

# Dementia as a European Priority

A policy overview  
2020



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# 1. Preface



As Alzheimer Europe celebrates 30 years since its establishment as Europe's umbrella organisation for dementia, we have been reflecting on our work and achievements over the decades, mapping out how the organisation has grown over that time, contributing to the policy and research discourse.

It is evident that across the European Commission, Council and Parliament, there has been a growing awareness and acknowledgement of the challenge faced by countries as the number of people living with a diagnosis of dementia continues to grow, as does the need for coordinated action at the European level to address it.

Across the health, social and research fields, we have seen a number of initiatives and projects which have aimed to improve the lives of people living with dementia. These initiatives have spanned the whole spectrum, from research into the causes and mechanisms of the diseases leading to dementia, the search for disease-modifying or preventative treatments to projects aimed at improving care practices and the daily lives of people living with dementia and their carers.

In parallel, Alzheimer Europe has campaigned along our members for the prioritisation of dementia, given a strong voice for people with dementia at a European level, provided opportunities and platforms for the exchange of knowledge and good practices, contributed to dozens of EU dementia research projects.

It is without a doubt that substantial progress has been made in the past 30 years, but dementia still is not given the priority it deserves, considering the number of people affected, the impact it has on people affected and their families and the financial cost to healthcare systems and budgets.

We are now at a critical juncture in the policy context of dementia at an EU level. As the EU is on the cusp of finalising its new programmes of work for the next seven years, the COVID-19 pandemic has forced a fundamental rethink of our policy priorities as a society.

During the COVID-19 crisis, the precarious position of people with dementia, carers and those working in the field of dementia has been further exposed. People with dementia and their carers have experienced a particularly difficult set of circumstances during the pandemic, as the support and connections which are so vital to maintaining the health and wellbeing of individuals living with dementia, have been reduced or halted. The pandemic has shown just how quickly progress can be halted or lost.

With the pandemic, communicable diseases and vaccines dominating discussions at an EU level, there is a real danger that conditions such as dementia will become deprioritised. If this happens, we risk losing, in the space of months, progress which has taken years to build.

For this reason, Alzheimer Europe presents this timely report to recall some of the progress achieved to date and clear recommendations for future priorities, which will be the focus of our work going forward.

## Jean Georges

Executive Director  
Alzheimer Europe

## 2. Introduction

Alzheimer Europe has campaigned for a number of years for dementia to be prioritised, both at a European and national level, across the fields of health, research and social policy. This report aims to provide an overarching and high-level overview of the current policy context in relation to dementia, examining the most relevant and high-profile actions of recent years, reflecting:

- The work of Alzheimer Europe and the European Dementia Movement
- Different actions and initiatives of the EU
- Progress and ongoing challenges made at a national level
- The outstanding challenges that must be addressed.

Section three identifies Alzheimer Europe's policy work in recent years, outlining the rationale of the approach and setting the foundations for the future of dementia policy. Additionally, the report highlights the work Alzheimer Europe has undertaken in gathering evidence to strengthen the case for dementia to be prioritised, as well as the steps taken to drive this agenda forward at a European level.

Section four outlines the challenges and the future implications for European countries if societies do not adequately prepare for the increasing number of numbers of people who are likely to develop dementia. As a result of the societal cost of dementia, as well as the rising numbers of people living with the condition, Alzheimer Europe has argued that policy frameworks must shift the way in which care, support and treatment of people with dementia and carers is delivered, from the point of diagnosis through to end of life. This section also examines the prejudice and stigma which are still associated with the condition.

Section five examines the previous actions of European institutions in relation to dementia, including declarations of support, such as the inclusion of dementia within the conclusions of the rotating Presidency of the Council of the European Union and Written Declarations of the European Parliament. Additionally, the section highlights EU-funded initiatives such as the EU Joint Actions on Dementia and research projects.

Section six focuses on progress at a national level, outlining the extent to which dementia has been prioritised within countries across Europe, highlighting how an increasing number of countries have developed dementia strategies focused on addressing the challenges faced by dementia.

Finally, section seven responds to the gaps identified throughout the report and provides recommendations to the European Union and national governments for next steps for dementia policy in three areas: health, research and social policy.



### 3. Alzheimer Europe's approach to improving dementia policy

Alzheimer Europe's approach to improving dementia policy across Europe has been one of constructive engagement with its national members, European policy and decision makers, researchers and other relevant stakeholders.

Key to this approach is ensuring that Alzheimer Europe adds value to the ongoing policy work of the EU and national organisations, building a strong evidence base which identifies good practice and highlights areas for improvement. As part of this, Alzheimer Europe works to strengthen the European dementia movement to ensure its members are most effectively able to lobby for change in their countries.

This section provides an overview of some of the key activities of Alzheimer Europe, underlining its approach to prioritising dementia and improving the lives of people with dementia, their families and carers.

#### 3.1 Campaigning for change

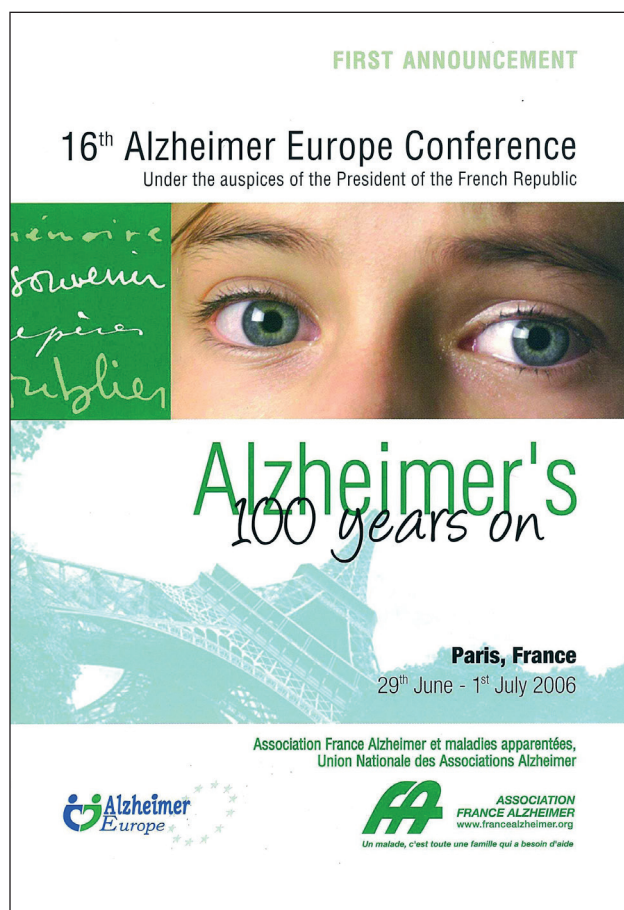
##### 3.1.1 Paris Declaration 2006

To mark 100 years since Alois Alzheimer first described the symptoms of the disease, Alzheimer Europe and its member organisations adopted a Declaration on the political priorities of the European dementia movement at the Alzheimer Europe Conference in Paris in June 2006.

In the "Paris Declaration", Alzheimer Europe calls on European and national policy makers to prioritise Alzheimer's disease and other forms of dementia.

