

# European Dementia Monitor 2023

Comparing and benchmarking national dementia strategies and policies



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# European Dementia Monitor 2023

Comparing and benchmarking national dementia strategies and policies

## 1. Introduction

## 1.1. Background and objectives of this publication

Since the launch of its Paris (2006) and Glasgow (2014) Declarations, Alzheimer Europe has been campaigning for the recognition of Alzheimer's disease (AD) and dementia as European and national policy and research priorities. In particular, Alzheimer Europe has been 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 a number of positive developments in this area, with an increasing number of countries having developed such strategies.

However, from our members we learn that policy implementation is often slow, with support and services often insufficient to meet the needs of people with dementia and their carers. Alzheimer Europe has therefore surveyed members to better understand the differences across

European countries and to track progress over time when it comes to the state of care, treatment, research, policies and laws related to dementia.

The 2023 edition of the European Dementia Monitor provides an update on the 2020 and 2017 publications and examines 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 Monitors. The four overarching categories and 10 sub-categories had previously been 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 2023 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
  - 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 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 website of the Joint Programme for Neurodegenerative Diseases Research (www. neurodegenerationresearch.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.

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 2020 Dementia Monitor survey to its member organisations across Europe, asking them to fill in and return the survey. Alzheimer Europe also reached out to its new member organisations in Armenia, Estonia, Lithuania, North Macedonia, Serbia and Ukraine, but was no longer able to include information on Bosnia and Herzegovina or Latvia.

Overall, all contacted member organisations from 37 European countries returned the questionnaire.

**Table 1** shows all countries for whom data has been included within the report (and their country abbreviations). As for previous editions of the Monitor, we received

separate responses from England and Scotland and included both responses for the United Kingdom where the responses differed.

Table 1: Countries included within the report

AM	Armenia	New
AT	Austria	
BE	Belgium	
BG	Bulgaria	
СН	Switzerland	
CY	Cyprus	
CZ	Czech Republic	
DE	Germany	
DK	Denmark	
EE	Estonia	New
ES	Spain	
FI	Finland	
FR	France	
GR	Greece	
HR	Croatia	
HU	Hungary	
IE	Ireland	
IL	Israel	
IS	Iceland	
IT	Italy	
JE	Jersey	
LT	Lithuania	
LU	Luxembourg	
МК	North Macedonia	New
MT	Malta	
NL	Netherlands	
NO	Norway	
PL	Poland	
PT	Portugal	
RO	Romania	
RS	Serbia	New
SE	Sweden	
SI	Slovenia	
SK	Slovakia	
TR	Turkey	
UA	Ukraine	New
UK-E	United Kingdom – England	
UK-S	United Kingdom - Scotland	

## 1.3. Limitations of the report

As shown in **table 1**, it was possible this time to fully update the report for all countries and include information from five additional countries. We were unfortunately unable to update information from Bosnia and Herzegovina and Latvia and therefore decided to exclude information from these countries rather than including incomplete or out-of-date information.

The subjective nature of some of the questions within the questionnaire should be considered, especially whether care services are "available" or "affordable". However, since Alzheimer Europe's member organisations work with and support people with dementia, their families and carers, their views most likely accurately reflect the experience of people living with dementia.

Furthermore, some 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 only pay for a patient's medications once a set amount has been reached (therefore the cost of Alzheimer's drugs may not be covered, unless the person has multiple medications and therefore exceeding this threshold). 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.

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 previous editions of the Dementia Monitor, the survey sent to members asked about a 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 2023, who shortened the list of services from 18 to 10.

The following 10 care services were identified by Alzheimer Europe members as having the greatest significance and impact on the quality of life of people with dementia and their carers:

- 1. Adaptations to the home
- 2. Alzheimer Cafés
- 3. Care coordination/Case management
- 4. Carer training
- 5. Day care
- 6. Home care
- 7. Respite care at home
- 8. Support groups for carers
- 9. Support groups for people with dementia
- 10. Residential/Nursing home care

Alzheimer organisations and national experts were asked to indicate whether they believed these services were sufficiently available, insufficiently available or absent 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 2020 Dementia Monitor, the vast majority of care services in Europe continue to be insufficiently available.

Only three countries (Denmark, Luxembourg and Norway) reported that at least 50% of the aforementioned services were sufficiently available.

None of the care services we looked at were reported as sufficiently available in Bulgaria, Cyprus, France, Greece, Hungary, Ireland, Israel, Italy, Jersey, Lithuania, North Macedonia, Poland, Romania, Serbia, Spain, Turkey, Ukraine and the United Kingdom (both England and Scotland).

As per **Figure 1 (see page 8)**, the types of services rated as sufficiently available varies considerably, with support groups for carers being rated as sufficiently available in 11 countries (out of 37), with care coordination (only in Denmark) and day care (only in Iceland and Luxembourg) having the lowest availability.

As the number of services was reduced from 18 to 10 since the last Dementia Monitor, it is difficult to draw any clear conclusions as to the trends in the provision of care services over the past three years.

However, as with the 2020 Dementia Monitor, it is possible to see clear differences between countries when it comes to the availability of carer services. As can be seen from Map 1 (see page 8), home care is sufficiently available as a service in a limited number of smaller and mainly Central, Northern and Western European countries, whereas this service was considered not to be available by the association in Bulgaria.

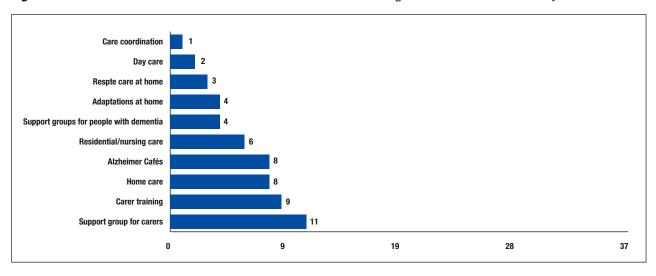
Similarly, support groups for carers were considered to be sufficiently available only in a limited number of countries spread across different regions of Europe. As can be seen from **Map 2** (see page 9), support groups for carers were deemed to be unavailable in countries such as Bulgaria and Turkey

**Table 2:** Availability of care services

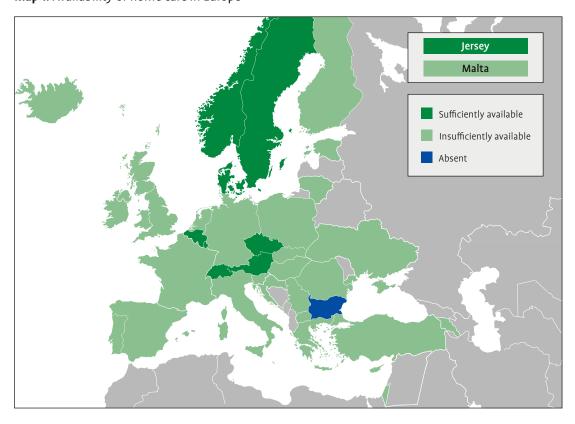
	Adaptations to the home	Alzheimer Cafés	Care coordination	Carer training	Day care	Home care	Respite care at home	Support groups for carers	Support groups for people with dementia	Residential / nursing care
AM	•	•	•	•		•	0	•	•	•
AT	•	•	•	•		•	•	•	•	•
BE	•	•	•	•		•	•	•	•	
BG	0	•	0	0		0	0	0	0	
СН	•	•	•	•		•	0	•	•	•
CY	•	0	•	0		•	0	•	•	•
CZ	•	•	•	•	•	•	•	•	•	•
DE	•	0	•	•	•	•	•	•	•	•
DK	•	•	•	•	•	•	•	•	•	•
EE	•	•	•	0	•	•	•	•	0	•
ES	•	•	•	•	•	•	•	•	•	•
FI	•	•	•	•	•	•	•	•	•	•
FR	•	•	•	•	•	•	•	•	•	•
GR	•	•	•	•	•	•	•	•	•	•
HR	•	•	0	•	•	•	0	•	•	•
HU	0	•	•	•	•	•	0	•	•	•
IE	•	•	0	•	•	•	•	•	•	•
IL	•	0	•	•	•	•	•	•	0	•
IS	•	•	•	•	•	•	•	•	•	•
IT	•	•	•	•	•	•	•	•	•	•
JE	•	0	0	•		•	•	•	•	•
LT	•	•	•	•	•	•	•	•	•	•
LU	•	0	•	•	•	•	•	•	•	•
MK	0	•	•	•	0	•	0	•	•	•
MT	0	•	•	•	•	•	•	•	•	•
NL	•	•	•	•	•	•	•	•	•	•
NO	•	•	•	•	•	•	•	•	•	•
PL	•	0	0	•	•	•	•	•	0	•
PT	•	•	0	•	•	•	0	•	•	•
RO	•	•	•	•	•	•	0	•	•	•
RS	•	0	•	•	•	•	0	•	0	•
SE	•	•	•	•	•	•	•	•	•	•
SI	•	•	0	•	•	•	•	•	•	•
SK	•	0	0	•	•	•	•	•	•	•
TR	0	0	•	•	•	•	0	0	0	•
UA	•	•	•	•	0	•	•	•	0	•
UK-E	•	•	•	•	•	•	•	•	•	•
UK-S	•		•	•	•	•	•	•	•	•

