Alzheimer Europe

European Dementia Monitor 2020

Comparing and benchmarking national dementia strategies and policies

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1. Introduction

1.1. Background and objectives of this publication

Alzheimer Europe and its national member organisations actively campaign to ensure that Alzheimer's disease and dementia are recognised as public health and research priorities at both the European and national levels. As the European population continues to age, the prevalence of dementia in the European population is forecast to increase. The condition is a major cause of disability and dependency, affecting both individuals as well as carers, families and societies. From research carried out over the past decade, we understand that:

- Dementia is more prevalent in an ageing population and it is estimated that by 2060, 28% of Europe's population will be aged over 65 and 12% aged over 80.[1]
- According to the Alzheimer Europe Yearbook 2019, the number of people currently living with dementia in Europe is almost 9.8 million. By 2050, this will almost double to 18.8 million.[2]
- Dementia accounts for 11.9% of the years lived with disability due to a non-communicable disease.[3]
- The total cost of illness of dementia disorders in EU27 countries in 2008 was estimated to be EUR 160 billion of which 56% were costs of informal care. The corresponding costs for the whole of Europe was EUR 177 billion.[4]
- The cost per person with dementia in the EU was about EUR 22,000 per year, while it was somewhat lower for the whole of Europe. The total societal costs per case were estimated to be 8 times more in Northern Europe than in Eastern Europe.[5]

Alzheimer Europe launched the Paris (2006) and Glasgow (2014) Declarations calling for national governments to adopt national dementia strategies and uphold the rights of people with dementia in their countries. In this time, we have seen positive developments in this area, with increasing numbers of countries having developed such strategies.

However, from engagement with our members, it is evident that policy implementation is often slow, with supports and services often being insufficient to meet the needs of people with dementia and their carers. In an attempt to quantify this somewhat, Alzheimer Europe has surveyed its members to capture the current state of care, treatment, research, policies and law related to dementia, in order to identify existing differences between countries and track progress over time.

The Dementia Monitor 2020 aims to provide an update on the 2017 publication, examining what changes and developments have taken place over the past three years both within, and between, countries in Europe. By doing so, this document is intended to be a tool which allows countries to compare their national situation with that of other European countries, whilst allowing Alzheimer Europe, as a European organisation, to identify what issues persist within the European system, how these differ across Europe and how these can be addressed to improve the experience of people with dementia, their families and carers.

1.2. Methodology

The methodology adopted for this report follows that which was used for the previous Dementia Monitor, published in 2017. The four overarching categories and 10 sub-categories have been previously identified by Alzheimer Europe members as being the most relevant policy areas for people with dementia, their families and carers. Members were consulted on these areas again in 2019 and confirmed that these remained the most relevant topics related to dementia. The categories and sub-categories are as follows:

1. Care aspects
    a. Availability of care services
    b. Affordability of care services
2. Medical and research aspects
    a. Treatment-reimbursement of AD medicines

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1 European Commission – DG Economic and Finance Affairs, 2015, The 2015 Ageing Report.

2 Alzheimer Europe, 2019, Dementia in Europe Yearbook 2019: Estimating the prevalence of dementia in Europe.

3 Prince, M., Albanese, E., Guerchet M, and Prina, M., 2014, World Alzheimer Report 2014: Dementia and Risk Reduction – An Analysis of Protective and Modifiable Risk Factors.

4 Wimo A., Jönsson, J., and Gustavsson, A., 2009, Cost of illness and burden of dementia – the base option. Available at http://www.alzheimer-europe.org/Our-Research/European-Collaboration-on-Dementia/Cost-of-dementia/Cost-of-illness-and-burden-of-dementia

5 Wimo A., Jönsson, J., and Gustavsson, A., 2009, Regional/National cost of illness estimates. Available at http://www.alzheimer-europe.org/Our-Research/European-Collaboration-on-Dementia/Cost-of-dementia/Regional-National-cost-of-illness-estimates

   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

Data and information on various policies and activities which affect people with dementia is variable. Where possible, Alzheimer Europe gathered data from publicly available data sources, including:

- The clinical trial registry (www.clinicaltrials.gov) for the countries in which clinical trials on Alzheimer's disease were recruiting research participants.
- The public websites of the Joint Programme for Neurodegenerative Diseases Research (www.neurodegenerationresearch.eu), the second Joint Action on Dementia (www.actondementia.eu) and the Active and Assisted Living Programme (www. aal-europe.eu) for the involvement of European countries in dementia research programmes.
- The websites of the Council of Europe (www.coe.int), the United Nations (www.un.org) and the World Organisation for Cross-border Co-operation in Civil and Commercial Matters (www.hcch.net) for the state of ratifications of European and International treaties.
- The website of the European Union Agency for Fundamental Rights (FRA) (www.fra.europa.eu/en), specifically in relation to voting rights across Europe.

For areas where publicly available data and information was unavailable (primarily on support and services within a country), Alzheimer Europe sent an updated version of the 2017 Dementia Monitor survey to its member organisation across Europe (as well as to experts in Latvia and Lithuania), asking them to answer the questions.

Overall, 27 of Alzheimer Europe's member organisations returned the questionnaire. Where countries did not respond, we have updated those sections where public-data was available, whilst using the 2017 responses for the rest of the report.

Table 1 shows all countries for whom data has been included within the report (and their country abbreviations), with those countries which returned a survey highlighted in **green**. For this survey, we received some responses back from regions and countries at a sub-state level (e.g. Flanders and Wallonia, Belgium as well as, England and Scotland, UK), which have been included to identify the differences in federal and devolved systems.

Table 1: Countries included within the report

EU Member States			Other European countries
Austria (AT)	**Germany (DE)**	**Poland (PL)**	Bosnia and Herzegovina (BA)
Belgium – Flanders (BE-FL)	**Greece (GR)**	**Portugal (PO)**	**Iceland (IS)**
Belgium – Wallonia (BE-W)	Hungary (HU)	Romania (RO)	**Israel (IL)**
Bulgaria (BG)	**Ireland (IE)**	Slovakia (SK)	**Jersey (JE)**
Croatia (HR)	**Italy (IT)**	Slovenia (SL)	Norway (NO)
Cyprus (CY)	Latvia (LV)	**Spain (ES)**	**Switzerland (CH)**
Czech Republic (CZ)	Lithuania (LT)	**Sweden (SE)**	**Turkey (TR)**
Denmark (DK)	**Luxembourg (LU)**	Sweden (SE)	United Kingdom – England (UK-E)
Finland (FI)	**Malta (MT)**		**United Kingdom – Scotland (UK-S)**
France (FR)	**Netherlands (NL)**		

1.3. Limitations of the report

As shown in **table 1**, for some countries, it was not possible to fully update the report, therefore certain sections for those countries have been left with the details from the 2017 monitor.

The subjective nature of some of the questions within the questionnaire should also be considered, including whether care is "adequately" available or whether dementia is considered as a research priority in the country. As the majority of Alzheimer Europe's member organisations work with and support people with dementia, their families and carers, they are well placed to advise on these matters. Whilst their answers reflect their views of policies and practice within their country, their views are most likely to accurately reflect the experience of people living with dementia.

Furthermore, the questions around the reimbursement of treatments and cost of care may not capture some of the nuances or specifics within countries. For example, some countries pay fixed amounts for a patient's medications up to a set amount (therefore the cost of Alzheimer's drugs may be covered, however, if a person has multiple medications they may exceed this threshold and therefore an individual thus has to pay). Additionally, a number of countries have means-testing or similar assessments (based on income/assets or the extent of the individual's care and support needs) which determine if a person will receive state-support and the extent of this support (e.g. hours of support or cost contribution).

Finally, this report aims to provide a high-level overview of policies and legislation for countries across Europe. As such, members of Alzheimer Europe have often emphasised the disconnect between policy, legislation and practice. Therefore, it is important to consider that whilst countries may have a dementia strategy or have signed and ratified a specific convention or treaty, this does not guarantee that the provisions are being fully implemented within the country.

2. Care aspects

2.1. Care availability

2.1.1. What did we look at and why?

In line with the 2017 Dementia Monitor, the survey sent to members asked about the range of services that support the quality of life and care of people with dementia throughout the course of the disease from mild to advanced dementia. The list was reviewed by national member organisations in 2019, who felt it remained a comprehensive list of services which were vital to the health and wellbeing of people with dementia and their carers.

Most home care services can be roughly divided into two categories: those providing assistance linked to a person's residence (e.g. cleaning, shopping, laundry, transport, meals-on-wheels etc.) and those linked to personal care (washing, dressing, eating, incontinence care, getting in and out of bed, taking medication etc.).

In line with these measures to help keep a person at home, services such as assistive technologies and adaptions to the home were included. However, it was also noted that residential care and end of life care would play a significant role for some people with dementia, and as such, these were also included within the list. Furthermore we looked at the needs of carers themselves and services such as respite care that can reduce the impact on caregivers.

The following 18 care services were identified by Alzheimer Europe members as having the greatest significance:

1. Care coordination/Case management
2. Home help
3. Meals on wheels
4. Incontinence help
5. Assistive technologies/ICT solutions
6. Tele Alarm
7. Adaptations to the home
8. Home care (Personal hygiene, medication)
9. Counselling
10. Support groups for people with dementia
11. Support groups for carers
12. Respite care at home (sitting service etc)
13. Holidays for carers
14. Carer training
15. Alzheimer Cafés
16. Day care
17. Residential/Nursing home care
18. Palliative care

Alzheimer organisations and national experts were asked to indicate whether they believed these services were sufficiently available (S), insufficiently available (I) or absent (A) in their country.

2.1.2 Results

The detailed answers regarding the availability of care services can be found in **table 2**.

As with the 2017 Dementia Monitor, the majority of care services in Europe continue to be insufficiently available.

However, an increased number of countries reported 50% or more of the aforementioned services being sufficiently available in their countries including: Austria, Belgium (including Flanders), Denmark, Finland, Germany, Israel, Jersey, Luxembourg, Netherlands and Sweden. This is an increase to the 2017 Dementia Monitor.

None of the care services we looked at were reported as sufficient in Bulgaria, Greece, Ireland, Latvia, Lithuania, Poland, Portugal, Romania, Turkey and the United Kingdom (both England and Scotland). This is a slight increase on the 2017 Monitor.

As per **figure 1**, the types of services rated as sufficiently available varies considerably, with incontinence help being rated as sufficiently available in 20 countries (out of 36), with care coordination (four countries) and assistive technologies (five countries) having the lowest availability.

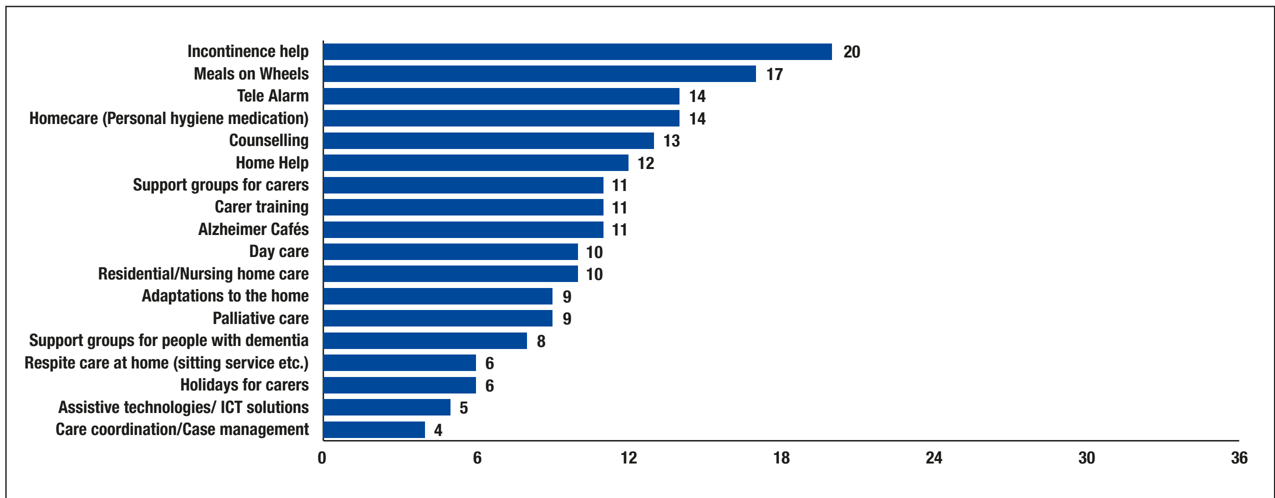
Broadly, the number of sufficiently available services has improved across Europe, compared to the 2017 Dementia Monitor. Incontinence help, meals on wheels, home help, counselling, support groups for carers, Alzheimer cafes, day care, support groups for people with dementia, palliative care, respite at home, and holidays for carers, all showed increases in the number of countries rating these services as sufficiently available (since 2017).

By contrast, home care, assistive technologies and care coordination showed a decrease (from 2017) in countries reporting sufficient availability. All other services showed no change.