The Declaration focused around four key areas related to dementia, outlining:

- Public health priorities
- Research and medical priorities
- Care and social support priorities
- Legal and ethical priorities.



The 16<sup>th</sup> Alzheimer Europe Conference took place in Paris, France, 29 June - 1 July 2006.

### 3.1.2 Glasgow Declaration 2014

Almost a decade later, at the Alzheimer Europe Conference in Glasgow in October 2014, Alzheimer Europe and its member organisations launched an additional call for action, the Glasgow Declaration.

The Declaration called for the creation of a European Dementia Strategy and national strategies in every country in Europe and demanded that world leaders recognise dementia as a public health priority and develop a global action plan on dementia.

Furthermore, signatories to the Declaration committed to fully promoting the rights, dignity and autonomy of people living with dementia. It noted that these rights are universal, and guaranteed in the European Convention of Human Rights, the Universal Declaration of Human Rights, the International Covenants on Economic, Social and Cultural Rights and Civil and Political Rights, and the Convention on the Rights of Persons with Disabilities.

The launch of the Declaration marked the start of a broad campaign in which signatures were gathered from individuals, organisations and policy makers from across Europe. The Declaration was translated into 17 languages and was used by national member organisations as a way to raise awareness and support for dementia as a policy priority within their country.

In total, 11,613 individuals, 206 organisations and 153 policy makers signed the Declaration.

Since this Declaration was launched, many European countries have developed and launched their own national dementia strategies and the World Health Organization (WHO) published its “Global action plan on the public health response to dementia 2017–2025” at the 70<sup>th</sup> World Health Assembly in May 2017.



From left to right: Geoff Huggins, John Laurie, Jeanette Maitland, Henry Simmons and Heike von Lützu-Hohlbein add their signatures to the Glasgow Declaration at the 24<sup>th</sup> Alzheimer Europe Conference in Glasgow, Scotland, 20-22 October 2014.

## 3.2 Building evidence

During this period of time, Alzheimer Europe has gathered and presented evidence across a variety of themes, to build a strong case for the prioritisation of dementia both at a national and European level, as well as to inform and guide the development of policy responses to dementia. Here we present an overview of some of the key work undertaken by Alzheimer Europe in the past five years.

### 3.2.1 Dementia in Europe Yearbooks

The Dementia in Europe Yearbooks are annual publications in which Alzheimer Europe gathers and presents information from a range of sources (including the expertise of our members, online resources and publications etc.), covering a range of subjects. The themes explored over the past five years include:

- 2019 – Estimating the prevalence of dementia in Europe
- 2018 – Comparison of national dementia strategies
- 2017 – Standards for residential care facilities in Europe
- 2016 – Decision making and legal capacity in dementia.

### 3.2.2 Alzheimer Europe Reports

In addition, Alzheimer Europe annually publishes reports examining a range of ethical and practical issues relating to the delivery of services and supports for people with dementia, their families and carers. The themes explored over the past five years include:

- 2020 – Legal capacity and decision making: the ethical implications of lack of legal capacity on the lives of people with dementia
- 2019 – Overcoming ethical challenges affecting the involvement of people with dementia in research: recognising diversity and promoting inclusive research
- 2018 – The development of intercultural care and support for people with dementia from minority ethnic groups
- 2017 – Discussion paper on the possible implications for ethics, policy and practice of recognising dementia as a disability
- 2016 – Discussion paper on ethical issues linked to the changing definitions/use of terms related to Alzheimer's disease

### 3.2.3 Carers survey

In 2017, Alzheimer Europe conducted a study in collaboration with Bangor University and five of its member organisations to better understand the experiences of informal carers about the diagnosis of dementia in five European countries: Czech Republic, Finland, Italy, the Netherlands and the United Kingdom (Scotland).

The findings of the survey demonstrated that significant differences continued to exist between countries. Some of the key findings include:

- Carers reported significant delays in diagnosis as it took an average of 2.1 years to receive the diagnosis

- Identified barriers to a timely diagnosis included professionals failing to identify that anything was wrong and the refusal of the person with dementia to seek help
- 19% of carers and 27.9% of people with dementia did not receive any information at the time of diagnosis.

### 3.2.4 Dementia Monitor

In 2017 and 2020, Alzheimer Europe published its Dementia Monitor publication, which compares the responses of European countries to the dementia challenge and provides a benchmark of national dementia policies. The report does so by scoring countries across 10 areas:

1. Care aspects
  - a. Availability of care services
  - b. Affordability of care services
2. Medical and research aspects
  - a. Treatment-reimbursement of Alzheimer's disease medicines
  - b. Availability of clinical trials
  - c. Involvement of country in European dementia research initiatives
3. Policy issues
  - a. Recognition of dementia as a priority
  - b. Dementia friendly Communities/Inclusiveness
4. Human rights and legal aspects
  - a. Recognition of legal rights
  - b. Ratification of International and European human rights treaties
  - c. Carer and employment support

In addition to being able to highlight differences between countries, Alzheimer Europe was able to identify trends in dementia policies and practice by repeating the exercise three years apart.

## 3.3 Working in partnership

### 3.3.1 The European Working Group of People with Dementia (EWGPWD)



The European Working Group of People with Dementia (EWGPWD) was launched by Alzheimer Europe and its member associations in 2012. The group is composed entirely of people with dementia who are nominated by their national Alzheimer associations. They work to ensure that the activities, projects and meetings of Alzheimer Europe duly reflect the priorities and views of people with dementia. The group operates independently, with members electing their own office bearers and setting an agenda of activities. The Chairperson is also an ex-officio member on the Board of Alzheimer Europe with full voting rights.



The members of the EWGPWD actively participate in Alzheimer Europe's annual conferences and give presentations at the European Parliament. In addition, they contribute to consultations for different European projects in which Alzheimer Europe is involved and to other areas of the organisation's work.

Members of the group have also contributed to research conducted by external organisations, on topics such as outcome measures that are meaningful to people with dementia and their carers, social health and people with dementia as peer-researchers. They attend international events and give media interviews, both in their countries and internationally.



*The first members of the European Working Group of People With Dementia (EWGPWD) meeting at the 23<sup>rd</sup> Alzheimer Europe Conference in St Julian's, Malta, 10-12 October 2013.*

### 3.3.2 European NGO community

Alzheimer Europe constructively engages with the broader European Non-Governmental Organisations (NGOs) community and is a founding member of the European Patients' Forum. More recently, Alzheimer Europe is also a member of the European Disability Forum. In addition, Alzheimer Europe collaborates in coordinated actions in areas of interest such as the EU4Health Civil Society Alliance.

Alzheimer Europe engages with members in a number of areas, to contribute the perspective of persons with dementia and to highlight areas of interest in the areas of health, research and social policy.



### 3.4 Constructive engagement with European and international organisations

In addition to the work Alzheimer Europe undertakes to usefully and meaningfully contribute to the policy discourse around dementia, the organisation also engages with policy makers at a national, European and international level. As part of this work, the organisation holds the following statuses:

- Accredited non-state actor with the WHO's Regional Office for Europe
- Consultative status with the Council of Europe
- Accredited patient organisation with the European Medicines Agency.