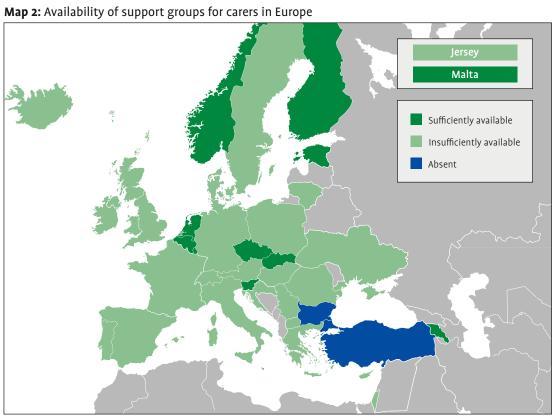
Sufficiently available Insufficiently available O Not available / absent

**Figure 1** shows the different services and the number of countries rating these services as sufficiently available.



Map 1: Availability of home care in Europe





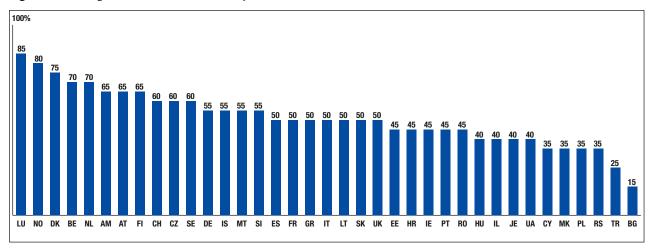


## 2.1.3 How did we score countries?

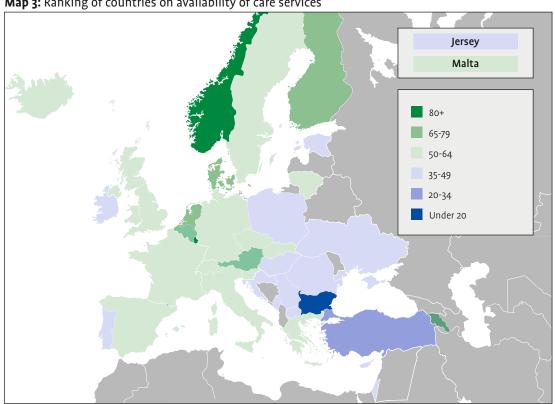
Countries could score a maximum of 20 points. For each of the 10 services, countries were scored 2 points if the service was ranked as sufficiently available, 1 point if it was ranked as insufficiently available and o points if it was not available

at all. 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



Map 3: 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, Alzheimer Europe asked member organisations to rate these services on how accessible they are 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 or partially funded through health insurance or social programmes, or whether people with dementia and their families had to self-fund to access these services.

#### 2.2.2. Results

The detailed answers regarding the financing of care services can be found in table 3 (see page 12).

Very few countries provide full funding for a majority of these services, with Denmark, Finland, Malta, Norway and the United Kingdom (Scotland) being the only countries which have at least 5 of these services being fully funded. By comparison, there are more countries in which 50% or more of these services are either absent or fully self-funded. This is the case in Bulgaria, Cyprus, Israel, Jersey, North Macedonia, Romania, Serbia, Switzerland, Turkey and Ukraine.

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 partial funding for services, with Alzheimer Cafés the only service for which a minority of countries provide some level of funding. The most commonly publicly funded services included day care, residential care and home care.

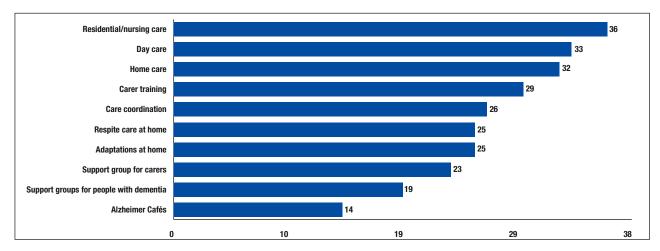
As in the previous section, the picture is mixed in relation to how services are funded:

- The majority of services continue to be funded (at least in part) in the majority of countries.
- Disappointingly, a significant number of countries (10) have a majority of services (50% or above) which need to be self-funded by the person with dementia and his/her family.
- Bulgaria was the only country where there was no public support for any of the listed care services according to Alzheimer Bulgaria.

#### 2.2.3 How did we score countries?

Countries could score a maximum of 20 points. Countries were scored 2 points if the service is fully funded, 1 point if the service is partly funded, and o 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 (see page 13), which shows the points expressed as percentages of the maximum possible score.

Figure 3 shows the number of countries in which there is some public funding (either full or partial) for the service in question.



**Table 3:** Financing of care services

	Adaptations to the home	Alzheimer Cafés	Care coordination	Carer training	Day care	Home care	Respite care at home	Support groups for carers	Support groups for people with dementia	Residential / nursing care
AM	•	•			•	•	0	•	•	•
AT		•	•	•				•	•	
BE			•						•	
BG	0	•	0	0	•	0	0	0	0	•
СН	•	•		•		•	0	•	•	
CY	•	0		0	•	•	0	•	•	•
CZ	•	•		•						
DE	•	0	•	•			•			
DK	•	•	•	•	•	•	•			•
EE	•	•	•	•	•			•	0	
ES	•	•						•	•	•
FI	•	•	•	•				•	•	
FR	•	•	•			•	•	•	•	
GR	•						•	•	•	
HR	•		0			•	0	•	•	
HU	•						0	•	0	
IE	•		0				•	•		
IL	•	0	•	•		•	•	•	0	
IS	•	•			•		•	•	•	•
IT	•		•			•	•	•	•	
JE	•	0	0	•				•	•	
LT	•	•					•	•	•	•
LU		•						•	•	
MK	0			•	0		0	•	•	
MT	0	0	•		•	•	•	•	•	•
NL			•			•				
NO			•	•	•	•	•	•	•	
PL			•				•	•	•	
PT	•		0				0	•	•	
RO	•	•				•	0	•	•	
RS	•	0	•		1		•	•	0	
SE	•		•					•	•	
SI			0							
SK	•	0	0				•	•	•	
TR	0	0	•	•	•		0	0	0	
UA	•	•			0			•	0	
UK-E	•	•	•					•	•	
UK-S			•			•		•	•	

Fully funded

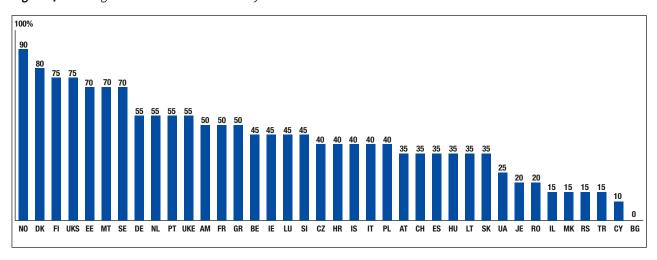
Partially funded

Self-funded

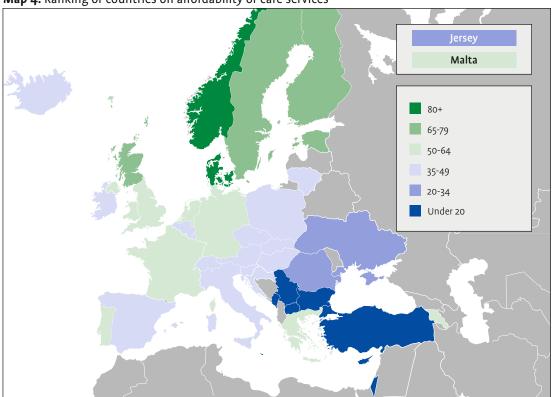
O Not available

<sup>1</sup> Two local governments (Subotica and Kragujevac) provide and finance day care.

Figure 4: Ranking of countries on affordability of care services



Map 4: Ranking of countries on affordability of care services



## 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 way¹ 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 and 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.

In addition to updating these questions which were already asked for the 2020 Monitor, Alzheimer Europe and its members decided to also identify whether the following interventions were fully, partly or not at all covered by national health systems:

- Medical food such as Fortasyn Connect
- Amyloid imaging for the differential diagnosis of Alzheimer's disease
- Incontinence help

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.

Finally, research into new treatments is progressing and disease modifying treatments have been authorised by the FDA for the treatment of mild cognitive impairment due to Alzheimer's disease and mild Alzheimer's dementia.

A decision by the European Medicines Agency is expected by the beginning of 2024. The introduction of these medicines will require investments to improve the infrastructure for timely diagnosis and for the infusion of these new medicines. Therefore, Alzheimer Europe also included a question on whether countries had set up a working group or other action to prepare for the advent of disease-modifying treatments.

## 3.1.2. Results

The detailed answers regarding the reimbursement of medicines, medical food, amyloid imaging and incontinence help can be found in **table 4** and the existence of strategies for the reduction of anti-psychotics and of government action on disease-modifying treatments can be found in **maps 5** and 6 (see pages 16 and 17).

There has been little change from the 2020 Dementia Monitor, with most countries offering some level of reimbursement for at least one or more acetylcholinesterase inhibitors. Only Armenia, France and Ukraine do not reimburse any of the currently available Alzheimer's medicines.

For the newly included interventions, we found the following information:

- Amyloid imaging is not available in all European countries and is only reimbursed in about half of the covered countries. At the same time, associations reported that access to amyloid imaging is limited to specific situations and populations and not generally available for the diagnosis of Alzheimer's disease.
- Fortasyn Connect is only available in a limited number of countries and with the exception of a pilot project in Sweden is not currently reimbursed.
- Incontinence help is available in all European countries and only six countries (Armenia, Bulgaria, Croatia, Cyprus, Greece and Romania) provide no financial support.