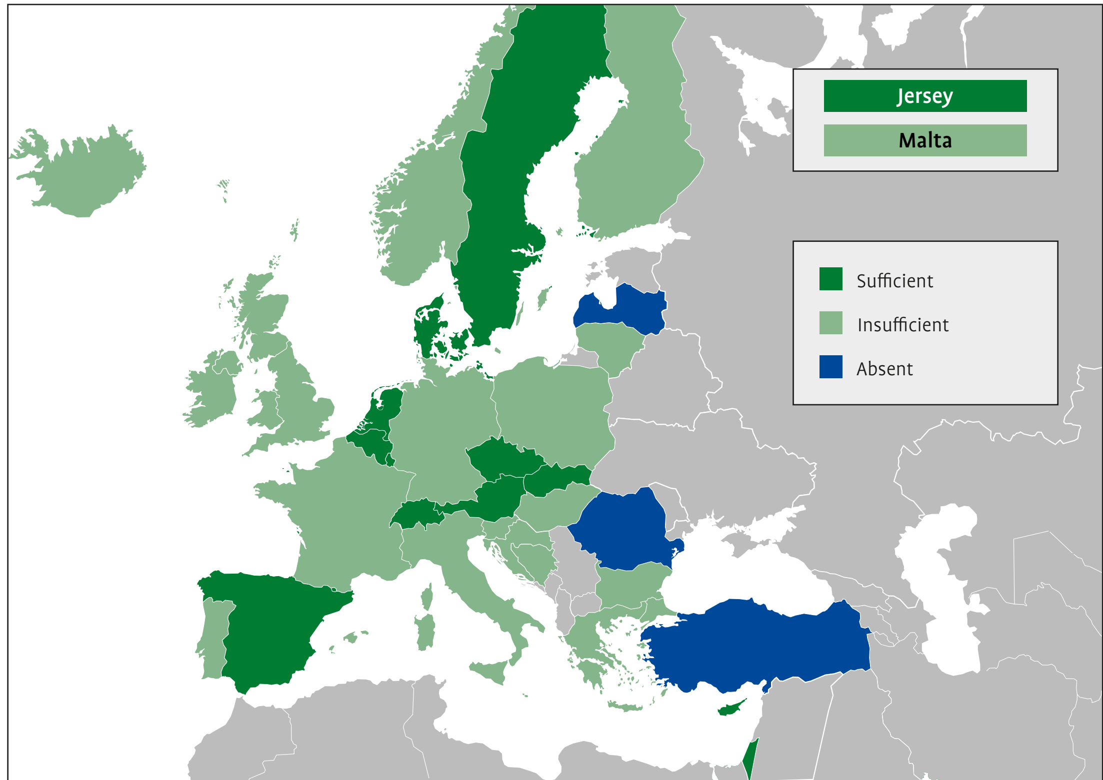
From these figures, there are both positive and negative conclusions which can be drawn in relation to care availability in Europe:

- There has been an increase in the number of countries where the majority of services are considered as being sufficiently available
- The majority of services have shown an increase in the number of countries reporting that they are sufficiently available
- With the exception of incontinence help, all other services have a majority of countries which report that these services are inadequately available or absent
- A majority of countries continue to report that most services are insufficiently available or absent.

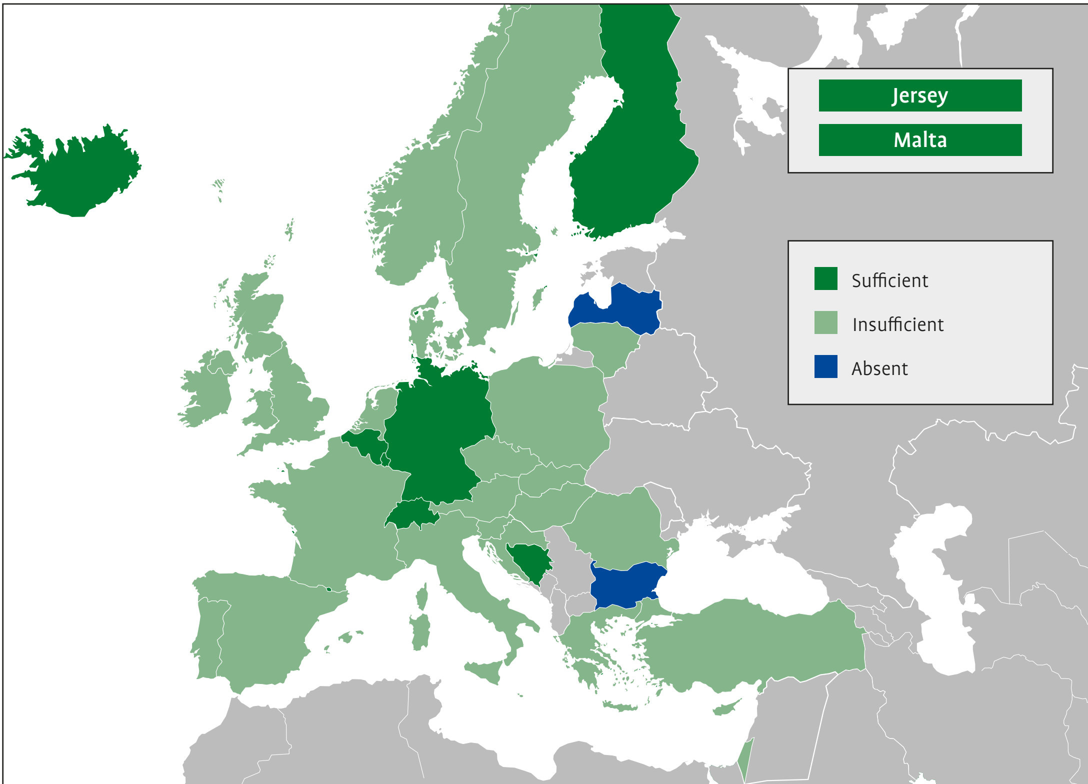
Figure 1: Number of countries rating service as sufficiently available (out of 36)



Map 1: Availability of home care in Europe



Map 2: Availability of day care in Europe



Map 3: Availability of residential care in Europe

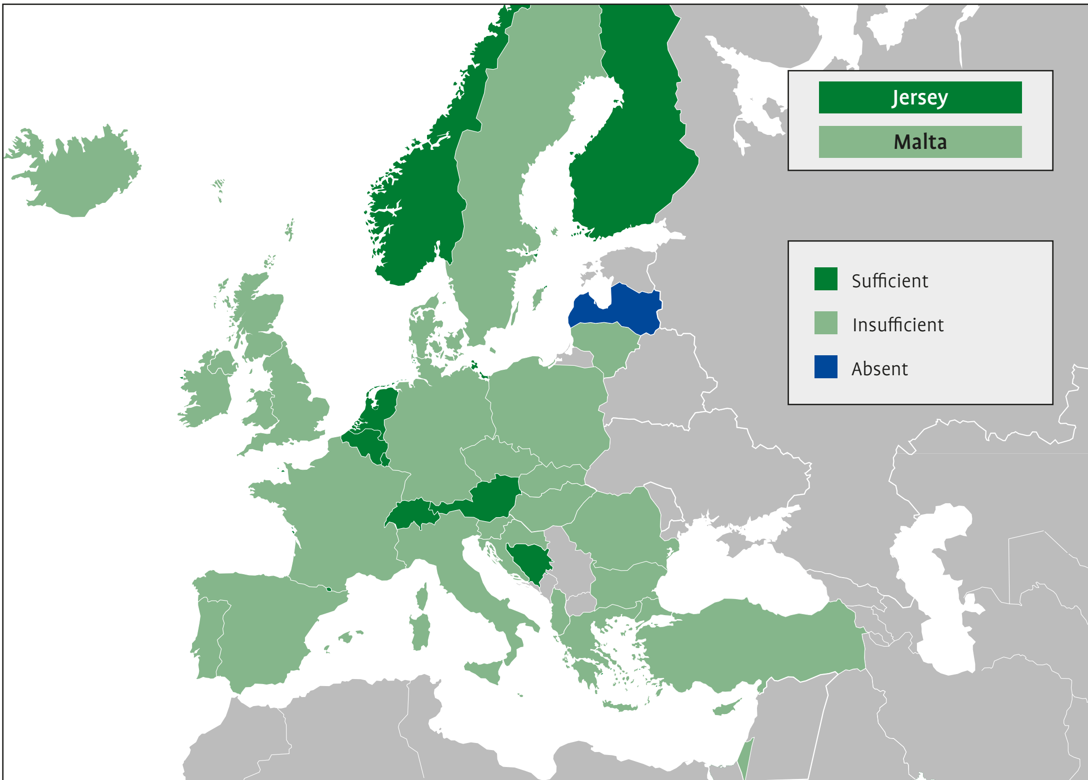


Table 2: Availability of care services

Care availability	AT	BA	BE (FL)	BE (W)	BG	CH	CY	CZ	DE	DK	ES	FI	FR	GR	HR	HU	IE	IL
Care coordination/ Case management	◍	○	●	○	○	○	◍	○	◍	●	◍	◍	◍	◍	○	◍	○	◍
Home Help	●	◍	●	●	◍	◍	●	●	●	●	◍	◍	◍	◍	◍	◍	◍	●
Meals on Wheels	●	○	●	●	◍	●	◍	●	●	●	◍	●	◍	○	◍	●	◍	◍
Incontinence help	●	●	●	●	○	●	◍	●	●	●	●	●	◍	○	●	◍	◍	●
Assistive technologies/ ICT solutions	◍	●	◍	◍	○	◍	○	◍	◍	●	◍	◍	●	◍	◍	◍	◍	●
Tele Alarm	●	○	●	●	○	◍	○	◍	●	●	●	●	●	◍	◍	○	◍	●
Adaptations to the home	●	○	●	●	○	◍	◍	◍	●	●	◍	◍	◍	◍	◍	○	◍	●
Homecare (Personal hygiene medication)	●	◍	●	●	◍	●	●	●	◍	●	●	◍	◍	◍	◍	◍	◍	●
Counselling	●	●	●	◍	○	●	●	◍	●	●	◍	●	◍	◍	●	◍	◍	●
Support groups for people with dementia	◍	○	◍	●	○	◍	◍	◍	◍	●	●	●	◍	◍	◍	◍	◍	●
Support groups for carers	●	○	◍	◍	◍	◍	◍	◍	◍	●	●	●	◍	◍	◍	○	◍	●
Respite care at home (sitting service etc.)	●	◍	●	●	◍	◍	◍	◍	◍	◍	◍	◍	◍	○	○	○	◍	●
Holidays for carers	◍	◍	●	◍	○	○	◍	○	●	◍	◍	◍	◍	○	○	○	◍	●
Carer training	●	◍	●	◍	○	◍	◍	◍	●	◍	◍	●	◍	◍	◍	○	◍	●
Alzheimer Cafés	◍	◍	●	●	○	●	○	◍	○	◍	◍	●	◍	◍	●	◍	◍	●
Day care	●	●	●	●	○	●	◍	◍	●	◍	◍	●	◍	◍	◍	◍	◍	◍
Residential/Nursing home care	●	●	●	●	◍	●	◍	◍	◍	◍	◍	●	◍	◍	◍	◍	◍	◍
Palliative care	◍	●	●	●	○	◍	○	◍	◍	◍	◍	●	○	◍	●	◍	◍	◍

● Sufficient ◍ Insufficient ○ Not available / absent

Table 2: Availability of care services continued

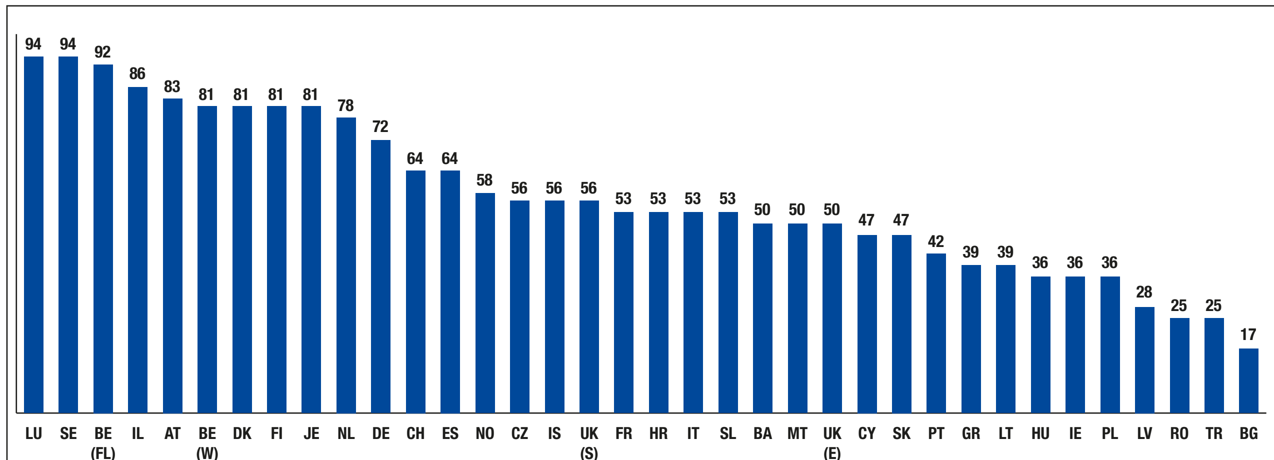
Care availability	IS	IT	JE	LT	LU	LV	MT	NL	NO	PL	PT	RO	SE	SK	SL	TR	UK (E)	UK (S)
Care coordination/ Case management	◐	◐	◐	◐	◐	◐	◐	◐	●	◐	○	○	●	◐	○	◐	◐	◐
Home Help	◐	◐	●	◐	●	◐	◐	●	○	◐	◐	○	●	◐	◐	◐	◐	◐
Meals on Wheels	◐	◐	●	◐	●	◐	●	●	●	○	◐	○	●	●	◐	○	◐	●
Incontinence help	◐	●	●	◐	●	◐	●	●	●	◐	◐	○	●	◐	◐	◐	◐	●
Assistive technologies/ ICT solutions	◐	◐	◐	○	◐	◐	○	◐	◐	◐	◐	○	●	○	◐	◐	◐	◐
Tele Alarm	◐	◐	◐	○	●	○	●	●	●	○	◐	○	●	○	◐	○	◐	◐
Adaptations to the home	◐	◐	●	◐	●	○	○	◐	◐	◐	◐	○	●	◐	◐	○	◐	◐
Homecare (Personal hygiene medication)	◐	◐	●	◐	●	○	◐	●	◐	◐	◐	○	●	●	◐	○	◐	◐
Counselling	◐	◐	●	○	●	◐	◐	◐	○	◐	◐	◐	●	◐	○	◐	◐	◐
Support groups for people with dementia	◐	◐	◐	◐	●	◐	○	◐	◐	◐	○	◐	●	○	●	○	◐	◐
Support groups for carers	◐	◐	●	◐	●	◐	◐	●	●	◐	◐	◐	●	●	◐	○	◐	◐
Respite care at home (sitting service etc.)	◐	◐	◐	◐	●	◐	◐	◐	○	◐	◐	◐	●	◐	◐	○	◐	◐
Holidays for carers	◐	◐	◐	○	●	○	○	●	○	○	○	○	●	○	◐	○	◐	◐
Carer training	◐	◐	●	◐	●	◐	◐	●	●	◐	◐	◐	●	◐	●	◐	◐	◐
Alzheimer Cafés	◐	◐	◐	◐	●	○	●	●	◐	○	◐	◐	●	◐	●	○	◐	◐
Day care	●	◐	●	◐	●	○	◐	◐	◐	◐	◐	◐	◐	◐	◐	◐	◐	◐
Residential/Nursing home care	◐	◐	●	◐	●	○	◐	●	●	◐	◐	◐	◐	◐	◐	◐	◐	◐
Palliative care	●	◐	●	◐	●	○	◐	◐	◐	○	◐	◐	●	◐	◐	◐	◐	◐

● Sufficient ◐ Insufficient ○ Not available / absent

2.1.3 How did we score countries?

Countries could score a maximum of 36 points. Countries were scored 2 points if the service is fully funded, 1 point if the service is co-funded or means tested and 0 points if the service has to be self-funded or if the service is not available in the country. Based on the results, it is possible to rank European countries as indicated in **figure 2**, which shows the points expressed as percentages of the maximum possible score.