#### 3.4.1 European Alzheimer's Alliance



Alzheimer Europe engages with the European Parliament, seeking to ensure that decision-makers are informed about the most pressing issues in relation to dementia and how they can help improve policy at the European level. As part of this work, Alzheimer Europe has cre-

ated the European Alzheimer's Alliance (EAA), which has been active in the European Parliament since 2007. The EAA is a non-exclusive, multinational and cross-party group that brings together Members of the European Parliament to support Alzheimer Europe and its members in making dementia a public health priority in Europe.

The EAA currently has 95 Members from 26 Member States of the European Union and the majority of political groups in the European Parliament.

As part of this engagement, Alzheimer Europe hosts lunch debates three times per year in the European Parliament. Attended by MEPs, researchers, national member organisations, the EWGPWD and industry partners, these debates provide a unique forum for stakeholders to share information, as well as allowing our members to engage with European decision-makers.

#### 3.4.2 European Group of Governmental Experts on Dementia

In summer 2018, the European Commission disbanded its Expert Group on Dementia, replacing all disease-specific expert groups with the Steering Group on Health Promotion, Disease Prevention and Management of Non-Communicable Diseases.

Following discussions between Alzheimer Europe, the Dutch Ministry of Health, Welfare and Sport, the Italian Ministry of Health and the Scottish Government, there was agreement that losing the European Commission Expert Group would be detrimental, as no other platform existed in which national governments were able to exchange knowledge and information specifically related to dementia.

A new group, the European Group of Governmental Experts on Dementia, was therefore brought together for the first time in December 2018, involving government representatives with responsibility for dementia in their countries. In addition, representatives of the European Commission, Organisation for Economic Cooperation and Development (OECD) and the World Health Organisation (WHO) were all invited to participate in the group as observers, with Alzheimer Europe providing the secretariat to the group.

In addition to the discussions and exchanges between members, the group also invites (on an ad-hoc basis) external experts to present on thematic areas relevant to work relevant to dementia policy and practice (e.g. data registries, end of life care etc.)

Since the inaugural meeting of the group in December 2018, the group has continued to meet bi-annually, with additional digital meetings held on an ad-hoc basis, e.g. during the COVID-19.

The group counts 34 countries in its members with the most recent online meeting of the group, in June 2020, having 22 countries attending.



*Members of the European Group of Governmental Experts on Dementia met on 17 and 18 June 2019, Amsterdam.*

### 3.5 Contribution to research projects

Over the past decade, Alzheimer Europe has increased its contribution to EU level research projects where it provides the perspectives of people living with dementia, supports the communication and dissemination activities and contributes to the ethical issues raised by the research.

At the time of writing, Alzheimer Europe is involved in 13 research projects, 12 of which are funded through EU programmes (Horizon 2020 and the Innovative Medicines Initiative) and one by the Luxembourg Fonds National de la Recherche, through its participation in the Joint Programme for Neurodegenerative Diseases Research (JPND).

## 4. Key challenges in dementia policy

The previous section of this report examined some of the areas in which Alzheimer Europe has been active and contributed to the development of policy in relation to dementia. In particular, the knowledge generation through our reports (Dementia in Europe Yearbooks, Dementia Monitor, Ethics Reports etc.) is fundamental to building an evidence base which can affect change, both at a European and national level.

This section outlines some of the key challenges which have been identified through this work and through engagement with national member organisations.

### 4.1 Prevalence of dementia

In determining the most suitable policy responses to a condition such as dementia, a key starting point must be to understand the extent to which the condition affects people.

Over the past three decades, a number of significant pieces of work have been undertaken to estimate the prevalence of dementia at a European level, including:

- EURODEM study in the early 80s (updated in 2000)
- Alzheimer Europe's project European Collaboration on Dementia – EuroCoDe (2006–2008)
- ALCOVE, the 1<sup>st</sup> EU Joint Action on Dementia (2011–2013).

As the most recent of these studies is six years old, Alzheimer Europe recognised the importance of establishing more recent dementia prevalence estimates, using the most up-to-date academic literature on the subject. Therefore this was chosen as the focus of the Dementia in Europe Yearbook 2019.

For both men and women, Alzheimer Europe developed estimates for different age groups. In doing so, it emerged that there had been a reduction in the prevalence of dementia over the past ten years when compared to 2008 estimates. This is likely as a result of the effect of public health campaigns and measures, such as better control of cardiovascular factors (high blood pressure, cholesterol), alcohol reduction, smoking cessation and promotion of physical activity, which address risk factors related to dementia. However, age continues to be a significant risk factor for dementia, as can be seen from the table of age specific prevalence rates of dementia in Europe, as shown in Table 1.

**Table 1: Dementia prevalence by age range (Alzheimer Europe 2019 estimates)**

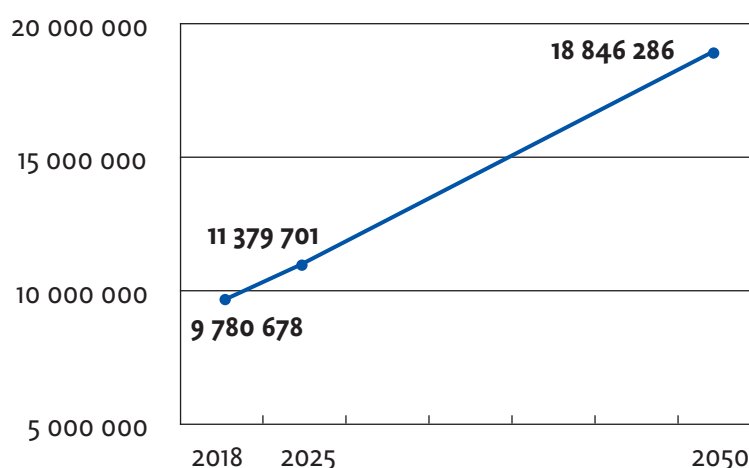
Age Range	Prevalence in men	Prevalence in women
60–64	0.2	0.9
65–69	1.1	1.5
70–74	3.1	3.4
75–79	7.0	8.9
80–84	10.7	13.1
85–89	16.3	24.9
90+	29.7	44.8

Using the 2019 estimates and applying these to UN population data, the number of people living with dementia in the European Union (EU27) is estimated to be 7,853,705 and in European countries represented by Alzheimer Europe members<sup>1</sup>, 9,780,678. This constitutes a significant reduction from 8,785,645 for the EU27 and from 10,935,444 for the broader European region, when applying the EuroCoDe prevalence estimates from almost a decade ago to current population estimates.

In addition to age being a significant demographic factor strongly correlated to dementia, we also note that women continue to be disproportionately affected by dementia with 6,650,228 women and 3,130,449 men living with dementia in Europe.

Finally, the key finding from this report, which illustrates the urgency and importance of prioritising dementia, is the fact that the numbers of people living with dementia will double by 2050, increasing to 14,298,671 in the European Union and 18,846,286 in the wider European region. This increase is due to the rapidly ageing population in Europe, which means that whilst fewer people may be impacted per 100 people in given age ranges, the overall numbers of people living with the condition will continue to rise, with inevitable increases also in the need for care and support from health and social care systems<sup>2</sup>.