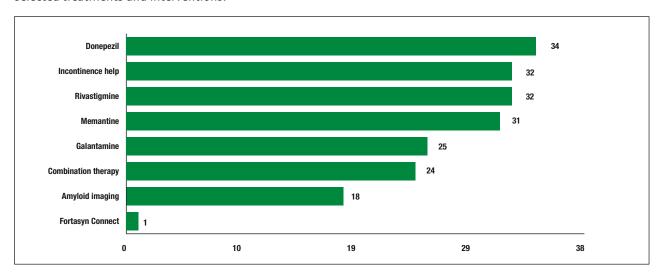
Table 4: Reimbursement/coverage rates for medicines, medical food, amyloid imaging and incontinence help

	Donepezil	Rivastigmine	Galantamine	Memantine	Combination therapy	Fortasyn Connect	Amyloid imaging	Incontinence help
AM	•	•	•	•	•	•	•	•
AT		•	•	•			•	•
BE		•			•	•	•	
BG	•	•	•	•	•	0	•	•
СН	•	•	•	•	•	•	•	•
CY	•	•	0	•	•	0	•	•
CZ	•	•	•	•	•	0	•	•
DE	•	•	•	•	•	•	•	•
DK	•	•	•	•	•	0	•	•
EE		•	•	•	•	•	•	•
ES	•	•	•	•	•	0	•	
FI							•	•
FR		•	•	•		•	•	•
GR	•	•	•	•	•	•	•	•
HR			0	•		0	•	•
HU	•	•	0	•	•	0	•	•
IE	•	•	•	•	•		•	•
IL	•	•	0	•	•	0	•	•
IS	•	•	•	•		0	•	•
IT	•	•	•	•	•		•	•
JE	•	•	•	•	•	0	•	•
LT	•	•	•	•	•	0	•	•
LU	•	•	•	•	•	•	•	•
MK		0	0	•		0	•	•
MT	•	•	•	•	•		•	•
NL	•	•	•	•	•	0	•	•
NO		•	•	•	•	0	•	•
PL <sup>1</sup>	• •	• •	0	• •	• •	0	•	
PT		•				0	•	•
RO	•	•	•	•	•	0		•
RS			•			0	0	•
SE	•		•	•	•	2	•	•
SI	•	•	•	•	•	0	•	•
SK	•	•	•	•	•	•	•	•
TR	•	•	0	•	•	0	0	
UA	•	•	•	•	•	0	•	•
UK-E	•	•	•	•	•		0	•
UK-S		•	•	•		•	•	•

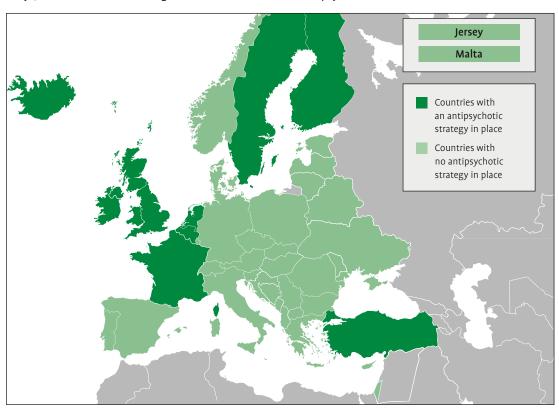
<sup>1</sup> Reimbursement is only available in two regions in Sweden (one of them as a temporary pilot).

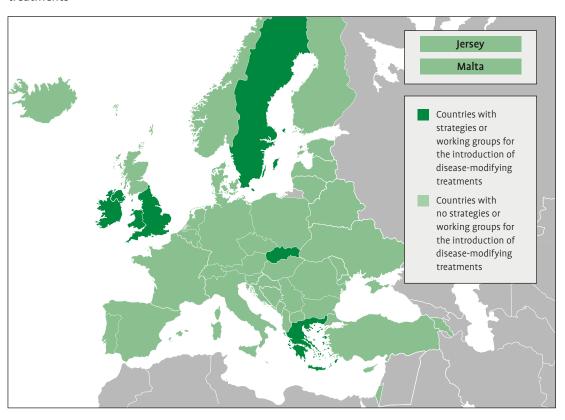
<sup>2</sup> Medicines are fully reimbursed for people over 75 in Poland but reimbursed at a lower rate for people under 75.

**Figure 5** below shows the number of countries providing full or partial reimbursement for the selected treatments and interventions.



Map 5: Countries with strategies for the reduction of anti-psychotics





Map 6: Countries with strategies or working groups for the introduction of disease-modifying treatments

With regard to strategies aimed at reducing the inappropriate use of anti-psychotics, 10 countries (see map 5) have such a strategy, namely Belgium, Finland, France, Iceland, Ireland, Netherlands, Sweden, Turkey and the United Kingdom (England and Scotland).

When it comes to countries having developed strategies or created working groups for the introduction of disease-modifying treatment, the list is even shorter. Only five countries (see map 6) are actively working on policies and strategies to facilitate the use of such new treatments (Greece, Ireland, Slovakia, Sweden and the United Kingdom (England only).

#### 3.1.3. How did we score countries?

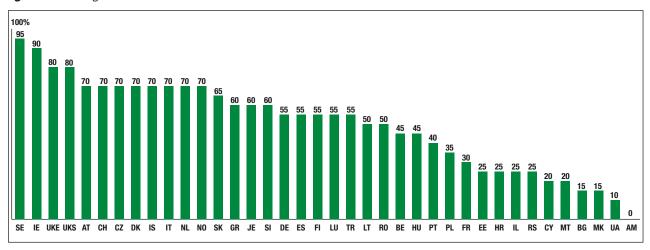
Countries could score a maximum of 20 points. For each of the four medicines, for the combination therapy, amyloid imaging, Fortasyn Connect and incontinence help, countries were scored 2 points1 if they were reimbursed/covered at least at 75%, 1 point if they were reimbursed/covered at a lower level and o points if they were not part of the reimbursement/coverage system or not available in the country.

Countries also scored 2 points if they had a strategy in place for the reduction of anti-psychotics and 2 points if they had a working group or other mechanism in place to prepare for the potential introduction of new treatments for Alzheimer's disease.

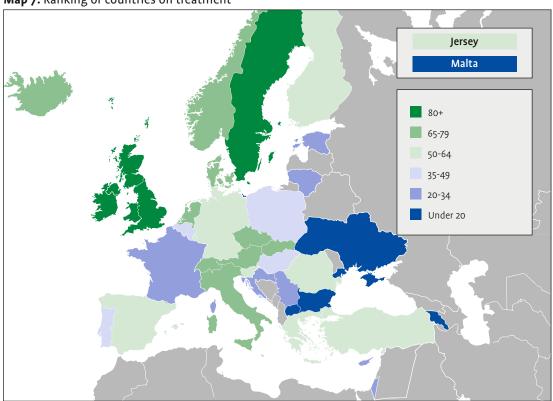
Based on the results, it is possible to rank European countries as indicated in figure 6, which shows the points expressed as percentages of the maximum possible score. .

<sup>1</sup> Poland was scored with 1.5 points for medicines, as medicines were only reimbursed at 100% for people over the age of 75.

Figure 6: Ranking of countries on treatment



Map 7: Ranking of countries on treatment



## 3.2. Clinical trials

## 3.2.1. What did we look at and why?

Participation in research and in clinical trials should be provided as an opportunity to all people diagnosed with Alzheimer's disease or dementia. However, access to such opportunities was shown to vary greatly in previous editions of the European Dementia Monitor and Alzheimer Europe therefore analysed the possibility of people with Alzheimer's disease and dementia to take part in clinical trials in the different European countries covered by the association.

In mid-2023, Alzheimer Europe had identified nine phase III trials which were actively recruiting to investigate six different compounds (ALOO1, AVP-786, KarXT, Masitinib, Masupirdine and Semaglutide) and their effect on dementia. Additionally, five clinical trials investigating four different compounds (ALZ-801, Donanemab, Gantenerumab and Lecanemab) were still active in 2022 and 2023 and are therefore included in this overview.

For this information, Alzheimer Europe consulted the website www.clinicaltrials.gov, where companies include information on all clinical trials, including the locations where participants can be recruited.

In detail, we looked at the following ten compounds which were studied:

- ALOO1 for the treatment of frontotemporal dementia (INFRONT-3 by Alector)
- ALZ 801 for the treatment of early Alzheimer's disease (APOLLOE4 by Alzheon)
- AVP-786 for the treatment of agitation in dementia of the Alzheimer's type (17-AVP-786-305, 20-AVP-786-306 and 20-AVP-786-307 by Otsuka)
- Donanemab for the treatment of early symptomatic Alzheimer's disease (TRAILBLAZER-ALZ 2 by Lilly)
- Gantenerumab for the treatment of early Alzheimer's disease (GRADUATE I and II by Roche)
- KarXT for the treatment of psychosis associated with Alzheimer's disease (ADEPT-1 by Karune Therapeutics)
- Lecanemab for the treatment of early Alzheimer's disease (CLARITY-AD by Eisai)

- Masitinib for the treatment of mild to moderate Alzheimer's disease (AB21004 by AB Science)
- Masupirdine for the treatment of agitation in dementia of the Alzheimer's type (by Suven Life
- Semaglutide for the treatment of early Alzheimer's disease (EVOKE and EVOKE Plus by Novo Nordisk)

#### 3.2.2. Results

The detailed answers regarding the possible participation of research participants in clinical trials can be found in table 5 (see page 20), showing the significant differences between European countries as to the number of clinical trials open for recruitment in different countries.

