP are working to elevate the disease discussion and raise broader awareness. The parliament also has an active cross-party memory disease group to maintain political attention on the issue.¹²⁴

Early Detection & Diagnosis

Experts note GPs sometime inadvertently slow diagnosis because they are unable to recognize symptoms or fail to ask the “right” questions of persons and their loved ones. In some cases, early onset Alzheimer’s disease is altogether missed or misdiagnosed as depression.

Stigma remains the most significant barrier to initiating diagnosis. Experts state that people worry about the repercussions of an Alzheimer’s disease diagnosis, citing fear of improper care, a loss of personal freedom, and discrimination or mistreatment.¹²⁵ As a result, people often delay or entirely forego entering the diagnostic pathway. In fact, it often takes an average of two years from first onset of symptoms to diagnosis. Upon entering a clinical environment, however, persons living with dementia are likely to receive a diagnosis and be referred to a specialist in a timely manner. However, geographic location, proximity to specialists and other demographic factors can slow the speed of diagnosis.

Diagnostic efforts are improving in Finland, but COVID-19 has led to increased wait times, making early diagnosis more difficult. Regardless, experts cited a well-developed funneling model to detect memory disorders, with recommended tests or questionnaires easily accessible through an online reference library. Healthcare professionals are now using more sensitive tests than the traditional mini-mental state examinations (MMSE), in addition to validated interviews to detect daily functional ability (using the ABC Dementia Scale)¹²⁶ to assess physical and psychiatric symptoms. However, providers hope cheaper and more sensitive biomarker tests can help mitigate the disparities in diagnostics access and improve early detection rates. Currently, efforts are underway to better educate and train GPs and nurses on current diagnostic tools and

follow-up processes. This work has clearly been effective as experts report that data trends indicate people are being diagnosed earlier in the disease compared to other countries.¹²⁷

Access to Care (Medical)

Despite a strong geriatrician to population ratio,¹²⁸ Finland—like many European countries—has poorer figures for GPs and neurologists. Although the qualifying process for an Alzheimer’s drug prescription makes therapies easily accessible to people with the disease,¹²⁹ reimbursement rates in Finland are actually less favorable than in comparable European countries.¹³⁰

Awareness & Monitoring

The national association, Muistiliitto, and other third-party organizations lead most anti-stigma activities in Finland. These organizations are unable to fund high-profile, mass-media campaigns, a key in national awareness efforts given the fear of discussing memory disabling diseases among the general public. On the other hand, the welfare and social office in Finland regularly publishes guidelines to advise people when they should seek an appointment regarding perceived cognitive decline. Although Finland does not have a specific diagnostic database,¹³¹ data related to reimbursement for Alzheimer’s medications is available.¹³²

Care Standards & Settings

Most individuals living independently will likely be institutionalized at some point in the care pathway; currently one-third of Finns with dementia live alone and 80-85% of long-term care residents are living with a memory disabling disease.¹³³ Long-term care facilities are often seen as the last resort; but limited access to family carers indicate institutionalization rates will

increase. Private care is available, yet unaffordable for many at an estimated monthly cost of €8,500 at a desirable institution. The quality of long-term care facilities in Finland varies greatly; municipalities primarily purchase services from private contractors funded by the national government.¹³⁴ To combat the shortage of skilled caregivers, legislation has been implemented requiring a nurse to person living with dementia ratio in care homes of at least 0.5, which must gradually increase to 0.7 by 2023.¹³⁵

Individuals living with dementia have access to long-term care based on a needs assessment, however, utilization is inexplicably decreasing despite growing need.¹³⁶ Furthermore, home care services coverage has shrunk despite calls for greater investments in 'aging at home'.¹³⁷ Experts cited that extensive wait times to enter long-term care facilities mean most people spend only the last two years of their life in these facilities.¹³⁸ Also, despite access to free care or care with only modest out-of-pocket costs, individuals are rarely able to choose the care they wish to receive. Many desire to move away from care institutions and towards a community or mixed-care approach.¹³⁹ Some NGOs, churches, and small local teams are trying to implement such a system, allowing those living with dementia to retain some autonomy. This preferred approach has prompted many to seek the reframing of memory disabling diseases as diseases of disability, which are subject to a mixed care approach with a more direct focus on autonomy.

Calls to Action

Finalize update to national plan (delayed due to the pandemic)

Due to COVID-19, Finland's efforts to update their NAP were indefinitely delayed. As the country moves past the initial pandemic response phase, Finland must focus on updating and implementing the national plan to ensure vital services and programs are established or resumed.

Invest in mass-media awareness campaigns focused on combating stigma

Stigma is an acute issue in Finland, and third-party organizations lack adequate resources to fund campaigns to combat it. The national government should provide specific funding for third parties to run campaigns against stigma or implement these campaigns by leveraging key communications channels at their disposal. Such efforts would improve diagnosis rates while also helping to protect those living with dementia who face discrimination.

Improve long-term care infrastructure to make it timelier and more accessible

While the healthcare system performs well in providing coverage, many living with dementia and their families face challenges when trying to access long-term care, including long wait times and lack of provider choice. Decision makers must make strategic investments to bolster long-term care infrastructure, placing an emphasis on home-based care. These efforts will improve quality-of-care, care delivery, and quality of life for those living with dementia and their family members.



France

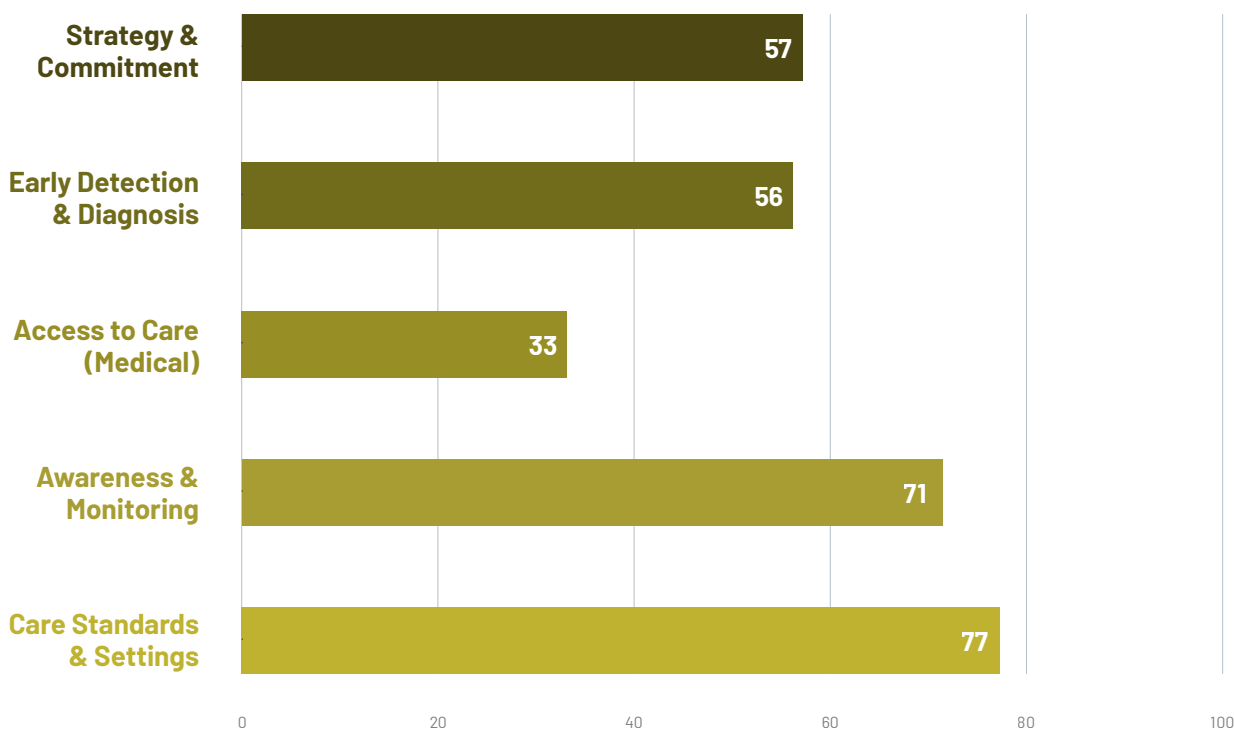
RANKING

5

Overview

Alzheimer's disease became the fourth leading cause of death in France in 2018.¹⁴⁰ The French Neurodegenerative Diseases Roadmap 2021-2022, preceded by four national Alzheimer disease-related plans, focuses on 18 key actions, many of which are centered on improving care pathways and integrating care.¹⁴¹ These efforts build on the three pillars of the 2014-2019 plan: improving diagnosis and management of persons, ensuring quality of life for those living with dementia and caregivers, and supporting research.¹⁴² However, there has been a precipitous decline in funding and political will following former President Sarkozy's well-funded and targeted plan, which ended in 2012. Since then, the focus of national plans has shifted to broader disease areas and received smaller budget allocations. Action plans for Alzheimer's disease have been on the country's agenda since the early 2000's, though conversations around prevention efforts have only started recently.¹⁴³

France Category Assessments



Country	France
AD or Dementia plan	Yes: Neurodegenerative Diseases Roadmap, (2021-2022)
Number of people living with Alzheimer's and other dementia (est.)	1,227,558 / (1.83%) / (2019) ¹⁴⁴
Awareness raising	Yes: (General dementia stigma & risk reduction, lifestyle, and Alzheimer's-specific campaigns)
Total Annual Costs	€34.7 billion (AD Population, 2016) ¹⁴⁵ €14 billion (Informal Care, 2015) ¹⁴⁶
Annual Nursing Home Care Cost per Person	€38,712 (2011) ¹⁴⁷

France's innovative efforts to improve the quality of life for those living with dementia are reflected in an experimental, purpose-built Alzheimer's disease village in the southwest region. Championed by the late Henri Emmanuelli, MP, Landais Alzheimer houses over 100 permanent residents and aims to preserve its residents' autonomy.¹⁴⁸ This experiment, in which specified care and freedom go hand in hand, is built to preserve independence and daily routine. Researchers are working to understand if living in this village may help slow the disease progression and whether it offers value for individuals living with Alzheimer's disease.¹⁴⁹

dementia. Currently, France has no specific plan for addressing Alzheimer's disease. While the two previous plans included important initiatives, the implementation strategy was poor. National leaders have focused investment in other disease areas, a political shift from the previous strong commitments by Sarkozy. A large disabilities reform will likely be implemented under the next presidency in 2022, potentially further diverting attention from Alzheimer's disease and other dementias. The Neurodegenerative Diseases Roadmap 2021-2022 seeks to fill gaps left by the previous plan,¹⁵² though advocates still hope the government will once again develop a standalone national dementia strategy.¹⁵³

Category Assessments

Strategy & Commitment

In 2008, then-President Nicolas Sarkozy called for the investment of €200 million for Alzheimer's disease research, training, and feeder initiatives. This was allocated as part of France's national Alzheimer's disease plan, which ran until 2012 and which received €1.6 billion in funding for a wide range of Alzheimer's disease initiatives.¹⁵⁰ From 2014 to 2019 under President Hollande's leadership, France initiated a broader neurodegenerative disease plan, pledging €470 million,¹⁵¹ which represented a decreased focus and funding for AD and

Early Detection & Diagnosis

The average time to receive an Alzheimer's disease diagnosis, from the first signs of disease, is about four years. Delays are driven in part by misdiagnosis; many persons living with dementia are misdiagnosed with depression or other mental disorders due to insufficient training of GPs. Advocacy by an informal caregiver can help accelerate a diagnosis, though—interestingly—a family history of Alzheimer's disease often increased chances of a delayed diagnosis.¹⁵⁴

As in many countries, GPs are the gatekeepers to care and treatment for Alzheimer's disease. While some incentives in France encourage persons to visit GPs

ahead of specialists,¹⁵⁵ there are currently no referral incentives for Alzheimer's disease. It is common for people to receive a diagnosis during a hospital visit; however, it is less common for a person to seek a specialist directly, as this incurs a reimbursement penalty.¹⁵⁶ The proportion of GPs to population is low, and GP workloads are increasing dramatically, especially in non-urban areas.¹⁵⁷ Most GPs have limited time with patients, which can reduce the likelihood of diagnosis. Some GPs also express reluctance to provide a referral for diagnosis, driven by their belief that this is fruitless given there is no cure for Alzheimer's disease.¹⁵⁸ Some experts mentioned that in certain cases GPs slowly prepare those living with dementia for disease progression, then refer them for diagnosis at a later stage.¹⁵⁹

Access to Care (Medical)

