

A large blue rectangular area containing several white five-pointed stars of varying sizes, arranged in a pattern that mimics the flag of the European Union.

# Dementia in Europe Yearbook 2018

## Comparison of national dementia strategies in Europe





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# 1. Foreword



It gives me great pleasure to introduce this comparative report on the dementia strategies from countries across Europe.

Alzheimer Europe covered this subject in our yearbook in 2012, with a more specific focus examining the approaches to

diagnosis, treatment and research in European countries. At that time, fewer countries had a specific dementia strategy. We now have 21 countries and regions with a dementia strategy, two countries whose governments have formally committed to the development of a strategy, two neurodegenerative strategies published and further work underway in other European countries.

By reviewing the content of the national dementia strategies in each country, it has been possible to get a sense of the convergence in approach to dementia policy and practice which has taken place in recent years. Similarly, it is evident that despite significant differences between countries (e.g. in the structure of health and social care systems or economic status), there is commonality in many of the challenges experienced, including coordinating different stands of care and support, in ensuring that all staff are able to provide high quality care and support from diagnosis to end of life, and raising societal awareness and understanding of the condition.

It is also welcome that we are beginning to see a holistic approach to dementia taken in many countries. Whilst care and support are undoubtedly significant aspects of

most strategies, it is apparent that there is recognition that many interdependent factors must be addressed in a coordinated way. For example, linking public awareness raising and early diagnosis, whilst ensuring that matters of legal capacity, decision-making and end of life care are connected to ensure persons with dementia receive care and support which reflects their needs and wishes.

Undoubtedly, this report shows that progress is being made across Europe. However, we must recognise that there is much work still to do. Many countries still do not have strategies and require support to convince their governments of the need to develop them. In countries which have strategies, we know that implementation is variable and further work is needed to hold governments to the commitments they have made.

We hope this report is helpful in outlining the current state-of-play of dementia policy across dementia, whilst also providing a useful reference point for those countries in the process of developing their own strategies.

I would finally like to thank member organisations who supported this work, the European Working Group of People with Dementia (EWGPWD) and their supporters for their personal reflections, and acknowledge the work of Owen Miller, Policy Officer, in collating the information from the strategies and writing this report.

**Jean Georges**  
Executive Director  
Alzheimer Europe

## 2. Introduction

### 2.1 Background to the report

Alzheimer Europe has developed this report as part of our 2018 Work Plan<sup>1</sup>, which has received funding from the European Union in the framework of the Health Programme.

For years, Alzheimer Europe has worked with national member organisations to ensure that dementia is recognised as a national priority in every country in Europe, whilst continually working towards dementia being made a priority at the European level. At the 24<sup>th</sup> Alzheimer Europe conference in Glasgow in 2014, The Glasgow Declaration was launched, calling for the creation of a European Dementia Strategy and for the development of national strategies in every European country. The signatories also called upon world leaders to recognise dementia as a public health priority and to develop a global action plan on dementia.

This report examines dementia strategies (or national plans) across European countries, with a specific view to providing a comparative overview of the priorities and areas of focus in relation to dementia. In doing so, it is possible to establish not only what areas of dementia policy and practice are being prioritised by national governments, but also the diversity of approaches to issues such as diagnosis, care and treatment, and research.

The information contained within this report was taken directly from the national strategies of each country, with a primary focus on the explicit commitments and actions contained within the documents.

The report analysed information from 21 national dementia strategies, as well as two national neurodegenerative strategies (see **Table 1** for more information). For **Belgium** and the **United Kingdom (UK)**, the sub-state level strategies are provided (i.e. **Flanders in Belgium**, and **England, Northern Ireland, Scotland and Wales** for the **UK**).

In compiling this information, we liaised with member organisations at the national level to confirm our analysis and understanding of the national strategies were correct and to ensure that, where we had used unofficial translations, meanings had not been altered during the translation.

Members of the European Working Group of People with Dementia (EWGPWD)<sup>2</sup> were invited to share their views on dementia strategies within their countries. We did not specify an area of focus, allowing people with dementia to comment on aspects such as:

- If/how they were involved in the process of developing the dementia strategy in their country.
- Any programme of work originating from the strategy that they had been involved in or had benefited from.
- Any thoughts on what they would have liked to have seen within their country's strategy and/or what they believed should be the focus of future strategies.

### 2.2 Relevance in the European policy context

In 2012, Alzheimer Europe published a yearbook primarily focusing on the progress of each country in Europe in relation to the development and implementation of national dementia strategies. Included within this report was an overview of the availability of medicines, the status of care and support, as well as the identification of any research activity within countries.

At the time, 11 national dementia strategies were in place, with five under development at the time of publication.

As shown in **Table 1**, 21 National Dementia Strategies are now in place, with two countries with national neurodegenerative strategies in place (which include dementia) and two countries (**Germany** and **Sweden**) having officially announced that they are in the process of developing national dementia strategies.

This progress has taken place in parallel to a number of developments at the European level, with the policy, practice and research landscape all having progressed significantly

<sup>1</sup> Alzheimer Europe is a non-governmental organisation aiming to raise awareness of all forms of dementia. As of December 2018, Alzheimer Europe has 42 member associations from 37 countries. For further information please visit: <http://www.alzheimer-europe.org>

<sup>2</sup> In 2012, Alzheimer Europe set up the European Working Group of People with Dementia (EWGPWD), comprised of people with different forms of dementia and of different ages and nationalities, to advise the board of Alzheimer Europe (through the Chair of the EWGPWD) and to participate (either as a group or through individual members) in all activities and projects organised by Europe Alzheimer.