There were no countries in which it was possible to participate in all of the openly recruiting trials. France was the country with most active clinical trials (8). In a marked positive change from the 2020 Dementia Monitor, there were 12 countries (Belgium, Croatia, Czech Republic, France, Germany, Italy, Jersey, Netherlands, Portugal, Spain, Sweden and the United Kingdom) in which it was possible to access four or more phase-III trials, compared to only three countries in the 2017 Dementia Monitor. Another positive trend was the decrease in the number of countries where it was not possible for volunteers to enrol in clinical trials (as none of the identified clinical trials were recruiting in those countries). This number decreased from 17 in the 2020 Dementia Monitor to 8 countries (Armenia, Cyprus, Lithuania, Luxembourg, Malta, North Macedonia).

### 3.2.3. How did we score countries?

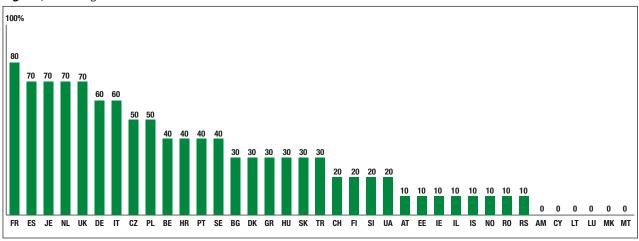
Countries could score a maximum of 10 points and were given 1 point for each compound for which at least one clinical trial was recruiting research participants in the country. Based on the results, it is possible to rank European countries as indicated in figure 7 (see page 21), which shows the points expressed as percentages of the maximum possible score.

**Table 5:** Compounds tested in phase III clinical trials recruiting or concluding in 2022 and 2023

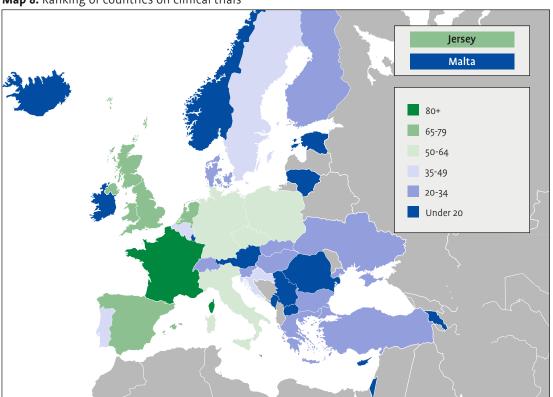
		1		e in chine	1	Ü			- Z unu 202	
	ALOO1	ALZ 801	AVP-786	Donanemab	Gantenerumab	KarXT	Lecanemab	Masitinib	Masupirdine	Semaglutide
AM										
AT										<b>✓</b>
BE	<b>✓</b>		✓ ✓		<b>✓</b>					<b>✓</b>
BG			<b>✓</b>			<b>✓</b>				\ \ \ \ \ \ \ \ \ \ \ \ \ \ \ \ \ \ \
СН	<b>✓</b>									<b>✓</b>
CY										
CZ		<b>✓</b>	<b>✓</b>	<b>✓</b>		<b>✓</b>				✓ ✓
DE	<b>✓</b>	<b>✓</b>	✓ ✓		<b>✓</b>		<b>✓</b>			<b>✓</b>
DK			<b>✓</b>		<b>✓</b>					<b>✓</b>
EE			✓ ✓							
ES	<b>✓</b>		<b>✓</b>		<b>✓</b>	<b>✓</b>	<b>✓</b>	<b>✓</b>		✓
FI					<b>✓</b>					>
FR	<b>✓</b>	<b>✓</b>	✓ ✓ ✓		<b>✓</b>	<b>✓</b>	<b>✓</b>	<b>✓</b>		<b>✓</b>
GR	<b>✓</b>		<b>✓</b>							<b>✓</b>
HR			<b>✓</b>		<b>✓</b>				<b>✓</b>	<b>✓</b>
HU			<b>✓</b>		<b>✓</b>					<b>✓</b>
IE										<b>✓</b>
IL										<b>✓</b>
IS		<b>✓</b>								
IT	<b>✓</b>		<b>✓</b>		<b>✓</b>	<b>✓</b>	<b>✓</b>			<b>✓</b>
JE <sup>1</sup>	<b>✓</b>	<b>✓</b>	<b>✓</b>	<b>✓</b>	<b>✓</b>		<b>✓</b>			<b>✓</b>
LT										
LU										
MK										
MT										
NL	<b>✓</b>	<b>✓</b>	<b>✓</b>	<b>✓</b>	<b>✓</b>		✓			✓
NO										✓
PL			<b>✓</b>	<b>✓</b>	<b>✓</b>				<b>✓</b>	<b>✓</b>
PT	<b>✓</b>		<b>✓</b>		<b>✓</b>					✓
RO										✓
RS										✓
SE	<b>✓</b>				<b>✓</b>		<b>✓</b>			✓
SI			<b>✓</b>							<b>✓</b>
SK			<b>✓</b>			<b>✓</b>				<b>✓</b>
TR	<b>✓</b>				<b>✓</b>					<b>✓</b>
UA			<b>✓</b>							<b>✓</b>
UK	<b>✓</b>	<b>✓</b>	<b>✓</b>	<b>✓</b>	<b>✓</b>		<b>✓</b>			<b>✓</b>

<sup>1</sup> Patients from Jersey can participate in clinical trials organised in the United Kingdom.

Figure 7: Ranking of countries on clinical trials



Map 8: Ranking of countries on clinical trials



## 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 European level:

- Joint Programme for Neurodegenerative Diseases Research (JPND)
- 2. 2023 Call on "Large scale analysis of omics data for drug target finding in neurodegenerative diseases"
- 3. 2022 Call on "Understanding the mechanisms of non-pharmacological interventions"
- 2022 Expert Working Group Call on "Concepts for health and social care research for neurodegenerative diseases"
- 5. 2021 Call on "Linking pre-diagnosis disturbances of physiological systems to neurodegenerative diseases"
- 6. 2021 Expert working group call on "The impact of COVID-19 on neurodegenerative disease research"
- 2020 Call on "Novel imaging and brain stimulation methods and technologies related to neurodegenerative diseases".

As we focused on research collaborations in the past three years, it was no longer possible to include information on countries participating in EU Joint Actions on Dementia.

The focus in this year's edition of the Dementia Monitor is therefore solely on countries involved in JPND and providing funding for the 2020-2023 calls for proposals.

For this section, Alzheimer Europe used the information publicly available on: www.neurodegenerationresearch.eu.

### 3.3.2. Results

The detailed answers showing each country's participation in JPND and funding of JPND calls for proposals can be found in **table 6**.

A total of 25 of the 37 European countries of this European Dementia Monitor are involved in JPND activities. The countries not represented are: Armenia, Cyprus, Estonia, Greece, Iceland, Lithuania, Malta, North Macedonia, Serbia and Ukraine.

When it comes to the JPND funding calls, between 17 and 19 countries participated in the calls for projects from 2020 to 2023, whereas the two calls for expert working groups were supported by 7 and 9 countries respectively.

Germany, France and the Netherlands were the most collaborative countries, participating in JPND, as well as contributing to all calls. Belgium, Italy, Luxembourg, Norway and Sweden participated in all but one of the calls.



 Table 6: Participation in European dementia research collaborations

	DNAL	2023 Call	2022 Call	2022 Working Group Call	2021 Call	2021 Working Group Call	2020 Call
AM							
AT	<b>✓</b>	<b>✓</b>					<b>✓</b>
BE	<b>✓</b>	<b>✓</b>	<b>✓</b>		<b>✓</b>	<b>✓</b>	<b>✓</b>
BG	✓ ✓						
СН	<b>✓</b>	<b>✓</b>	<b>✓</b>		<b>✓</b>		<b>✓</b>
CY							
cz	<b>✓</b>	<b>✓</b>	<b>✓</b>		<b>✓</b>		\/ \/ \/ \/ \/ \/ \/ \/ \/ \/ \/ \/ \/ \
DE	<b>✓</b>	<b>✓</b>	<b>✓</b>	<b>✓</b>	<b>✓</b>	<b>✓</b>	<b>✓</b>
DK	<b>✓</b>		<b>✓</b>		<b>✓</b>		<b>✓</b>
EE							
ES	✓	<b>✓</b>	✓				<b>✓</b>
FI	<b>✓</b>		<b>✓</b>		<b>✓</b>		
FR	✓	<b>✓</b>	<b>✓</b>	<b>✓</b>	<b>✓</b>	<b>✓</b>	<b>✓</b>
GR							
HR	✓ ✓						
HU	<b>✓</b>	✓			<b>✓</b>		<b>✓</b>
IE	<b>✓</b>	<b>✓</b>		<b>✓</b>			<b>✓</b>
IL	<b>✓</b>		<b>✓</b>		<b>✓</b>		
IS		✓ ✓					
IT	<b>✓</b>	<b>✓</b>	<b>✓</b>	<b>✓</b>	<b>✓</b>	<b>✓</b>	
JE <sup>1</sup>							
LT							
LU	<b>✓</b>	<b>✓</b>	<b>✓</b>		<b>✓</b>	<b>✓</b>	✓ ✓
LV			<b>✓</b>		<b>✓</b>		<b>✓</b>
MK							
MT			•	•			
NL	<b>/</b>	<b>✓</b>	<b>✓</b>	<b>/</b>	<b>/</b>	<b>/</b>	<b>✓</b>
NO	<b>/</b>	•	<b>/</b>	<b>✓</b>	<b>/</b>	<b>✓</b>	<b>—</b>
PL	<b>/</b>	<b>✓</b>	<b>V</b>		<b>/</b>		<b>✓</b>
PT	<b>/</b>		<b>✓</b>		<b>✓</b>		
RO	<b>✓</b>						
RS	,	,		,	,	,	,
SE	✓ ✓	<b>✓</b>		<b>✓</b>	<b>✓</b>	<b>✓</b>	<b>✓</b>
SI		,	,		,		
SK	✓ ✓	<b>/</b>	<b>/</b>		✓ ✓		<b>✓</b>
TR	<b>~</b>	<b>~</b>	<b>~</b>		<b>~</b>		<b>~</b>
UA	<b>✓</b>					. /	
UK	<b>~</b>					<b>✓</b>	