During 2018, the French health ministry decided to cut all reimbursement of Alzheimer's disease therapeutics (previously reimbursed at 65%), arguing the clinical impact was not great enough to justify the investment.¹⁶⁰ Unsurprisingly, this decision led to a dramatic drop in prescribing rates. Further, this resulted in uproar among some organizations within the Alzheimer's disease diagnosis and care pathway community, who pursued legal action against the decision to end reimbursement.¹⁶¹

Awareness & Monitoring

France's national health insurance system tracks GP and hospital visits information, which is included in the publicly available aggregated national dataset.¹⁶² Researchers can track the number of individuals who receive a diagnosis, see a specialist, and enroll in therapies through the French National Alzheimer database (BNA).¹⁶³

Care Standards & Settings

All care services are reimbursed by the long-term illness (ALD) public insurance system, providing robust coverage for individuals living with long-term chronic conditions.¹⁶⁴ However, essential services for those living with dementia are underfunded, there are separate compensation rates for those younger and older than 60, and Alzheimer's disease is only considered a disability for those diagnosed before 60, producing various health inequities.¹⁶⁵ As in other countries, COVID-19 has exacerbated challenges within the care system. Experts noted that the lack of integrated and coordinated care for those living with Alzheimer's disease has been especially problematic, revealing a myriad of communication issues between hospitals and nursing homes (e.g., lack of information-sharing) that negatively impact quality of care.¹⁶⁶ The pandemic also increased reliance on informal carers and worsened conditions for those providing social and long-term care. Moreover, most nursing homes have limited telemedicine capabilities, signaling the need to improve digital health infrastructure.¹⁶⁷

In addition, the recruitment and retention of caregivers remains a significant problem.¹⁶⁸ A recent survey found a burnout rate of 40% among French nursing home care workers.¹⁶⁹ To help strengthen the labor pipeline, the French government has increased the national salary for formal caregivers,¹⁷⁰ and has initiated several public campaigns to improve the image and reputation of formal caregiving.¹⁷¹

Calls to Action

Recommit to funding Alzheimer's disease and other dementias at the same levels as the previous Sarkozy plan (€1.6 billion, 2014)

French policymakers have reneged on their previous commitments to Alzheimer's disease and other dementias, leading to a precipitous drop in funding and initiatives. Restoring the level of funding on par with Sarkozy's plan would reinvigorate the French fight against Alzheimer's disease and other dementias. Specific investments in diagnostic tools, diagnostic infrastructure, and HCP training would increase the capacity and timeliness of diagnoses, while also reducing misdiagnoses. Investments in improved organizational guidelines and communications between relevant stakeholders—GPs, specialists, caregivers, and those living with dementia themselves—would better integrate the care pathway and improve quality of life.

Revisit reimbursement strategies for Alzheimer's disease drugs

France has experienced a significant decline in Alzheimer's drug prescriptions following the removal of these drugs from reimbursement lists. The government must rethink its strategy and approach to reimbursing Alzheimer's drugs, ensuring that those living with dementia are not forced to bear the financial burden of treatment. This should produce better health outcomes for persons reliant on greater drug access, restore trust in the reimbursement process, and help overcome the negative outlook associated with an Alzheimer's disease diagnosis.

Work with healthcare system stakeholders to better define and improve the care pathway

In France, navigating care pathways remains complex, confusing, and frustrating for those living with dementia and their loved ones. The amount of support third-party organizations can provide is limited. Governments must act to better define the care pathway by improving communication between the medical and social care sectors. These efforts will help improve health and care outcomes as well as quality of life for people living with dementia.



Germany

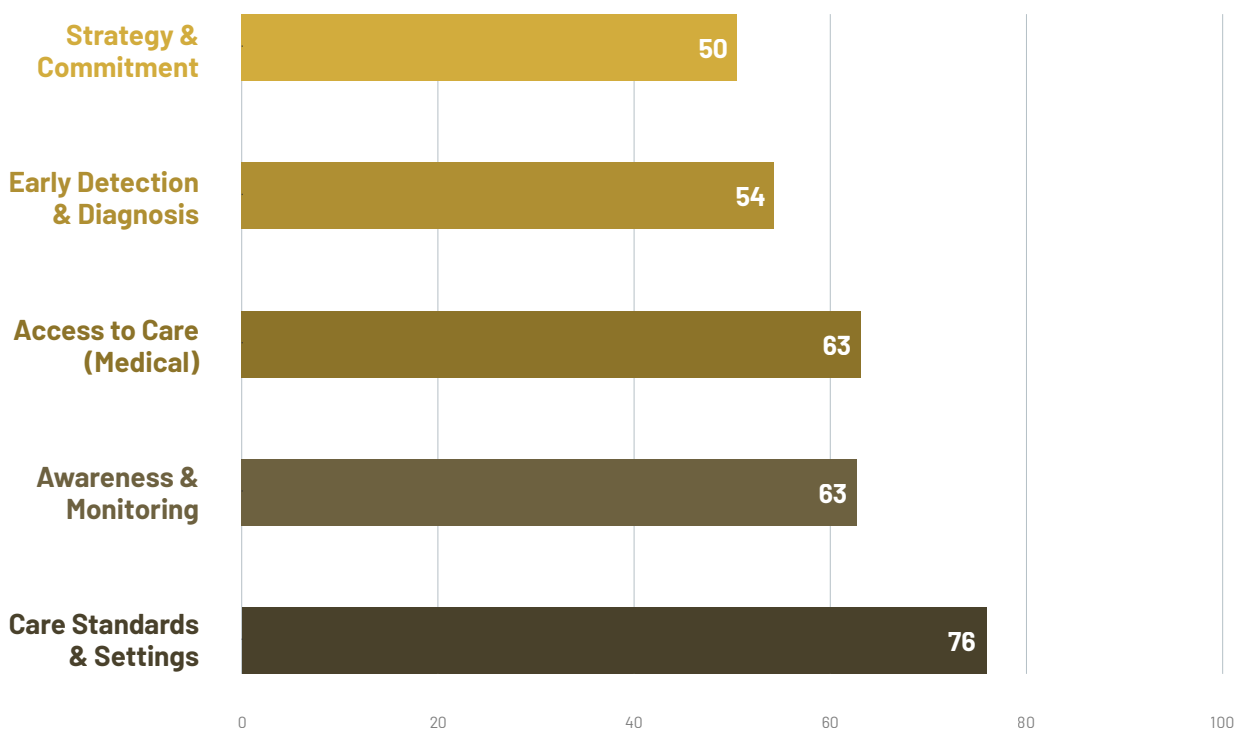
RANKING

3

Overview

Germany is one of a handful of ‘super-aged’ societies globally,¹⁷² and according to the German Alzheimer Association’s projections, at least two million Germans will be living with dementia by 2050.¹⁷³ To help address this growing challenge, the German government adopted a robust National Dementia Strategy in 2020¹⁷⁴ and has made considerable investments in supporting research institutions and strengthening the national social care system.¹⁷⁵ With the recent implementation of a national plan, new coordination efforts between medical and social care are predicted to improve health outcomes and provide a clearer care pathway.¹⁷⁶

Germany Category Assessments



Country	Germany
AD or Dementia plan	Yes: National Dementia Strategy, (2020)
Number of people living with Alzheimer's and other dementia (est.)	1,585,166 / (1.91%) / (2019) ¹⁷⁷
Awareness raising	Yes: (General dementia stigma & risk reduction, lifestyle, and Alzheimer's-specific campaigns)
Total Annual Costs	€52.7 billion (AD Population, 2016) ¹⁷⁸ €29.1 billion (Informal Care, 2019) ¹⁷⁹
Annual Nursing Home Care Cost per Person	€45,911 (2019) ¹⁸⁰

The average annual cost for a person living dementia is estimated at €30,179; 65% is paid by families, with the remaining costs subsidized by the country's long-term care insurance system.¹⁸¹ Though indirect informal costs for people living with dementia are higher than in some comparative countries, the universal healthcare system in Germany has led to lower direct medical costs than in others, such as the UK, Spain, and France.¹⁸²

Category Assessments

Strategy & Commitment

The 2020 National Dementia Strategy, which reflects input from many stakeholders and advocacy organizations, outlines several key priorities, including: the development of dementia communities; support systems for those living with dementia and relatives; improved long-term care and other services; and further research on Alzheimer's disease and other dementias.¹⁸³ Despite a strong framework to guide program implementation, funding and allocations remain barriers.¹⁸⁴ Furthermore, Germany's government does not currently provide funding for Alzheimer's Cafes or for national Alzheimer's disease associations core activities.¹⁸⁵ Though Germany has made some commit-

ments to support dementia-friendly communities,¹⁸⁶ the country lacks strong visibility and advocacy for Alzheimer's disease. There is no dementia coordinator, no Ministry of Health affiliate, and no parliamentary group that addresses Alzheimer's disease specifically. Germany does, however, participate in several prominent regional and international initiatives, including the Alzheimer Cooperative Valuation in Europe (ALCOVE),¹⁸⁷ DEM2,¹⁸⁸ the Glasgow 2014 Convention,¹⁸⁹ and the European Alzheimer's Alliance.¹⁹⁰

Early Detection & Diagnosis

While Germany has a large network of about 200 gedächtnisambulanzen (GA) or memory clinics, inconsistencies and discrepancies have led to calls for more formalized structures, organizational standards, and better integration with the national healthcare system.¹⁹¹ Surprisingly, a relatively high number of clinics also focus on early-onset Alzheimer's disease.¹⁹² Furthermore, the German National Alzheimer's Plan committed to fund research on diagnostic tools and processes.¹⁹³ Though sadly, those already having difficulty accessing care, such as migrant groups, are especially unlikely to be properly screened and diagnosed.¹⁹⁴ Additionally, a recent study demonstrated large variations in cost of diagnosis for dementias in

Germany.¹⁹⁵ Yet, reimbursement policies do not account for these differences, and reforms that strengthen and standardize the diagnostic pathway are needed to ensure that access, payer value, and provider incentive are aligned.¹⁹⁶

Access to Care (Medical)

Similar to Sweden, Germany reimburses most Alzheimer's disease-relevant therapies.¹⁹⁷ Germany also has some of the shortest specialist wait times among countries reviewed.¹⁹⁸ Thankfully, healthcare professionals face very few challenges accessing diagnostic tools in most settings (though it is more difficult to access Amyloid-PET testing), and there are a number of active Alzheimer's disease-related clinical trials taking place in the country.^{199,200} Relative to other countries, Germany has an average GP to population ratio, but a very strong ratio of neurologists to population.²⁰¹ Additionally, the German government has produced a strategic framework for post-diagnostic support, which includes advice, counselling, and peer support services for those living with dementia.²⁰²

Awareness & Monitoring

Germany has broader, more accessible dementia reporting than most countries.²⁰³ There is no national registry specific to those living with Alzheimer's disease, but some data for broader neurodegenerative diseases can be tracked through an evaluation of the insurance claims database.²⁰⁴ While surveillance relies on private and public data,²⁰⁵ the national plan has outlined efforts to make data collection more robust.²⁰⁶

In terms of awareness, the Federal Ministry for Family Affairs, Senior Citizens, Women and Youth (BMFSFJ) has made a clear commitment in the national plan to

raising the public profile of Alzheimer's disease and other dementias with specific calls to destigmatizing the diseases.²⁰⁷ The BMFSFJ has worked to fund a growing number of locally run awareness campaigns and is hoping to implement novel communication strategies under broader Dementia Friends initiatives.²⁰⁸ Dementia Friends programming is currently run by the German Alzheimer's Association and largely funded through the Ministry of Health. The national plan implementation began in 2020 and should be completed by 2026; by 2024 local dementia associations will launch innovative campaigns to redefine the future of dementia awareness.²⁰⁹

Care Standards & Settings

Most persons living with dementia in Germany can readily access home-based care and day care services,²¹⁰ though relationship-based care (RBC) is still being developed in Germany and has yet to be fully implemented.²¹¹ There are some incentivized schemes to improve RBC and care more generally, including policies that discount or surcharge hospital costs in relation to the quality of care provided.²¹² Thankfully, even in most non-specialized care settings, there are dementia experts on staff to support those living with dementia.²¹³ The government also provided financing to researchers to spur new developments in care through the German Innovation Fund, while the Federal Ministry of Education and Research (BMBF) has focused many of its investments in research for new nursing technologies.²¹⁴ The BMBF has also funded initiatives to support informal carers, such as the jointly-funded ReDiCare project.²¹⁵ ReDiCare is piloting the use of a staged assistance framework for care to alleviate the burden on familial carers. The results of this project will be used to inform future care standards legislation.²¹⁶



Policies to support carers are part of national legislation, including access to counseling services and Family Care Time (allowing familial carers to take a hiatus from work to provide care).²¹⁷ However, consultation for care decisions is not included (though is still provided in some cases) and case management is addressed in legislation but is poorly funded.²¹⁸ Access to carer support and training is also available and supported at the national level;²¹⁹ training is now, however, not as robust as experts would hope, nor is it mandatory.