**The number of people with dementia in Europe EU27 + Non-EU from 2018 to 2050**



## 4.2 Societal and cost implications associated with dementia

As part of the work undertaken by the EuroCoDe project, a specific focus was given to the societal cost of dementia, estimating how much the total disease burden was for both formal and informal care costs.

The coordinators of the research, Anders Wimo, Karolinska Institutet, Linus Jönsson, I3 Innovus and Anders Gustavsson, I3 Innovus estimated that the total cost of illness of dementia disorders in EU27 in 2008 was EUR 160 billion, of which 56% was estimated to be the costs of informal care. The corresponding costs for the EU 27 + EEA and candidate countries, was EUR 167 billion and EUR 177 billion for the whole Europe.

From their previous estimates, (based on 14 million people having the disease by 2030), the result was that dementia would cost the whole of Europe EUR 250 billion by 2030.

As noted in the previous sub-section, the rise in the number of people with dementia is expected to be slower than previously estimated, with the numbers of 2018 being almost a million lower than estimated by the EuroCoDe figures. However, the continued increase in the number of people living with dementia

<sup>1</sup> This results in figures for the EU27 + Bosnia and Herzegovina, Iceland, Israel, Montenegro, Norway, North Macedonia, Switzerland, Turkey and the United Kingdom.

<sup>2</sup> More information on the prevalence of dementia in Europe can be found in the Dementia in Europe Yearbook 2019 available at: <https://www.alzheimer-europe.org/Publications/Dementia-in-Europe-Yearbooks>



is evidence that the costs of dementia will continue to grow, costing economies hundreds of billions of Euros each year as a result of formal and informal care.

This is an area which clearly needs to be revisited to bring the figures up to date, however, the evidence is clear that governments must continue to provide significant investment into health and social care systems to ensure that they meet the inevitable increase in demand for services in years to come.



*First meeting of the EuroCoDe group in February 2006 in Brussels*

#### **4.2.1 Treatments, drugs and the lack of a cure for dementia**

Owing to the progressive nature of dementia, people with dementia often require increasing levels of care and support services. The absence of a disease-modifying treatment or cure therefore continues to prove challenging.

At present, only four drugs exist for Alzheimer's dementia: donepezil, galantamine, rivastigmine and memantine ease some of the symptoms of dementia, but do not modify or cure the underlying disease which causes it.

Over the past decade, we have seen a number of promising developments for medications which aimed to slow the progression of the symptoms of dementia or modify the disease, with many focusing on beta-amyloid in the brain. Unfortunately, no disease modifying drugs have come to market in this time, with a number of high-profile drugs/compounds proving unsuccessful during phase 3 trials.

Such is the low success rate of drug development in this area, that as recently as two years ago, Pfizer, a major international pharmaceutical company, decided to withdraw from investing and undertaking further research into drug development in the fields of dementia and neuroscience more broadly.

As such, the importance of public support for research through Horizon 2020 (and the forthcoming Horizon Europe) and Public-Private Partnerships, such as the Innovative Medicines Initiatives (IMI 1 & 2), are vital to ensuring continued research into disease mechanisms and research into new treatments.

However, in addition to the focus on disease modifying treatments, there must also be a greater focus on psychosocial interventions and other forms of care and support for people with dementia.



#### 4.2.2 Diagnosis, detection and identification of dementia

The diagnosis of dementia remains challenging, with under-diagnosis or late diagnosis across European countries resulting in people receiving insufficient or no support to live with the condition. Screening tests for diagnosing dementia include the use of cognitive scoring tests, such as MMSE, ACE-III, which involve standardised questionnaires or tasks, from which a cognitive score is then given.

Over the past decade, research into understanding dementia and the disease process has been a focus for many projects, including at a European level (AMYPAD, EPAD etc.). This research has improved the understanding of dementia, allowing for more nuanced and specific diagnoses of dementia to be made by clinicians, both in relation to the type of dementia and the stage of the condition. Specifically, the recognition of dementia as a spectrum, with the identification of prodromal and pre-clinical stages (where activities of daily life are relatively unimpaired), has come into focus.

Through the use of methods such as PET, CT and MRI scanning, as well as blood and CSF testing, there has been a significant evolution in the way in which the underlying disease mechanisms of dementia are understood, resulting in a move towards detection and interventions targeted at the earlier stages of the condition.

As this research progresses, it is anticipated it will become possible to detect the underlying condition up to 10–20 years before symptoms emerge. In addition to detecting the disease earlier and improving diagnostic methods of dementia, this improved understanding of the condition also offers the possibility of improving prevention and treatment.

#### 4.2.3 Awareness and stigma associated with dementia

Much work has taken place in recent years, particularly by national Alzheimer's associations, to raise awareness of the experiences of people with dementia, to challenge the stigma and misunderstandings associated with the condition and to encourage members of society to play their part in supporting people living with the condition.

Projects such as dementia friendly/inclusive communities, Dementia Friends and other public awareness campaigns have sought to educate the public and introduce measures which allow people with dementia to play an active role within their communities.

Whilst such activities are absolutely vital in raising the profile of dementia, work carried out by Alzheimer Europe in 2017 during its Carers Survey indicated that dementia continues to be stigmatised within society, with awareness remaining poor, even among health and social care professionals. This creates barriers which result in poorer outcomes for people with dementia, their families and carers, whether through difficulty obtaining diagnosis, reluctance of an individual to seek help or engagement with clinicians.

This provides some insight into the challenges of stigma which exist and demonstrates the need for greater awareness of dementia, both amongst the public and health and social care professionals, particularly into the importance of timely diagnosis of dementia.

As part of this, support must be put in place for platforms which allow for the exchange of policy and good practice, such as the European Group of Government Experts on Dementia (mentioned in section three). Additionally, there must be resources put into testing and building upon new ways of working, through coordinated efforts such as the Joint Actions on Dementia (outlined in section five).

## 5. Actions taken at a European level

There have been a number of actions taken at a European level over the past decade which have helped prioritise dementia on the policy agenda. This section briefly outlines what has been achieved over the past decade at the European level, forming the basis of the recommendations in section seven.

### 5.1 Actions by the European Commission

#### 5.1.1 European Commission initiative on Alzheimer's disease and other dementias

On 22 July 2009, the European Commission Communication on a European initiative on Alzheimer's disease and other dementias (COM(2009) 380 final) to tackle Alzheimer's disease, dementia and other neurodegenerative conditions, which noted that the shared health and social challenges of these conditions necessitated coordinated actions to ensure efficient prevention, diagnosis, treatment and care for people affected.