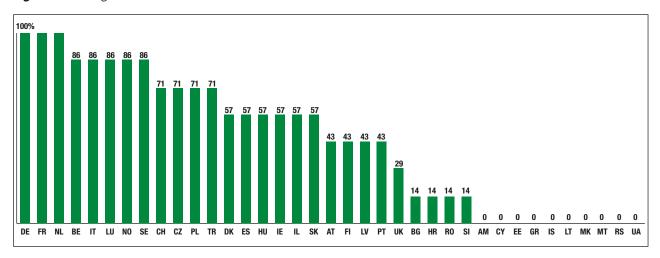
<sup>1</sup> As a British crown dependency, Jersey cannot join the Joint Programme for Neurodegenerative Diseases research (JPND) and the score of Jersey on this question is not taken into account for its overall score and ranking.

## 3.3.3. How did we score countries?

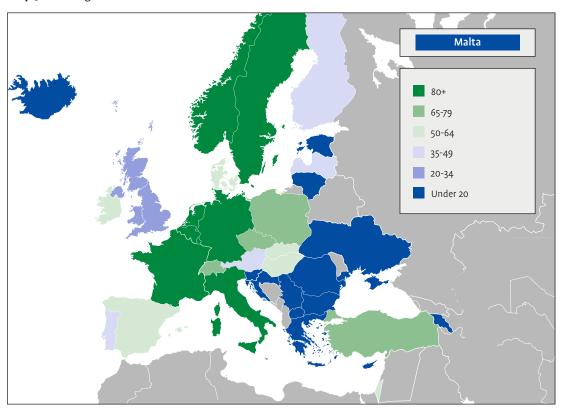
Countries could score a maximum of 7 points. For participation in JPND and each of the calls for funding, countries scored 1 point. Based on the results, it is possible to rank

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 research collaboration



Map 9: Ranking of countries on research collaboration



## 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. Has your country ever had a national Alzheimer's/ dementia strategy or was dementia included in a more general mental health or non-communicable diseases strategy?
- 2. Is this strategy still ongoing?
- 3. Are there regional strategies in your country?
- 4. Does the dementia strategy have specific allocated funding for the implementation of its activities?
- 5. Is there a government-appointed organisation or person in charge of the overall coordination of dementia policies?
- 6. Is your country represented in the European Group of Governmental Experts on Dementia coordinated by Alzheimer Europe?
- 7. Has your country contributed data to the WHO Global Dementia Observatory?
- 8. Does your country have a brain health strategy?

- 9. Is dementia recognised as a national research
- 10. Does the national Alzheimer's association receive funding from government programmes for its core activities or its projects?

The Monitor built on the questions of the 2020 edition but included questions on the WHO Dementia Observatory and the existence of brain health strategies which had previously not been asked.

#### 4.1.2. Results

The detailed answers can be found in table 7 (see page 26). Unfortunately, the number of countries with an ongoing dementia strategy has gone from a high of 26 countries for the 2020 Dementia Monitor to 22 countries, with a number of strategies coming to an and or not being renewed (France, Israel, Luxembourg, Portugal). In addition, of the 22 countries with a strategy, 12 countries reported that no dedicated funding had been attributed to the dementia strategy.

When it comes to the recognition of dementia as a research priority, the trend was also negative as there was a decrease from 15 countries reporting that dementia was a research priority in 2020 to only 9 in 2023.

There also seemed to be a very clear East/West divide when it comes to the recognition of dementia as a policy priority, as Western and Northern European countries typically answered positively to more questions. Three Eastern European countries (North Macedonia, Serbia and Ukraine) did not score any points in this category, whereas Scotland (UK) scored 100 percent.

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

						91 - 9				
	National strategy (ever)	National Strategy (ongoing)	Regional/local strategies	Allocated funding	National coordination of strategy	European Group of Governmental Experts	WHO Global Dementia Observatory	Brain Health Strategy	Research priority	Funding for national AD association
AM	<b>✓</b>	<b>✓</b>	✓		<b>✓</b>			✓	<b>✓</b>	
AT	<b>✓</b>	<b>✓</b>	<b>✓</b>	<b>✓</b>	<b>✓</b>	<b>✓</b>	<b>✓</b>			<b>✓</b>
BE			<b>✓</b>			<b>✓</b>	<b>✓</b>	<b>✓</b>		<b>✓</b>
BG						✓ ✓				
СН	<b>✓</b>	<b>✓</b>	✓		<b>✓</b>	✓ ✓	<b>✓</b>			<b>/</b>
CY	<b>✓</b>	<b>✓</b>			✓	<b>✓</b>	✓			
CZ	<b>✓</b>	<b>✓</b>			<b>✓</b>	<b>✓</b>	<b>✓</b>		<b>✓</b>	<b>✓</b>
DE	<b>✓</b>	<b>✓</b>	<b>✓</b>	<b>✓</b>	<b>✓</b>	<b>✓</b>	<b>✓</b>		<b>✓</b>	<b>✓</b>
DK	✓	✓	<b>✓</b>				<b>✓</b>			
EE				<b>✓</b>		<b>✓</b>	✓			<b>✓</b>
ES	<b>✓</b>	<b>✓</b>	<b>✓</b>		<b>✓</b>					<b>✓</b>
FI	<b>✓</b>	<b>✓</b>		<b>✓</b>		<b>✓</b>	<b>✓</b>		<b>✓</b>	<b>✓</b>
FR	<b>/</b>					<b>✓</b>	<b>✓</b>		<u> </u>	<b>✓</b>
GR	<b>✓</b>	<b>✓</b>	✓	<b>✓</b>	<b>✓</b>	<b>✓</b>	<b>✓</b>	✓		<b>✓</b>
HR	<b>✓</b>	<b>✓</b>			<b>✓</b>					<b>✓</b>
HU							<b>✓</b>			
IE	<b>✓</b>	<b>✓</b>			<b>✓</b>	<b>✓</b>	<b>✓</b>			<b>/</b>
IL	<b>✓</b>		<b>✓</b>		<b>✓</b>	<b>✓</b>	✓			<b>/</b>
IS	<b>✓</b>	<b>✓</b>				<b>✓</b>			<u> </u>	<b>/</b>
IT	<b>✓</b>	✓	<b>✓</b>	<b>✓</b>	<b>✓</b>	<b>✓</b>	<b>✓</b>		<b>✓</b>	<b>/</b>
JE							1			<b>✓</b>
LT						<b>/</b>	✓			
LU	<b>✓</b>					<b>✓</b>				<b>✓</b>
MK	•			•	,		•			,
MT	<b>/</b>	✓ ✓	,	<b>/</b>	✓ ✓	✓ ✓	✓ ✓			✓ ✓
NL	<b>/</b>	✓ ✓	<b>/</b>	<i>y</i>	<i>y</i>	✓ ✓	✓ ✓		<b>✓</b>	<b>~</b>
NO	<b>/</b>	✓ ✓2	<b>~</b>	<b>~</b>	<b>~</b>			<b>✓</b>		
PL	<b>/</b>	<b>V</b> <sup>2</sup>				<b>✓</b>	✓			
PT	<b>/</b>		<b>✓</b>			,				<b>✓</b>
RO						<b>✓</b>				
RS	,	,	,	,	,	,	,	,		,
SE	<b>/</b>	✓ ✓	✓	<b>✓</b>	✓ ✓	✓ ✓	✓ ✓	<b>✓</b>		<b>✓</b>
SI	<b>✓</b>	~	<b>✓</b>		~	<b>~</b>	<b>~</b>			
SK			<b>✓</b>			,	,			
TR						<b>✓</b>	<b>✓</b>			
UA	1				1	1				
UK-E	<b>/</b>	<b>✓</b>	<b>/</b>	<b>✓</b>	<b>/</b>	<b>/</b>	1	,	✓ ✓	<b>/</b>
UK-S	<b>✓</b>	<b>✓</b>	<b>✓</b>	<b>✓</b>	<b>✓</b>	<b>✓</b>	✓	✓	<b>~</b>	<b>~</b>

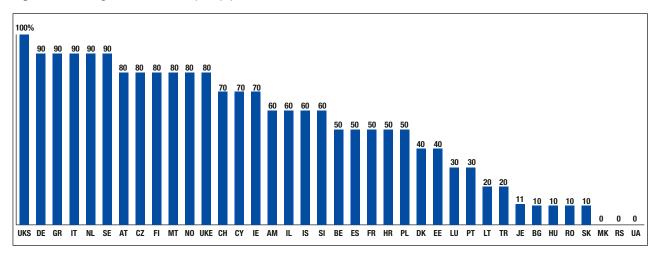
<sup>1</sup> As a British crown dependency, Jersey was not asked to contribute to the Global Dementia Observatory. The score of Jersey in this category does not take this specific question into consideration.