Figure 2: Ranking of countries on availability of care services



2.2. Financing of care services

2.2.1. What did we look at and why?

In addition to identifying which services were available in European countries, it is important to find out how accessible these services were for people with dementia and their carers. For that reason, national member organisations and experts were provided with the same list of services as in the previous chapter and asked whether these services were fully funded (F), co-funded or means tested (C) or whether people with dementia and their families had to self-fund (S) to access these services.

2.2.2. Results

The detailed answers regarding the financing of care services can be found in **table 3**.

Compared to the 2017 Dementia Monitor, there is little change in the way in which services and supports are funded within European countries.

Very few countries provide full funding for the majority of services, with Denmark, Finland, Malta and Norway being the only countries which have 50% or more services being fully funded (the same number of countries as 2017). By comparison, there is a significant number of countries in which 50% or more of services are self-funded. This is the case in Bosnia-Herzegovina, Bulgaria, Croatia, Cyprus, Greece, Italy, Latvia, Poland and Romania.

There has been an increase in the number of countries providing some level of support for assistive technologies, tele alarms, meals on wheels, adaptations to home, counselling, carer training, incontinence help, residential care, palliative care and day care. Conversely, fewer countries provided funding for holidays for carers, Alzheimer cafes, support groups for people with dementia, respite care, support groups for carers, home helps and home care. There was no change in the level of funding for care coordination.

Figure 3 provides a breakdown, by service, of the number of countries which provide some level of public funding for specific services. A majority of countries provide full or co-funding for the majority of services, with holidays for carers, assistive technologies and Alzheimer cafes the only services for which a minority of countries provide some level of funding.

The most commonly publicly-funded services include day care, palliative care, incontinence help, home care and residential care. Conversely, holidays for carers and assistive technologies are some of the least supported by public finance.

As in the previous section, the picture is mixed in relation to how services are funded:

- The majority of services continue to be funded (at least in part) in the majority of countries

- The majority of services showed an increase in the number of countries providing some level of funding
- Disappointingly, a significant number of countries (9) have a majority of services (50% or above) which are self-funded
- Some services show a reduction in support from the state compared to 2017, including support groups and Alzheimer cafes.

2.2.3. How did we score countries?

Countries could score a maximum of 36 points. Countries were scored 2 points if the service is fully funded, 1 point if the service is co-funded or means tested and 0 points if the service has to be self-funded or if the service is not available in the country. Based on the results, it is possible to rank European countries as indicated in **figure 4**, which shows the points expressed as percentages of the maximum possible score.

Figure 3: Number of countries in which there is public support for care service (out of 36)

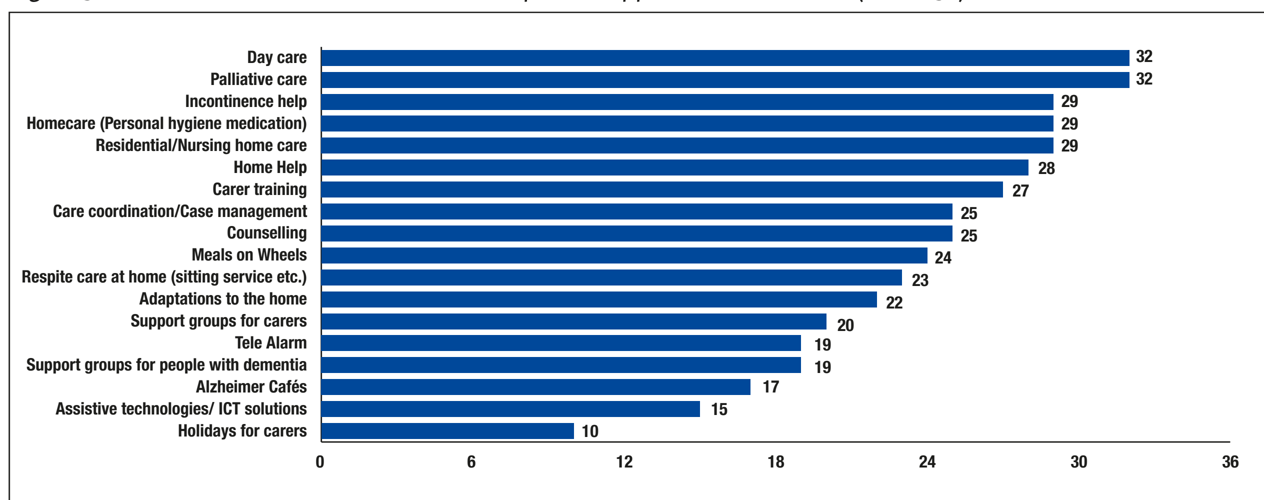


Figure 4: Ranking of countries on public support for care service

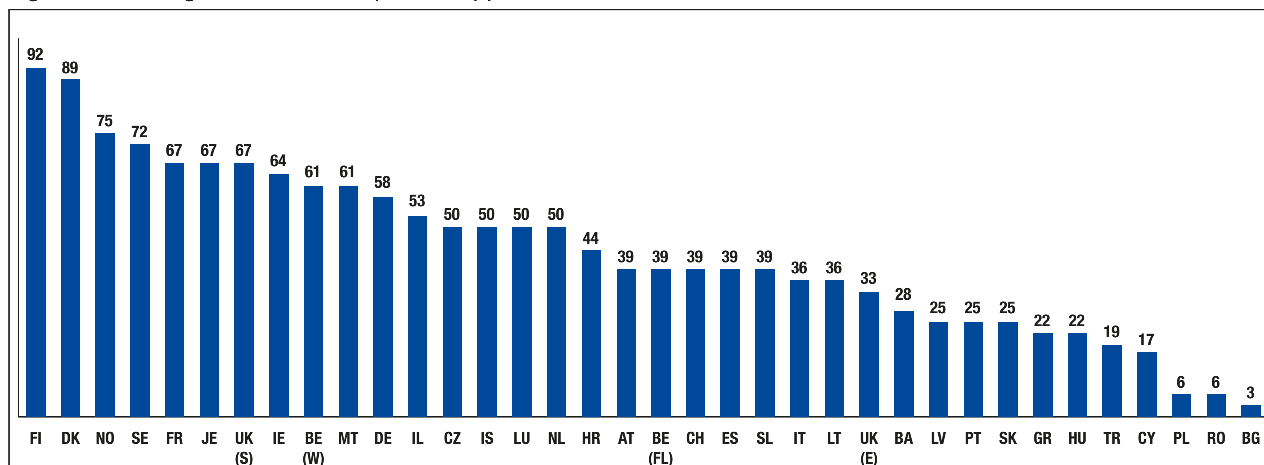


Table 3: Financing of care services

Public support of care services	AT	BA	BE (FL)	BE (W)	BG	CH	CY	CZ	DE	DK	ES	FI	FR	GR	HR	HU	IE	IL
Care coordination/Case management	Fully funded	Co-funded	Co-funded	Fully funded	Self funded	Self funded	Co-funded	Not available	Fully funded	Fully funded	Fully funded	Fully funded	Fully funded	Co-funded	Self funded	Self funded	Self funded	Co-funded
Home help	Co-funded	Co-funded	Co-funded	Not available	Self funded	Co-funded	Self funded	Co-funded	Co-funded	Fully funded	Co-funded	Fully funded	Co-funded	Co-funded	Co-funded	Co-funded	Fully funded	Co-funded
Meals on wheels	Co-funded	Not available	Self funded	Co-funded	Co-funded	Self funded	Self funded	Co-funded	Self funded	Co-funded	Self funded	Fully funded	Co-funded	Self funded	Co-funded	Co-funded	Fully funded	Co-funded
Incontinence help	Fully funded	Co-funded	Co-funded	Co-funded	Not available	Fully funded	Self funded	Co-funded	Co-funded	Fully funded	Co-funded	Fully funded	Co-funded	Co-funded	Fully funded	Co-funded	Co-funded	Co-funded
Assistive technologies/ ICT solutions	Self funded	Self funded	Self funded	Co-funded	Not available	Co-funded	Self funded	Self funded	Self funded	Co-funded	Self funded	Co-funded	Self funded	Self funded	Self funded	Self funded	Co-funded	Co-funded
Tele Alarm	Self funded	Not available	Co-funded	Co-funded	Not available	Fully funded	Self funded	Co-funded	Co-funded	Fully funded	Co-funded	Co-funded	Self funded	Self funded	Self funded	Self funded	Co-funded	Co-funded
Adaptations to the home	Co-funded	Self funded	Co-funded	Co-funded	Self funded	Self funded	Self funded	Co-funded	Co-funded	Fully funded	Co-funded	Co-funded	Co-funded	Self funded	Co-funded	Self funded	Co-funded	Co-funded
Homecare/ Personal hygiene	Co-funded	Co-funded	Fully funded	Fully funded	Self funded	Co-funded	Self funded	Co-funded	Fully funded	Fully funded	Co-funded	Fully funded	Fully funded	Self funded	Self funded	Co-funded	Co-funded	Co-funded
Counselling	Self funded	Fully funded	Fully funded	Co-funded	Self funded	Fully funded	Co-funded	Fully funded	Fully funded	Fully funded	Co-funded	Fully funded	Fully funded	Co-funded	Fully funded	Self funded	Self funded	Fully funded
Support groups for people with dementia	Self funded	Self funded	Self funded	Fully funded	Not available	Self funded	Co-funded	Fully funded	Co-funded	Fully funded	Self funded	Fully funded	Fully funded	Co-funded	Fully funded	Self funded	Fully funded	Fully funded
Support groups for carers	Self funded	Self funded	Self funded	Fully funded	Self funded	Self funded	Co-funded	Fully funded	Fully funded	Fully funded	Self funded	Fully funded	Fully funded	Co-funded	Co-funded	Self funded	Fully funded	Co-funded
Respite care at home/ Sitting service	Co-funded	Self funded	Co-funded	Co-funded	Self funded	Self funded	Self funded	Co-funded	Co-funded	Fully funded	Co-funded	Fully funded	Co-funded	Self funded	Self funded	Self funded	Co-funded	Self funded
Holidays for carers	Co-funded	Self funded	Self funded	Self funded	Not available	Self funded	Self funded	Not available	Co-funded	Co-funded	Self funded	Fully funded	Co-funded	Self funded	Self funded	Self funded	Co-funded	Self funded
Carer training	Self funded	Self funded	Co-funded	Self funded	Not available	Co-funded	Co-funded	Co-funded	Fully funded	Fully funded	Co-funded	Fully funded	Fully funded	Co-funded	Co-funded	Self funded	Fully funded	Co-funded
Alzheimer Cafés	Self funded	Self funded	Self funded	Co-funded	Not available	Self funded	Not available	Self funded	Not available	Fully funded	Self funded	Fully funded	Fully funded	Co-funded	Co-funded	Self funded	Fully funded	Co-funded
Day care	Co-funded	Self funded	Co-funded	Fully funded	Not available	Co-funded	Co-funded	Co-funded	Co-funded	Co-funded	Co-funded	Fully funded	Co-funded	Co-funded	Co-funded	Co-funded	Co-funded	Fully funded
Residential/ Nursing home care	Co-funded	Fully funded	Co-funded	Fully funded	Self funded	Co-funded	Self funded	Co-funded	Co-funded	Fully funded	Co-funded	Fully funded	Co-funded	Self funded	Co-funded	Co-funded	Co-funded	Co-funded
Palliative care	Fully funded	Fully funded	Co-funded	Fully funded	Self funded	Fully funded	Self funded	Fully funded	Fully funded	Fully funded	Fully funded	Fully funded	Fully funded	Self funded	Fully funded	Fully funded	Fully funded	Co-funded