Table 1: Position of countries in relation to a National Dementia Strategy

Countries with a dementia-specific strategy			
Austria	Greece	Netherlands	UK, Northern Ireland
Belgium (Flanders)	Ireland	Norway	UK, Scotland
Cyprus	Israel	Portugal	UK, Wales
Czech Republic	Italy	Slovenia	
Denmark	Luxembourg	Switzerland	
Finland	Malta	UK, England	
Countries with a neurodegenerative diseases strategy			
France	Spain		
Countries with no strategy			
Albania	Germany <sup>3</sup>	Macedonia	Slovakia
Bosnia and Herzegovina	Hungary	Monaco	Sweden <sup>4</sup>
Bulgaria	Iceland	Montenegro	Turkey
Croatia	Latvia	Poland	
Estonia	Lithuania	Romania	

as part of the EU health and research programmes. These include the EU Health Programme, the second Joint Action on Dementia, research projects funded through the Horizon 2020 programme, the extension of the public-private Innovative Medicines Initiative, as well as proposals currently under development in relation to the European Social Pillar. A summary of some key developments in European-level policy can be found in the box overleaf.

One disappointment from 2018 was the decision by the European Commission to disband the Group of Governmental Experts on Dementia (on which Alzheimer Europe, the Organisation for Economic Cooperation and Development (OECD) and World Health Organization (WHO) sat as observer members) being superseded by the 'Member States Steering Group on Health Promotion, Disease Prevention and Management of Non-Communicable Diseases'<sup>5</sup>. This is somewhat reflected in the **French** and **Spanish** approaches to national strategies, both of which have grouped dementia within the bracket of a neurodegenerative condition and published strategies on these conditions as a whole.

More positively, at an international level the WHO adopted a Global Action Plan on Dementia (2017–2025), committing to developing ambitious national strategies and implementation plans. The global plan aims to improve the lives of people with dementia, their families and the people who care for them, while decreasing the impact of dementia on

communities and countries. Its seven areas for action are: dementia as a public health priority; dementia awareness and friendliness; dementia risk reduction; dementia diagnosis, treatment, care and support; support for dementia carers; information systems for dementia; and dementia research and innovation.

As part of this, delegates at the World Health Assembly called on the WHO Secretariat to offer technical support, tools and guidance to Member States as they develop national and sub-national plans and to draw up a global research agenda for dementia. The importance of the Global Dementia Observatory (GDO) as a data and knowledge exchange platform offering easy access to key data from Member States across policy, service delivery, and information and research, was recognised as a vital resource. On a related note, Alzheimer Europe was delighted to be accredited by the WHO Regional Office for Europe this year.

It is noteworthy that across the strategies, there is a clear policy consensus about some of the key priorities which must be addressed, both in relation awareness raising within society, care and treatment, and research. Whilst the strategies naturally reflect the socioeconomic and policy context of their respective areas, the fact that broad themes can be extracted and presented coherently, is evidence of a convergence in approach to dementia across Europe.

<sup>3</sup> The German Federal Government has committed to publishing a national dementia strategy, building on the 'Fields of Action' document published by the German Alliance for People with Dementia published in 2012.

<sup>4</sup> The Swedish National Board of Health and Welfare has been tasked with identifying the long-term strategic issues related to dementia (e.g. models of care). The Board was expected to present a first outline of the work plan to the Swedish Government in October 2018, with the finalised plan expected to be published in 2022.

<sup>5</sup> Alzheimer Europe, working with previous members of the group, hosted a similar 'expert group' to ensure that a vital forum for information and knowledge sharing is not lost. The first meeting of the group took place between 3–4 December 2018.

## Significant European policy and research developments since 2012

- Glasgow Declaration (2014) – The Glasgow Declaration calls for the creation of a European Dementia Strategy and national strategies in every country in Europe. The declaration also called for world leaders to recognise dementia as a public health priority and to develop a global action plan on dementia. Over 11,600 individuals signed the declaration, with more than 200 organisations and in excess of 150 policy makers showing their support by signing the pledge.
- Horizon 2020 (2014–2020) – This programme is the biggest EU Research and Innovation programme, with approximately EUR 80Bn of funding available over 7 years, aiming to deliver more breakthroughs and discoveries in research.
- Innovative Medicines Initiatives (IMI) 1 & 2 (2008–2013 & 2014–2020) – As part of Horizon 2020, the IMI2 is a continuation of the original IMI scheme, representing the largest private-public medicines initiative in the world. It was officially launched in July 2014 and has funded a number of key dementia research projects, including EPAD, AMYPAD, ROADMAP and PARADIGM, all of which involve Alzheimer Europe.
- European Parliament Written Declarations (2015 and 2016) – Two Written Declarations were made with the support of MEPs in the European Alzheimer’s Alliance in 2015 and 2016. The 2015 declaration encouraged both the European Council and the European Commission to prioritise greater collaboration in research, care and prevention. The 2016 declaration called for dementia to be recognised as a public health priority, as well as identifying the need for a strategy to meet challenges presented by dementia.
- EPSCO Council adopts Luxembourg EU Presidency Conclusions (2015) – The Employment, Social Policy, Health and Consumer Affairs (EPSCO) Council of the Luxembourg EU Presidency, adopted conclusions on a number of health-related items, including conclusions on “Supporting people living with dementia”. One of these included calling on all Member States to address dementia as a priority, to develop national strategies or actions plans and to strengthen the collaboration between European countries.
- Second European Action on Dementia (2016–2019) – Following ALCOVE (Alzheimer Cooperative Valuation in Europe – the first ‘Joint Action on Dementia’), the European Commission supported the launch of a second Joint Action through its health programme. The programme aims to promote collaborative actions among Member States to improve the lives of people living with dementia and their carers, and focuses on four key areas: Diagnosis and post-diagnostic support; Crisis and care coordination; Residential care; and, dementia-friendly communities.
- European Social Pillar (2017) – The European Social Pillar, proclaimed by EU Members in 2017, sets out 20 principles in three areas: Equal Opportunities and Access to the Labour Market; Fair Working Conditions; and, Social Protection and Inclusion. As part of this, the Commission is currently drafting a directive in relation to Principle Nine, ‘Work-Life Balance’, which would give carers the right to five days of paid leave each year. Other relevant pillars include:
  - Healthcare – Everyone has the right to timely access to affordable, preventive and curative health care of good quality.
  - Inclusion of people with disabilities – People with disabilities have the right to income support that ensures living in dignity, services that enable them to participate in the labour market and in society, and a work environment adapted to their needs.
  - Long-term care – Everyone has the right to affordable long-term care services of good quality, in particular home-care and community-based services.
- Alzheimer Europe Carers’ Survey (2018) – In June 2018, at a lunch debate in the European Parliament, Alzheimer Europe presented the final findings from the European Carers Survey, which had explored the experience of carers in the diagnostic and post-diagnostic processes in five countries across Europe. The results showed that the process of diagnosis is still taking too long and carers often do not receive adequate support after the diagnosis has been made.