<sup>2</sup> Poland does not have a dementia strategy, but dementia policies and priorities are included in the National Health Programme (2021-2025).

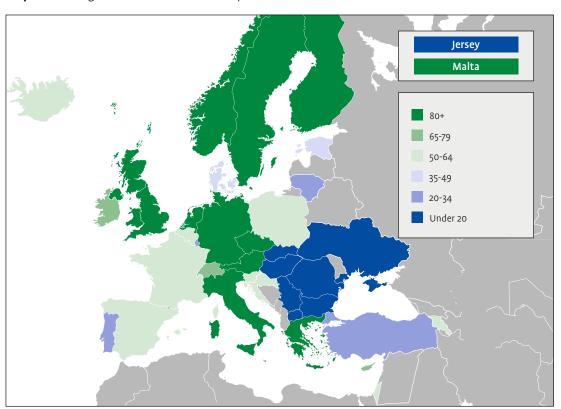
## 4.1.3. How did we score countries?

Countries could score a maximum of 10 points. On the question of national dementia strategies, countries could score a maximum of three points if they had an ongoing national dementia strategy, but only scored one point if they had a strategy in the past or if there were only regional dementia strategies in the country. For all other questions, countries scored 1 point for each positive answer. Based on the results, it is possible to rank European countries as indicated in figure 9, which shows the points expressed as percentages of the maximum possible score.

Figure 9: Ranking of countries on policy prioritisation of dementia



Map 10: Ranking of countries on dementia prioritisation



## 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 how developed the dementia-friendly initiatives are in their country. With Alzheimer Europe's campaign to have dementia recognised as a disability, we also wanted to find out from national associations whether they felt that

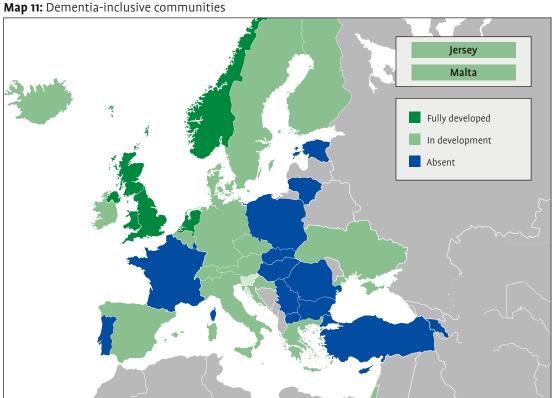
dementia was recognised as a disability in their country and whether their organisation was a member of a national federation of associations promoting the rights of persons with disabilities.

#### 4.2.2. Results

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

Wide differences exist across Europe, with only two countries (Netherlands and United Kingdom) having working groups for people with dementia and carers, a dementia friends programme and fully developed dementia-friendly communities.

In seven European countries (France, Lithuania, North Macedonia, Poland, Romania, Serbia and Ukraine), none of these initiatives have been started. This compares to 9 countries which did not report any of these initiatives in the 2020 Dementia Monitor, but three of these countries (North Macedonia, Serbia and Ukraine) were not included in the 2020 edition. This represents a positive trend, as more countries and organisations are beginning to develop dementia-inclusive activities. When it comes to the recognition of dementia as a disability, only 18 out of 27 countries reported this to be the case in their country. Even fewer associations (7) reported that they were members of a national federation of associations for and with persons with disabilities.



**Table 8:** Country responses on dementia-inclusiveness

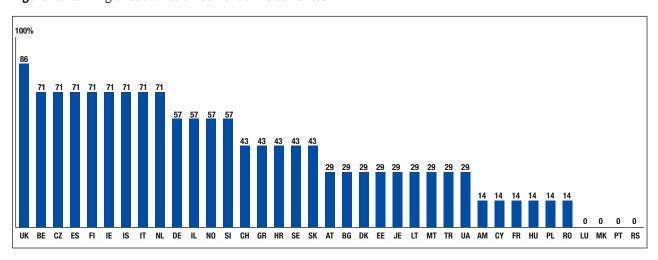
	National strategy (ever)	National working group for carers	Dementia Friends programme	Dementia recognised as a disability	Alzheimer association member of disability federation
AM			<b>✓</b>		
AT	<b>✓</b>				
BE	<b>✓</b>	✓		<b>✓</b>	<b>✓</b>
BG			<b>✓</b>	<b>✓</b>	
СН	<b>✓</b>			✓	
CY	<b>✓</b>				
CZ	<b>✓</b>	✓	<b>✓</b>	✓	
DE	<b>✓</b>		<b>✓</b>		<b>✓</b>
DK			<b>✓</b>		
EE		✓	<b>✓</b>		
ES	<b>✓</b>	<b>✓</b>	<b>✓</b>	<b>✓</b>	
FI	<b>✓</b>	✓	✓		✓
FR					✓
GR			✓	✓	
HR			✓	✓	
HU			✓		
IE	✓	✓	✓		✓
IL		✓	✓	✓	
IS	✓	✓		✓	✓
IT	✓	✓	✓	✓	
JE			✓		
LT				✓	✓
LU					
MK					
MT	✓				
NL	✓	✓	✓		
NO	✓			✓	
PL				✓	
PT					
RO				✓	
RS					
SE			✓	✓	
SI	✓	✓	<b>✓</b>		
SK	✓	✓	✓		
TR			✓	✓	
UA				<b>✓</b>	
UK	✓	✓	✓	<b>✓</b>	

## 4.2.3. How did we score countries?

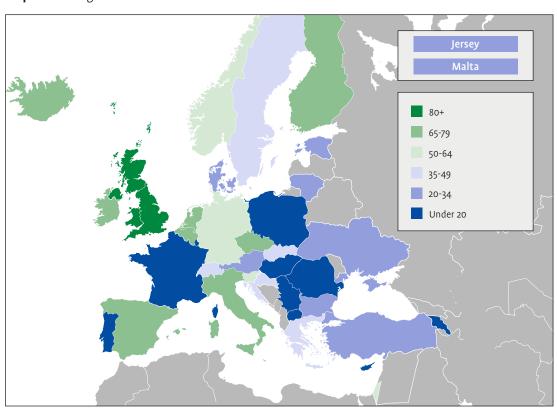
Countries could score a maximum of 7 points. Countries scored one point for each positive answer, with the exception of the question on dementia-inclusive communities. Countries with fully-developed dementia-inclusive communities were scored 2 points, and countries with

dementia-friendly communities in development were scored 1 point. Based on the results, it is possible to rank European countries as indicated in **figure 10**, which shows the points expressed as percentages of the maximum possible score.

Figure 10: Ranking of countries on dementia-inclusiveness



Map 12: Ranking of countries on dementia-inclusiveness



## 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 healthcare 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. Is supported decision-making enshrined in national legislation?
- 3. Are there legal mechanisms for people to appoint or to have appointed health care proxies?
- 4. Are there legal mechanisms for people to appoint or to have appointed financial proxies?
- 5. Are people with dementia under guardianship or other protective measures protected against the loss of citizenship and the right vote?

With the exception of the question on assisted decision-making, these are the same questions as for the 2020 edition of the Dementia Monitor.

#### 5.1.2. Results

Table 9 (see page 32) provides the full results of the country responses.

This section is particularly encouraging, as the number of countries complying with all Alzheimer Europe's legal recommendations is increasing. Whilst this number was 8 for the 2020 Dementia Monitor, this number has increased to 18 (Austria, Croatia, Czech Republic, Denmark, France, Germany, Iceland, Ireland, Israel, Italy, Jersey, Netherlands, Norway, Portugal, Slovenia, Spain, Sweden and the United Kingdom (England only)). On the other side, Bulgaria, North Macedonia, Poland and Romania did not have any of the required legal safeguards in place.

## 5.1.3. How did we score countries?

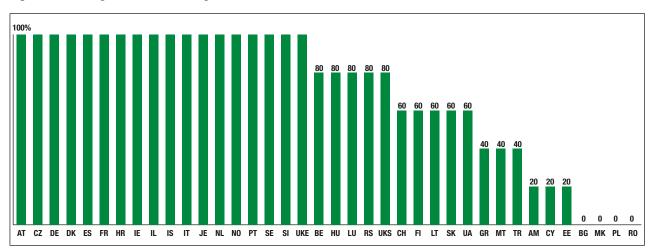
Countries could score a maximum of 5 points. Countries were scored 1 point if the different legal safeguards and mechanisms were in place for people with dementia in the country.

Based on the results, it is possible to rank European countries as indicated in figure 11 (see page 33), which shows the points expressed as percentages of the maximum possible score.