Fully funded   Co-funded   Self funded   Not available

Table 3: Financing of care services continued

Public support of care services	IS	IT	JE	LT	LU	LV	MT	NL	NO	PL	PT	RO	SE	SK	SL	TR	UK (E)	UK (S)
Care coordination/Case management	Co-funded	Fully funded	Fully funded	Co-funded	Co-funded	Co-funded	Fully funded	Fully funded	Fully funded	Self funded	Not available	Not available	Fully funded	Co-funded	Not available	Self funded	Fully funded	Fully funded
Home help	Co-funded	Co-funded	Co-funded	Co-funded	Co-funded	Co-funded	Fully funded	Self funded	Co-funded	Self funded	Co-funded	Self funded	Fully funded	Co-funded	Self funded	Co-funded	Self funded	Co-funded
Meals on wheels	Co-funded	Co-funded	Co-funded	Co-funded	Co-funded	Self funded	Fully funded	Co-funded	Co-funded	Self funded	Co-funded	Not available	Co-funded	Co-funded	Co-funded	Not available	Self funded	Co-funded
Incontinence help	Co-funded	Fully funded	Fully funded	Co-funded	Co-funded	Self funded	Fully funded	Fully funded	Co-funded	Self funded	Self funded	Self funded	Fully funded	Co-funded	Co-funded	Co-funded	Co-funded	Co-funded
Assistive technologies/ ICT solutions	Fully funded	Self funded	Co-funded	Co-funded	Co-funded	Self funded	Self funded	Self funded	Fully funded	Self funded	Self funded	Self funded	Co-funded	Not available	Co-funded	Self funded	Co-funded	Co-funded
Tele Alarm	Co-funded	Self funded	Co-funded	Self funded	Co-funded	Self funded	Co-funded	Co-funded	Fully funded	Self funded	Self funded	Not available	Co-funded	Not available	Co-funded	Not available	Self funded	Co-funded
Adaptations to the home	Fully funded	Self funded	Co-funded	Co-funded	Co-funded	Self funded	Self funded	Co-funded	Fully funded	Self funded	Self funded	Self funded	Co-funded	Self funded	Co-funded	Not available	Co-funded	Co-funded
Homecare/ Personal hygiene	Co-funded	Fully funded	Co-funded	Co-funded	Co-funded	Self funded	Fully funded	Fully funded	Fully funded	Co-funded	Co-funded	Self funded	Fully funded	Co-funded	Co-funded	Not available	Co-funded	Fully funded
Counselling	Co-funded	Self funded	Co-funded	Co-funded	Co-funded	Co-funded	Co-funded	Co-funded	Co-funded	Co-funded	Self funded	Self funded	Co-funded	Self funded	Not available	Self funded	Self funded	Co-funded
Support groups for people with dementia	Self funded	Self funded	Fully funded	Self funded	Co-funded	Co-funded	Self funded	Co-funded	Fully funded	Self funded	Not available	Self funded	Fully funded	Not available	Co-funded	Not available	Self funded	Fully funded
Support groups for carers	Self funded	Self funded	Fully funded	Self funded	Co-funded	Co-funded	Self funded	Co-funded	Fully funded	Self funded	Co-funded	Self funded	Fully funded	Self funded	Co-funded	Not available	Self funded	Fully funded
Respite care at home/ Sitting service	Self funded	Co-funded	Co-funded	Co-funded	Co-funded	Co-funded	Fully funded	Co-funded	Fully funded	Self funded	Self funded	Self funded	Co-funded	Co-funded	Co-funded	Not available	Co-funded	Co-funded
Holidays for carers	Self funded	Self funded	Self funded	Self funded	Co-funded	Self funded	Self funded	Self funded	Fully funded	Self funded	Not available	Not available	Co-funded	Not available	Self funded	Not available	Self funded	Co-funded
Carer training	Co-funded	Self funded	Fully funded	Co-funded	Co-funded	Co-funded	Co-funded	Co-funded	Co-funded	Self funded	Co-funded	Co-funded	Co-funded	Self funded	Co-funded	Co-funded	Self funded	Fully funded
Alzheimer Cafés	Self funded	Self funded	Fully funded	Self funded	Co-funded	Self funded	Fully funded	Self funded	Fully funded	Self funded	Co-funded	Self funded	Co-funded	Not available	Co-funded	Not available	Co-funded	Co-funded
Day care	Fully funded	Co-funded	Co-funded	Co-funded	Co-funded	Co-funded	Fully funded	Co-funded	Co-funded	Self funded	Co-funded	Self funded	Co-funded	Co-funded	Co-funded	Co-funded	Co-funded	Co-funded
Residential/ Nursing home care	Fully funded	Co-funded	Co-funded	Co-funded	Co-funded	Self funded	Fully funded	Co-funded	Self funded	Self funded	Co-funded	Self funded	Fully funded	Co-funded	Co-funded	Co-funded	Co-funded	Co-funded
Palliative care	Fully funded	Fully funded	Fully funded	Co-funded	Co-funded	Co-funded	Co-funded	Fully funded	Co-funded	Self funded	Co-funded	Co-funded	Fully funded	Co-funded	Co-funded	Fully funded	Fully funded	Fully funded

Fully funded · Co-funded · Self funded · Not available

3. Medical and research aspects

3.1. Treatment

3.1.1. What did we look at and why?

There are currently four drugs recommended for the treatment of Alzheimer's disease: Donepezil, Rivastigmine and Galantamine all work in a similar way and are known as acetylcholinesterase inhibitors (AChEI). They are indicated for the treatment of mild to moderate Alzheimer's disease. Memantine works in a different way to the other three and has an indication for the treatment of moderate to severe Alzheimer's disease.

In our survey, we asked whether the above mentioned four medicines are available and whether as well as at what level they are reimbursed or covered by the national health system. In addition, we enquired whether the combination therapy of an AChEI and memantine was covered by the national health system and if so, at what level.

Another treatment-related question concerned the use of antipsychotic drugs. People with dementia who experience behavioural and psychological symptoms of dementia are often, and inappropriately, prescribed antipsychotic drugs. These drugs have been linked to serious side effects and research has shown that inappropriate prescription of antipsychotic drugs can be extremely harmful. For that reason, we questioned countries on whether a strategy for the reduction of the use of antipsychotics for people with dementia had been put in place.

3.1.2. Results

The detailed answers regarding the reimbursement of medicines and of combination therapy can be found in **table 4**.

There has been little change from the Dementia Monitor in 2017, with most countries offering some level of reimbursement for at least one or more acetylcholinesterase inhibitors.

The most striking change from 2017 was the decision in France to stop funding all dementia-related medications which was announced in 2018. The decision was

Map 4: Countries with a strategy aimed at reducing the inappropriate use of antipsychotics

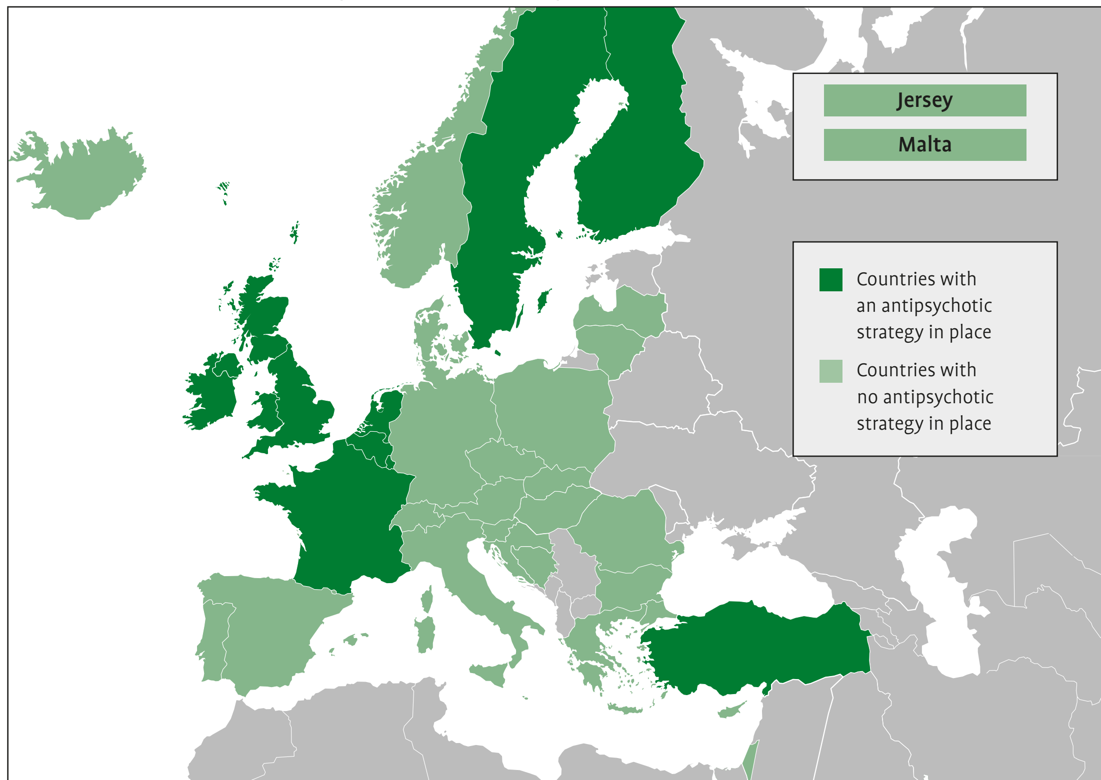


Table 4: Reimbursement/coverage rates for AD medicines and combination therapy by country

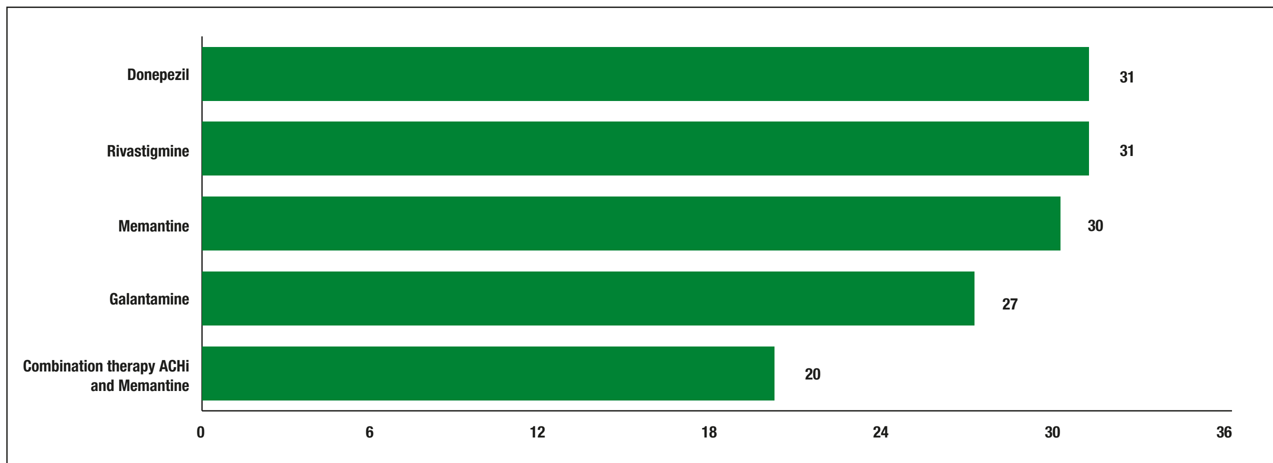
	Donepezil	Rivastigmine	Galantamine	Memantine	Combination	Anti-psychotic strategy
AT	100%	100%	100%	100%	Yes – on request	
BA	No	No	No	75-99%	No	
BE (FL)	10%-74%	10%-74%	10%-74%	10%-74%	10%-74%	Yes
BE (W)	75%-99%	75%-99%	75%-99%	75%-99%	No	Yes
BG	No	10%-74%	75%-99%	10%-74%	No	
CH	100%	100%	100%	100%	No	
CY	10%-74%	10%-74%	10%-74%	10%-74%	No	
CZ	100%	10%-74%	100%	100%	No	
DE	100%	100%	100%	100%	100%	
DK	100%	100%	100%	100%	100%	
ES	100%	100%	100%	100%	0-10%	
FI	10%-74%	10%-74%	10%-74%	10%-74%	10%-74%	Yes
FR	No	No	No	No	No	Yes
GR	75%-99%	75%-99%	75%-99%	75%-99%	75%-99%	
HR	10%-74%	10%-74%	No	10%-74%	No	
HU	10%-74%	10%-74%	no	10%-74%	10%-74%	
IE	100%	100%	100%	100%	100%	Yes
IT	100%	100%	100%	100%	100%	
IL	75%-99%	75%-99%	No	No	No	
IS	10%-74%	10%-74%	10%-74%	10%-74%	10%-74%	
JE	100%	100%	100%	100%	100%	
LT	75%-99%	No	No	75%-99%	No	
LU	75%-99%	75%-99%	75%-99%	75%-99%	75%-99%	Yes
LV	No	No	No	No	No	
MT	100%	No	No	No	No	
NL	No	100%	100%	100%	No	Yes
NO	100%	100%	100%	No	No	
PL	10%-74%	10%-74%	No	No	No	
PT	10%-74%	10%-74%	10%-74%	10%-74%	10%-74%	
RO	100%	100%	100%	100%	100%	
SE	100%	100%	100%	100%	100%	Yes
SK	100%	100%	100%	100%	No	
SL	100%	100%	100%	100%	100%	
TR	100%	100%	100%	100%	100%	Yes
UK-E	100%	100%	100%	100%	100%	Yes
UK-S	100%	100%	100%	100%	100%	Yes

surprising given France's previously strong record in relation to dementia policy and raised significant concerns from persons with dementia and their carers in France. Only France and Latvia offer no reimbursement for any dementia medications.

With regard to strategies aimed at reducing the inappropriate use of anti-psychotics, 10 countries (see **map 4**) have such a strategy, namely Belgium (Flanders and Wallonia), Finland, France, Ireland, Luxembourg, Netherlands, Sweden, Switzerland, Turkey and the United Kingdom (England and Scotland).

Figure 5 shows that there is an overall positive picture in relation to the number of countries providing partial or full reimbursement of medications. However, there are significantly fewer countries reimbursing combination therapy with AChEI's and memantine.

Figure 5: Number of countries reimbursing dementia medications (out of 36)



3.1.3. How did we score countries?

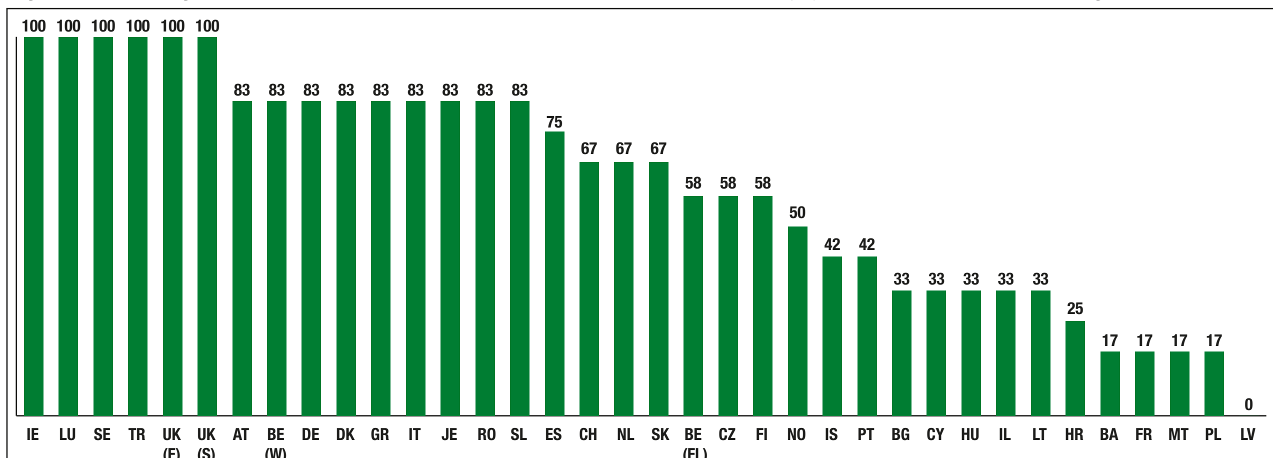
Countries could score a maximum of 12 points. For each of the four medicines and for the combination therapy, countries were scored 2 points if they were reimbursed/ covered at least at 75%, 1 point if they were reimbursed/ covered at a lower level and 0 points if they were not part of the reimbursement/coverage system.

Countries also scored 2 points if they had a strategy for the reduction of anti-psychotics in place.