Calls to Action

Establish a government task force to coordinate efforts to address Alzheimer's disease and dementia across agencies, departments, and regions

Currently, the diagnosis, care, and treatment of Alzheimer's disease and other dementias is siloed within regions and communities. The government should erect a federal framework to centrally support and coordinate these efforts. This would improve resource allocation, provide cost saving efficiencies, and broaden access to care.

Tailor care policies and strategies to better accommodate the needs of those living with Alzheimer's disease and other dementias

Because German care initiatives are not tailored to Alzheimer's disease and other dementias, many persons living with dementia are not guaranteed consistent care that addresses their specific needs. The government should work to establish more specific

care guidelines and programs for Alzheimer's disease and other dementias. These adjustments will help ensure that those living with dementia receive better, more tailored care, which will improve overall health outcomes and enhance quality of life.

Increase political representation for Alzheimer's disease and other dementias

German decision makers must demonstrate a commitment to Alzheimer's disease and other dementias through increased political attention. The creation of government working groups and the appointment of designated officials for AD and other dementias would help ensure that these issues remain in focus politically.



Italy

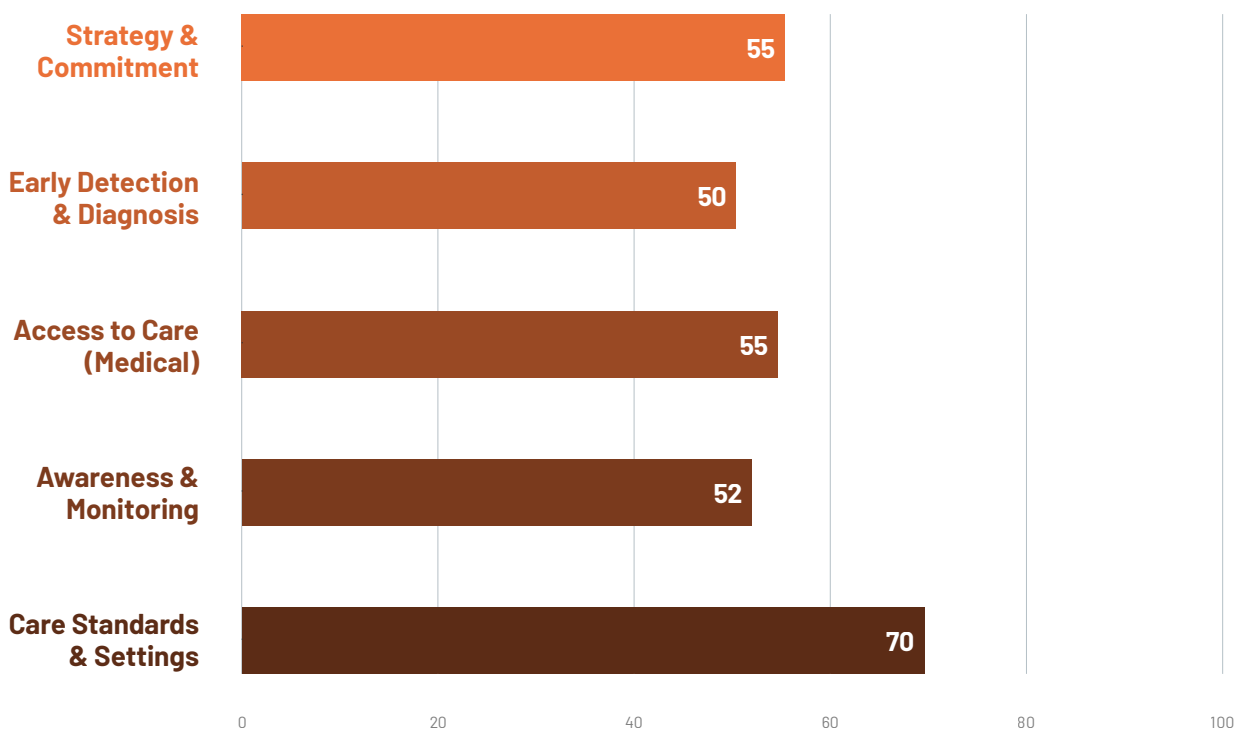
RANKING

8

Overview

Italy is the second fastest aging country in the world, with over 2% of individuals living with dementia. The Italian Ministry of Health launched the first Dementia National Plan in 2014. Since then, 11 regions have established committees to support implementation of the plan. Studies indicate generally low utilization of formal resources in parts of Italy, though this has been attributed to 'scarce and fragmented' availability of services for those living with dementia.²²⁰ Experts note great opportunity for improvement. Further, informal caregivers carry a tremendous burden in Italy, so large social care improvements are needed to support the families of those living with dementia.²²¹

Italy Category Assessments



Country	Italy
AD or Dementia plan	Yes: National Dementia Plan, (2014)
Number of people living with Alzheimer's and other dementia (est.)	1,279,366 / (2.12%) / (2019) ²²²
Awareness raising	Yes: Limited Government Engagement (General dementia stigma & risk reduction, lifestyle, and Alzheimer's-specific campaigns)
Total Annual Costs	€15.60 billion (AD Population, 2019) ²²³ €12.3 billion (Informal Care, 2018) ²²⁴
Annual Nursing Home Care Cost per Person	€46,720 ²²⁵

The Interceptor project is a strategic Alzheimer's disease program jointly run by the Italian Ministry of Health and Italian Medicines Agency aimed at improving early diagnosis by identifying the most accurate and cost-effective biomarker combinations, and applying them to new organizational models.²²⁶ Since 2017, the overarching goal of the initiative has been to develop a sustainable, country-specific framework for identifying persons living with MCI most at risk for Alzheimer's disease, while improving the delivery of pharmacological interventions to people living with high-risk MCI and prodromal AD.²²⁷

Category Assessments

Strategy & Commitment

Though approved in 2014, the National Dementia Plan only recently received funding. The 2021 budget established the Fund for Alzheimer's and Dementia, which included €15 million for program implementation through 2023.²²⁸ The primary objective is to finance social policies in the NAP and make investments in regional healthcare infrastructure to increase early diagnosis and improve monitoring and treatment for those living with dementia. While this sum is not entirely sufficient, it represents a step forward in

national efforts, and stakeholders are now awaiting the Ministry of Health's direction for specific allocation.²²⁹

Early Detection & Diagnosis

In Italy, GPs can only denote a 'suspicion of Alzheimer's disease' and are required to refer people to a specialist or neurologist for formal diagnosis. Those living with dementia can also be diagnosed at dedicated memory clinics. People can circumvent GPs by pursuing a diagnosis from private specialists, however, this private route is more unusual, since most costs of other paths to an Alzheimer's disease diagnosis are reimbursed through the public system.

The diagnostic process in Italy can be slow, and most people are diagnosed at a later stage of the disease. The stigma of the disease often discourages persons from seeking an initial diagnosis, an issue that is particularly prevalent in Southern Italy. Even with a referral, a person can wait up to 6 months to see a specialist. Equally, GPs themselves can unintentionally act as a barrier to diagnosis. Experts stated that some GPs discount the possibility of Alzheimer's disease for younger persons, considering the disease a concern for older adults. For older persons, some GPs devalue diagnosis, noting that treatment is "not worth the trouble." On the other hand, a recent report released

by Alzheimer Europe in collaboration with Federazione Alzheimer Italia and other national associations, indicated that in some cases the Italian diagnosis process can be shorter than in other comparative countries.²³⁰ Interestingly, the report cited that Italy had much higher rates of “family member initiated” diagnosis (83.6%) than in other countries and not inconsequential rates of private clinic diagnosis (26.1%).²³¹ Regardless, most surveyed in Italy (60.3%) felt as though the diagnosis was not made in a timely manner, much higher than rates recorded in other countries.²³²

Access to Care (Medical)

Overall, most experts credit Italy for having strong universal access to healthcare. Reimbursement for Alzheimer’s disease-related drugs²³³ and generic treatments for managing Alzheimer’s disease symptoms are easily accessible and available throughout the country. There are, however, discrepancies in access to digital Alzheimer’s disease innovations among regions.

Awareness & Monitoring

In Italy, the national government does not run any national campaigns to combat stigma associated with Alzheimer’s disease and other dementias. National and local advocacy organizations run their own campaigns, but due to financial constraints they are generally unable to run mass market efforts.

Existing data is fragmented, siloed, and inconsistent. All national figures are currently estimates and approximations. Experts hope greater funding will be allocated to establish a national registry and improve nationwide collection and organization of Alzheimer’s disease data.

Care Standards & Settings

At the end of 2020, the Italian government established a pilot caregiver loan program to help offset the financial burden informal carers face. Though this program is not dedicated specifically for Alzheimer’s disease carers, the fund will make €75 million available over three years to informal carers. Despite the development of care pathway guidelines and calls for these to be implemented in the national plan, not all regions have adopted or implemented pathways for those with Alzheimer’s disease and other dementias.²³⁴ Where they have been implemented, integrated pathway plans are ill-defined and generally insufficiently structured.²³⁵ Furthermore, although the Federazione Alzheimer Italia has repeatedly asked the Italian government to develop and implement more robust dementia training for GPs, the training and funding by the national government remains insufficient.²³⁶

Calls to Action

Coordinate program management efforts across regions to expand accessibility

Regional wealth disparities and localized policies have created large differences in access to diagnostics, care, and treatment. Italy should provide national policies and guidelines to mitigate these variations in access. This will help improve health outcomes in poorer regions, while also lessening the burden nationwide.

Increase national funding to aid full implementation of key initiatives of the new national action plan and beyond

Decision makers must ensure the plan receives the necessary funding to implement key programs and ensure this hard-won strategy is effective. This must include financing social policies as well as general infrastructure improvements to close gaps in the care pathway, expanding capacity and preparing for future (tools for biomarker testing, etc.).

Commit more resources to increase GPs' ability to receive training and leverage diagnostic tools

Many Italian GPs lack the appropriate level of training, and there are regional disparities in the availability of diagnostic tools. The government must seek to make training more robust and publicly funded, while also ensuring enough investments to make diagnostic and screening tools available nationwide.



Slovenia

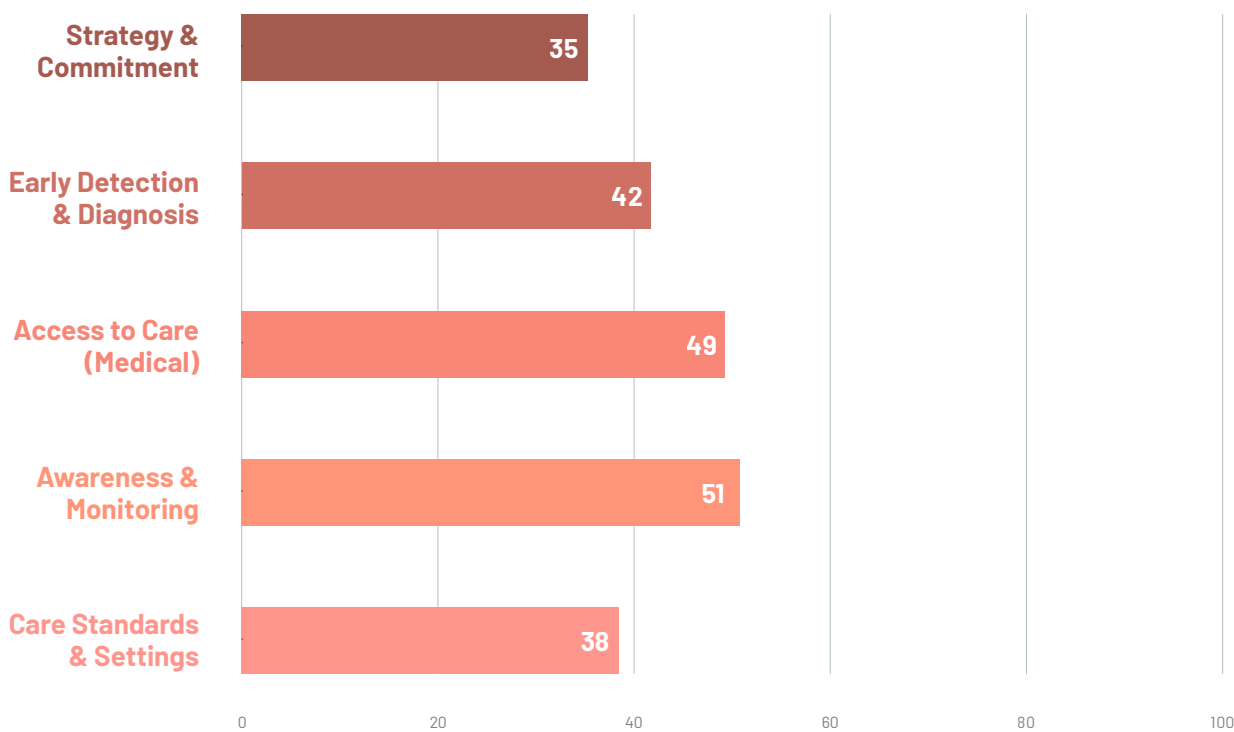
RANKING

9

Overview

After decades of efforts by stakeholders, the Slovenian Government finally approved long-term care legislation, which will hopefully be passed by Parliament in September and then put into force, with the goal of full implementation no later than mid-2024.²³⁷ Experts remain optimistic the government will soon adopt these necessary LTC reforms. Currently, Slovenia has few private care services available and existing public care services remain underdeveloped or only partially implemented.²³⁸ While other countries in this *Index* provide publicly funded services, Slovenia only partially covered dementia services, with some paid completely out of pocket.²³⁹