## 2.3 Overview of approach

Working with members, Alzheimer Europe collated copies of the reports and/or summaries of the reports. Whilst the majority of the national strategies had been officially translated into English by their respective governments, some were only available in their national languages. In these instances, we used a summary provided by a member organisation (**Austria** and **Czech Republic**), or we used an unofficial translation, mostly by running the document through Google Translate (**Cyprus, France, Italy, Luxembourg, Netherlands, Portugal** and **Spain**). In these cases, consulting with the member organisations was crucial to ensure that mistakes had not been made in relation to the actions or commitments translated from the documents.

### Themes and grouping

The topics used within this comparative report have been chosen broadly on the basis of those which occurred most frequently within the national dementia strategies. This was an iterative process whereby topics were adapted on an ongoing basis subject to the content of strategies; in particular, the report was constructed in such a way as to provide the most representative overview of priorities. A spreadsheet was created listing all the strategies published,

the year of publication, which included all identified actions/commitments made within the strategy, as well as any other relevant information relating to the topic.

The topics are grouped into seven sections (as listed in the contents page) on the basis of the similarities in the actions/commitments of the governments. For example, whilst it may be intuitive to group together the topics of 'awareness raising' and 'diagnosis' (as the former is likely to play a considerable role towards improving the latter), the approach of the majority of governments was to incorporate elements of societal education, dementia friendly/inclusive communities, with a considerable number also tying in educational messaging around prevention. As such, awareness raising, dementia friendly communities and prevention, have been grouped together under the same section.

### Online summaries

As well as publishing this report and making it available online, Alzheimer Europe will use the information identified within this report to update the relevant sections of the website, providing summaries of each strategy, in each country<sup>6</sup>.

## 2.4 Areas of interest within the strategies

This sub-section will address some points of interest identified during the comparative analysis, without going into the same level of detail as those in the rest of the report. However, these points are useful to consider as they provide an insight into the context in which the national dementia strategies have been developed by governments, as well as their ability to effect change as policy drivers in their own right.

### Open-ended vs. time-limited

One such discrepancy between strategies was identified between governments that opted for an open-ended national strategy and those that did not. The **Czech Republic, Flanders (Belgium)** and **Scotland (UK)** all have short-term time-limited strategies, of four years (**Czech**) and three years (**Flanders** and **Scotland**); by comparison, **Denmark, Finland,**

**Netherlands** and **Malta** all have time-limited eight year strategies. However, about a third of the strategies (eight including one of the neurodegenerative strategies) were open ended, with no date in place for completion.

As part of the **Portuguese** strategy, the devolved regions have one year to develop regional dementia plans, detailing how they will give effect to the national dementia strategy.

For strategies which have no stated date for conclusion, unless advised otherwise by the national association, this report assumes that the strategy continues to be in effect with stakeholders working towards implementation. The **Cypriot** strategy is, ostensibly, concluded. However, the national society indicated that many of the actions of the strategy were not completed and that they are still advocating that the government should work towards the aims and, where necessary, update them.

<sup>6</sup> Available at <https://www.alzheimer-europe.org/Policy-in-Practice2/National-Dementia-Strategies>

## Terminology

Across the different strategies, there was significant variation in the language and terminology used in relation to different aspects of services, awareness raising or support.

Whilst very few of the strategies were prescriptive as to the nature of individual services (the majority of strategies focused on more high-level descriptions of inputs/ outputs), some strategies (including **Greece** and **Malta**) provided detailed descriptions of some services that should be provided and the nature of the staff who should provide them. One such example was that of day care services in **Greece**, which seemed to outline a more community-based, clinician-intensive service delivered by Allied Health Professionals, nurses and social workers, by comparison to a more socially-focused model, which prioritises social connections, participation in the person's community and meaningful activity.

This is not to suggest that the approaches are mutually exclusive or that one approach should be favoured over the other – indeed the implementation of the **Greek** model incorporates these different elements. Rather, by identifying this point, this report's identification of this point demonstrates that whilst many strategies may refer to similar services (e.g. day care centres, post-diagnostic support etc.), the delivery of services and practice of professionals is likely to be significantly different, even when common terminology is used. As most countries did not offer this level of detail in terms of service delivery, it has not been possible to explore in more depth the extent to which there is variation on commitments made under the same heading.

## National strategies vs action plans

A related aspect is that of the names of dementia strategies. In some cases, they are referred to as national dementia strategies, national action plans or health action plans (amongst other). Whilst in the majority of the cases there was no explanation given as to why the governments had chosen a specific name, there were some instances in which a fuller explanation was given or presented itself.

The **English**, **Irish** and **Swiss** strategies all had separate 'action plans' which chartered the progress of their strategies (usually about midway through the term of their fixed terms strategy). Some of the strategies also had implementation plans or accountability measures "built-in" through appendices.

This document has included the comparison of **Germany's** "Fields of Action" document as a point of reference

as it contains actions and commitments, and is an official publication of the Federal Ministry of Health. However, it is important to note that it is not a strategy or action plan per se. We have therefore referred to it as a "strategic document" throughout to acknowledge this distinction.

The distinction between a strategy and action plan is illustrated in the case of the **Portuguese** strategy. It is noted within the strategy itself that stakeholders involved in its drafting proposed the inclusion of more defined and specific measures in order to achieve the proposed commitment. In this instance, the stakeholders were told that this was not the suitable place to include such a measure, as the strategic document was solely to address high-level overarching priorities, with "regional action plans" the most suitable level for details around implementation.