In this section, six countries (Ireland, Luxembourg, Sweden, Turkey and the UK (England and Scotland)) receive full marks as all medicines and combination therapy are reimbursed/covered at a high level and the countries have an anti-psychotic strategy in place. Only one country (Latvia) receives no points, since none of the medicines are reimbursed and no strategy is in place.

Based on the results, it is possible to rank European countries as indicated in **figure 6**, which shows the points expressed as percentages of the maximum possible score.

Figure 6: Ranking of countries on reimbursement of medicines and anti-psychotic medication strategies



3.2. Clinical trials

3.2.1. What did we look at and why?

There is currently no cure or disease modifying treatment for Alzheimer's disease, with the current available treatments having limited efficacy in mitigating the symptoms of dementia. As such, dementia researchers continue to conduct clinical trials and research into drug development, in an effort to find a breakthrough in treating the underlying diseases. At the conclusion of 2019, Alzheimer Europe had identified six phase III trials which were actively recruiting to investigate different compounds (COR388, Gantenerumab, Omega-3, Guanfacine and AVP-786) and their effect on dementia. Ongoing clinical trials no longer recruiting were not included in this overview.

In detail, we looked at the following six studies:

- GAIN, investigating COR-388
- GRADUATE 1, investigating Gantenerumab
- GRADUATE 2, investigating Gantenerumab
- LO-MAPT, investigating Omega-3
- NORAD, investigating Guanfacine
- 17-AVP-786-305, investigating AVP-786

3.2.2. Results

The detailed answers regarding the possible participation of research participants in clinical trials can be found in **table 5**, showing the significant differences between European countries as to the number of clinical trials open for recruitment in different countries.

In a marked change from the 2017 Dementia Monitor, there were no countries in which it was possible to participate in all of the openly recruiting trials. Only in three countries was it possible to access four or more phase-III trials (France, Spain and the UK – England). In 17 countries, it was not possible for volunteers to enrol in clinical trials (as none of the identified clinical trials were recruiting in those countries), up from nine in the 2017 Dementia Monitor.

3.2.3. How did we score countries?

Countries could score a maximum of 6 points and were given 1 point for each clinical trial which was recruiting research participants in the country.

Based on the results, it is possible to rank European countries as indicated in **figure 7**, which shows the points expressed as percentages of the maximum possible score.

Figure 7: Ranking of countries on number of clinical trials open for recruitment

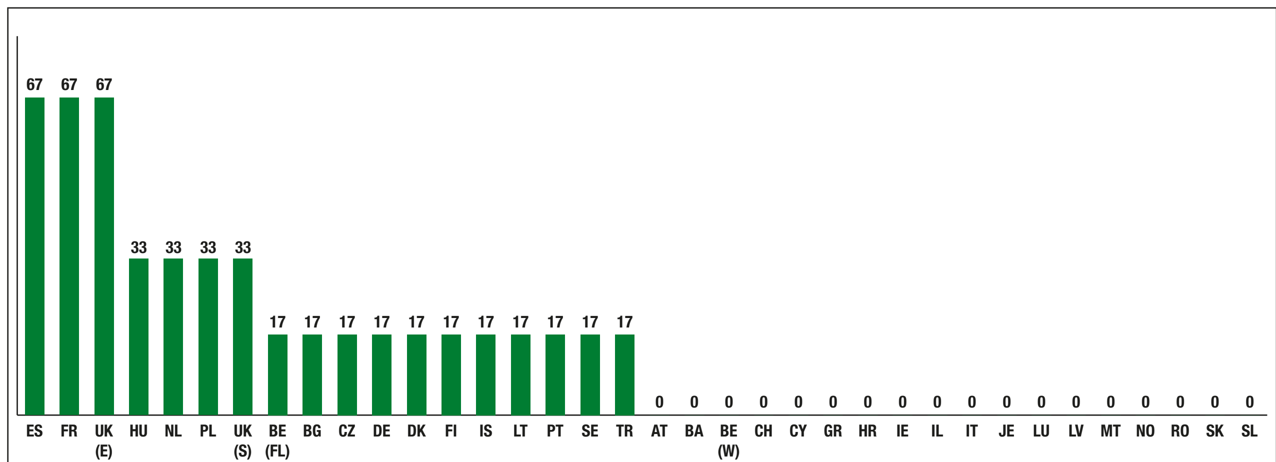


Table 5: Phase III clinical trials open for recruitment in European countries as at December 2019

Country	GAIN (COR388)	GRADUATE 1 (Gantenerumab)	GRADUATE 2 (Gantenerumab)	LO/MAPT (Omega-3)	NORAD (Guanfacine)	17-AVP-786-305 (AVP-786)
AT						
BA						
BE (FL)			✓			
BE (W)						
BG						✓
CH						
CY						
CZ						✓
DE		✓				
DK			✓			
ES	✓	✓	✓			✓
FI			✓			
FR	✓	✓		✓		✓
GR						
HR						
HU		✓				✓
IE						
IL						
IT		✓				
IS						
JE						
LT		✓				
LU						
LV						
MT						
NL	✓		✓			
NO						
PL	✓		✓			
PT			✓			
RO						
SE			✓			
SK						
SL						
TR			✓			
UK (E)	✓		✓		✓	✓
UK (S)	✓		✓			

3.3. Involvement in European dementia research

3.3.1. What did we look at and why?

Since dementia cannot be solved by any country on its own, more and more countries are collaborating and are contributing to pan-European research initiatives. As part of the European Dementia Monitor, Alzheimer Europe looked at the participation of countries in the following research collaborations at EU level:

1. Representation on the Management Board of the EU Joint Programme on Neurodegenerative Diseases Research (JPND)
2. Participation in the 2nd Joint Action on Dementia (JA-DEM2)

In addition, Alzheimer Europe checked whether the country had participated in the following calls:

3. Active and Assisted Living (AAL) 2016 call "Providing integrated solutions based on ICT to support the wellbeing of people living with dementia and their communities"
4. JPND 2019 call on "personalized medicine for neurodegenerative diseases"
5. JPND 2018 call on "health and social care for neurodegenerative diseases"
6. JPND 2017 call on "pathway analysis across neurodegenerative diseases"
7. JPND 2016 call on "harmonisation and alignment in brain imaging methods for neurodegeneration"
8. JPND 2015 call on "risk and protective factors, longitudinal cohort approaches and advanced experimental models"
9. JPND 2014 call for "working groups to inform cohort studies in neurodegenerative disease research"

For this section, Alzheimer Europe used the information publicly available on: www.neurodegenerationresearch.eu, www.aal-europe.eu, and www.actondementia.eu.

3.3.2. Results

The detailed answers showing each country's participation in European dementia research collaborations and funding of pan-European dementia research initiatives can be found in **table 6**.

In relation to the JPND research calls, 2019 saw the highest number of participating countries compared to previous years. Additionally, 29 out of the 36 surveyed countries are on the Management Board of the JPND, however, participation in the pan-European research calls varied considerably. The Active and Assisted Living call (AAL) had the fewest participating countries with only eight countries involved.

Italy and Spain were the most collaborative countries, participating in all programmes and research calls. France, Germany, Luxembourg, Netherlands, Norway, Poland and the UK-England, also participated in a high number of calls. Only Jersey and Lithuania were not involved in any of the above research collaborations, with all other countries involved in at least one of them.

3.3.3. How did we score countries?

Countries could score a maximum of 9 points. For participation in each of the aforementioned categories, countries scored 1 point. Based on the results, it is possible to rank European countries as indicated in **figure 8**, which shows the points expressed as percentages of the maximum possible score.

Figure 8: Ranking of countries on European dementia research collaborations and funding of pan-European dementia research initiatives

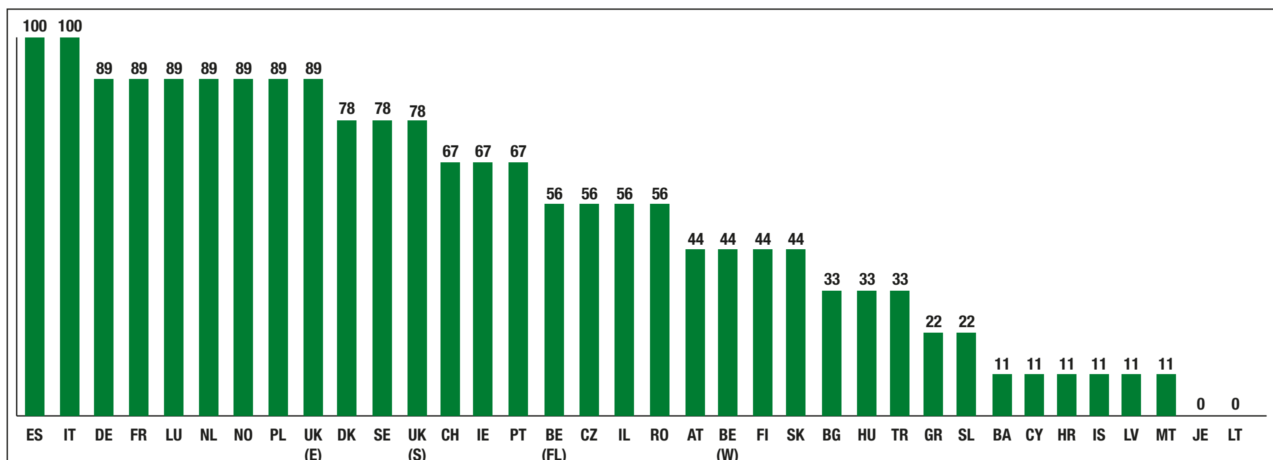


Table 6: Participation in European dementia research collaborations and funding of pan-European dementia research initiatives

	JPND (management board)	2019 JPND (personalised medicine)	2018 JPND (Health and social care)	2017 JPND (pathway analysis)	2016 JPND (brain imaging)	2015 JPND (risk and protective factors)	2014 JPND (cohort studies)	2nd Joint Action (JA-DEM2)	2016 AAL (ICT solutions)
AT	✓					✓	✓		✓
BA	✓								
BE (FL)	✓	✓	✓			✓	✓		
BE (W)	✓	✓				✓	✓		
BG	✓							✓	✓
CH	✓		✓	✓	✓	✓	✓		
CY		✓						✓	
CZ	✓	✓	✓	✓			✓		
DE	✓	✓	✓	✓	✓	✓	✓	✓	
DK	✓	✓	✓	✓	✓	✓	✓		
ES	✓	✓	✓	✓	✓	✓	✓	✓	✓
FI	✓	✓	✓			✓			
FR	✓	✓	✓	✓	✓	✓	✓	✓	
GR							✓	✓	
HR	✓								
HU	✓	✓		✓					
IE	✓	✓	✓	✓	✓		✓		
IL	✓	✓		✓		✓			✓
IS	✓								
IT	✓	✓	✓	✓	✓	✓	✓	✓	✓
JE									
LT									
LU	✓	✓	✓	✓		✓	✓	✓	✓
LV		✓							
MT								✓	
NL	✓	✓	✓	✓	✓	✓	✓	✓	
NO	✓	✓	✓	✓	✓	✓	✓	✓	
PL	✓	✓	✓	✓		✓	✓	✓	✓
PT	✓	✓				✓	✓	✓	✓
RO	✓	✓		✓		✓		✓	
SE	✓	✓	✓	✓	✓	✓	✓		
SL	✓	✓	✓	✓		✓			
SK	✓						✓		
TR		✓	✓			✓			
UK (E)	✓	✓	✓	✓		✓	✓	✓	
UK (S)	✓	✓		✓		✓	✓	✓	

4. Policy issues

4.1. Recognition of dementia as a priority

4.1.1. What did we look at and why?

A number of countries have already published dementia strategies, whilst some are in the process of developing such documents. However, dementia is not yet a priority in all European countries. As well as looking at strategies already in place, we wanted to look further at the public recognition of dementia at a national level.

National Alzheimer's associations are vital to increasing awareness of the growing public health challenge of dementia, so we also looked at how national Alzheimer's associations are funded and whether they receive specific government funding for their core activities and/or specific projects.

As part of our survey, we asked national organisations the following questions:

1. Is dementia recognised as a research priority in your country?
2. Does your country have a national Alzheimer's/ dementia strategy or is a national strategy in development?
3. Does the dementia strategy have specific allocated funding for the implementation of its activities?
4. Is there a government-appointed organisation or person in charge of the overall coordination of dementia policies?
5. Does the national Alzheimer's association receive funding from government programmes for its core activities or central office?
6. Does the national Alzheimer's association receive funding from government programmes for projects or specific services?
7. Has the country attended a meeting of the European Group of Governmental Experts on Dementia?

Question 7 was added to this edition of the Dementia Monitor, following the establishment of the Expert Group in December 2018, bringing together dementia policy leads from countries across Europe.

4.1.2. Results

The detailed answers can be found in **table 7**, with the total numbers of each country, with each policy outlined in **figure 9**.

It is encouraging to see that the number of countries with an existing dementia strategy or one in development continues to increase and currently, there are 27 countries (with Flanders having its own strategy, and separate strategies for England and Scotland in the United Kingdom), compared with 21 countries in the 2017 Dementia Monitor. However, fewer than 50% of countries report that funding had been put in place to implement the strategies or had a dedicated body or person within the government to lead the government's response.

Another positive trend was the slight increase in the number of countries where dementia is considered as a research priority, increasing to 15 countries, from 11 in 2017.

A number of mostly Eastern European countries (Bosnia and Herzegovina, Hungary, Latvia and Romania) did not score any points.