Slovenia Category Assessments



Country	Slovenia
AD or Dementia plan	Concluded (preparing next plan): National Dementia Plan, (2016–2020)
Number of people living with Alzheimer's and other dementia (est.)	34,137 / (1.65%) / (2019) ²⁴⁰
Awareness raising	Yes: Limited Government Engagement (General dementia stigma & risk reduction and lifestyle campaigns)
Total Annual Costs	€167.3 million (Total Cost of Illness, 2008) €92.6 million (Informal Care, 2008) ²⁴¹

Slovenia had only limited participation in Horizon 2020 dementia research projects (the EU's largest R&D funding program to date),²⁴² participating in only three Horizon projects and did not coordinate any consortium projects.²⁴³ Though Slovenia has seen success in implementing some programs, such as the 2012 introduction of Alzheimer's Cafés (which spread quickly to over 60 sites), lack of funding hampers the development, implementation, and accessibility of services.²⁴⁴

Spominčica, the main advocacy organization that aids people with dementia, their families, and caregivers, has led the charge on Alzheimer's disease awareness in Slovenia over the past several decades. The organization has launched campaigns to educate the general public and carers, while also providing training to ensure caregivers are best able to deliver the necessary care.²⁴⁵ The association's awareness campaigns and training programs are co-funded by the Ministry for Health, Ministry for Labor, Family, Social Affairs and Equal Opportunities, Municipality of Ljubljana, and the FIHO Foundation, following annual tenders for services. Spominčica has a strong track record of winning these tenders and thus are able to fund various awareness raising activities, Alzheimer Cafes, and consultation services for patients and carers. Further, Spominčica launched the Dementia Friends movement in Slovenia during 2018. The campaign, which brings together various stakeholders as "members" hoping to create a more dementia friendly Slovenia, has engaged several

high-profile government officials, including the President of the Slovenian Parliament, the Secretary of State for Health, and the Ministers for both Social and Internal Affairs, to increase national visibility.²⁴⁶

Category Assessments

Strategy & Commitment

The Ministry of Health established the first government-approved Dementia Management Strategy in mid-2016, which ran through 2020.²⁴⁷ But instead of renewing the dedicated national dementia plan, the government intends to integrate it into a broader health plan. Both ADI and Alzheimer Europe are working with Spominčica to advocate for a reinstatement of a standalone plan to protect progress. The 2016–2020 plan sought to encapsulate many themes included within dementia-related EU and WHO documents (e.g., the WHO GAP on dementia).²⁴⁸ For example, the plan stressed the creation of dementia-friendly communities by promoting local activities.²⁴⁹ This plan was developed by a working group appointed by the Ministry of Health, which included representatives from relevant ministries and various non-governmental stakeholders, such as Spominčica, healthcare and social care experts from clinics, community healthcare centers and care homes.²⁵⁰ It covered five key areas: increasing awareness and reducing stigma; early diagnosis; treatment

(especially pharmaceutical therapies) access; comprehensive social care access; and palliative care.²⁵¹ In 2019, the Prime Minister spoke at a neurological disease conference and highlighted the work of Spominčica in promoting much-needed legislation on the issue.²⁵² The conference integrated those living with dementia and caregivers into the panel discussions, helping to more clearly articulate the emotional and financial costs of Alzheimer's disease and other dementias.²⁵³

While Slovenia has a national coordinator of dementia policies²⁵⁴ and small efforts have been made to develop dementia friendly communities,²⁵⁵ there is no visible political leadership for Alzheimer's disease in the Ministry of Health.²⁵⁶ Despite strong MEP commitment to the European Alzheimer's Alliance²⁵⁷ and moderate participation in the 2014 Glasgow Declaration,²⁵⁸ there has been lackluster commitment to ALCOVE and DEM2.²⁵⁹

Early Detection & Diagnosis

Structural barriers inhibit early detection and diagnosis in Slovenia. Compared to other countries, Slovenia suffers from a low ratio of PET scanners to persons²⁶⁰ and a high proportion of persons with unmet need because medical examinations are difficult to access.²⁶¹ While CSF testing is available and reimbursed in larger hospitals, GPs rarely direct persons with suspected dementia to the proper diagnostic procedures and the country has no early-onset AD clinics.²⁶² Overall, this signals a demonstrated lack of resources to ensuring earlier detection and better diagnosis. Slovenia also has a poor clinical trial climate with only three Alzheimer's disease related trials carried out over the past year.²⁶³ However, this is likely due to the country's comparatively small eligible population, which makes Slovenia an unattractive site for clinical trials, rather than an unwillingness by hospitals or persons to participate.

Lack of reimbursement for diagnostics tests is another barrier. Although 88% of Slovenian GPs surveyed said they viewed early diagnosis as valuable,²⁶⁴ they believed diagnostic activities were not significantly reimbursed.²⁶⁵ Additionally, GP consultations in Slovenia are very short (approximately seven minutes), which can limit the GP's ability to properly evaluate the concerns of those living with dementia and caregivers.²⁶⁶ Worryingly, there is no GP dementia training or education in the general curriculum, and postgraduate dementia-specific education is only available to GPs, not to other allied health professionals.²⁶⁷

Access to Care (Medical)

While the ratio of relevant healthcare professionals to persons is not as robust as in other countries, there are bright spots when it comes to access to care. Slovenia reimburses most available Alzheimer's disease related drugs.²⁶⁸ Slovenia also provides post-diagnostic support through community nurses, recognizing the need for linkages in care between medical and social sectors, though community work is sometimes poorly organized and structured.²⁶⁹

Awareness & Monitoring

The government does not run advertising campaigns to combat Alzheimer's disease stigma. Spominčica has led the majority of awareness efforts and has continuously demonstrated the ability to increase political engagement on the issue.

Reporting on Alzheimer's disease and dementia is generally poor, and the numbers of persons living with dementia are not routinely monitored, making it more difficult to accurately address the needs of the disease population. There are also no current plans to improve data collection in Slovenia.

Care Standards & Settings

After decades of campaigning, stakeholders view the newly announced long-term care legislation—the first-of-its-kind in Slovenia—as a potential watershed moment.²⁷⁰ This legislation could considerably improve outcomes for those living with Alzheimer’s disease, but it has yet to be passed by Parliament, is not expected to be fully implemented until mid-2024, and the funding picture remains unclear.²⁷¹ Given the lack of support in the past, large numbers of familial carers have been forced to exit the workforce to provide care to their loved ones,²⁷² which hopefully can be rectified through this legislation.

As a result of the previous Dementia Management Strategy, the Ministry of Health had published a call for co-financed dementia education and awareness programs for 2017 and 2018, resulting in seven financed programs, one of which Spominčica coordinated. In the Spominčica program, over 100 seminars and intensive training sessions were held for healthcare professionals (18 hours total), formal carers (12 hours total), and informal carers (six hours total) across all 12 Slovenian regions.²⁷³ Funding for caregiver training is still only partially covered by public funds, imposing a sizable financial burden on informal carers or formal caregivers seeking training.

Calls to Action

Ensure the country’s first long-term care law is funded with specific provisions for Alzheimer’s disease and other dementias, while protecting progress by renewing the standalone dementia plan

After finally approving long-term care legislation, Parliamentarians must aggressively push to pass these policies and include disease-specific policies within this legislation that allocate funding commensurate with need to relieve the unfair burden on those living with Alzheimer’s disease and other dementias. The passage of these reforms would represent a sea change in Slovenia’s healthcare landscape, as long as this legislation is adequately funded and implemented. Policy-makers should also reconsider their intent to address Alzheimer’s disease and other dementias through a grouped health strategy, which could undermine progress. A recommitment to the previous standalone strategy for dementia will help protect previously implemented programs and provide much-needed commitment to ongoing efforts.

Invest in mass-media awareness campaigns focused on combating stigma

Despite clear evidence that stigma hampers diagnosis efforts, there are no publicly run awareness campaigns to combat it in Slovenia. Especially in this area, the government must commit resources to enable advocacy partners to run effective campaigns or undertake them on their own.



Finance capacity building for specific diagnostic procedures

In Slovenia, limited funding for diagnostic tools from the Sick Fund and Ministry of Health budget has led to shortages of PET scanners and MRI machines, as well as the personnel needed to operate them. Though most diagnostic procedures for Alzheimer's disease and other dementias are covered by the healthcare system, long wait times and uneven accessibility inhibits diagnosis. Policymakers must bolster the diagnostic infrastructure through targeted investments with a goal of boosting nationwide diagnosis rates.



Spain

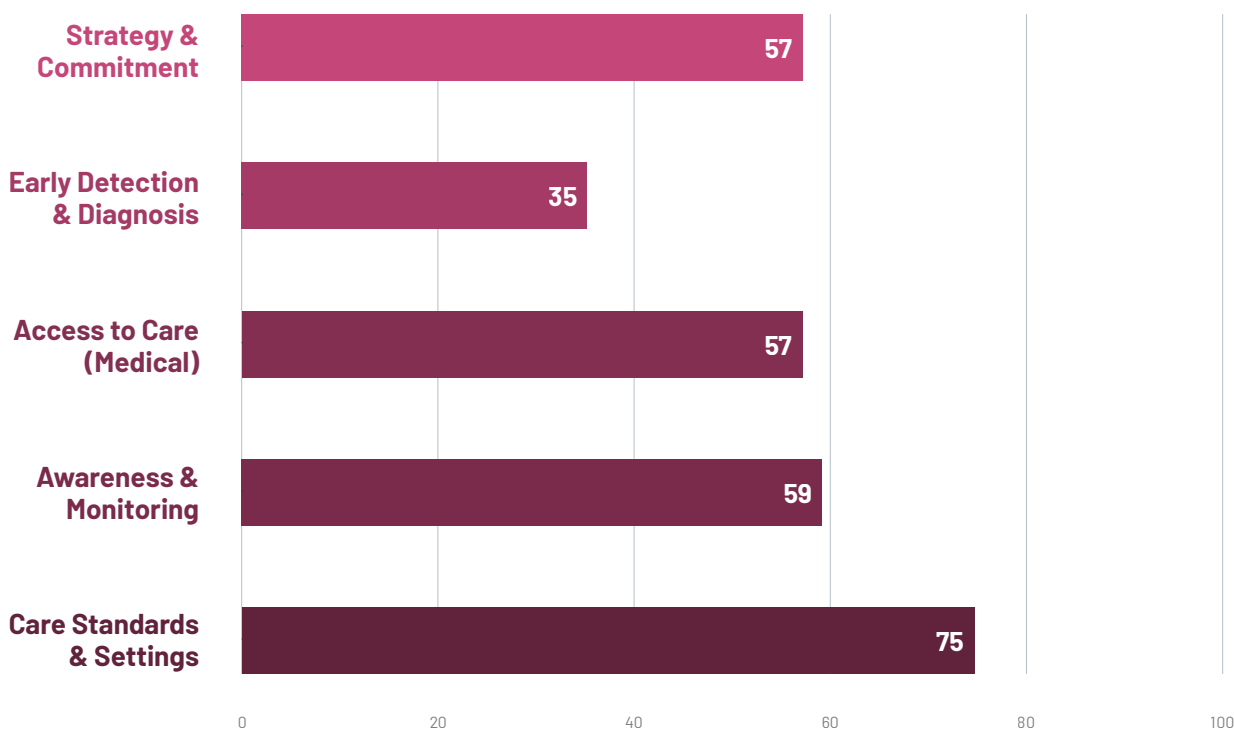
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Overview