Again, this section does not seek to advocate a specific approach to creating or naming a strategy, rather it intends to draw attention to the different status of dementia strategies, as well as the ability these documents have to change policy, practice and services, to improve the lives of people with dementia, their families and carers.

## Resources and funding

As a final consideration, the status of the strategies, in some cases, is linked to the funding and available resources to implement the intended outcomes. Broadly speaking, the strategies can be broken down into four categories.

We know from discussions with some members that the lack of funding or dedicated resource has limited the implementation and realisation of the aims of some of the strategies:

- Fully funded (resources identified and secured): **Denmark**.
- Fully costed (funding sources identified but not secured): **Greece**.
- Limited funding commitments for specific work: Some strategies (e.g. **England**, **Finland**, **Germany**, **Netherlands** and **Norway**).
- No information on costing/resources: All other strategies.

From discussions with member organisations, we are aware that in a number of circumstances there are strategies with no resources dedicated to them, making the process of achieving significant change within their societies and systems more difficult.

## 2.5 Structure of the report

As noted previously, the report is grouped into seven sections with each containing a small introductory explanation of the rationale of the thematic grouping, some high level observations in relation to the strategies, with a more in-depth explanation of the individual themes/areas.

We invited members of the European Working Group of People With Dementia (EWGPWD) to contribute their views on dementia strategies within their countries based on their experience. These “personal reflections” provide a useful insight into how high level policy documents are perceived by those whose lives they aim to improve.

## 2.6 Limitations of the report

Before moving to the main body of the yearbook, it is important to acknowledge the limitations of this report. Considering some of the points above in relation to the approach, purpose and context of these national dementia strategies, attempting to present overarching themes which are truly representative and broadly applicable is difficult.

Furthermore, it is imperative to recognise that this yearbook is primarily concerned with the content of the dementia strategies. We are aware of examples of excellent work which have taken place (and/or are ongoing) within countries, that have not been included within their strategies for various reasons.

Therefore, where a country or strategy is listed as having no/little detail of any work or commitment under a certain section or subsection, it should not be inferred that this represents a lack of action, work or commitment in this area – it only reflects the lack of content within the strategy itself. Equally, the inclusion of commitments or action points within the strategy is not a guarantee or demonstrative that they have, or will be, implemented.

As such, whilst this yearbook provides a useful insight into the policy context as it currently stands in Europe (including the progress made since the 2012 yearbook and the 2014 Glasgow Declaration), the information within must be viewed with these caveats in mind.

## 3. Development and implementation of strategies

This section seeks to provide an overview of the more procedural aspects around the strategies, specifically around their development, implementation and governance. We were particularly interested to see the extent to which people with dementia, their families and carers were involved in the process.

As these were more technical issues concerning policy development and process, these sections have been grouped together separately from other aspects of the strategies that primarily focus on policy, practice and research.

### 3.1 Development and involvement

Across the strategies, there was a common theme which emphasised the importance of ensuring that people with dementia, their families and carers are involved in the decision-making process in relation to their own care, as well as the planning and delivery of services, and the development of policy. Despite this, it was not evident that all strategies had followed this process of involvement throughout their development.

of people with dementia and carers, including **Austria, Denmark, Luxembourg, Norway** and **Scotland**. **Northern Ireland's** strategy notes a specifically commissioned piece of research from the Alzheimer's Society which was used to inform the direction of the strategy. From these strategies, there appeared to be a mix between organisations which involved people with dementia and their carers separately, and those which involved them alongside a broader audience (including academics, clinicians, care providers etc.). **Denmark** and **Malta** were notable for the focus on engaging service providers as part of the development of their strategies.

#### Steering committees

The majority of strategies provide a breakdown of the members of the steering committees/working groups which had overseen the drafting of the national strategy. This invariably included members of the government (primarily though not exclusively from the health departments), clinicians, academics, service providers, and, in every case, the relevant Alzheimer's Association(s). However, fewer than a quarter of the strategies contained more information beyond the make-up of the steering committee, so it is difficult to establish the extent to which the views of people with dementia were used to shape the direction of the strategy.

In addition, a number of other strategies (including **Austria, Denmark, Malta, Portugal**, and **Scotland**) also set out broader public consultations which allowed for input from any interested parties (including members of the public, professionals, service providers and other organisations) to contribute to the development of the strategy.

As such, we can see some level of consistency in terms of clinical, governmental and professional involvement in the development of dementia strategies. It was pleasing to see that Alzheimer's organisations were involved in the process of developing the strategies, especially in countries where people with dementia, their families and carers had not been directly involved in the process.

#### Workshops/dialogue events

A small number of strategies articulated an approach of holding workshops or events to gather the lived experience

### 3.2 Implementation of the strategy

In developing the yearbook, we were interested in examining how governments committed to the delivery of the actions of the plan, to ensure it benefited people with dementia, their families and carers. Countries approached this in considerably different ways, with some providing detailed

information regarding timescales, departmental/organisational responsibility and in a limited number of cases (notably **Denmark** and **Finland**), specific costing or sources of funding. In all strategies, the Health Ministry/Directorate had overarching responsibility for the implementation of

the plan, either through an existing structure or through a delegated committee or group.

## Interim progress reviews/reports

**England, Ireland** and **Switzerland** all produced interim progress reports, detailing the progress made in each area, detailing the next steps and future work. In the case of **Switzerland**, this resulted in the extension of the lifetime of the strategy in order to allow sufficient time to progress work towards the implementation of the commitments.

The review of **England's** strategy (specifically the implementation plan) focused on key actions (18/50 committed actions) related to its implementation but was also the only interim report which contained some form of public consultation.

## Action plans

A considerable number of strategies contained indicators, setting out the purpose of an intended goal or commitment, the responsible organisation or department, as well as measures for success (and how this would be demonstrated) and timescales for implementation. These were presented in a number of ways, including incorporation within the main texts of the strategy, annexes or as an accompaniment.

Strategies which included such action plans included **Denmark, England, Finland, Flanders, Germany, Ireland, Luxembourg, Northern Ireland, Slovenia** and **Wales**.