The objective of the initiative was to tackle the main problems posed by Alzheimer's disease and dementia in four key areas. Under each theme were specific actions which the initiative would seek to address, which have been outlined below:

1. Acting early to diagnose dementia and to promote well-being with age
  - To incorporate the “dementia dimension” into the European Union's ongoing and future actions on health prevention, especially those related to cardiovascular health and physical activity
  - To produce a set of recommendations, which would help the citizens to prevent dementia diseases
  - To include the “dementia dimension” in flexible European policies on retirement and in the framework for action on older people in the European Pact for Mental Health and Wellbeing.
2. A shared European effort to better understand dementia conditions: improving epidemiological knowledge and coordination of research
  - To improve epidemiological data on Alzheimer's disease and other dementias, implementing the conclusions of the EuroCoDe Project
  - To use the planned European Health Examination Survey to provide new Europe-wide data on the prevalence of people with early cognitive deficiencies
  - To adopt a proposal for a Council Recommendation on a pilot Joint Programming initiative on combating neurodegenerative diseases as a pilot, in particular Alzheimer's disease.
3. Supporting national solidarity with regard to dementias: sharing best practices for care of people with dementia
  - To map existing and emerging good practices related to treatment and care for persons with from Alzheimer's disease and other forms of dementia and to improve the dissemination and application of such practices
  - To develop, by means of the Open Method of Coordination, quality frameworks for medical and care services for people with dementias
  - To use facilities provided for in the EU Disability Action Plan (DAP) 2003–2010 to support patients' organisations.

#### 4. Providing a forum to reflect on rights, autonomy and dignity of patients

- To establish, using the facilities provided by the Health Programme, a European Network for rights and dignity of people with dementia, which should formulate recommendations on dignity, autonomy and social inclusion, and to share best practices on respecting the rights of vulnerable adults and tackling patient abuse.

This Communication from the European Commission set in motion many of the key areas of work in relation to dementia, including both the Joint Actions on Dementia (outlined in the following subsection), the Joint Programme on Neurodegenerative Disease Research (JPND) and the place of dementia as a priority within the Framework Programmes for research (including Horizon 2020).

#### 5.1.2 1<sup>st</sup> Joint Action on Dementia – Alzheimer Cooperative Valuation in Europe (ALCOVE)



ALCOVE was a collaboration on dementia, implemented between 2011 and 2013 and co-financed by the EU Health Programme 2008–2013 and the participating Member States.

The Joint Action was led by France (Haute Autorité de la Santé) and involved 30 partners from 19 European countries (Belgium, Cyprus, Czech Republic, Finland, France, Greece, Hungary, Italy, Latvia, Lithuania, Luxembourg, Malta, Netherlands, Norway, Portugal, Slovakia, Spain, Sweden and the United Kingdom).

The purpose of the Joint Action was to build upon existing knowledge of the condition, as well as to promote the exchange of information between Member States, with the aim of preserving the health, quality of life, autonomy, and dignity of people living with dementia and their caregivers.

The communication defined four strategic objectives for EU action and Member State cooperation:

1. Acting early to diagnose dementia and promote well-being with age
2. A shared European effort to better understand dementia conditions: Improving epidemiological knowledge and coordination of research
3. Supporting national solidarity with regard to dementias: sharing best practices for care of people suffering dementia
4. Respecting the rights of people with dementia.



Alzheimer Europe and ALCOVE sign a memorandum of understanding, in 2012

### 5.1.3 2<sup>nd</sup> Joint Action on Dementia – Act on Dementia



Building on the success of the first Joint Action on dementia (ALCOVE), the European Commission supported the launch of a 2<sup>nd</sup> Joint Action (Act on Dementia) through its Health Programme (2014–2020).

Act on Dementia was coordinated by the Scottish Government on behalf of the United Kingdom with participation from Bulgaria, France, Greece, Italy, Netherlands, Norway, Poland, Romania, Spain and the United Kingdom. In addition, contributions to the Joint Action were made by Cyprus, Germany, Luxembourg, Malta, Portugal and Alzheimer Europe as collaborating stakeholders.

The aim of Act on Dementia was to promote collaborative actions among Member States to improve the lives of people living with dementia and their carers. The 2<sup>nd</sup> Joint Action was distinct from its predecessor, with a greater focus on the development of guidance and approaches to support Member States to implement good practice. Specifically, work packages aimed to provide cost-effective and practical examples of the core components of good dementia diagnosis, care and support. These areas of work focused on four key areas:

1. Diagnosis and post-diagnostic support (coordinated by France)
2. Crisis and care coordination (coordinated by the Netherlands)
3. Residential care (coordinated by Norway)
4. Dementia-friendly communities (coordinated by the United Kingdom).



Work Package leads at the 29<sup>th</sup> Alzheimer Europe Conference in The Hague, Netherlands, 23-25 October 2019.

The Joint Action concluded in October 2019, with the findings and reports from the project published on the Act on Dementia website: [www.actondementia.eu](http://www.actondementia.eu)



#### 5.1.4 EU funding of dementia research

Over the past decade, the European Union's support for, and funding of, dementia research has been crucial to the sector. Some of the most significant pan-European projects of the past decade have been projects which have received funding under the Seventh Framework Programme (FP7) and Horizon 2020, as well as those funded by the Innovative Medicines Initiatives. In addition, the Joint Programme – Neurodegenerative Disease Research has also funded a number of research projects related to dementia.

In the first three FP7 calls, 30 neuroscience projects were funded totalling EUR 135 million. Projects ranged from basic to clinical research, including the identification of genes and molecules present in brain diseases, the pathophysiology of diseases, and the development of new therapies and diagnostic tools. Research relevant to neuroscience was also funded in other health priority areas, leading to an additional EUR 247 million across an additional 49 research projects.

Figures for Horizon 2020 are more difficult to establish as the programme is ongoing. The most recently available figures, however, showed that at the beginning of 2019 (with two years remaining on the programme, EUR 664 million was spent on frontier research, collaborative research, training and mobility of researchers, in the field of neurodegenerative diseases. Of this funding, EUR 339 million was spent on projects which focused, or contained some level of focus, on Alzheimer's disease. More broadly, basic, transitional and clinical, and care/management research, accounted for EUR 195 million across 91 projects.

#### 5.1.5 Operating Grant funding for Alzheimer Europe

Alzheimer Europe has been fortunate to receive funding in the form of operating grants from the EU health programme to allow it to carry out its core activities. This enabled the organisation to carry out its key strategic objectives, including:

- Providing a voice to people with dementia and their carers
- Make dementia a European priority
- Promoting a rights based approach to dementia
- Support dementia research
- Strengthen the European dementia research.

The operating grant funding has allowed Alzheimer Europe a.o. to coordinate the activities of the European Working Group of People with Dementia, produce its annual policy Yearbooks and ethics reports, organise its Annual Conferences and support the work of its national member organisations. More details on these activities can be found in section three.



## 5.2 Presidencies of the Council of the European Union

### 5.2.1 2008 French Presidency conclusions on neurodegenerative diseases

On 17 December 2008, at the end of the French Presidency of the Council of the European Union, Employment, Social Policy, Health and Consumer Affairs Council meeting adopted “Conclusions on public health strategies to combat neurodegenerative diseases associated with ageing and in particular Alzheimer’s disease”.

The Council identified their reasons for taking this step, including:

1. Recognition of the challenges faced with a doubling of the ageing population
2. The fact that increased longevity should be accompanied by a certain quality of life
3. That the prevalence of neurodegenerative diseases, in particular Alzheimer’s disease, rises with age.



French President Nicolas Sarkozy calls for EU action on Alzheimer’s disease, 31 October 2008

Citing existing European tools and initiatives, the Council drew attention to:

- Chapter 1 (on dignity) of the EU Charter of Fundamental Rights that patients can grow old with dignity
- The Commission’s White Paper “Together for Health: a Strategic Approach for the EU 2008–2013” (in which the primary strategic objective is to promote good health throughout a person’s life cycle)
- The commitment made in 1996 by the European Parliament to support European action to combat Alzheimer’s disease.