Figure 9: Number of countries with specific dementia policies (out of 36)

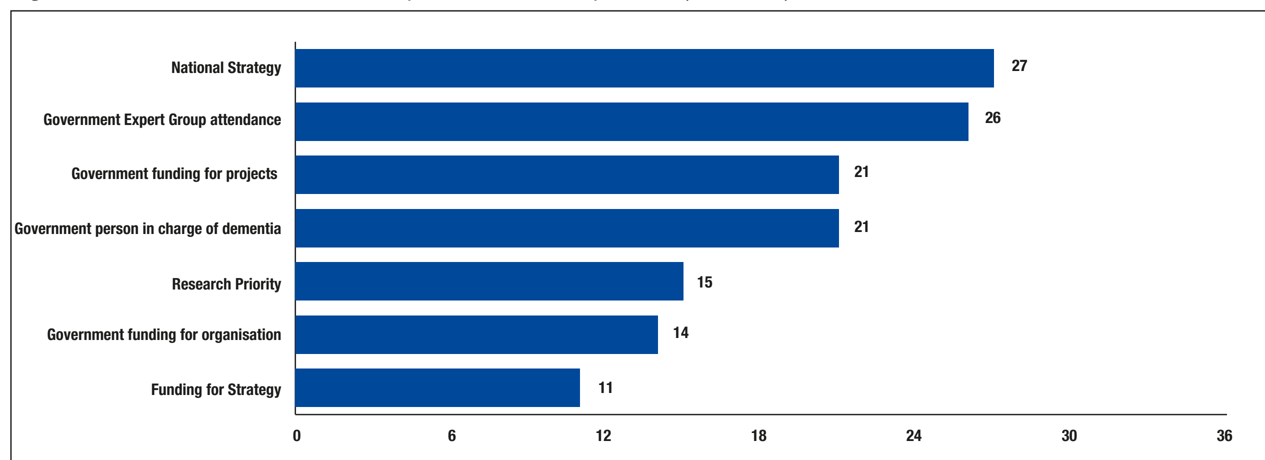


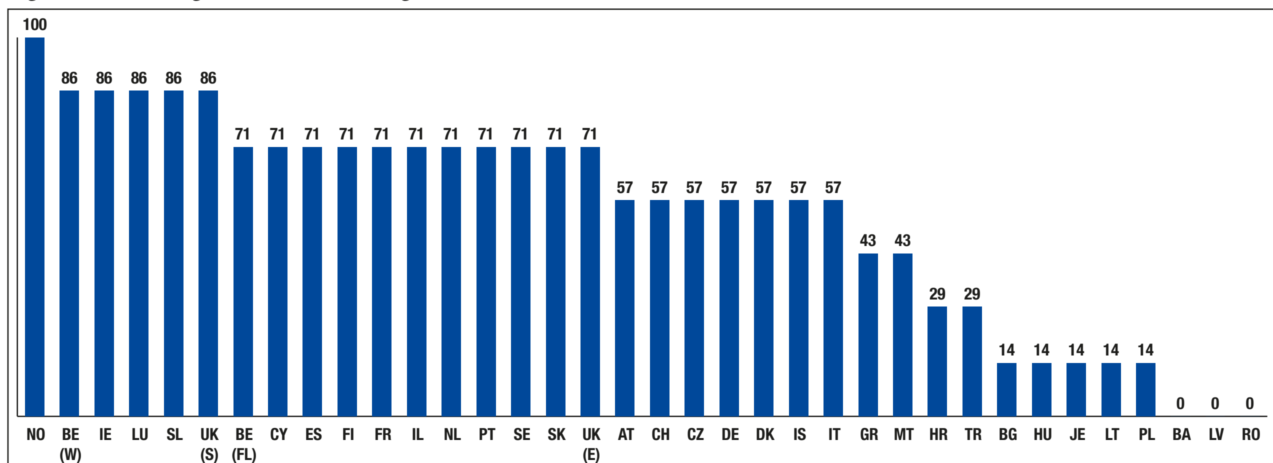
Table 7: Country responses on recognition of dementia as a policy priority

	Research Priority	National Strategy	Funding for Strategy	Government person in charge of dementia	Government funding for Alz Organisation	Government funding for projects	Government Expert Group Attendance
AT		✓		✓	✓		✓
BA							
BE (FL)		✓	✓	✓	✓		✓
BE (W)	✓		✓	✓	✓	✓	✓
BG							✓
CH		✓			✓	✓	✓
CY		✓		✓	✓	✓	✓
CZ		✓		✓		✓	✓
DE	✓	✓				✓	✓
DK	✓	✓	✓			✓	
ES		✓		✓	✓	✓	✓
FI		✓		✓	✓	✓	✓
FR		✓	✓	✓		✓	✓
GR		✓		✓			✓
HR		✓				✓	
HU							✓
IE	✓	✓		✓	✓	✓	✓
IL	✓	✓	✓	✓			✓
IS	✓	✓				✓	✓
IT	✓	✓		✓			✓
JE						✓	
LT	✓						
LU	✓	✓	✓	✓	✓	✓	
LV							
MT		✓		✓			✓
NL	✓	✓	✓			✓	✓
NO	✓	✓	✓	✓	✓	✓	✓
PL							✓
PT		✓		✓	✓	✓	✓
RO							
SE		✓	✓	✓	✓		✓
SL	✓	✓		✓	✓	✓	✓
SK	✓	✓			✓	✓	✓
TR		✓		✓			
UK-E	✓	✓	✓	✓		✓	
UK-S	✓	✓	✓	✓		✓	✓

4.1.3. How did we score countries?

Countries could score a maximum of 7 points and were scored 1 point for each yes answer. Based on the results, it is possible to rank European countries as indicated in **figure 10**, which shows the points expressed as percentages of the maximum possible score.

Figure 10: Ranking of countries on legal issues



4.2. Inclusiveness and dementia-friendly initiatives

4.2.1. What did we look at and why?

"Dementia-friendly communities" is a term used to describe a wide range of activities, projects and initiatives aimed at improving the quality of life for people with dementia. In the absence of a cure, and with the increasing ageing demographic and the rising number of people with dementia, it is important to see how communities are supporting people with dementia to enable them to live well. The dementia-friendly community approach aims at changing the attitudes towards and the perception of people living with dementia, as well as reducing the stigma surrounding dementia.

Dementia Friends programmes are run in a number of European countries to raise awareness of dementia in society and encourage people to take action in support of people with dementia. Some national organisations also set up working groups of people with dementia which work alongside national associations to ensure that the activities, policies and projects duly reflect the priorities, views and needs of people with dementia. Some organisations have also done so for informal caregivers of people with dementia. Alzheimer Europe asked member organisations in how far dementia friendly initiatives have been developed in their country.

4.2.2. Results

The detailed answers regarding inclusiveness can be found in **table 8**.

Wide differences exist across Europe, with only a single country (Belgium – Wallonia) reporting as having working groups for people with dementia and carers, a dementia friends programme and fully developed dementia-friendly communities.

In nine European countries (Bosnia and Herzegovina, Czech Republic, Hungary, Lithuania, Luxembourg, Latvia, Poland, Romania and Slovakia), none of these initiatives have been started. This compares to 14 countries which did not report any of these initiatives in the 2017 Dementia Monitor. Whilst this number is still high, it represents a positive trend that more countries are beginning to develop dementia-inclusive activities.

4.2.3. How did we score countries?

Countries could score a maximum of 5 points. Countries with a national working group of people with dementia or a Dementia Friends programme scored 1 point for each. In this edition of the Dementia Monitor, we also considered the involvement of carers as vital to a dementia-inclusive society. Therefore, we scored countries on whether they had a national working group of informal carers (1 point).

Countries with fully-developed dementia-friendly communities were scored 2 points, and countries with dementia-friendly communities in development were scored 1 point. Based on the results, it is possible to rank European countries as indicated in **figure 11**, which shows the points expressed as percentages of the maximum possible score.

Figure 11: Ranking of countries on dementia-inclusive issues

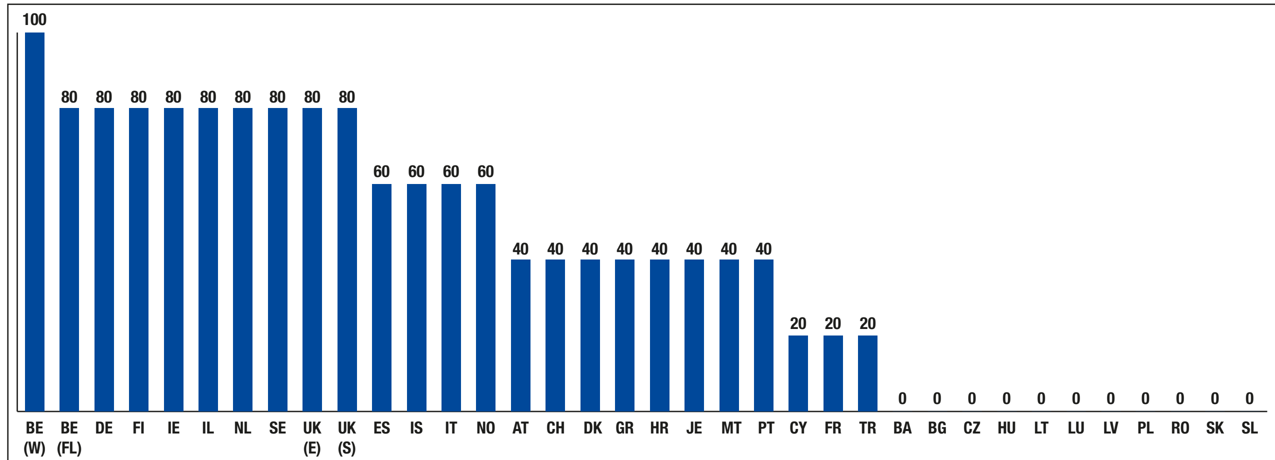


Table 8: Country responses on legal issues

	Working group of persons with dementia	Working group of informal carers	Dementia Friends Programme	Dementia-friendly communities
AT				●
BA				
BE (FL)	●	●		●
BE (W)	●	●	●	●
BG				
CH	●			○
CY			●	
CZ				
DE	●	●	●	○
DK			●	○
ES	●	●		○
FI	●	●	●	○
FR				○
GR				○
HR			●	○
HU				
IE	●	●	●	○
IL			●	●
IS	●	●		○
IT	●	●		○
JE			●	○
LT				
LU				
LV				
MT			●	○
NL	●		●	●
NO	●			●
PL				
PT				○
RO				
SE	●	●	●	○
SK				
SL				
TR			●	
UK-E	●		●	●
UK-S	●	●	●	○

● Developed ○ In development

5. Human rights and legal aspects

5.1. Legal issues

5.1.1. What did we look at and why?

Information on legal issues can serve to empower people with dementia and their carers by ensuring that they are aware of their rights and of certain legal measures designed to offer some form of protection. With regard to health-care decision-making by people with dementia, our survey looked at issues such as the use of advance directives, consent, health care proxies, and financial proxies. Alzheimer Europe asked member associations to answer the following questions on legal issues in their country:

1. Is there a legal framework for advance directives?
2. Are there legal mechanisms for people to appoint or to have appointed health care proxies?
3. Are there legal mechanisms for people to appoint or to have appointed financial proxies?

Alzheimer Europe also examined whether people under guardianship or with limited legal capacity were protected from losing the right to vote, primarily using reports of the Fundamental Rights Agency (for EU countries).

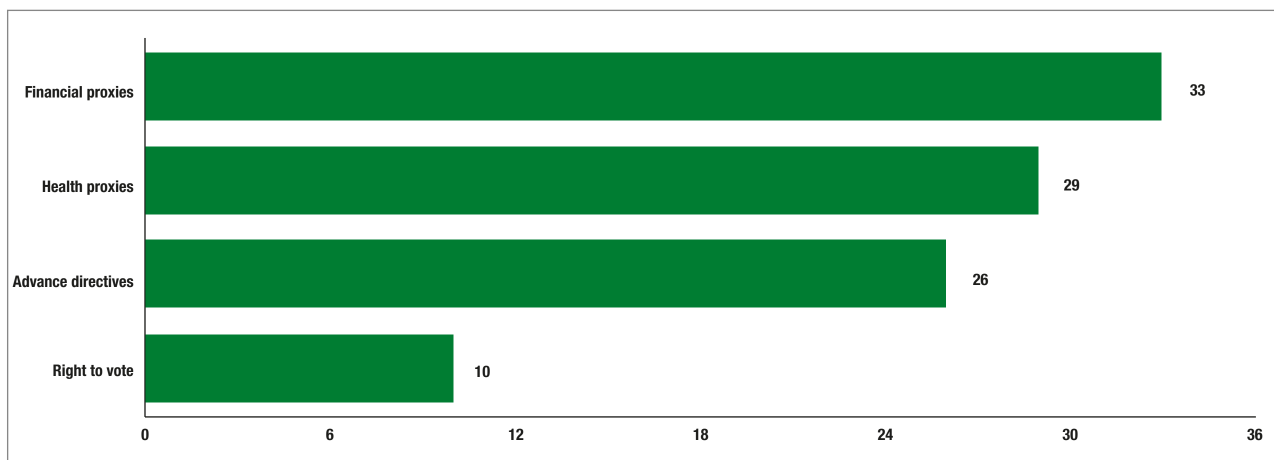
5.1.2. Results

Table 9 provides the full results of the country responses.

Overall, the findings from countries were broadly positive, with eight countries (Austria, Croatia, Israel, Italy, Turkey, UK- England and Scotland) scoring full marks in this section, an increase of two countries compared with 2017. Additionally, slightly more than half of countries scored 75%, having three of the four legal mechanisms in place.

As can be seen from **figure 12**, the majority of countries have legal provisions for at least one of advance directives, health proxies or financial proxies. By contrast, less than a third of countries protect the voting rights of persons under guardianship or who have been deemed to have lost capacity.

Figure 12: Number of countries with specific legal protections (out of 36)



5.1.3. How did we score countries?

Countries could score a maximum of 4 points. Countries were scored 1 point if the different legal safeguards and mechanisms were in place for people with dementia in the country.

Based on the results, it is possible to rank European countries as indicated in **figure 13**, which shows the points expressed as percentages of the maximum possible score.