As noted previously, **Portugal** was distinct from this approach, giving regions one year to produce regional action plans which would outline how they will implement the national strategy.

## Implementation committees and governance

A number of strategies indicated that specific committees would be established to oversee the implementation of the strategy, including **Cyprus, Greece, Israel, Italy, Malta, Northern Ireland, Portugal, Scotland** and **Wales**. There was little detail in the strategies as to how these governance groups would operate or what the composition of their membership would be.

The most detailed governance structure was outlined within the **Swiss** plan, setting out the three distinct bodies which would oversee the implementation of the

strategy. The primary body with responsibility was the coordination committee composed of statutory governmental bodies, a consultative group which included patient organisations and other stakeholders, and a platform group which contained offices of the cantons etc. which had direct responsibility for the implementation of projects within the strategy.

## Other points of interest

Many of the strategies were linked into, or are strands of, overarching policy drivers. **Norway's** was the only strategy which was a direct auxiliary of another care strategy, linked in with other areas of work and funding streams across different areas. All other strategies, whilst fitting in with a wider agenda, were distinct strategies in their own right.

Some examples of these linkages included the **Czech Republic** and **Finland** proposing changes to health and social care legislation to allow for shifts in the provision of care services for people with dementia. In addition, **Finland, Germany, Northern Ireland, Scotland** and **Wales** all articulated links and parallels with existing domestic policy such as health and social care, local delivery through better coordination of services and quality improvement as well as other areas of reform.

The **Finnish, Norwegian** and **Welsh** strategies were the only strategies to explicitly reference the usage of routinely gathered data as a measurement against the commitments in the strategy (though other strategies recognised the importance of routine data gathering – see section 8.2).

**Malta's** strategy references the need to ensure that people with dementia, their families and carers are involved in the process of implementation, whilst the strategies of **Cyprus** and **Flanders** also committed to ensuring people with dementia were involved in future dementia policy. **Germany** was distinct in its commitment to develop over 500 local groups to ensure that people with dementia, their families and carers were involved in policy decision-making processes, including in relation to the implementation of the national strategy. The **Norwegian** strategy also proposed national questionnaires as well as the development of quality indicators which would allow people with dementia and their carers to share their experiences in relation to policy and services.

**Ireland** was distinct in that in addition to its own governance arrangements, including an interim review, it committed to an independent evaluation of its strategy and the implementation of the actions contained therein.

Overall, we can see that there is a broad range of approaches to the implementation of the strategies, focused on a number of different areas. Again, it is perhaps disappointing that there is not more clarity on how the governance arrangements will ensure that the experiences of people with dementia, their families and carers will help play a role in

the implementation of the strategies. However, it is encouraging to see such a variety of methods used to ensure the strategies are implemented, including the clear links with other policy agendas that support improvements both to policy and practice.

### 3.3 Personal accounts



I am proud to sit on the Monitoring Group for the Irish National Dementia Strategy although I think the Minister for Health would find it easier if I didn't!

A strategy is a critical first step, each country needs to consider what it wants to achieve for its citizens living with dementia. However, strategies have to be implemented. To be successful, a strategy must be funded appropriately and there must be a significant attitudinal change from government and health care providers.

When the **Irish** National Strategy was developed I stated that words are not enough, we need action and implementation. And we needed to see a realisation of our basic human rights. I am frustrated because I see little practical change for me and my family after four years of the Irish strategy.

People living with dementia are denied their human rights from the time of diagnosis. We are not always respected or informed. As we live with the disease we navigate systems and structures which are not person centred or rights based. As a result, either deliberately or by omission our human rights are denied.

I have a human right to healthcare. The Irish National Dementia Strategy is working toward upholding these rights but we have a long way to go yet.

**Helen Rochford-Brennan** is Chair of both the European Working Group of People with Dementia (EWGPWD) and the Irish Dementia Working Group.



All people living with and affected by dementia should be at the centre of discussions about how services are provided.

This was highlighted with the impact of people in Wales made when sharing their experiences of dementia with the Welsh government ahead of the country's Dementia Action Plan. This was a fantastic example of what happens when you involve the people who are going to be in receipt of these services.

It started when a couple of people with dementia and a carer became involved in the development of the Welsh Dementia Action Plan 2018–2022 by them attending a public consultation session, one of only two that were planned. They swiftly realised the lack of public engagement, especially from those who were actually affected by dementia, diagnosed, carers and family members, all whom this was on behalf of.

After speaking to the Welsh Government lead to explain the importance and the right of people with lived experience being involved in these consultations and in the policy-making processes, the Welsh Government provided additional funding to hold a series of public dialogues and expert meetings across Wales.

People with dementia, their carers and families were engaged as key experts on dementia task groups within the Welsh Government, with two phases of wider public consultations held across Wales, where over 400 people with dementia, their carers and families provided input into the Welsh Dementia Action Plan.

The Welsh Government and the officials involved, listened, acted, edited and supported all the voices that mattered. It really was 'Nothing about us, without all of us'!

By sitting equally on the task and finish group as experts in our own right, we not only made valid contributions, but instigated major changes to the initial draft. It was an amazing experience and example of true collaboration and inclusion, the experts by experience and the professional experts.

This ultimately affected the nature of the Welsh Dementia Action Plan and the lives of people affected by dementia. Our involvement changed the whole plan, which in turn, will change lives.

We also changed the minds of the people at the top, the people in those positions that have the influence to make the necessary decisions. We were no longer a 'tick box' consideration, but equal members of the group and society as a whole.

The Welsh Government continues to engage people living with and affected by dementia by guaranteeing places for people diagnosed and affected by dementia on the Implementation and Advisory Group to carry the plan forward, to be equally involved and to oversee that what is put in place, also has a collaborative rights based approach.

**Chris Roberts** is Vice-Chair of the European Working Group of People with Dementia (EWGPWD) and a member of the 3 Nations Working Group.