More broadly, the Council also acknowledged the work already carried out to make Alzheimer’s disease a public health priority at the EU level, whilst also noting the work carried out by national associations.

The Conclusions were not legally binding but called for action to be taken by the Member States, Commission as well as the Social Protection Committee. Both the Member States and the Commission have been called on to:

1. Recognise dementia as a priority for action
2. Take account of the potential consequences of the increase of the diseases
3. Reflect together on existing quality criteria.

Member States were asked to establish national dementia strategies, as well as to improve the distribution of information, promote coordination and collaboration between all parties, evaluate administrative procedures and to improve the skills of professionals to ensure a high quality of care.

The Commission was asked to adopt an initiative which should have four main themes: research, exchange of best practices on all aspects of the disease, the improvement of the quality of epidemiological information and the exchange of best practices on the issues of protection and patients’ rights.

In addition, the Commission was called upon to take initiatives to develop methodologies and capabilities at an EU level, use existing Community programmes and activities (including the ongoing work of the Commission on health care and long-term care) and use connections between actions developed on these diseases and those developed to address mental health issues in the ageing population.

The Council also asked the Social Protection Committee to continue to promote the sharing of experiences and the exchange of best practice in specified areas, as well as to continue its activities on quality in long-term care.

### 5.2.2 2014 Italian EU Presidency dementia conference

On 14 November 2014, the Italian EU Presidency held a conference entitled “Dementia in Europe: a challenge for our common future” in Rome, Italy.

The aim of the conference was to introduce activities on dementia on an EU level together with seeking a wider approach that included the contribution of other international institutions and bodies in order to maximise the possibility of larger cooperation. There were five key themes covered during the course of the conference:

- Activities on dementia at EU level
- Activities on dementia at international level
- Activities related to the Italian Dementia Strategy
- Strengthening activities at national levels
- The way forward.

### 5.2.3 2015 Luxembourg EU Presidency conclusions

On 7 December 2015, the Employment, Social Policy, Health and Consumer Affairs (EPSCO) Council of the Luxembourg EU Presidency, adopted conclusions (2015/C 418/04) on a number of health-related items, including conclusions on “people living with dementia: improving care policies and practices”, calling on all Member States to address dementia as a priority, to develop national strategies or actions plans, and to strengthen the collaboration between European countries.

As part of this, particular emphasis was placed on the need to uphold the human rights of people living with dementia, on dementia as a cause of disability, on the need to promote healthy lifestyles – especially where brain health is concerned – to reduce the risk of dementia, as well as the importance of recognising that people can live well with dementia.

The Council specifically invited Member States and the Commission to:

- Recognise that continued collaboration across sectors among Member States and at EU level will allow for a valuable contribution to improve the support of people living with dementia
- Recognise the benefits of the empowerment of people living with dementia and encourage their inclusion in decision-making processes
- Support a gender-sensitive, individual and research-based approach in the elaboration of strategies, plans and programmes on dementia
- Recognise the important role of families and caregivers

- Emphasise the work of non-governmental organisations and voluntary work in the field of dementia aiming to contribute effectively to national strategies, action plans or programmes.



Meeting of the EPSCO Council during the Luxembourg EU Presidency 2015.

#### 5.2.4 2016 Dutch EU Presidency dementia conference

On 9–10 May 2016, the Dutch EU Presidency held a two-day conference dedicated to dementia entitled “Living well with(out) dementia” in Amsterdam, Netherlands.

The aim of the conference was to highlight the importance of dementia as a public health priority and the need for European and global collaboration to promote research and exchange good practices. The conference was broken down into three key sections focusing on living well without dementia and the growing importance of prevention and risk reduction, on living well with dementia at home and living well with dementia in care homes.



Dutch Presidency Conference Living well with dementia, 9 May 2016



### 5.2.5 2016 Slovak EU Presidency dementia conference

On 29 November 2016, the Slovak EU presidency held a conference entitled “Alzheimer’s disease – epidemic of the third millennium: Are we ready to face it?” in Bratislava, Slovakia.

The conference brought together over 100 experts from different EU Member States and was an opportunity to highlight policy and research initiatives in dementia taking place at a global, European and national level.

The conference was structured around four panel discussions, which explored specific areas relevant to dementia policy and practice. These were:

- Dementia as a global health priority and scientific challenge
- Prevention and intervention strategies in Alzheimer’s disease
- National programmes and action plans on dementia
- Alzheimer’s disease trip through the EU presidency.

Jean Georges, Executive Director of Alzheimer Europe, attended the conference on behalf of Alzheimer Europe.



Slovak Presidency Conference on Alzheimer’s disease, 29 November 2016

### 5.2.6 2017 Maltese EU Presidency dementia conference

On 15–16 May 2017, the Maltese EU Presidency hosted a meeting of the Government Group of Experts in St Julian's, Malta. The focus of the meeting was on the Promotion of the Rights of People with Dementia.

During the meeting, the troika of Presidencies (Malta, Slovakia and the Netherlands) signed a joint statement, calling for continued action by both the Commission and Council in relation to dementia. The statement affirmed the importance of research and of improving the quality of life for people living with dementia and their loved ones and called upon Member States:

- To participate in, promote and support the international cooperation in dementia research, e.g. in the European Joint Programme on Neurodegenerative Diseases Research (JPND), as well as related research and innovation programmes
- To work together in the exchange and implementation of best practices in dementia care, diagnostics and prevention in, but not limited to, the EU Joint Action Act on Dementia and in the EU Governmental Expert Group on Dementia
- To support persons with dementia to have the best possible quality of life, to live a life with dignity and to participate in society, in accordance with their human rights
- To stimulate and promote the development of a society that supports and accepts people with dementia as worthy members of society
- To support patient advocacy by national and international Alzheimer organisations.



*Dr Boris Banovsky (Slovakia), Dr Justyne Caruana, (Malta) and Mr Martin van Rijn, (Netherlands), sign the joint statement during the meeting of the governmental experts, 15-16 May 2017.*



## 5.3 European Parliament

### 5.3.1 Written Declaration 0080/2008 on Alzheimer's Disease

On 6 February 2009, the European Parliament adopted Written Declaration 80/2008 on the priorities in the fight against Alzheimer's disease, gathering the support of 465 MEPs. The declaration called for the European Commission and the Member States to recognise Alzheimer's disease as a European public health priority and to develop a European Action Plan. It stated:

1. Alzheimer's disease currently affects 6.1 million Europeans and that figure will double or triple between now and 2050 with the ageing of the population
2. The disease is the most common cause of dependency
3. It is vital that political commitment be made in the areas of research, prevention and social protection
4. Calls on the Commission, the Council and the governments of the Member States to recognise Alzheimer's disease as a European public health priority and to develop a European action plan with a view to:
  - a. promoting pan-European research on the causes, prevention and treatment of Alzheimer's disease
  - b. improving early diagnosis
  - c. simplifying procedures for patients and carers and improving their quality of life
  - d. promoting the role of Alzheimer's associations and giving them regular support.
5. The EP President should forward this declaration, together with the names of the signatories, to the Commission, the Council and the governments of the Member States, as well as to the national, regional and local authorities concerned.