Figure 13: Ranking of countries on legal issues

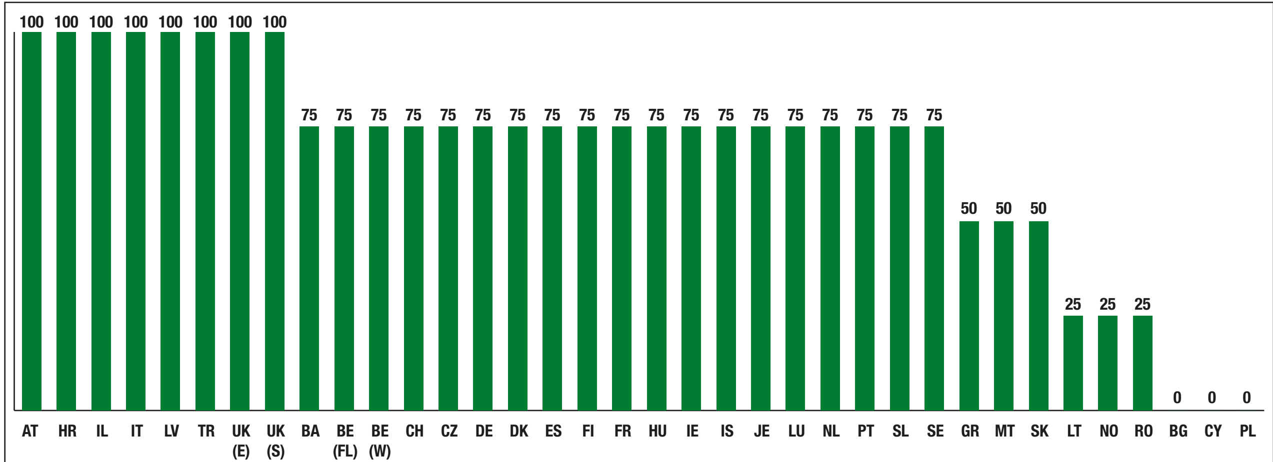


Table 9: Country responses on legal issues

	Advance directives	Health proxies	Financial proxies	Right to vote
AT	✓	✓	✓	✓
BA	✓	✓	✓	
BE (FL)	✓	✓	✓	
BE (W)	✓	✓	✓	
BG				
CH	✓	✓	✓	
CY				
CZ	✓	✓	✓	
DE	✓	✓	✓	
DK	✓	✓	✓	
ES	✓	✓	✓	
FI	✓	✓	✓	
FR	✓	✓	✓	
GR	✓	✓	✓	
HR	✓	✓	✓	✓
HU	✓	✓	✓	
IE	✓	✓	✓	
IL	✓	✓	✓	✓
IS	✓	✓	✓	
IT	✓	✓	✓	✓
JE	✓	✓	✓	
LT			✓	
LU	✓	✓	✓	
LV	✓	✓	✓	✓
MT		✓	✓	
NL		✓	✓	✓
NO			✓	
PL				
PT	✓	✓	✓	
RO			✓	
SE			✓	✓
SK		✓	✓	
SL	✓	✓	✓	
TR	✓	✓	✓	✓
UK (E)	✓	✓	✓	✓
UK (S)	✓	✓	✓	✓

5.2. International and European treaties

5.2.1. What did we look at and why?

It is important to recognise and promote the rights, dignity and autonomy of people living with dementia. These rights are universal, and guaranteed in the European Convention of Human Rights, the Universal Declaration of Human Rights and the Convention on the Rights of Persons with Disabilities.

For this section, Alzheimer Europe used the information publicly available on the following websites: un.org, coe.int, hcch.net to identify whether countries had signed or/and ratified the following European/International Treaties:

1. United Nations Convention Rights of People with Disabilities (UNCRPD)
2. Optional Protocol to the Convention on the Rights of Persons with Disabilities
3. The Hague Convention for the Protection of Vulnerable Adults
4. Council of Europe Convention on Human Rights and Biomedicine
5. Additional Protocol to the Convention on Human Rights and Biomedicine concerning Genetic Testing for Health Purposes
6. Additional Protocol to the Convention on Human Rights and Biomedicine, concerning Biomedical Research.

5.2.2. Results

The detailed answers regarding the signing and ratification of treaties can be found in **table 10**.

With the exception of Jersey, all countries have ratified the UN Convention for the Rights of People with Disabilities, of which, Bulgaria, Czech Republic, Iceland and Romania have signed the Optional Protocol, whilst Ireland, Norway and Poland neither signed nor ratified the Optional Protocol.

Fewer than a third of countries (Austria, Cyprus, Czech Republic, Germany, Finland, France, Latvia, Portugal, Switzerland and the UK – Scotland) have ratified The Hague Convention on the Protection of Vulnerable Adults, whilst a further seven (Belgium [Flanders included], Greece, Ireland, Italy, Luxembourg, Netherlands and Poland), have signed the Convention.

In relation to Council of Europe Conventions and Protocols, over half of the countries have ratified the Council of Europe Convention on Human Rights and Biomedicine, whilst fewer than a quarter have signed or ratified the protocol on genetic testing, with half of countries having signed or ratified the protocol on biomedical research.

Portugal has signed and ratified all of the treaties and protocols covered in this section, the only one of our member countries to have done so. Conversely, Jersey has not signed or ratified any, however, this is explained by its non-state position as a Crown Dependency.

5.2.3. How did we score countries?

Countries could score a maximum of 12 points. For each of the international treaties/conventions, countries received 2 points if they ratified them and 1 point if they only signed them. Based on the results, it is possible to rank European countries as indicated in **figure 14**, which shows the points expressed as percentages of the maximum possible score.

Figure 14: Ranking of countries on ratification and signature of international and European treaties/convention

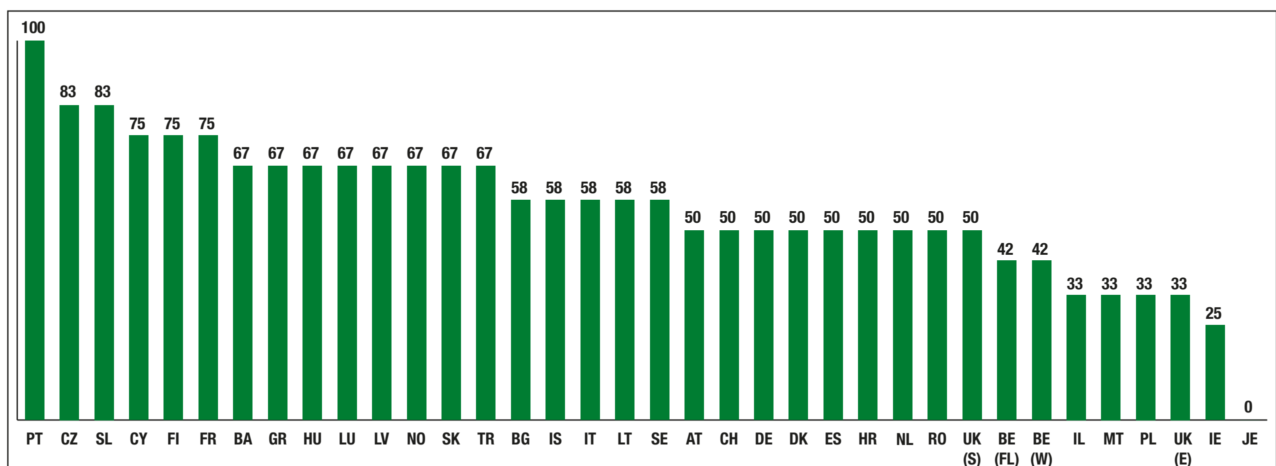


Table 10: Signature and ratification of treaties

	UN Convention on people with disabilities	UNCRPD optional protocol	Hague Convention on protection of adults	CoE Human Rights Biomedicine Convention	CoE Genetic testing protocol	CoE Protocol Biomedical Research
AT	Signed and ratified	Signed and ratified	Signed and ratified	Absent	Absent	Absent
BA	Signed and ratified	Signed and ratified	Absent	Signed and ratified	Absent	Signed and ratified
BE (FL)	Signed and ratified	Signed and ratified	Signed	Absent	Absent	Absent
BE (W)	Signed and ratified	Signed and ratified	Signed	Absent	Absent	Absent
BG	Signed and ratified	Signed	Absent	Signed and ratified	Absent	Signed and ratified
CH	Signed and ratified	Absent	Signed and ratified	Signed and ratified	Absent	Absent
CY	Signed and ratified	Signed and ratified	Signed and ratified	Signed and ratified	Absent	Signed
CZ	Signed and ratified	Signed	Signed and ratified	Signed and ratified	Signed and ratified	Signed
DE	Signed and ratified	Signed and ratified	Signed and ratified	Absent	Absent	Absent
DK	Signed and ratified	Signed	Absent	Signed and ratified	Absent	Signed
ES	Signed and ratified	Signed and ratified	Absent	Signed and ratified	Absent	Absent
FI	Signed and ratified	Signed and ratified	Signed and ratified	Signed and ratified	Signed	Absent
FR	Signed and ratified	Signed and ratified	Signed and ratified	Signed and ratified	Signed	Absent
GR	Signed and ratified	Signed and ratified	Signed	Signed and ratified	Absent	Signed
HR	Signed and ratified	Signed and ratified	Absent	Signed and ratified	Absent	Absent
HU	Signed and ratified	Signed and ratified	Absent	Signed and ratified	Absent	Signed and ratified
IE	Signed and ratified	Absent	Signed	Absent	Absent	Absent
IL	Signed and ratified	Signed and ratified	Absent	Absent	Absent	Absent
IS	Signed and ratified	Signed	Absent	Signed and ratified	Signed	Signed
IT	Signed and ratified	Signed and ratified	Signed	Signed	Absent	Signed
JE	Absent	Absent	Absent	Absent	Absent	Absent
LT	Signed and ratified	Signed and ratified	Absent	Signed and ratified	Absent	Signed
LU	Signed and ratified	Signed and ratified	Signed	Signed	Signed	Signed
LV	Signed and ratified	Signed and ratified	Signed and ratified	Signed and ratified	Absent	Absent
MT	Signed and ratified	Signed and ratified	Absent	Absent	Absent	Absent
NL	Signed and ratified	Signed and ratified	Signed	Signed	Absent	Absent
NO	Signed and ratified	Absent	Absent	Signed and ratified	Signed and ratified	Signed and ratified
PL	Signed and ratified	Absent	Signed	Signed	Absent	Absent
PT	Signed and ratified	Signed and ratified	Signed and ratified	Signed and ratified	Absent	Signed and ratified
RO	Signed and ratified	Signed	Absent	Signed	Absent	Signed
SE	Signed and ratified	Signed and ratified	Absent	Signed and ratified	Absent	Signed
SK	Signed and ratified	Signed and ratified	Absent	Signed and ratified	Signed and ratified	Signed and ratified
SL	Signed and ratified	Signed and ratified	Absent	Signed and ratified	Absent	Signed and ratified
TR	Signed and ratified	Signed and ratified	Absent	Absent	Absent	Signed and ratified
UK (E)	Signed and ratified	Signed and ratified	Signed and ratified	Absent	Absent	Absent
UK (S)	Signed and ratified	Signed and ratified	Signed and ratified	Absent	Absent	Absent

● Signed and ratified ● Signed ○ Absent

5.3. Carer and employment support

5.3.1. What did we look at and why?

People can be diagnosed with dementia during their working years and are able to live well and continue to work, thus it is important for them to also know their rights and for systems to be flexible enough to allow people with dementia to continue in employment for as long as possible. As the condition progresses, people with dementia will generally require increasing levels of care, most of which is provided by informal or family caregivers. The majority of carers do not access formal services and therefore could be missing out on valuable support. It is therefore important for governments to provide adequate support to carers via a carer's allowance and via flexible mechanisms which allow carers to combine care with work.

Alzheimer Europe asked its member associations to answer the following questions about employment and carer support in their countries:

1. Are there any provisions in laws/legal framework to protect the rights of people with dementia in employment?
2. Is there a public mechanism for carers to receive a carer's allowance?
3. Is there a statutory right for workers to have paid leave when caring for someone with dementia?
4. Is there a statutory right to flexible working hours when caring for someone with dementia?
5. Is there a statutory right for workers to have unpaid leave when caring for someone with dementia?

5.3.2. Results

The detailed answers regarding support for employment and carers can be found in **table 11**.

Although the majority of countries had some form of carer's allowance, all the other employment rights were only recognised in a minority of European countries. Only Belgium (Flanders and Wallonia) received full marks in this section, as all employment and carers' rights were recognised in the country.

In a number of mostly Eastern European countries (Bosnia and Herzegovina, Croatia, Cyprus, Greece, Hungary and Poland), none of these rights were recognised.

Figure 15 shows the total number of countries who provide supports for the rights of carers and people with dementia. Consistent with the 2017 Dementia Monitor, a majority of countries offer some form of carer's allowance. However, fewer than half offer the right to unpaid carer's leave, with less than a third having legal protections in place in relation to employment rights for people with dementia, paid leave for carers or the right to flexible working hours.

Figure 15: Number of countries with employment and carers protection (out of 36)

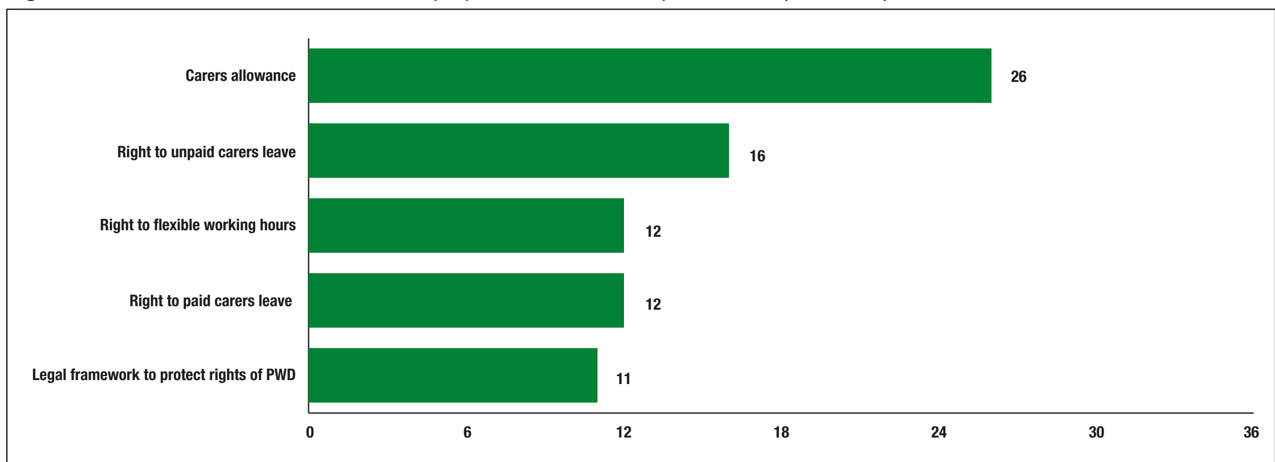


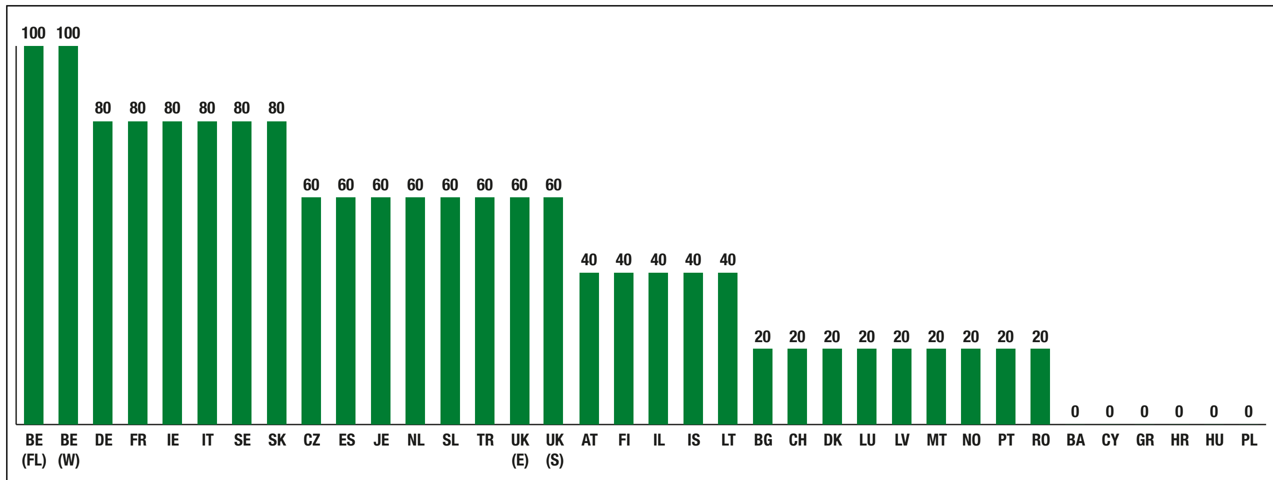
Table 11: Carers' and employment rights recognised in participating countries