## 4. Human rights and legal matters

A key aspect of dementia policy and campaigning work across Europe over the past two decades has been to emphasise that people with dementia have the same human rights and that they should not be treated differently because of their condition. This approach is one that is embedded within the European Convention on Human Rights (ECHR) and the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)<sup>7</sup>.

As such, we were keen to see the extent to which PANEL principles (participation; accountability; non-discrimination and equality; empowerment; and legality) were evident in the strategies. In doing so, we have broken down the analysis into two subsections, with the first providing a broader overview of how rights were referred to and incorporated into strategies, and the second examining legal matters in relation to rights, including through legal capacity, proxy decision-making etc.

### 4.1. References to human rights

The approach across strategies was broadly similar, with most commitments and inclusion of rights being broad in nature and lacking details regarding specific, legally-enforceable rights. Whilst no strategy referred to the PANEL principles, there was much within the strategies which reflected the nature of the principles (including some aspects of participation and accountability).

need to move away from a medical model in the care and treatment of people with dementia.

**Luxembourg** proposed a greater focus on ensuring that individuals were made more aware of their legal rights, as well as a human right awareness campaign targeted at both the public and professionals.

#### Overview of inclusion of rights

There were many common aspects of rights which applied across a number of strategies, the focus of which centred on the dignity, respect, autonomy and self-determination of people with dementia, which largely related to ensuring that the wishes of people are respected and that people are not deprived of their liberty.

Again, it is notable that the neurodegenerative strategies of **France** and **Spain** followed similar, if less detailed, commitments in relation to the rights of people with neurodegenerative conditions. The **French** strategy specifically calls for the rights of the person and ethical thinking to be a driver for systematic change, whilst the **Spanish** strategy calls for the promotion of the rights and dignity of persons with disabilities and for a reduction in stigma, through media messaging.

Both **Germany** and **Wales** placed a more specific focus on the self-determination, specifically relating to participation and equal opportunity to participate in decision-making processes. Additionally, the **Maltese**, **Scottish** and **Swiss** strategies mention rights in relation to ethical care and support, whilst the **Norwegian** and **Slovenian** strategies drew more explicit links between rights and the capacity of the individual. The **Portuguese** strategy refer to the needs and preferences of people with dementia as well as ethical principles around informed consent and autonomy.

#### Reference to International Conventions

A number of countries refer to international rights treaties including **England**, **Germany**, **Greece**, **Northern Ireland**, **Norway** and **Slovenia**. Between these countries, the following treaties were mentioned:

Both **Finland** and **Flanders** were distinct in that they drew links between rights and specific aspects of the way in which health and care services are delivered. The **Finnish** strategy identifies that the procurement of services must be done in such a way as to ensure that the rights of people with dementia are upheld. Similarly, **Flanders** noted the need to uphold the full rights of people with dementia and the

- European Convention on Human Rights.
- United Nations Convention on the Rights of Persons with Disabilities.
- The UN Convention on Human Rights.
- The International Covenant on Economic, Social and Cultural Rights.

The **Greek** strategy was distinct as it sought to establish a specific legislative provision in relation to the international conventions and agreements to which **Greece** is a signatory,

<sup>7</sup> Not all European countries are within the jurisdiction of the ECHR, whilst some have not ratified the UNCRPD. However, the similar protections afforded by both conventions can be seen as robust indicators of legal rights which should be afforded to people with dementia and their carers.



to ensure that effect is given to these rights in practice, especially on legal capacity and rulings of the European Court of Human Rights (ECtHR).

Alzheimer Europe was also delighted to see a reference to the Glasgow Declaration within the **Slovenian** and **Welsh** strategies in the context of the rights of people with dementia and their carers.

## Other

A number of points of interest arose which were not generalisable, as they were unique to their respective strategies.

The **English** strategy discussed the possibility of collaborating with the UN Independent Expert on the Human Rights of Older People, Rosa Kornfield-Matte, in relation to international human rights commitments and how these relate to people with dementia.

Both **England** and **Wales** referred to Dementia Action Alliance “rights statements” that have been developed by the third sector (NGOs), which reflect rights of individuals (although these are not grounded in law).

The **Cypriot** strategy was distinct in its proposal to create a specific commissioner for people with dementia who would have responsibility for overseeing and ensuring that the rights of people with dementia were respected and upheld.

## 4.2 Legal matters (including legal capacity, proxy decision-making etc.)

### Legislative changes

As noted in the previous section, the **Greek** strategy notes the obligations of the Greek state as a signatory to such international conventions. As such, the strategy proposes the establishment of a specific legislative committee to examine domestic law in relation to the legal rights of people with dementia and carers, including on issues around legal capacity, proxy decision making, deprivation of liberty, privacy, health and autonomy.

In line with the recommendations of an independent review of mental health and learning disabilities, the **Northern Irish** strategy notes the intention of the government to bring forward a unified mental health and capacity law, which would embed principles (e.g. best interest) in the legislation.

The **Luxembourg** strategy proposes reforms to its current legislation for protecting adults with incapacity, with a focus on the individual needs of the person and only intervening as is strictly necessary, with regular reviews and promotion of the retention of autonomy. As part of this, the concept of a “trusted person” will be introduced, who can help communicate the wishes of the person with dementia when they are no longer able to do so for themselves.

Another commitment is the introduction of a “house counsel” in an effort to involve the person and their families to uphold the rights of people in long-stay institutions.

The **German** strategic document committed to a legislative review by the Federal Government, in relation to future planning and compulsory measures, to balance the powers

of the proxy decision-maker and the autonomy of the individual. As part of this, the Länder will examine the financing of guardians and legal agents. Similarly, the **Swiss** and **Irish** strategies noted that recent reforms to their own legislation had sought to achieve similar aims, namely improving the patients’ rights with regard to autonomy, including ensuring that advance directives were able to help ensure patients wishes were respected.

The **Portuguese** strategy contains a recommendation in relation to the legal framework concerning the rights of people with incapacity, including the legal frameworks around care and research.

The **Spanish** neurodegenerative strategy embedded protocols in regulation/legislation for the use of physical and chemical restraint.