### 5.3.2 Written questions

From time to time, individual members of the European Parliament raised issues relevant to dementia policy in Written Questions addressed to Commissioners.

On 28 March 2018 Deirdre Clune (EPP, Ireland), MEP, member of the European Alzheimer's Alliance, submitted a written question (E-001919-18) to the then Health Commissioner, Vytenis Andriukaitis, about why the Expert Group on Dementia had been disbanded.

The question submitted was as follows:

*Dementia is a major public health issue. By 2060, 28% of the population will be aged over 65 and 12% aged over 80. In 2015, dementia affected some 10.5 million citizens aged between 30 and 95+ years of age in Europe. This number is estimated to increase to 13.42 million people by 2030. Dementia accounts for 11.9% of the years lived with disability due to a non-communicable disease. There is still no cure for dementia.*

1. *With regard to these figures and the growing public health threat of dementia, why has the Commission dismantled the Government Expert Group on Dementia, which included the participation of Member*



Deirdre Clune MEP speaks at an Alzheimer Europe lunch debate

*States and civil society and enabled them to go back to their respective national and European authorities to share expertise and good practice?*

2. *How does the Commission now intend to encourage Member States to share expertise and good practice and to adopt national strategies regarding Alzheimer's?*
3. *How is the Commission now taking stock of the various recommendations that EU Presidencies have made on dementia and the findings of research programmes such as the Joint Action on Alzheimer Cooperation Valuation in Europe (ALCOVE) and the 2<sup>nd</sup> EU Joint Action on Dementia?*

As noted in section 3, as a result of this decision, Alzheimer Europe, working with the Health Ministries of Italy, Netherlands and Scotland, re-established and continued to coordinate a dementia-specific governmental expert group.

On 4 September 2020, European Alzheimer's Alliance Vice-Chair, Hilde Vautmans MEP (Renew, Belgium), submitted a written question (E-004837/2020) to the European Commission asking about the place of dementia and cognitive disabilities in the forthcoming European Disability Strategy. The question submitted was as follows:

*Dementia is a progressive, life-limiting condition which affects almost eight million people in the EU, for which there is no cure and no disease-modifying treatment. It often affects memory. However, as a neurodegenerative condition, it can also affect cognitive skills, speech, mobility, etc. In line with Article 1 of the United Nation's Convention on the Rights of Persons with Disabilities (CRPD), which recognises physical, mental, intellectual and sensory disabilities, the symptoms of dementia qualify it as a disability. Therefore, the following questions relate to the development of the next European Disability Strategy.*



Hilde Vautmans MEP addresses the European Parliament

- *Will the Commission ensure that the strategy recognises the CRPD definition of disability?*
- *Will the strategy take specific account of the unique nature of disabilities caused by progressive conditions such as dementia, as well as the need for focused policy responses, both by the Member States and in support provided by the EU?*
- *To what extent will the European Disability Strategy link to other EU and international policies, inter alia, the EU4Health Programme, the European Pillar of Social Rights and the CRPD?*

On 23 September 2020 European Alzheimer's Alliance Vice-Chair, Christophe Hansen MEP (EPP, Luxembourg), submitted a written question (E-005199/2020) to the European Commission asking about the place of dementia and cognitive disabilities in the future research priorities of the EU, including within Horizon Europe. The question submitted was as follows:

Dementia affects almost 8 million people in the European Union and the number is expected to double by 2050. Currently, there is no cure for dementia, there is no disease-modifying treatment and only four symptom-modifying drugs exist on the market. As such, research into new ways of detecting, treating and supporting people with dementia is vitally important:

- How much money has been allocated to dementia and Alzheimer's research projects as part of Horizon 2020 and does this result in an increase, decrease or plateau in the funding for dementia and Alzheimer's research in the forthcoming Horizon Europe research programme?
- Will research into dementia and Alzheimer's disease be identified as a specific priority as part of the Horizon Europe research programme?
- Does the Commission consider to prioritize dementia as a future "mission", as was done for cancer?



Christophe Hansen MEP moderates an Alzheimer Europe lunch debate

On 30 September 2020, European Alzheimer's Alliance Chairperson, Sirpa Pietikainen MEP (EPP, Finland), submitted a written question (E-005368/2020) to the European Commission asking about the place of dementia in the future priorities of the EU. The question submitted was as follows:

According to Alzheimer Europe's *Dementia in Europe Yearbook 2019*, based on UN 2018 population estimates, there are 7,853,705 people living with dementia in the European Union. Primarily as a result of the ageing demographics in Europe, by 2050, this figure will almost double to 14,298,671. The distinct and needs of people with dementia (of which Alzheimer's disease is the most common form), mean it requires specific consideration as an issue in its own right, beyond being grouped under broader categories of mental health or non-communicable diseases.



Sirpa Pietikainen MEP hosts an Alzheimer Europe lunch debate

- Where does the Commission envisage dementia being placed in future EU workstreams (including in the EU4Health Programme, the Health cluster of the Horizon Europe research programme, the Green paper on Ageing etc.)?
- Will the Commission undertake further coordinated action on dementia as it has done in the past, e.g. through the European Initiative on Alzheimer's disease and other dementias, and if not, the rationale behind this?
- How is the Commission working with the WHO European Regional Office and Member States to implement international health policies, such as the Sustainable Development Goals (in particular number 3) and the Global Action Plan on the Public Health Response to Dementia 2017–2025?

## 6. National policy developments

In addition to the work undertaken at an EU level, the development and implementation of policies related to dementia takes place at a national (and sub-national) level. As such, this section of the report considers the current national context, which has shaped the recommendations in section seven.

Since the launch of the Paris and Glasgow Declarations, we have seen a considerable increase in the number of countries with dedicated strategies on dementia, as demonstrated in Table 2.

**Table 2: Status of dementia strategies by country 2020**

Country	Government Dementia Strategy	Year published
Austria	Yes	2015
Belgium	No	N/A
Belgium (Flanders)	No <sup>3</sup>	N/A
Bosnia and Herzegovina	No	N/A
Bulgaria	No	N/A
Croatia	No (but committed to developing)	N/A
Cyprus	Yes	2014
Czech Republic	Yes	2019
Denmark	Yes	2017
Estonia	No	N/A
Finland	Yes <sup>4</sup>	2012
France	No <sup>5</sup>	N/A
Germany	Yes	2020
Greece	Yes	2016
Hungary	No	N/A
Iceland	Yes	2020
Ireland	Yes	2014
Israel	Yes	2013
Italy	Yes	2014
Jersey	No (under development)	N/A
Latvia	No	N/A
Lithuania	No	N/A
Luxembourg	Yes	2013
Malta	Yes	2015
Montenegro	No	N/A
Netherlands	Yes	2013
Norway	Yes	2016
North Macedonia	No	N/A
Poland	No	N/A