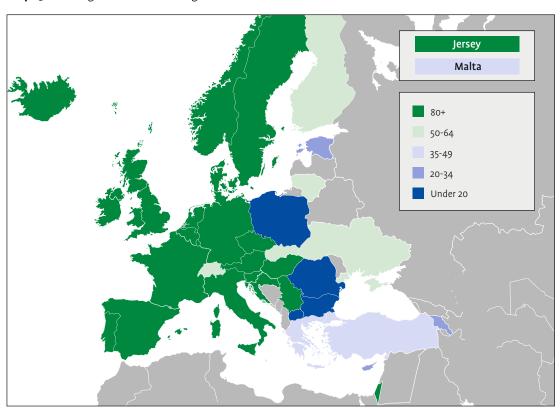
 Table 9: Country responses on legal issues

				1	
	Framework for advance directives	Supported decision making in legislation	Mechanism to appoint financial proxy	Mechanism to appoint healthcare proxy	Protection from loss of right to vote
AM					<b>✓</b>
AT	<b>✓</b>	<b>✓</b>	<b>✓</b>	<b>✓</b>	<b>✓</b>
BE	<b>✓</b>		<b>✓</b>	<b>✓</b>	✓
BG					
СН	✓		✓	✓	
CY					✓
CZ	✓	<b>✓</b>	<b>✓</b>	<b>✓</b>	✓
DE	✓	<b>✓</b>	✓	✓	✓
DK	✓	<b>✓</b>	✓	<b>✓</b>	✓
EE			<b>✓</b>		
ES	✓	<b>✓</b>	<b>✓</b>	✓	✓
FI			✓	✓	✓
FR	✓	<b>✓</b>	<b>✓</b>	<b>✓</b>	✓
GR			✓	✓	
HR	✓	✓	✓	✓	✓
HU	✓	<b>✓</b>	<b>✓</b>	<b>✓</b>	
IE	✓	<b>✓</b>	<b>✓</b>	✓	✓
IL	✓	✓	✓	✓	✓
IS	✓	✓	<b>✓</b>	✓	✓
IT	✓	<b>✓</b>	<b>✓</b>	<b>✓</b>	✓
JE	✓	✓	✓	✓	✓
LT	✓		<b>✓</b>	✓	
LU	✓	<b>✓</b>	✓	<b>✓</b>	
MK					
MT			✓	✓	
NL	✓	<b>✓</b>	✓	<b>✓</b>	✓
NO	<b>✓</b>	<b>✓</b>	<b>✓</b>	<b>✓</b>	✓
PL					
PT	✓	<b>✓</b>	✓	<b>✓</b>	✓
RO					
RS	<b>✓</b>	<b>✓</b>	<b>✓</b>	<b>✓</b>	
SE	✓	<b>✓</b>	<b>✓</b>	<b>✓</b>	✓
SI	✓	<b>✓</b>	<b>✓</b>	<b>✓</b>	✓
SK			<b>✓</b>	<b>✓</b>	✓
TR		<b>✓</b>	✓		
UA			<b>✓</b>	<b>✓</b>	✓
UK-E	✓	<b>✓</b>	✓	<b>✓</b>	✓
UK-S	✓		✓	<b>✓</b>	✓

Figure 11: Ranking of countries on legal issues



Map 13: Ranking of countries on legal issues



## 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:

- United Nations Convention Rights of People with Disabilities (UNCRPD)
- Optional Protocol to the Convention on the Rights of Persons with Disabilities
- The Hague Convention for the Protection of Vulnerable Adults
- 4. Council of Europe Convention on Human Rights and Biomedicine

#### 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

(UNCRPD). However, since Jersey is a British crown dependency, it cannot sign or ratify international treaties and is therefore not included this section. The Optional Protocol to the UNCRPD has also been signed and ratified by a majority of countries. Only Ireland, Israel, Netherlands, Norway, Poland and Switzerland have neither signed nor ratified this optional protocol. When it comes to the Council of Europe Convention on Human Rights and Biomedicines, over half of countries (24) have already ratified this convention, whereas the Hague Convention has only been ratified by 14 countries and the United Kingdom limiting its application to Scotland only. Whereas Portugal was the only country in 2020 to have ratified all four conventions, this number has now grown to 7 with Cyprus, Czech Republic, Estonia, Finland, France and Greece also having ratified all international treaties since then.

#### 5.2.3. How did we score countries?

Countries could score a maximum of 8 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 12** (see page 36), which shows the points expressed as percentages of the maximum possible score.

**Table 10:** Signature and ratification of treaties

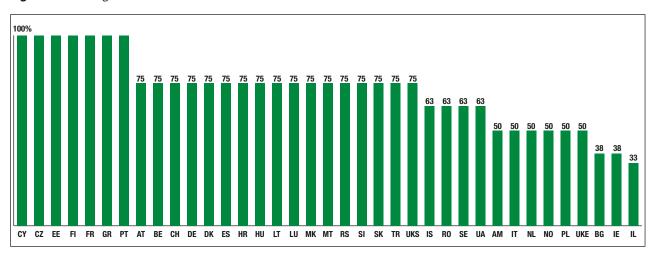
	UNCRPD	Optional Protocol to UNCRPD	Hague Convention	CoE Convention
AM	•	•	0	0
AT	•	•	•	0
BE	•	•	•	0
BG	•	•	0	•
СН	•	0	•	•
CY	•	•	•	•
CZ	•	•	•	•
DE	•	•	•	0
DK	•	•	0	•
EE	•	•	•	•
ES	•	•	0	•
FI	•	•	•	•
FR	•	•	•	•
GR	•	•	•	•
HR	•	•	0	•
HU	•	•	0	•
IE	•	0	•	0
IL	•	0	0	1
IS	•	•	0	•
IT	•	•	•	•
JE <sup>2</sup>				
LT	•	•	0	•
LU	•	•	•	•
MK	•	•	0	•
MT	•	•	•	0
NL	•	0	•	•
NO	•	0	0	•
PL	•	0	•	•
PT	•	•	•	•
RO	•	•	0	•
RS	•	•	0	•
SE	•	•	0	•
SI	•	•	0	•
SK	•	•	0	•
TR	•	•	0	•
UA	•	•	0	•
UK-E	•	•	0	0
UK-S		•	<b>3</b>	0

<sup>1</sup> As a non-member of the Council of Europe (CoE), Israel is unable to sign or ratify the CoE Convention on Human Rights and Biomedicine. The score of Israel in this category does not take this specific question into consideration.

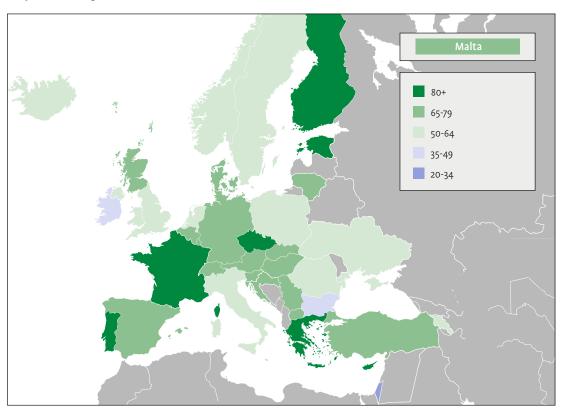
<sup>2</sup> As a non-member of the Council of Europe (CoE), Israel is unable to sign or ratify the CoE Convention on Human Rights and Biomedicine. The score of Israel in this category does not take this specific question into consideration.

<sup>3</sup> At the time of ratification, the United Kingdom declared that the Convention shall extend to Scotland only.

Figure 12: Ranking of countries on international treaties and conventions



Map 14: Ranking of countries on international conventions



### 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 flexible mechanisms which allow carers to combine care with work.

Like in 2020, 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 (see page 38).

Although the overwhelming majority of countries (31 out of 38) had some form of carer's allowance, all the other employment rights were only recognised in a minority of European countries. 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 or the right to flexible working hours.

Only the Czech Republic, the Netherlands and the United Kingdom (Scotland only) received full marks in this section, as all employment and carers' rights were recognised in these countries, whereas in three countries (Armenia, Cyprus and Ukraine), none of these rights was recognised.

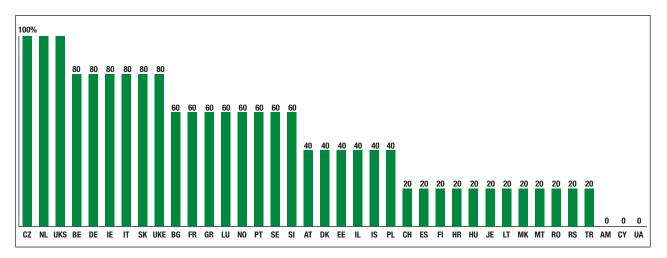
**Table 11:** Carers' and employment rights

	Rights of people with dementia in employment	Carers' allowance	Right to paid leave	Right to flexible hours	Right to unpaid carers' leave
AM					
AT		<b>✓</b>	<b>✓</b>		
BE		<b>✓</b>	<b>✓</b>	<b>✓</b>	<b>✓</b>
BG		<b>✓</b>	<b>✓</b>		<b>✓</b>
СН			<b>✓</b>		
CY					
CZ	<b>✓</b>	<b>✓</b>	<b>✓</b>	<b>✓</b>	<b>✓</b>
DE		<b>✓</b>	<b>✓</b>	<b>✓</b>	<b>✓</b>
DK		<b>✓</b>	<b>✓</b>		
EE		<b>✓</b>	<b>✓</b>		
ES		<b>✓</b>			
FI		<b>✓</b>			
FR		<b>✓</b>	<b>✓</b>		<b>✓</b>
GR			<b>✓</b>	<b>/</b>	<b>✓</b>
HR	<b>✓</b>				
HU		<b>✓</b>			
IE			<b>/</b>	<b>/</b>	<b>✓</b>
IL	<b>✓</b>	·		<b>/</b>	·
IS	✓ ·				
IT	<b>✓</b>	<u>·</u>	<b>/</b>	<b>/</b>	<b>✓</b>
JE		<b>✓</b>			·
LT		<b>✓</b>			<b>✓</b>
LU			/		
LV		<b>✓</b>			
MK		<b>✓</b>			
MT		<b>✓</b>			
NL	<b>✓</b>		<b>✓</b>	<b>/</b>	<b>✓</b>
NO	<b>✓</b>	<b>✓</b>			<b>✓</b>
PL		<u>✓</u>			<b>✓</b>
PT		<b>✓</b>		<b>/</b>	<b>✓</b>
RO					
RS		<u> </u>			
SE	<b>✓</b>	<u> </u>			
SI	<b>✓</b>		<u> </u>		
SK		<u> </u>		<b>/</b>	<b>✓</b>
TR		<u> </u>	,	·	·
UA		•			
UK-E	<b>✓</b>	<b>✓</b>			
UK-S	<i>y</i>		<b>✓</b>	<b>/</b>	<b>*</b>
01/ 3	•	•			

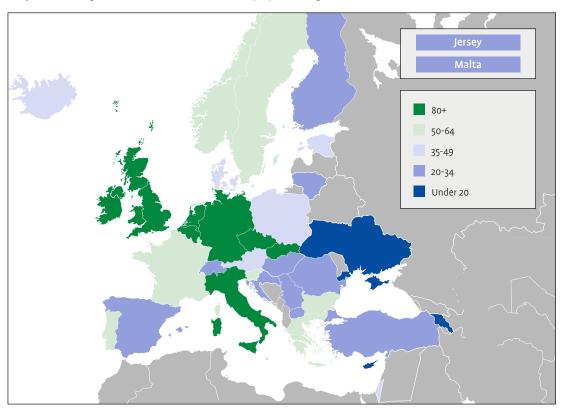
#### 5.3.3. How did we score countries?