### Policy/practice changes

The **German** strategic document included a commitment from all partners to reducing deprivations of liberty, with the Federal Government proposing to revise criteria for compulsory measures whilst the Länder and German medical association committed to revising the information they provide around compulsory measures.

As part of its legislative changes, **Northern Ireland** committed to publish a Code of Practice in relation to the provisions of the Bill, intended to guide the practice of professionals who would give effect to the legislation.

The **Slovenian** strategy approached the issue of decision-making in a slightly different way, seeking to promote

social advocacy to help support the person realise their rights, through diagnosis, planning for the future in order to ensure that the person receives high-quality treatment after diagnosis and equal access to treatment and therapeutic measures.

The **Maltese** strategy also discussed the need for people with dementia to be supported to make decisions regarding their health and welfare as well as dealing with financial and legal issues at an early stage of dementia, committing to ensuring that people were offered the psychological support to do so. The **Spanish** neurodegenerative adopted a similar approach, setting out what information should be provided for people diagnosed with the condition, as well as the professionals who support them.

The **Norwegian** strategy noted that use of compulsory measures under the Patients' Rights Act in relation to people who lack capacity had been reviewed and that it had identified that it was the skills and understanding of staff which needed strengthened, not the legislation itself. As such, the health directorate developed resources and education materials to upskill professional application of the legislation.

## Awareness raising

A number of strategies identified the importance of ensuring that both professionals, members of the public and people living with dementia were aware of the legal provisions surrounding legal matters, particularly in relation to proxy decision-making etc.

The **German** strategic document, in line with other changes in policy and legislation, committed to increasing the amount of information available for professionals, people with dementia, their families and carers, particularly around guardianship and proxy decision-making. A similar approach was taken within the **Spanish** neurodegenerative strategy.

The **Irish** strategy referenced its intention to implement the National Consent Policy, as well as promoting awareness of its assisted decision-making legislation, to ensure that people with dementia are supported to participate in all decisions that affect them, according to their wishes.

However, a notable exception was the **Israeli** strategy which, although including the rights of the person with dementia, also specifically addressed the rights and entitlements of the familial caregiver.

## 4.3 Personal account



When I was diagnosed with dementia it felt like falling off a cliff into a dark hole, I struggled to find information and access services. I was viewed by medical professionals as a hopeless case, not a person with a disability needing support and services to live as well as possible. When I turned 65 I changed from being a person with a cognitive issue to an older person.

Being an 'official' older person brought access to older peoples' services but older people are traditionally encouraged to accept their fate and not offered rehabilitation.

I want dementia to be viewed as a disability to ensure those of us living with the condition are afforded the rights and supports that other living with a disability are offered. If I was in a wheelchair no one would question my need for a ramp but cognitive ramps are not forthcoming.

I believe framing dementia as a disability would encourage a rights based approach and a better understanding of the human rights issues that affect those of us living with dementia.

**Helen Rochford-Brennan** is Chair of both the European Working Group of People with Dementia (EWGPWD) and the Irish Dementia Working Group.

## 5. Diagnosis, post-diagnostic support, care and treatment

In all of the strategies, the majority of commitments and actions are focused on issues relating to the care and support of people for people with dementia. Significant attention was given in all strategies to the coordination of health, social care and other supports in community settings, as was the need to ensure that professionals working in these fields were sufficiently qualified and skilled to be able to deliver the highest quality care.

The following sub-sections have been created to encompass the different commitments and issues within strategies, providing an overview of the approaches to these. Across

the strategies examined, different emphasis and linkages were made, reflecting the health and care systems, structures and policies within each country.

As such, these sub-sections may contain aspects which overlap with other themes (e.g. where workforce development or awareness raising is a tool to improve diagnosis). However, the content of the subsections reflects the framing of the issue within the strategy in which it was found e.g. if a strategy committed to an awareness campaign under the heading of 'diagnosis' in the strategy, it has been included under the heading of 'diagnosis' in this report.

### 5.1 Diagnosis/assessment of dementia

All of the strategies acknowledged the importance of getting a timely diagnosis of dementia, to allow for effective treatment and interventions, to allow the person to plan for the future and to ensure services and supports can be put in place to help the person live well with the condition for as long as possible.

Each strategy focused on different aspects of diagnosis, with some referring to the tools used to achieve the diagnosis, whereas others focus on the process of receiving a diagnosis. Although all strategies noted the importance of a timely diagnosis, only **Denmark** and **Wales** had specific targets relating to increasing the number of people diagnosed.

#### Process of receiving a diagnosis

Referral systems were a focus for many strategies, with many identifying that the referral and care pathways between primary and secondary healthcare settings, required improvement, both in relation to diagnosis and management of the condition. This was seen as especially true for more complex cases where specialist services may be required. These elements were seen as crucial to a timely and well-coordinated diagnosis, and were found in the **Cypriot, Czech, Danish, Irish, Maltese, Northern Irish** and **Welsh** strategies.

**Italy** was the only country to make reference to a multi-disciplinary team approach covering both diagnosis and coordination of interventions for dementia (although the highly variable nature of implementation was noted).

**Malta** identified the need to reduce waiting times for appointments with specialists for individuals with suspected cognitive impairment, whilst **England** committed to a maximum national average for an initial assessment of six weeks following a GP referral, with no-one waiting months for an initial assessment of dementia.

The priorities of the neurodegenerative strategies are similar in nature to those of the national dementia strategies.

**Spain** highlights the need for responsive referral processes between primary and secondary health for the early detection of neurodegenerative conditions, with specific programmes for people with high genetic risk. The **French** strategy similarly prioritises the quality of diagnosis for people with a neurodegenerative condition, with priority given to establishing shared assessments and guarantees of access to personalised care.

#### Memory clinics/services

Another common area within strategies related to where a diagnosis should take place, whether in primary settings or secondary settings, and whether this should be in a dementia-specific service such as a memory clinic. From the services described in the strategies, there appeared to be two distinct approaches to the delivery of diagnostic services – one focused on primary care, the other on regional services.