	Legal framework to protect employment rights of PWD	Carers allowance	Right to paid carers leave	Right to flexible working hours	Right to unpaid carers leave
AT		✓	✓		
BA					
BE (FL)	✓	✓	✓	✓	✓
BE (W)	✓	✓	✓	✓	✓
BG					✓
CH		✓			
CY					
CZ			✓	✓	✓
DE	✓	✓	✓		✓
DK		✓			
ES		✓		✓	✓
FI		✓			✓
FR	✓	✓		✓	✓
GR					
HR					
HU					
IE		✓	✓	✓	✓
IL				✓	✓
IS	✓	✓			
IT	✓		✓	✓	✓
JE	✓	✓		✓	
LT		✓			✓
LU		✓			
LV		✓			
MT		✓			
NL		✓	✓		✓
NO		✓			
PL					
PT		✓			
RO		✓			
SE		✓	✓	✓	✓
SL	✓	✓	✓		
SK		✓	✓	✓	✓
TR	✓	✓	✓		
UK (E)	✓	✓		✓	
UK (S)	✓	✓			✓

5.3.3. How did we score countries?

Countries could score a maximum of five points and received 1 point for each of the employment-related rights which were guaranteed in the country. Based on the results, it is possible to rank European countries as indicated in **figure 16**, which shows the points expressed as percentages of the maximum possible score.

Figure 16: Ranking of countries on carer and employment rights



6. Overall ranking

Table 12 shows the rank each country was able to achieve in each of the ten categories, with the country (or countries) who have finished at the top of the rankings, highlighted in **blue**.

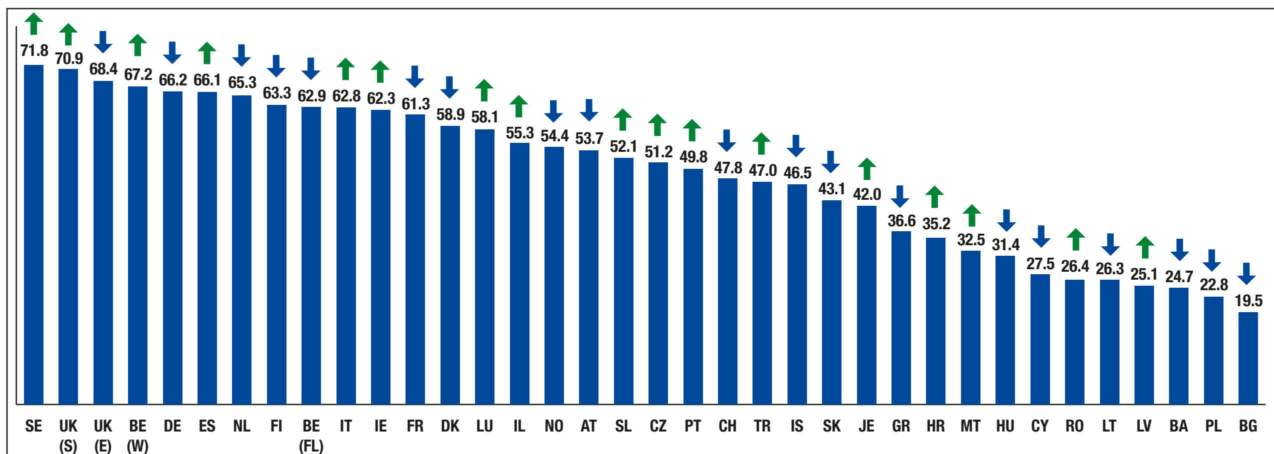
The UK – England, had the highest number (3) of categories in which it ranked first place, with Belgium (Wallonia), Italy, Luxembourg, Spain, Sweden, Turkey and the UK (Scotland) ranking first in 2 categories. Austria, Belgium (Flanders), Croatia, Finland, France, Ireland, Israel, Latvia, Norway, Portugal and Spain, also ranked first in a single category.

In order to calculate the overall ranking of countries, we based the global score on a combined score of the ten different categories with each contributing 10% to the overall score. This score is presented as a percentage of the overall maximum score which countries could have achieved and leads to the following ranking as shown in **figure 17**. In this figure, we also show whether countries have increased their overall percentage score, compared to the 2017 Monitor.

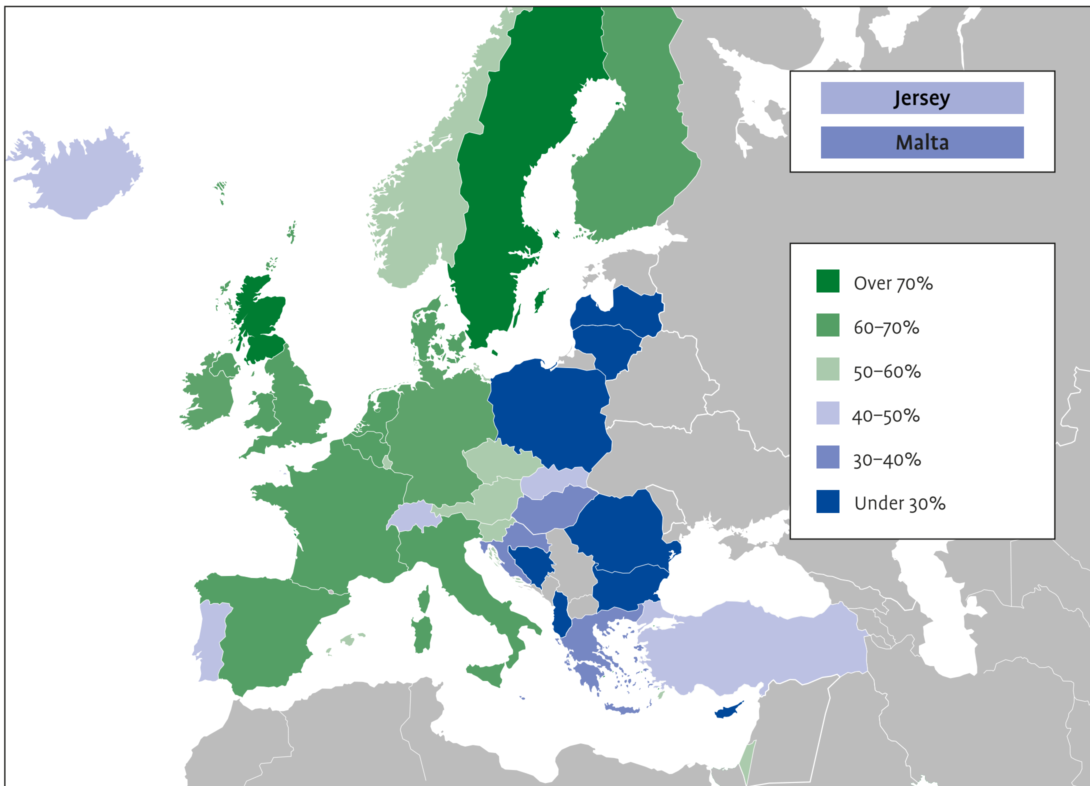
According to the overall ranking, Sweden and the UK – Scotland, were the countries which had the most dementia-friendly policies in place, with Bulgaria and Poland the countries which need to make the most progress and reforms to improve the dementia friendly policies in their countries.

When looking at the map of Europe (see **map 5**), we can see that there are significant differences across Europe with countries in Northern and Central Europe generally scoring better than countries in Southern Europe.

Figure 17: Overall ranking of countries



Map 5: Overall score of European countries



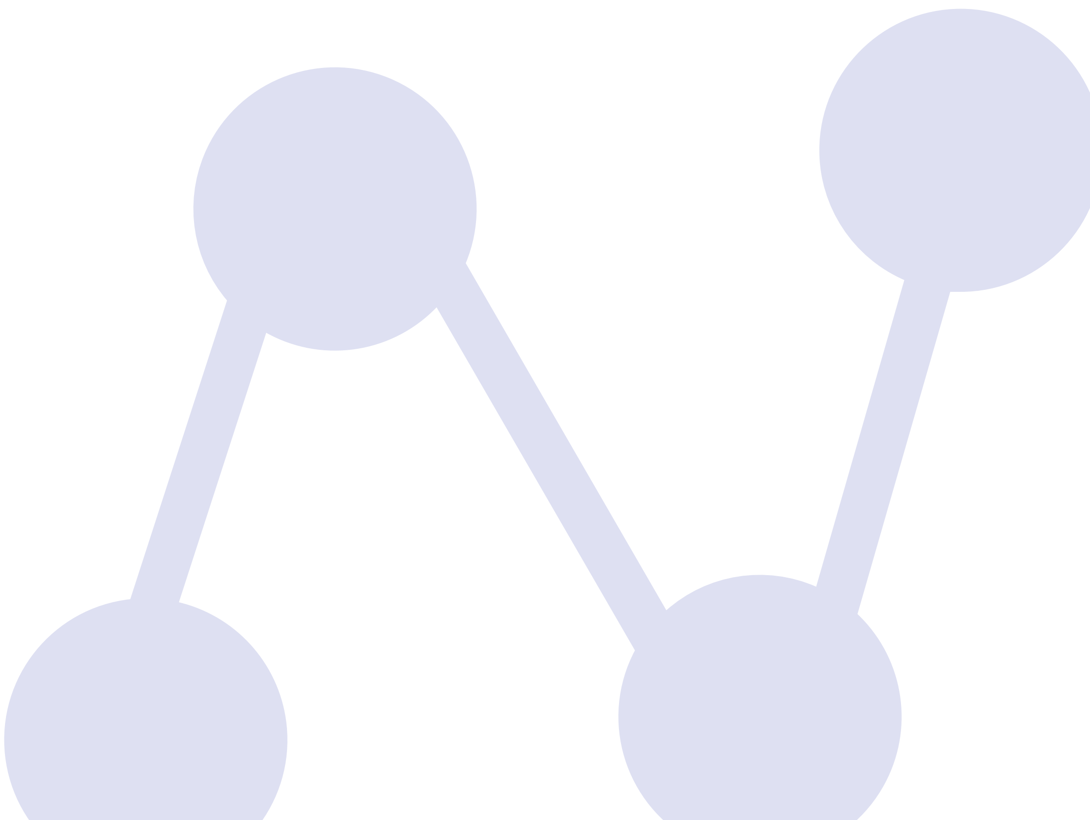


Table 12: Ranking of countries per category

	Care Availability	Care Affordability	Treatment	Clinical Trials	Research Collaboration
AT	5	18	7	19	20
BA	22	26	32	19	29
BE(FL)	3	18	20	8	16
BE (W)	6	9	7	19	20
BG	36	36	26	8	24
CH	12	18	17	19	13
CY	25	33	26	19	29
CZ	15	13	20	8	16
DE	11	11	7	8	3
DK	6	2	7	8	10
ES	12	18	16	1	1
FI	6	1	20	8	20
FR	18	5	32	1	3
GR	29	30	7	19	27
HR	18	17	31	19	29
HU	31	30	26	4	24
IE	25	8	1	19	13
IL	4	12	26	19	16
IS	15	13	24	8	29
IT	18	23	7	19	1
JE	6	5	7	19	35
LT	29	23	26	8	35
LU	1	13	1	19	3
LV	33	27	36	19	29
MT	22	9	32	19	29
NL	10	13	17	4	3
NO	14	3	23	19	3
PL	31	34	32	4	3
PT	28	27	24	8	13
RO	34	35	7	19	16
SE	1	4	1	8	10
SK	25	27	17	19	20
SL	18	18	7	19	27
TR	34	32	1	8	24
UK(E)	22	25	1	1	3
UK(S)	15	5	1	4	10

Table 12: Ranking of countries per category continued

	Dementia as a Priority	Dementia Inclusiveness	Legal Rights	International Conventions	Care and Employment Rights
AT	18	15	1	19	17
BA	34	26	9	7	31
BE(FL)	7	2	9	29	1
BE (W)	2	1	9	29	1
BG	29	26	34	15	22
CH	18	15	9	19	22
CY	7	23	34	4	31
CZ	18	26	9	2	9
DE	18	2	9	19	3
DK	18	15	9	19	22
ES	7	11	9	19	9
FI	7	2	9	4	17
FR	7	23	9	4	3
GR	25	15	28	7	31
HR	27	15	1	19	31
HU	29	26	9	7	31
IE	2	2	9	35	3
IL	7	2	1	31	17
IS	18	11	9	15	17
IT	18	11	1	15	3
JE	29	15	9	36	9
LT	29	26	31	15	17
LU	2	26	9	7	22
LV	34	26	1	7	22
MT	25	15	28	31	22
NL	7	2	9	19	9
NO	1	11	31	7	22
PL	29	26	34	31	31
PT	7	15	9	1	22
RO	34	26	31	19	22
SE	7	2	9	19	3
SK	7	26	28	7	9
SL	2	26	9	2	3
TR	27	23	1	7	9
UK(E)	7	2	1	31	9
UK(S)	2	2	1	19	9

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