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 13, which shows the points expressed as percentages of the maximum possible score.

Figure 13: Ranking of countries on carer and employment rights



Map 15: Ranking of countries on carer and employment rights



## 6. Overall ranking

Table 12 (see pages 42-43) 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 green and countries finishing last in the category highlighted in blue.

France had the highest number (4) of categories in which it ranked in first place, with the Czech Republic, the Netherlands and Scotland, UK ranking first in 3 categories.

On the low-ranking side, North Macedonia ranked last in 5 categories and Armenia in 4, whereas Bulgaria, Cyprus, Serbia and Ukraine each ranked last in 3 different categories.

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 14.

According to the overall ranking, the Netherlands, Scotland (UK) and the Czech Republic were the countries which had

the most dementia-friendly policies in place, with North Macedonia, Bulgaria and Romania the countries which need to make the most progress and reforms to improve the dementia friendly policies in their countries.

In figure 14, we also show whether countries have increased their overall percentage score, compared to the 2020 Monitor. It is interesting to see that 18 of the countries previously included in the Monitor were able to increase their overall percentage, whereas 11 countries ended up with lower scores than three years ago.

Like in 2020, none of the countries exceeded a score of over 80% showing that all countries have opportunities to further improve the support and care they provide to people with dementia and their carers.

When looking at the map of Europe (see map 16), we can see as well that there continue to be very significant differences across Europe with countries in Northern, Western and Central Europe generally scoring better than countries in Eastern Europe.

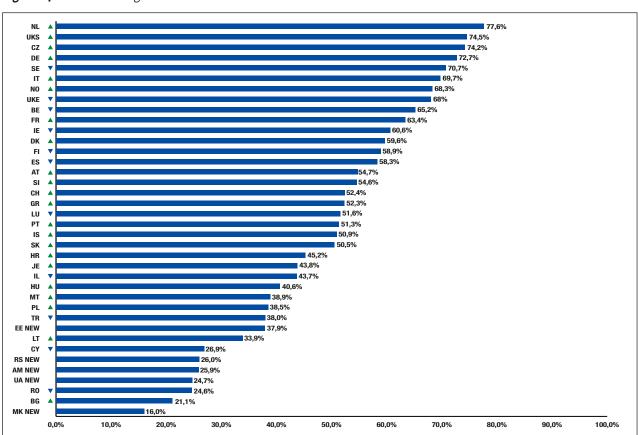


Figure 14: Overall ranking of countries

Map 16: Overall scores of countries

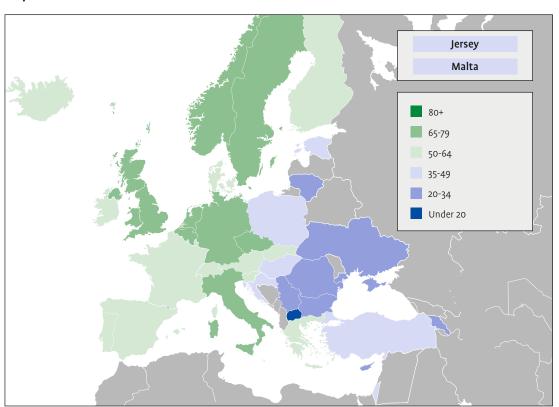




 Table 12: Ranking of countries per category

	Care availability	Care affordability	Treatment	Clinical Trials	Research collaboration
AM	65%	50%	0%	0%	0%
AT	65%	35%	70%	10%	43%
BE	70%	45%	45%	40%	86%
BG	15%	0%	15%	30%	14%
СН	60%	35%	70%	20%	71%
CY	35%	10%	20%	0%	0%
CZ	60%	40%	70%	50%	71%
DE	55%	55%	55%	60%	100%
DK	75%	80%	70%	30%	57%
EE	45%	70%	25%	10%	0%
ES	50%	35%	55%	70%	57%
FI	65%	75%	55%	20%	43%
FR	50%	50%	30%	80%	100%
GR	50%	50%	60%	30%	0%
HR	45%	40%	25%	40%	14%
HU	40%	35%	45%	30%	57%
IE	45%	45%	90%	10%	57%
IL	40%	15%	25%	10%	57%
IS	55%	40%	70%	10%	0%
IT	50%	40%	70%	60%	86%
JE	40%	20%	60%	70%	
LT	50%	35%	50%	0%	0%
LU	85%	45%	55%	0%	86%
MK	35%	15%	15%	0%	0%
MT	55%	70%	20%	0%	0%
NL	70%	55%	70%	70%	100%
NO	80%	90%	70%	10%	86%
PL	35%	40%	35%	50%	71%
PT	45%	55%	40%	40%	43%
RO	45%	20%	50%	10%	14%
RS	35%	15%	25%	10%	0%
SE	60%	70%	95%	40%	86%
SI	55%	45%	60%	20%	14%
SK	50%	35%	65%	30%	57%
TR	25%	15%	55%	30%	71%
UA	40%	25%	10%	20%	0%
UK-E	50%	55%	80%	70%	29%
UK-S	50%	75%	80%	70%	29%

 Table 12: Ranking of countries per category continued

	Dementia as a priority	Dementia- inclusiveness	Legal rights	International conventions	Care and employment
АМ	60%	14%	20%	50%	0%
AT	80%	29%	100%	75%	40%
BE	50%	71%	80%	75%	80%
BG	10%	29%	0%	38%	60%
СН	70%	43%	60%	75%	20%
CY	70%	14%	20%	100%	0%
cz	80%	71%	100%	100%	100%
DE	90%	57%	100%	75%	80%
DK	40%	29%	100%	75%	40%
EE	40%	29%	20%	100%	40%
ES	50%	71%	100%	75%	20%
FI	80%	71%	60%	100%	20%
FR	50%	14%	100%	100%	60%
GR	90%	43%	40%	100%	60%
HR	50%	43%	100%	75%	20%
HU	10%	14%	80%	75%	20%
IE	70%	71%	100%	38%	80%
IL	60%	57%	100%	33%	40%
IS	60%	71%	100%	63%	40%
IT	90%	71%	100%	50%	80%
JE	11%	29%	100%		20%
LT	20%	29%	60%	75%	20%
LU	30%	0%	80%	75%	60%
MK	0%	0%	0%	75%	20%
МТ	80%	29%	40%	75%	20%
NL	90%	71%	100%	50%	100%
NO	80%	57%	100%	50%	60%
PL	50%	14%	0%	50%	40%
PT	30%	0%	100%	100%	60%
RO	10%	14%	0%	63%	20%
RS	0%	0%	80%	75%	20%
SE	90%	43%	100%	63%	60%
SI	60%	57%	100%	75%	60%
SK	10%	43%	60%	75%	80%
TR	20%	29%	40%	75%	20%
UA	0%	29%	60%	63%	0%
UK-E	80%	86%	100%	50%	80%
UK-S	100%	86%	80%	75%	100%

# 7. Acknowledgements

We would like to thank the following individuals and associations for their support in completing our country questionnaire, which provides the basis for much of the information in the Dementia Monitor. Where provided to us, we have included the specific individuals who completed and returned the questionnaire, otherwise, we have included the name of the association.

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Johanna Püringer, Demenz Selbsthilfe Austria, Austria	Denis Mancini, Association Luxembourg Alzheimer, Luxembourg		
Sabine Henry-Gössing, LINAL, <b>Belgium</b>	Charles Scerri, Malta Dementia Society, Malta		
Jef Pelgrims & Olivier Constant, Alzheimer Liga Vlaanderen, <b>Belgium</b>	Marco Blom, Alzheimer Nederland, Netherlands		
Irina Ilieva, Alzheimer Bulgaria Association, <b>Bulgaria</b>	Gabriela Novotni, Institute for Alzheimer's Disease and Neuroscience, <b>North Macedonia</b>		
Ninoslav Mimica, Alzheimer Hrvatska, <b>Croatia</b>	Luisa Klaveness, Nasjonalforeningen for folkehelsen, Norway		
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Claudine Snape, Dementia Jersey, <b>Jersey</b>	Jim Pearson, Alzheimer Scotland, <b>United Kingdom</b> (Scotland)		
Sonata Mačiulskytė, Demencija Lietuvoje, <b>Lithuania</b>			



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