Spain recently approved the National Alzheimer's Plan 2019-2023, though funding has not yet been finalized.²⁷⁴ A key focus of this plan is to improve diagnostic efforts across Spain, with a goal of reaching the WHO benchmark of diagnosing at least half of those affected by Alzheimer's disease.²⁷⁵ This is a pressing need, as the number of persons living with Alzheimer's disease is estimated to grow from 700,000 to 2 million by 2050.²⁷⁶ Current specialist capacity to diagnose and provide treatment in Spain is already at its limit, and will only be stretched more in the coming years, further inhibiting efforts to diagnose, treat, and care for those with dementia.²⁷⁷

Spain Category Assessments





Country	Spain
AD or Dementia plan	Yes: National Alzheimer's and Other Dementias Plan, (2019-2023)
Number of people living with Alzheimer's and other dementia (est.)	852,741 / (1.83%) / (2019) ²⁷⁸
Awareness raising	Yes: (Lifestyle, and Alzheimer's-specific campaigns)
Total Annual Costs	€20.8 billion (2016) ²⁷⁹
Annual Care Cost per Person	€31,890 (2016) ²⁸⁰
Annual informal care (caregiver time) per person	€17,596 (2020) ²⁸¹

Due to the COVID-19 pandemic, people living with Alzheimer's disease and caregivers in most countries have seen decreased support, though the Spanish Alzheimer's Confederation has tried to provide resources to mitigate this challenge.²⁸² Regardless, the cost of care for persons living with Alzheimer's disease or dementia continues to burden families, with 71% of the estimated €24,184 annual cost not covered by public funding.²⁸³ Furthermore, while there are examples of good care practices in Spain, many have not been integrated across all institutions or regions.²⁸⁴

The Spanish public has been uniquely exposed to Alzheimer's disease following the public diagnosis of the country's first post-Franco Prime Minister, Adolfo Suarez, who eventually succumbed to AD. Likewise, Pasqual Maragall, former Mayor of Barcelona and President of Catalonia, announced his Alzheimer's disease diagnosis and established the Pasqual Maragall Foundation to further Alzheimer's research.²⁸⁵ In 2015, Queen Sofia, an ADI Global Ambassador, was nominated for a Nobel Peace Prize for her foundation's work in the fight against Alzheimer's disease.²⁸⁶ However, low levels of awareness and knowledge among the general public still persist and may explain the lessened political focus on Alzheimer's disease.²⁸⁷

Across Spain there are over 170 day centers under the CEAFA (Confederación Española de Familiares de Enfermos de Alzheimer) umbrella,²⁸⁸ including the Day Care Center for People with Alzheimer's Disease in Benavente, which recently received international praise for its innovative efforts to tackle the disease.²⁸⁹ Started in 2019, the center provides mentally and physically stimulating activities for patients. Due to its success, an expansion of the center is currently underway²⁹⁰ and it is also being used as a blueprint for other programs.

Category Assessments

Strategy & Commitment

Despite approval of the National Alzheimer's Plan 2019-2023, a lack of funding has stalled action and implementation. The plan was designed with the oversight of multiple agencies, creating administrative challenges, and included no provision for budget allocations or clearly defined funding proposals. The plan seeks to improve detection and diagnosis, expand person-centered care, and make greater investments in social and welfare services, along with research efforts. Our experts identified further

barriers to funding, among them, the fact that research is generally a low priority in Spain. Further, some experts believe Alzheimer's disease and other dementias initiatives only receive political attention when they are used by the non-ruling party to criticize incumbents for lack of "follow through."²⁹¹

Early Detection & Diagnosis

Relative to the other European countries in this report, Spain performed worst in early detection, not least because it is extremely common for Spanish persons living with early-stage dementias or MCI to go undiagnosed. According to a recent study, severity of dementia is extremely correlated with diagnosis in Spain; 64% of persons living with severe dementia have been diagnosed compared to only 5% of those with mild dementia.²⁹² Experts noted that previously delays to diagnosis were estimated to be about three years, but believe this delay has shortened in recent years.²⁹³ One major challenge is the lack of coordination and organization in the diagnostic environment, a goal of the current national plan. For example, persons are often sent to specialists only to receive a vague cognitive impairment or "under study" diagnosis, while some GPs wait until symptoms are more acute to make a formal diagnosis. People are also generally reticent to seek diagnosis given the stigma in Spain.

While GPs have been empowered to order CT scans, which can narrow the diagnostic possibilities, they are unable to make a formal diagnosis and cannot prescribe Alzheimer's disease-related drugs. In some cases, GPs can even circumvent specialists and refer persons to family associations who can provide cognitive therapies in some cases.²⁹⁴ While all neurologists understand the

importance of an Alzheimer's disease diagnosis, some are still unwilling to provide a formal diagnosis until the disease becomes more advanced.

Geography also plays a role. Experts stated that in regions where the neurology group is interested in Alzheimer's disease and dementia, people have access to more advanced diagnostic tools (MRIs, CSF testing, amyloid PET scans) and will likely receive a quicker diagnosis.²⁹⁵ High levels of autonomy in regional healthcare provisions also lead to variations in access to multi-biomarker testing and disparities in regional funding for programs and reimbursement.²⁹⁶

Access to Care (Medical)

In Spain, there are currently no incentives for GPs to refer persons to specialists for diagnosis. There are, however, incentives in place to keep drug expenses low, which encourages some GPs to discontinue symptomatic treatments for Alzheimer's disease. Additionally, wait times for dementia specialists in Spain are extraordinarily long at 10 months.²⁹⁷ Specialists themselves acknowledge these wait times as barriers to diagnosis.²⁹⁸

Awareness & Monitoring

There are no national databases or registries for Alzheimer's disease and other dementias in Spain, though efforts have been made by the CMBD (Basic Minimum Data Set) to consolidate regional data from hospitalizations to inform estimations of regional and national prevalence.²⁹⁹ There is some data collected by the government when people are evaluated for a dependency allowance, yet most of the data is specific to physical, rather than cognitive disabilities. Thankfully, CEAFA has been actively partnering with

regional authorities to collect real data on the number of persons living with Alzheimer's disease under the framework of the "Census of people affected by AD in Spain" project.³⁰⁰

Spain's government does not run any national awareness campaigns. While greater attention is starting to be paid to Alzheimer's disease, there is no government department charged with running campaigns or advocacy. Third parties do run newspaper, newsletter, social network, and radio campaigns to increase Alzheimer's disease awareness, including FAE (Fundación Alzheimer España)—which also produces dementia related podcasts³⁰¹—and CEAFA, who annually run awareness campaigns tied to the national Alzheimer Plan and programming for Alzheimer's International Day.³⁰²

Care Standards & Settings

In Spain, most caregiving responsibilities are handled by families, who bear roughly 70% of costs associated with care. Although formal care is available, Spain, like most other countries in Europe, is currently experiencing a significant formal caregiver shortage. Experts report that formal services for day and residential care are insufficient.³⁰³ Moreover, Spain has some of the lowest per capita long-term care spending (through compulsory schemes) in Western Europe.³⁰⁴ Despite recent attempts to reduce regional disparities, variations in care approaches still exist and gaps in care are still common for those with chronic conditions, such as dementia.³⁰⁵ However, Spain does participate in the SELFIE initiative, an EU Horizon 2020 project to identify and develop integrated care pathways matched with incentives to increase the uptake of integrated care.³⁰⁶

Provisions are in place that should allow the government to provide support for informal caregivers. However, funding is not properly distributed, and local governments often have trouble keeping up with demand. Bureaucratic procedures can also make it difficult for those living with dementia to access care in a timely manner.

Calls to Action

Create a federalized, consolidated system for managing and overseeing the diagnosis, treatment, and care while regions allocate necessary resources to equalize the dementia paradigm across Spain

To overcome regional and demographic divides in access to diagnosis, care, and treatment, the national government must develop a consolidated system to oversee and manage the delivery and availability of Alzheimer's disease and dementia programs. To improve disease monitoring, regional disparities must be mitigated and a federally integrated plan for data collection must be implemented. To ensure Alzheimer's disease and other dementia needs are equitably addressed, the federal government must enact mandates to cover relevant procedures, such as multi-biomarker testing. Regional governments must play their part in changing dementia care in Spain by addressing the fragmented detection and early diagnosis infrastructure and working to ensure dementias receive commensurate funding.



Streamline and expand the remittance and financial aid system for informal caregivers

In Spain, existing incentives for informal caregivers are too limited in scope, and bureaucratic inefficiencies further prevent these programs from providing meaningful assistance to those living with dementia and their loved ones. Informal carer incentives need to be reformed to make them more accessible and more aligned with the costs of delivering care.

Prioritize investments in Alzheimer's disease and other dementias research and innovation

Research on Alzheimer's disease and other dementias receives little funding in Spain. Policymakers need to direct investments towards R&D programs to stimulate innovation in developing new tools, techniques, practices, and treatments, which will be critical to reducing overall disease costs and improving care quality. Furthermore, this includes a needed focus on the social dimension of living with dementia, which should consider the influence of dementia on daily life and how best to increase quality of life for those living with dementia.



Sweden

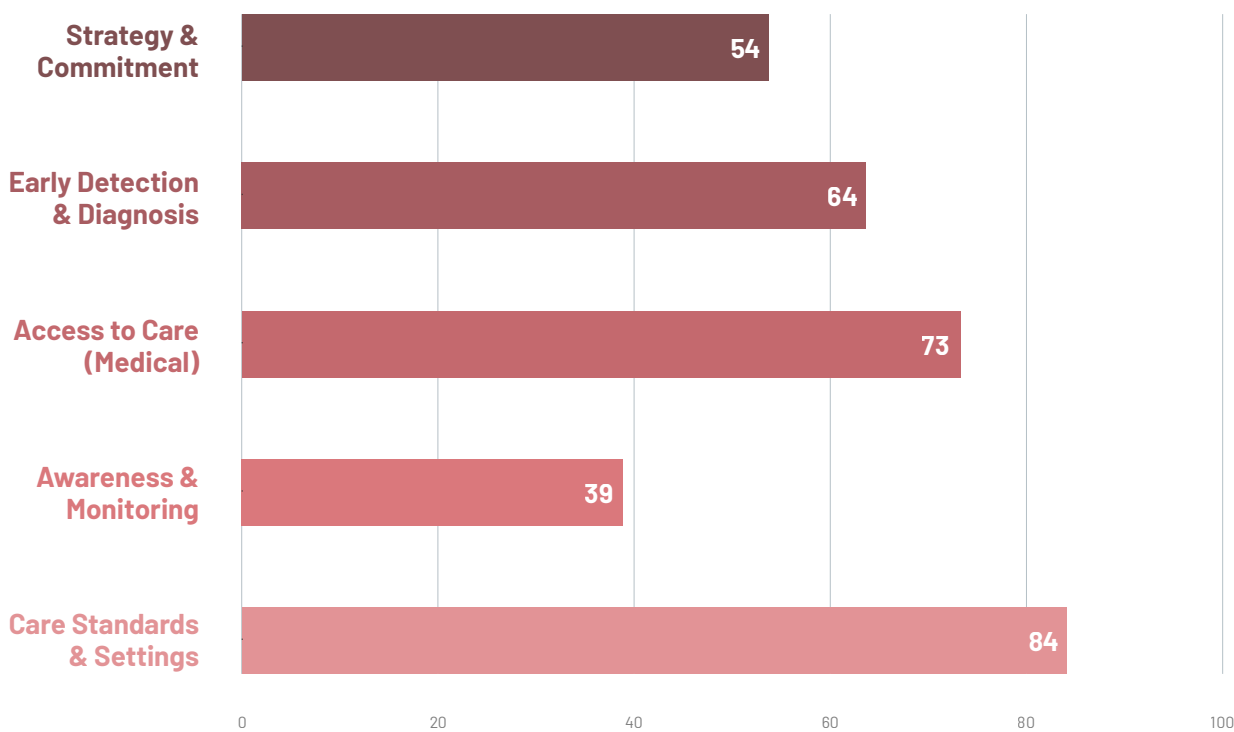
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Overview

Sweden's national plan (2018-2022) is centered on care management and organization, emphasizing the need for person-centered care, family caregiver support, and carer education.³⁰⁷ Municipalities play an important role in funding and implementing care, providing those living with Alzheimer's disease a wide range of services including day-time activities and in-home care.³⁰⁸ However, studies have found that national guidelines have not been fully integrated within municipal level care services.³⁰⁹ And, in spite of local efforts, informal carers still bear the brunt of care-related costs, estimated between €6.8 billion and €14.1 billion annually.³¹⁰

Sweden Category Assessments





Country	Sweden
AD or Dementia plan	Yes: National Dementias Strategy, (2018-2022)
Number of people living with Alzheimer's and other dementia (est.)	168,243 / (1.66%) / (2019) ³¹¹
Awareness raising	Yes: Limited Government Engagement (General dementia stigma & risk reduction campaigns)
Total Annual Costs	€578.1 million (Informal Care, 2008) ³¹² €6.30 billion (AD Population, 2012) ³¹³

The Swedish research landscape is very robust for Alzheimer's disease and other dementias. The Karolinska Institutet leads and coordinate research at the forefront of the fight against Alzheimer's disease, with projects ranging from risk reduction to the role of technology in supporting daily activities for those living with Alzheimer's disease.³¹⁴ At Lund and Gothenburg Universities, researchers have helped shorten the diagnostic process for Alzheimer's disease by working to validate the use of blood tests.³¹⁵ Furthermore, Queen Silvia, an Honorary Ambassador for ADI, has not only led awareness efforts but also pushed for innovations in care.³¹⁶ In addition to creating the Queen Silvia Nursing Award, which awards best practices in dementia care,³¹⁷ Queen Silvia has also recently partnered with IKEA to design more affordable homes for those with Alzheimer's disease.³¹⁸

Category Assessments

Strategy & Commitment

Sweden's National Dementias Strategy represents years of development and planning, yet still fails to address many aspects of Alzheimer's disease and other dementias and provides no guidance on funding. The plan is centered on how to treat older persons post-diagnosis, rather than providing programs for more nuanced issues (addressing children of diagnosed parents, younger persons, risk reduction, and MCI). This framing

means funding is provided under the auspices of elder programs, making it more difficult for lawmakers to enact policies specific to Alzheimer's disease and other dementias.