3 Flanders' Continuing to build a dementia-friendly Flanders together: Updated Dementia concluded in 2019

4 France's Le plan maladies neuro-dégénératives 2014–2019 concluded in 2019

5 Finland's National Memory Programme 2012–2020 concluded in 2020

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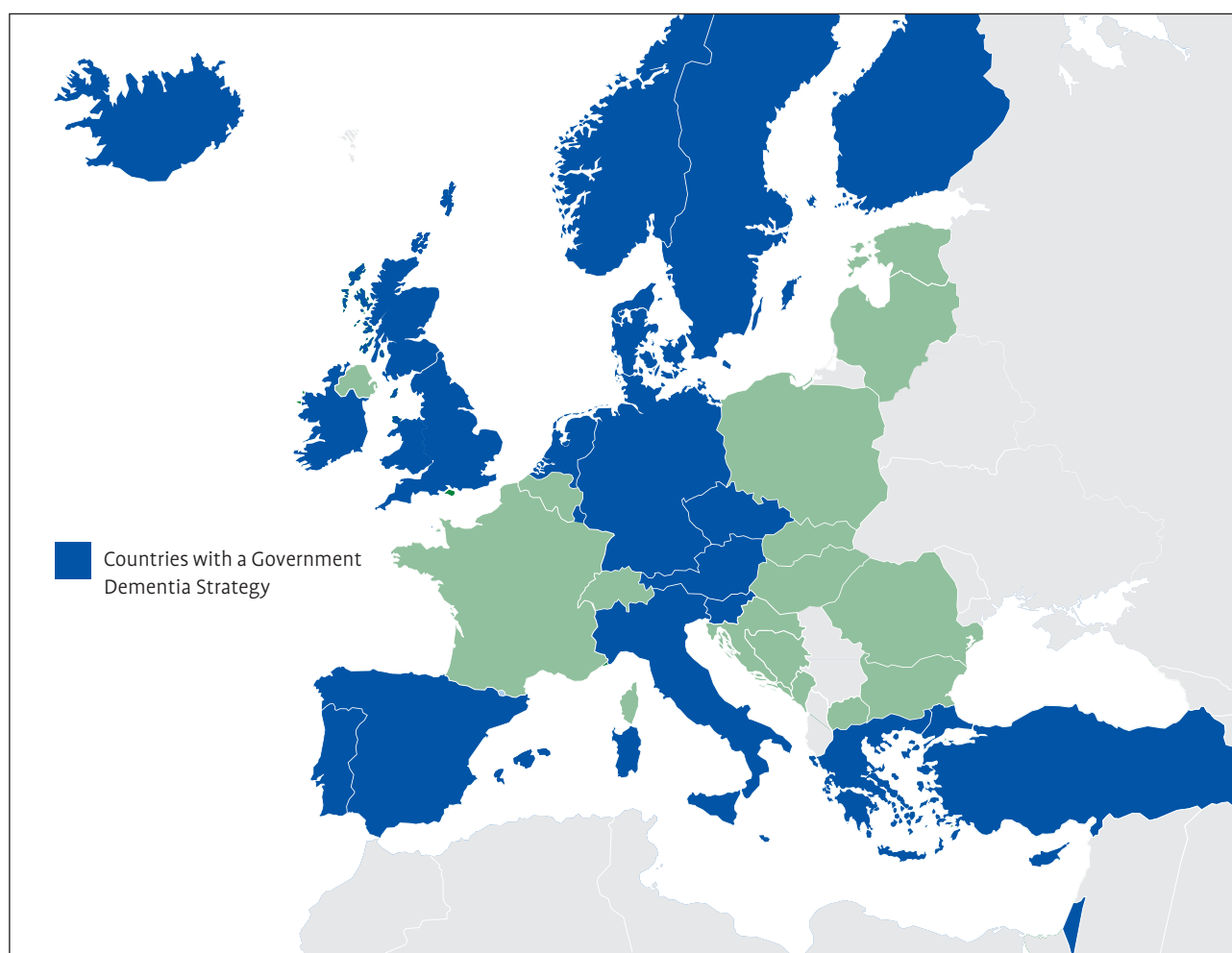


Country	Government Dementia Strategy	Year published
Portugal	Yes	2018
Romania	No	N/A
Slovakia	No	N/A
Slovenia	Yes <sup>6</sup>	2014
Spain	Yes	2019
Sweden	Yes	2018
Switzerland	No <sup>7</sup>	N/A
Turkey	No	N/A
United Kingdom – England	Yes <sup>8</sup>	2015
United Kingdom – Northern Ireland	No	N/A
United Kingdom – Scotland	Yes	2017
United Kingdom – Wales	Yes	2018

6 The Slovenian Dementia Management Strategy in Slovenia until 2020 concluded in 2020

7 The Swiss National Dementia Strategy 2014–2019 concluded in 2019

8 The UK Government's Prime Minister's challenge on dementia 2020 concluded in 2020





## 7. Recommendations for future actions

In this report, Alzheimer Europe has outlined the current position of dementia policy, nationally and at an EU level, spanning over a decade through to the present day. It is evident that there has been a great deal of progress over the past decade, however, it is equally apparent that there is much still to do.

In particular, dementia has not received the same level of prominence as other disease and public health issues within EU policy, neither within the Council of the European Union, nor the European Commission's official publications and communications.

Below, Alzheimer Europe sets out priorities under three headings, where we believe the greatest focus must now be placed to ensure that the progress made thus far is not lost.

Both the EU and national governments have a crucial role to play in ensuring progress is made in improving the lives of people with dementia and carers. As such, the recommendations below are aimed at the EU or national governments (or both where both actors have a remit).

### Health

- Prioritisation of dementia within policies relating to chronic disease, mental health and ageing, both at an EU and national level
- Support for training programmes for health and social care professionals to ensure the highest quality of care for people with dementia, from the point of diagnosis through to end of life care, including through EU Cohesion Funds
- Support from the EU for the European Group of Governmental Experts on Dementia to provide a platform for the exchange of good practice between countries
- Continued core funding to Alzheimer Europe through the EU4Health Programme

### Policy

- Ratification by all European countries of the:
- United Nations Convention on the Rights of Persons with Disabilities (UNCPRD) and its optional protocol
- The Hague Convention on the protection of vulnerable adults
- The Council of Europe's Convention on Human Rights and Biomedicine, as well as the Additional Protocols on Genetic Testing and Biomedical Research
- Support for Member States to work towards the implementation of the World Health Organization's Global Action Plan on Dementia 2017–2025

## Research

- Prioritisation of dementia research in EU Research Programmes (including Horizon Europe) providing a fair allocation of resources and funding for existing programmes and better coordination between programmes
- Recognition of the importance of a holistic approach to dementia research (basic, clinical and care research), ensuring calls for proposals extend across all areas
- Support for the creation of an “Alzheimer’s Research Council” to identify research priorities at an EU level.

## Social

- Recognition of dementia as a disability and inclusion of dementia in disability policies
- Recognition of the impact of dementia on informal carers, with adequate supports and services in place to ensure their health and well-being
- Support for people with dementia and carers in employment, including full implementation of the measures contained within the EU’s Work-life Balance Directive
- Support for platforms and methods of exchange between countries of good practices related to long-term care and funding of dementia care.



Alzheimer Europe’s members gathered together for the 29<sup>th</sup> Alzheimer Europe Conference in the Hague



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