Early Detection & Diagnosis

In Sweden, large hospitals are generally well-equipped to detect and diagnose Alzheimer's disease. At the primary care level, however, staffing limitations, along with limited access to training and tools, inhibit GPs from making necessary referrals, either to memory clinics or other specialists. In Sweden, GPs are not empowered to make a diagnosis on their own. Though technically people can demand a diagnostic referral, experts suggest many are reluctant to do so as GPs are perceived as authorities.³¹⁹ Unfortunately, most people living with Alzheimer's disease are not diagnosed until the middle or late stages. Moreover, wait times for diagnosis at memory clinics can take 6 to 9 months. The new clinic at the Karolinska Institutet, on the other hand, has the capability to provide diagnosis within two weeks, utilizing a range of tools, including brain scans, CSF testing, and more. Furthermore, Professors Hansson, Blennow, and Zetterberg are developing a blood test methodology at Lund and Gothenburg Universities, which they hope can be used in primary care settings, an effort that could reshape the Alzheimer's disease diagnostic landscape.³²⁰

There are, however, many societal issues that hamstring early detection and diagnosis efforts. According to experts, people lack information regarding diagnosis and detection, and the implications of a diagnosis. Many also fear the possible repercussions of a positive diagnosis, including the loss of autonomy through the possible removal of driving or hunting licenses. Equally, the stigma of Alzheimer's disease also acts as a barrier to diagnosis. While efforts have been made to reframe Alzheimer's disease as a middle-aged disease and encourage earlier testing and screening to allow for earlier treatment, many are still reluctant to enter the diagnostics pathway.

The current lack of treatments beyond symptomatic therapies can also lead GPs to question the need for a formal diagnosis.³²¹ Specialized training is available for healthcare professionals, but it is limited and not mandatory. Many GPs lack knowledge about Alzheimer's disease and are unable to properly provide referrals. Memory clinic staff report that many GPs cannot effectively screen persons for dementia; however, GPs in areas with older populations were more likely to have greater exposure to Alzheimer's disease and greater sensitivity to its symptoms.³²² Promisingly, the government's pandemic response has included digital transformation for diagnosis and screening, though efforts to train GPs to provide neurodegeneration diagnosis and screening remotely are ongoing.³²³

Access to Care (Medical)

Pharmaceutical therapies for Alzheimer's disease are available consistently across Sweden and are generally fully reimbursed.³²⁴ Yet, non-pharmacological forms of treatment for behavioral and psychological symptoms (e.g., music therapy) are available in only a handful of municipalities and only used in the later stages of the

disease.³²⁵ On the other hand, average and maximum wait times for specialists are among the lowest in the countries assessed.³²⁶ To alleviate the burden on a strained GP workforce, efforts are also underway to increase training opportunities for nurses.³²⁷ Municipalities must also strategize on how best to reach those living with dementia in more rural areas, as it has been shown that approximately half (46%) of those living with Alzheimer's disease currently live alone.³²⁸

Awareness & Monitoring

While national campaigns for Alzheimer's disease advocacy have been run, the responsibility for these efforts falls to small organizations like the Alzheimer Foundation of Sweden, which is funded almost completely through private donations. Unfortunately, the government has not made targeted investments in the national advocacy efforts needed to help effectively eradicate stigma.

While Sweden has no Alzheimer's disease-specific registry, its national registry for dementia (SveDem) is very comprehensive with wide coverage and helps to inform policy and evaluation of services.³²⁹ The Karolinska Institutet has attempted to consolidate more general dementia and cognitive impairment data, though there is more work to be done for MCI and early onset related data.³³⁰ SveDem has grown to include data from all memory clinics in the country and about 75% of primary care facilities.³³¹ Nursing home participation is also on the rise, however, experts worry some GPs may experience "registry fatigue" and fail to register all persons living with dementia.³³²



Care Standards & Settings

The Karolinska Institutet, in conjunction with the private Sophia Hospital, issues Silvia Care certificates to certify caregivers and healthcare professionals caring for persons with a range of conditions, including Alzheimer's disease and other dementias.³³³ Experts cited that because employers do not currently pay "Silvia certified" employees higher, the Alzheimer's Foundation has funded these certifications to simply ensure the workforce is better trained.³³⁴ That being said, demand for advanced care certificates is growing, with many facilities internationally now seeking Silvia-accreditation.³³⁵

Less than half of Sweden's municipalities provide institutional care specifically for those with dementia.³³⁶ While there are orderly care pathways for diseases such as for cancer, there are none for Alzheimer's disease and other dementias.³³⁷ The lack of strong case management frameworks and rigid care pathways means that those living with dementia and their loved ones are susceptible to being overlooked or simply lost amidst the complexity of the current landscape.³³⁸

Make Alzheimer's disease and other dementias funding distinct from broader investments in elder care

Currently, Alzheimer's disease and other dementias funding falls under broader investments in elder care. Funding should be more targeted and tailored to the specific needs of this population.

Expand and consolidate data for a better functioning national registry

The government should work with the Karolinska Institutet to strengthen the existing SveDem registry by expanding the scope of data collected and establishing comprehensive systems to capture dementia data. Bolstering these systems will enable policymakers to optimize allocation of limited resources and better evaluate the efficacy of Alzheimer's disease programs.

Calls to Action

Fully integrate national plan guidelines within local and municipal care services

Sweden's national plan has not been fully integrated into the existing local and municipal care services infrastructure. The central government must prioritize harmonizing NAP measures within these structures to improve in the delivery of services to those living with dementia, their families, and caregivers.



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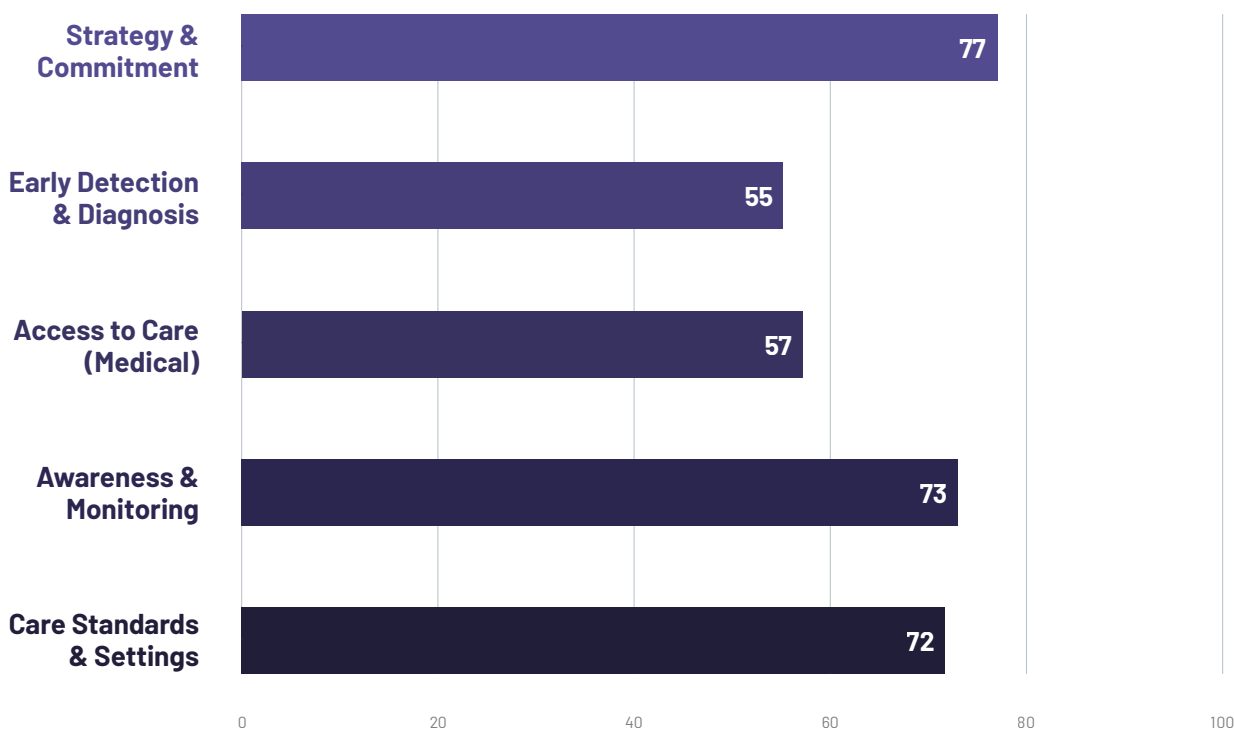
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The United Kingdom

Overview

Over one million people in the UK will be living with Alzheimer's disease or other dementias by 2024.³³⁹ The total cost of care for those living with dementia is expected to reach almost £100 billion (€116 billion) by 2040.³⁴⁰ Two-thirds of care costs are paid by those living with dementia and their families, with informal care costing £13.9 billion (€16.3 billion) per year and largely uncovered social care costing £15.7 billion (€18.4 billion) per year.³⁴¹ The four countries that constitute the UK have their own dementia strategies: England—Dementia Challenge 2020, Scotland—the 3rd National Dementia Strategy, Wales—Dementia Action Plan 2018-2022, and Northern Ireland—Dementia Together NI 2013-2017.³⁴² While these plans are similar in structure and approach, they differ in scope and robustness. Scotland's plan is much more focused on innovative care integration, approaches, and services than

The United Kingdom Category Assessments



Country	The United Kingdom
AD or Dementia plan	England —Concluded: Challenge on Dementia, (2015-2020) Scotland —Concluded (under review): National Dementia Plan, (2017-2020) Northern Ireland —Yes: Regional Strategy, (2011) Wales —Yes: Dementia Action Plan, (2018-2022)
Number of people living with Alzheimer's and other dementia (est.)	1,031,396 / (1.56%) / (2019) ³⁴³
Awareness raising	Yes: (General dementia stigma & risk reduction, lifestyle, and Alzheimer's-specific campaigns)
Total Annual Costs	£34.7 billion (€40.38 billion)(Total Cost of Illness, 2019) ³⁴⁴ £13.9 billion (€40.38 billion)(Informal Care, 2019) ³⁴⁵
Annual Nursing Home Care Cost per Person	£45,530 (€52,987) (2017, in 2019-2020 £s) ³⁴⁶

the others, including commitments to providing diagnosed persons with technologies that can safeguard their independence and health.³⁴⁷ On the other hand, the English and Welsh plans include monitoring and evaluation frameworks which have been highlighted by others as best practices.^{348,349} This report focuses mostly on the Alzheimer's disease and other dementias landscape in England and Scotland (representing approximately 93% of the UK's population).

Previously Prime Minister Cameron enacted Dementia 2020, an ambitious initiative to make England a leader in providing dementia care and support and in facilitating critical research on dementia and other neurodegenerative diseases. More recently, the current government has committed to doubling the funding for dementia research and to finding "a cure for dementia."³⁵⁰ Though support for research on dementias in the UK is historically strong, it is not commensurate with the impact of these diseases.³⁵¹ Despite dementias costing the UK an estimated £26 billion (€30 billion) annually, research funding amounts to about £74 million (€86 million)³⁵²—a cost to research disparity of 350:1.

The UK has surprisingly low ratios of relevant specialists to potential numbers of persons living with dementia compared to other Western and Northern European countries.³⁵³ Wait times are also longer, which undermines efforts by the government to effectively treat all patients in a timely manner.³⁵⁴ Community-provided services remain a crucial part of care, especially for early onset Alzheimer's disease. In the UK, organizations like the Young Dementia Network Steering Group help guide local care commissions to implement best practices.³⁵⁵ Across the UK and particularly in Scotland, there is a clear emphasis on community interventions not only for those living with dementia but also for caregivers.³⁵⁶ In the UK, a self-directed support system has been implemented in recent years, allowing those living with dementia more choice and more flexibility to choose from a list of pre-vetted care providers best suited to their needs.³⁵⁷

Category Assessments

Strategy & Commitment

The UK has had very visible political champions for Alzheimer's disease and other dementias in recent years, including former Prime Ministers Cameron and May, Prime Minister Boris Johnson, members of the All-Parliamentary Group on Dementia, and members of the Scottish and Welsh parliaments.^{358,359,360} The NHS has an appointed National Clinical Director for Dementia and Older People's Mental Health, and dementia programs are overseen by the Minister for Care, Helen Whately, MP, at the Department of Health and Social Care.^{361,362} In recent years, the government has demonstrated a strong commitment to Alzheimer's- and dementia-friendly communities, both in England and in Scotland.^{363,364} The UK is heavily engaged internationally, participating in Alzheimer Cooperative Valuation in Europe and Joint Action on Dementia 2.³⁶⁵ The UK also hosted the drafting of Alzheimer's Europe 2014 Glasgow Declaration.³⁶⁶

Government funding for long-term care initiatives is relatively strong,³⁶⁷ and the government also allocates funds for national Alzheimer's associations' core activities and specific projects and works with third-party organizations and NGO's to jointly fund Alzheimer's Cafes.³⁶⁸ With England's national plan concluded, there is some worry that the government has not committed to a clear next step.³⁶⁹ Though, on the whole, all national plans in the UK have been strongly aligned with the 18 priorities highlighted by Alzheimer Europe.³⁷⁰

Early Detection & Diagnosis

The Alzheimer's disease diagnosis rate in the UK is 61.8% for those aged 65 or older, a slight decline from pre-COVID-19 rates, likely resulting from strained services and patients' fears of entering medical settings.³⁷¹ The UK has fewer memory and early-onset Alzheimer's disease clinics per capita compared to other countries, and a limited number of PET scanners.^{372,373,374} While the use of CSF analysis is reimbursed under the NHS, it is only recommended for initial screening for younger persons with suspected rapidly progressing dementias.³⁷⁵ Relative to its size, the UK had few clinical trials related to Alzheimer's disease in 2020.³⁷⁶

The UK performs well in terms of healthcare professional training and support, though there are some notable gaps. Dementia-specific training for healthcare professionals is extremely variable and is not mandatory across the UK.³⁷⁷ GPs have cited lack of training as a barrier to early diagnosis of pre-dementia MCI and early-stage Alzheimer's disease and other dementias.³⁷⁸ Community Psychiatric Nurses also lack expertise in enacting memory aiding strategies for those living with dementia.³⁷⁹ To address these gaps, Health Education England developed the Dementia Training Standards Framework—knowledge and skills needed by various health and care workers—which was reviewed and updated in 2018.³⁸⁰ However, an audit revealed several weaknesses in the framework and recommended improvements in “pharmacological interventions in dementia care,” “leadership,” and “end of life care.”³⁸¹ In Scotland, the Standards of Care for Dementia in Scotland and Promoting Excellence educational frameworks have been designed to spur needed change and fulfill commitments outlined in the national dementia strategy.³⁸²

Access to Care (Medical)

Surprisingly, the UK has comparatively poor ratios of GPs (77), geriatricians (2), and neurologists (1.1) to patients (per 100,000).³⁸³ Furthermore, the average length of GP appointments in the UK is shorter than in most countries.³⁸⁴ The UK also performs poorly in terms of average and maximum specialist wait times.³⁸⁵ Surveys identify lack of training, lack of Alzheimer's disease competency, and inadequate access to diagnostic tools by GPs as key barriers to timely diagnosis.³⁸⁶

On the other hand, the UK provides good post-diagnostic support to most living with dementia,³⁸⁷ through dedicated Dementia Advisers in England and Link Workers in Scotland, who aid in planning and case coordination.³⁸⁸ However, post-diagnostic support is still too limited, with many persons unable to access it easily.³⁸⁹ Reimbursement policies for Alzheimer's disease-related drugs are generally strong.³⁹⁰ Following only Sweden, the UK not only provides higher levels of reimbursement, but also has lower thresholds to access treatments.³⁹¹

Awareness & Monitoring

Despite a national EHR infrastructure in the UK, there are currently no incentives to encourage healthcare providers and payors to participate in digital transformation and data standardization program.³⁹² The number of over 65 persons with diagnosed dementia is monitored through the NHS' Quality Outcomes Framework, yet the data reported is not homogeneous.³⁹³ While the national plans of England and Scotland call for Alzheimer's disease data to be collected as a part of public health surveillance, the Welsh and Northern Irish plans do not.³⁹⁴ To help collate cohort data for researchers, the Medical Research Council has orga-

nized Dementias Platform UK (DPUK), an initiative that connects the National Institute for Health Research, universities, and industry to build research networks that can improve understanding on "how dementias start."³⁹⁵

Though national plans in the UK call for general dementia campaigns focused on stigma and risk reduction,³⁹⁶ there are no Alzheimer's disease-specific awareness efforts. Alzheimer's disease associations have, however, launched several public and targeted campaigns.³⁹⁷ For example, the innovative film *Small Changes*, created by the Alzheimer's Society, has helped the public and family members better understand the effects of dementia, including possible behavioral shifts.³⁹⁸ The Dementia is Everyone's Business—North Lanarkshire Partnership, coordinated by Alzheimer Scotland, is an initiative that enlists community business to raise awareness and provide services tailored for those living with dementia.³⁹⁹ An equally impactful initiative from the Halton Safeguarding Adults board has brought attention to financial abuses targeting vulnerable older adults with a focus on dementia.⁴⁰⁰

Care Standards & Settings

In the UK, dementia care services are administered by community councils, which are responsible for conducting needs assessments and facilitating a range of institutional, community and in-home care services. Specialized housing and care options are also available to those living with dementia.⁴⁰¹ Councils provide at least one recommended and approved care home provider, which can be contested by the persons applying or their loved ones, should it not seem to meet their needs.⁴⁰² NHS indirectly funds care services by directing monies to the respective councils. Demand for services have increased in recent years, but the supply of services is insufficient to meet current and future

needs.⁴⁰³ Though several in-home services (homecare /personal hygiene, meals on wheels, home help, adaptations to the home, tele alarm) are fully or partially covered by the government in Scotland, in England the majority of these services are paid for out-of-pocket, with the remainder being partially subsidized.⁴⁰⁴ Prime Minister Johnson promised to address the high costs of social care and adjusted provisions for informal caregivers, but not government action has been taken to date.⁴⁰⁵

Relationship-based care is widely available and popular under the NHS, and has been implemented and supported by national policies.⁴⁰⁶ Incentives to encourage the use of RBC are also in place.⁴⁰⁷ In fact, all national plans in the UK outline initiatives to increase innovative care models and services.⁴⁰⁸ While the use of assistive technologies/ICT solutions and tele-alarms in the UK is insufficient, telemonitoring is more established and widely integrated than in most countries.⁴⁰⁹ The UK has policies in place to promote telemedicine and protect data.⁴¹⁰ National policies in the UK seek to support caregivers through the 2018-2020 Carers Action Plan,⁴¹¹ yet these efforts have only reached a minority of caregivers.⁴¹² Despite the rise in informal carers, only Scotland runs a working group for these caregivers.⁴¹³ The 2014 Care Act was intended to support informal carers, but this legislation has been poorly adopted,⁴¹⁴ which has led some experts to propose new solutions, such as assistive technologies to enable greater freedom for both informal carers and their loved ones. These innovative approaches could be better integrated to support informal carers, providing them with tools and strategies to enhance their wellbeing.⁴¹⁵

Calls to Action

Enact a comprehensive plan to address labor challenges in the formal care sector

High turnover and burnout rates, combined with poor pay and challenging working conditions, are destabilizing the UK's formal caregiver sector. To guarantee the availability of care for those living with Alzheimer's disease and other dementia, the government must strengthen the caregiving pipeline and attract the next generation of carers to the workforce. This will require a more developed career pathway, increased attention to training and certification, and a global perceptual shift for caregiving.⁴¹⁶

Make training and education pathways more robust to combat lower specialist ratios

The UK needs more specialists to handle the growing needs of those living with Alzheimer's disease and other dementias. The government must pursue measures to make training and education more attractive, affordable, and accessible to specialists in these areas, which is necessary to maintain high levels of care and improve diagnosis rates.

Redress reimbursement policies for diagnostic procedures and social care

In the UK, not all diagnostic procedures are covered, making it difficult for some living with dementia to secure a diagnosis. Policymakers should reform reimbursement policies to ensure diagnostic tools are universally available. To ensure that those living with dementia and their families are able to receive the care and support necessary, the government should reform



social care policies to reduce burdens on informal carers and increase the use of more cost-effective and desirable community-centered care services.⁴¹⁷

Develop an updated national dementia strategy for England

While Wales and Northern Ireland still have active plans and Scotland is reviewing their recently concluded one, the next step for English dementia policy is unclear. As the most populous nation with the highest dementia prevalence in the UK, England must quickly update its previous plan or develop a new one. A national plan is needed to direct resources, guide implementation, and set achievable targets and goals for Alzheimer's disease and other dementias.



The European Union

Category Assessments

Strategy & Commitment

In 2008, European Commission President Barroso collaborated with French President Sarkozy to unveil the “Communication on a European initiative on Alzheimer’s disease and other dementias.” This pan-European project focused on improving early diagnosis of dementias, enhancing research coordination, sharing best practices, and protecting the dignity and rights of those living with dementia. Following this, the Commission released the “Proposal for a Council Recommendation on measures to combat neurodegenerative diseases” in 2009, which solicited more cooperation through a joint programming initiative, the JPND.

By 2011 the EU Joint Programme—Neurodegenerative Diseases Research (JPND) had developed a strategic research agenda and had established the largest global research effort for the disease group to date.⁴¹⁸ Additionally, the 2009 Communication precipitated two further initiatives: ALCOVE (2011–2013) and DEM2 (2016–2019). ALCOVE worked to develop operational criteria to facilitate more timely and earlier diagnosis based on best practices and national level evaluations.⁴¹⁹ DEM2 sought to gain consensus and expertise on the most effective approaches for providing improved diagnosis and post-diagnosis support to those living with dementia or other neurocognitive disorders.⁴²⁰ Further, the private-public Innovative Medicines Initiative (IMI), which was supported by the European Commission, has been critical in funding Alzheimer’s disease and other dementia research. Financed by €435 million in grants, IMI has supported over 20 distinct initiatives (representing approximately 10% of its budget) over the past 10 years,⁴²¹ ranging from gene-specific research to big data approaches to enable predictive case finding.⁴²²

In response to findings from these initiatives, the Council of the EU released two subsequent documents: “Council conclusions on public health strategies to combat neurodegenerative diseases associated with ageing and in particular Alzheimer’s disease” (2018) and “Council conclusions on supporting people with dementia: improving care policies and practices” (2015). Both sought to improve the coordination, cooperation, and sharing of best practices between Member States, experts, associations, and NGOs. Likewise, the 2016 European Parliament’s declaration on the prioritization of a European Dementia strategy sought to spur an EU-level strategy to combat rising rates of Alzheimer’s disease

and other dementias.⁴²³ Following this, the Governmental Expert Group on Dementia was created by the European Commission to aid in the development of dementia-related legislation and policy,⁴²⁴ only to be dismantled in 2018, and then resuscitated by Alzheimer Europe. The EU's 2021 Green Paper for Ageing is hopefully indicative of greater commitment to age-related issues, such as Alzheimer's disease, in the coming years.⁴²⁵

Within the European Parliament, the European Alzheimer's Alliance (EAA), founded in 2007 by Alzheimer's Europe, now has almost 100 members from 26 Member States. The Alliance—comprised of MEPs and the Brain Mind Pain group and supported by organizations like the Pain Alliance Europe and the European Federation of Neurological Associations (EFNA)—provides a space for discussion of Alzheimer's disease and related diseases topics. The group works to help those living with brain, mind, and pain disorders and to reduce stigma and discrimination, ensure equal access to treatment, and empower those living with dementia to increase engagement with policymaking and R&D.⁴²⁶

Early Detection & Diagnosis

Funded partially by the EU through the IMI, the Models of Patient Engagement for Alzheimer's Disease (MOPEAD) project is a public-private initiative focused on improving early diagnosis.⁴²⁷ The project partners run several regional sites across the EU, including in Germany, Slovenia, Spain, and Sweden, which seek to develop and assess models for the early detection of Alzheimer's disease.⁴²⁸ Currently, MOPEAD researchers are evaluating four distinct models: an online neuropsychological test; a neuropsychological test at a memory clinic; a neuropsychological test given by GPs; and a neuropsychological test given to persons with type-2 diabetes.⁴²⁹ The EU and the European Federation of

Pharmaceutical Industries and Associations' (EFPIA) Innovative Medicines Initiative (IMI) have contributed over €2 million to the project thus far.⁴³⁰ Additionally, the EU's Horizon 2020 program has provided funding to private sector partners, such as SensApp, to create other innovative early diagnosis tools. SensApp is hoping to use EU funding to further develop an ultra-sensitive system for detecting Alzheimer's disease biomarkers within plasma, allowing for quicker and non-invasive screening.⁴³¹

Completed in October 2020, the IMI funded European Prevention of Alzheimer's Dementia (EPAD) project was a cross-sectoral public-private initiative with 39 participating organizations.⁴³² EPAD focused on facilitating earlier and more targeted interventions, via improved early-staged identification of Alzheimer's disease.⁴³³ Another active IMI initiative, the Amyloid Imaging to Prevent Alzheimer's Disease (AMYPAD) project, is focused on improving PET scan diagnosis tool capacity and improving early diagnosis rates by uncovering more pre-symptomatic details about the disease.⁴³⁴

Access to Care (Medical)

Developed as a result of detailed discussions with those living with dementia, experts, regulators, pharmaceutical industry partners, and academics, the European Medicines Agency (EMA) established new guidelines for clinical trials of investigational products related to Alzheimer's disease in 2018.⁴³⁵ The new guidelines will allow investigational products to be tested on pre-symptomatic persons and encourage the qualification of early-stage biomarkers for Alzheimer's disease.⁴³⁶

Awareness & Monitoring

Through the publication of the research, the ongoing MOPEAD project has sought to inform the public on risk mitigation measures, providing expertise about steps that people can take to reduce the risk of Alzheimer's disease.⁴³⁷ The MOPEAD website highlights publications on risk reduction for the general public and also documents public awareness and education campaigns for use by Alzheimer's disease and other dementias associations.

Care Standards & Settings

In 2013, the ALCOVE initiative provided crucial recommendations to both European policymakers and healthcare professionals on best practices in care.⁴³⁸ These included how best to provide care for those with behavioral and psychological symptoms and how to fairly navigate the legal and ethical concerns regarding advance directives and competency assessments.⁴³⁹

One of ALCOVE's central objectives has been reducing the risk associated with the use of psychotropic drugs and ensuring best practices for prescription and delivery of these medicines.⁴⁴⁰ The RADAR-AD project, an IMI initiative with research institutions, universities, and private healthcare firms as partners, is leveraging mobile technologies to provide remote, non-invasive monitoring of those living with Alzheimer's disease.⁴⁴¹ The technology allows tracking of digital biomarkers that can be used to develop tailored care strategies, while also keeping stakeholders informed of the person's wellbeing.⁴⁴²

Select Case Studies



ABOARD: New Consortium in the Netherlands

The newly adopted ABOARD-project is a Dutch effort to combat the rising prevalence of Alzheimer's disease in the Netherlands.

A private-public partnership with over 30 participants, including insurers, hospitals, charities, and established companies like Philips, the project is closely aligned with the Netherlands' National Dementia Strategy 2021-2030. A total of €8.8 million has been allocated to implement the initiative over the next five years.

ABOARD reflects a concerted effort to improve Alzheimer's disease detection efforts, increase awareness and implement risk reduction interventions. The consortium leverages new developments in the field to prepare for a future in which Alzheimer's disease is stopped before it manifests clinically. The initiative focuses on early diagnosis and personalized risk profiles to predict disease trajectories, paving the way for targeted treatment.



UNDERSTAND TOGETHER CAMPAIGN: Embracing People Living with Dementia in Ireland

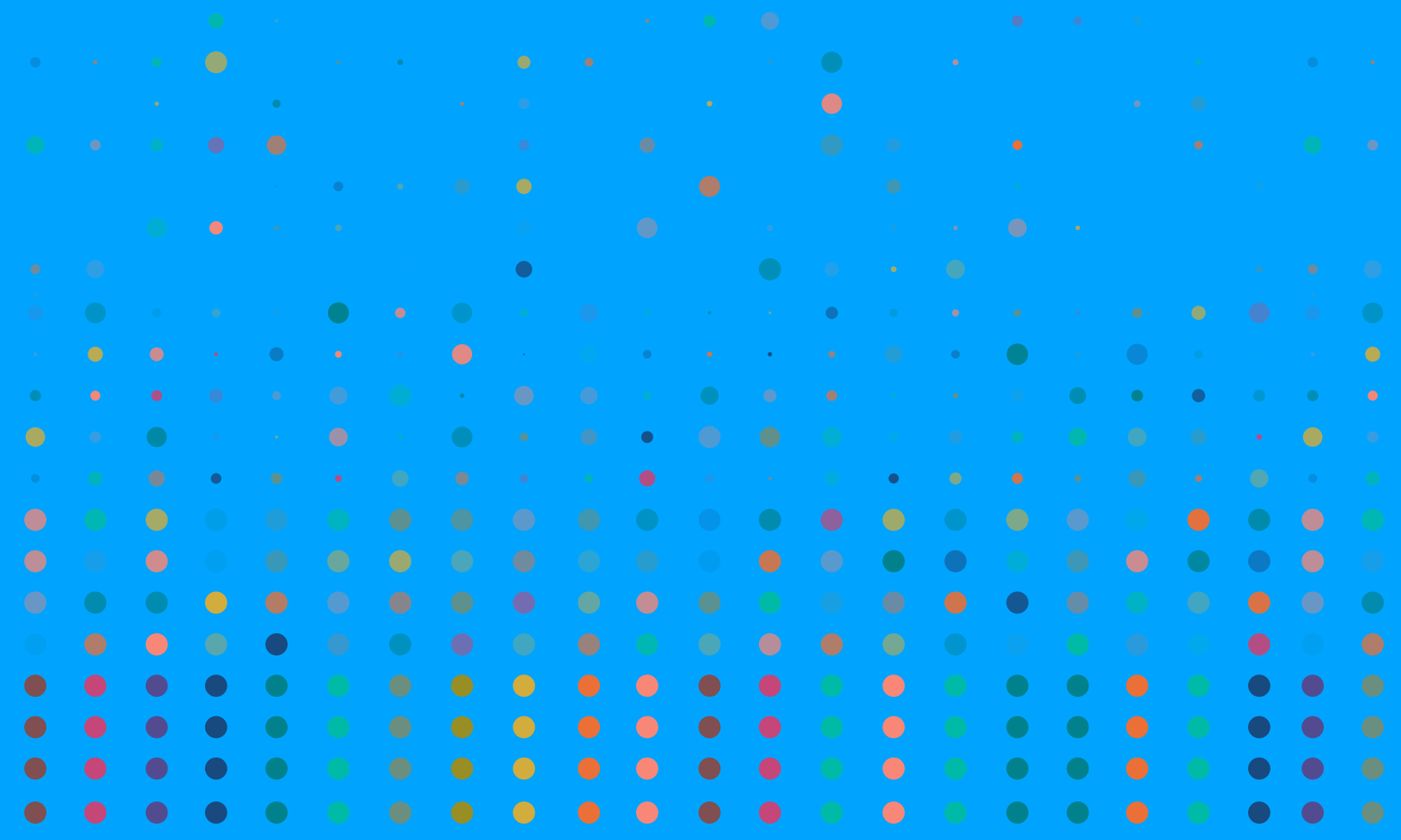
The Understand Together Campaign, funded by the Irish government and The Atlantic Philanthropies, is a key initiative of the National Dementia Strategy and is led by the Health Service Executive (HSE).⁴⁴³

Much more than a traditional awareness and information program, the campaign provides public support for those living with dementia and their families through the support of a dementia inclusive Ireland.⁴⁴⁴ Understand Together encourages new organizations and communities to find practical ways to improve the lives of those living in Ireland, while also increasing the visibility of the many critical local services and programs already provided.⁴⁴⁵ The approach has led to investments in both existing and new dementia-specific programs, with a focus on stakeholder expansion to include more private sector partners and community members, thereby working to increase advocates and build nationwide momentum.⁴⁴⁶

Understand Together has already made a profound impact, inspiring many to contribute to making their communities more dementia inclusive and to protecting the human rights of those living with dementia.⁴⁴⁷ “Community Champions” of the program by no means think their work is done. Facilitators understand that a sustained approach is most likely to erode stigma and ensure dementia is continually prioritized by government.⁴⁴⁸ Furthermore, Understand Together is designed as an iterative and flexible campaign with a solution-oriented focus, which allows adjustments and adaptations to the realities on the ground.⁴⁴⁹ The project is underway to make Ireland not only dementia friendly but dementia inclusive as well, an important distinction which should be pursued by all countries wishing to enshrine the dignity of those living with dementia.



Concluding Remarks



Alzheimer's disease and other dementias rates, related cost, and care needs are increasing rapidly

Across Europe—and globally—the prevalence of Alzheimer's disease and other dementias is on the rise as our populations continue to age and experience greater longevity. By 2050, almost 20 million people across Europe will be living with dementia.⁴⁵⁰ Providing support for these individuals will require a more comprehensive infrastructure for detection, monitoring, diagnosis, treatment, and care, along with more advanced legislation and policies for effectively protecting informal carers and the rights of persons living with dementia and facilitating greater access to services and treatments. As the need for caregivers increases, there will need to be an increased effort by governments to provide and fund training for informal and formal carers alike.

Yet, initiatives to diagnose, treat, and care for those living with dementia remain largely underfunded

Despite these growing needs, programs to ensure diagnosis, treatment, and care are severely underfunded in most countries, while existing initiatives are being poorly implemented. Key facets of the challenge, such as early detection and the stigma associated with the

disease, remain regrettably overlooked by many governments. In doing so, decision makers have limited the efficacy of current and future interventions.

Progress must be made to ensure that newfound longevity is paired with healthy aging

As we commence the UN Decade of Healthy Ageing, all stakeholders must evaluate the needs of those living with Alzheimer's disease or other dementias and their loved ones to ensure that the benefits of longevity are preserved for this growing population. Pervasive discrimination and stigma have for too long treated signs of cognitive impairment as natural signs of aging, and considered Alzheimer's disease and other dementias as untreatable, monolithic conditions, which has only compounded the difficulties faced by those living with dementia and their loved ones. European governments—which have demonstrated excellence in both promoting innovation and improving health system quality—must now show leadership in fundamentally rethinking how we diagnose, treat, and care for those living with Alzheimer's disease.



Appendix A

Data & Metrics

[Click here to view scoring breakdown.](#)



Appendix B

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ABOUT THE GLOBAL COALITION ON AGING

The Global Coalition on Aging (GCOA) aims to reshape how global leaders approach and prepare for the 21st century's profound shift in population aging. GCOA uniquely brings together global corporations across industry sectors with common strategic interests in aging populations, a comprehensive and systemic understanding of aging, and an optimistic view of its impact. Through research, public policy analysis, advocacy, and strategic communications, GCOA is advancing innovative solutions and working to ensure global aging is a path to health, productivity and economic growth.

ABOUT ALZHEIMER'S DISEASE INTERNATIONAL

Alzheimer's Disease International (ADI) is the international federation of over 105 Alzheimer and dementia associations from around the world, in official relations with the World Health Organization. ADI's vision is prevention, care and inclusion today, and cure tomorrow. ADI believes that the key to winning the fight against dementia lies in a unique combination of global solutions and local knowledge. As such, it works locally, by empowering Alzheimer and dementia associations to promote and offer care and support for persons with dementia and their care partners, while working globally to focus attention on dementia and campaign for policy change from governments.