Where a primary care approach was proposed, the diagnostic process was primarily driven through primary care, with initial assessment at this level and followed by input from

specialist services (usually secondary healthcare such as old age psychiatry, neurology etc.) where necessary. Follow-up through provision of information or other interventions was also advocated in the **Irish, Finnish, Greek, Maltese** and **Welsh** strategies.

The **Norwegian** approach identified the need for greater cooperation between different specialists and personnel, though noted that specialist health services and the municipalities had their own agreements. The **Swiss** approach proposed the establishment and expansion of regional, networked centres which would have responsibility for diagnostic services.

**Northern Ireland** did not commit to one location or another, instead proposed a broader Memory Service which would provide a minimum level of service regardless of location.

**Flanders** was the only strategy to specifically address dementia in younger people, setting out the cooperation between different types of memory/cognitive services in relation to general hospitals and ongoing monitoring.

## Training for professionals

Regardless of the service approach for diagnosis, a number of strategies highlighted that training for professionals was crucial in the detection and diagnosis of dementia. In the majority of strategies, the focus was on the need for awareness, clinical guidance and training of primary care professionals for the detection of dementia. This was present in the **Danish, Finnish, Flemish, Greek, Irish, Israeli, Luxembourg, Maltese, Northern Irish, Slovenian** and **Spanish** strategies.

**Flanders, Finland** and **Israel** also highlighted the need for pharmacists, occupational health professionals and community practitioners, respectively, in recognising and identifying individuals who may be at risk of, or may have, dementia. As part of this, **Flanders** published an e-learning module (FAZODEM) specifically for pharmacists.

With specific relation to the process of diagnosis, the **Slovenian** strategy was the only one to refer to the importance of training secondary healthcare specialists in specific diagnostic testing procedures (e.g. lumbar punctures).

## Tools for assessment/clinical guidelines

In addition to training, many of the strategies provided specific information on the development of tools or resources to support the process of assessing or diagnosing dementia. Additionally, some strategies focused on the need for clinical guidelines.

The **Luxembourg** strategy committed to a more thorough diagnostic test for secondary care, based on national pathways for diagnosis.

**Denmark** and **Wales** included the need to develop a robust clinically validated dementia assessment tool(s) for use in the **Welsh** language and commission research into assessment of dementia. **Switzerland**, in addition to the use of more tools for the early detection of dementia, was distinct in its commitment to specific instruments for interdisciplinary assessments. Beyond solely health and social care, **Germany** took a similar approach for social security, committing to reviewing the assessments of capacity and ability for people with dementia.

Additionally, **Denmark, Germany, Northern Ireland, Norway** and **Scotland** all identified the need for the adoption of national clinical guidelines for dementia, with the latter also tying this into guidelines for providers on a staged health concept. Similarly, some strategies including those for the **Czech Republic, Malta** and **Portugal** all indicated their intention to follow internationally recommended standards, with the **Portuguese** strategy specifically identifying the WHO guidelines.

## Public awareness

The **Flanders** strategy was an exception insofar as whilst most strategies included some level of public awareness campaign, however, this was the only which specifically linked the issues of receiving a timely diagnosis to such a campaign.

## Other

There were other aspects included within the strategies related to diagnosis which were distinct from matters purely related to the process of diagnosis itself.

A 'key outcome' contained in the **Scottish** strategy identified the purpose of timely diagnosis as a means to ensure that individuals could be involved in the process of their diagnosis and care planning.

Both **Ireland** and **Wales** acknowledged the need to examine the issues around attempting to diagnose dementia in people with learning disabilities, as a result of this population's susceptibility to younger onset dementia. **Wales** also committed to exploring the needs of people with dementia who also have some form of sensory loss.

The **Norwegian** strategy noted that more needed to be done to ensure that the distinct needs of people from Black, Asian and Minority Ethnic origin were considered in relation to the diagnostic process.

The **Greek** strategy was notable for its intention to create a standardised register of people diagnosed with dementia to help improve data recording to inform policy-making. As part of this, the **Greek** system proposed including additional information (e.g. degree of disability) to ensure they receive support commensurate with their needs. Similarly, **Ireland's** strategy committed to ensuring appropriate recording and coding of dementia in primary care settings and the development of practice-based dementia registers.

The **Northern Irish** strategy is unique in its reference to a statutory regulatory service (the Regulation and Quality Improvement Authority) reviewing the effectiveness of diagnostic and memory services.

**Portugal** identified the needs to carry out a survey to establish what health and social care resources existed in each region.

## 5.2 Post-diagnostic support (PDS)

Post-diagnostic support provision across the strategies varied considerably and in some cases it was not evident that it was a distinct service in its own right or that there was a specific commitment to post-diagnostic support (PDS) in the strategies. As such, this section only includes commitments which either directly refer to PDS or were made within the sections around diagnosis.

information provision e.g. future planning, counselling, referrals etc.

Some strategies were broader in terms of the service offer and which aspects should be included. The **Greek** strategy committed to establishing a regional person or service which would support the person, whilst the **Luxembourg** strategy committed to meeting the assessed needs of people with dementia.

### Information provision

One of the areas of focus amongst many strategies was that of the provision of information following the diagnosis, across areas such as day to day living with the condition, future planning, available services and supports (including welfare/benefits).

These elements were acknowledged within the **Slovenian** strategy as being crucial for both people with dementia and their carers, referencing the provision of link workers within other countries. Similarly, the **Israeli** strategy spoke of the need to create comprehensive care plans with the patient and their family immediately after diagnosis, but with less detail as to how this should be done.

This was evident in the **Finnish** strategy, with the responsibility for information spread across the public sector, third sector etc. Somewhat similarly, **Luxembourg** also proposed more work on awareness raising in relation to the availability of specialist services that exist for people with dementia outside existing structures for older people.

Both the **German** strategic document and **Finnish** strategy placed responsibility on public providers to deliver support to people after a diagnosis including information about the condition, guidance and advice, counselling services and peer support services.

**Greece** placed the responsibility for information provision on regional services, including information sharing and awareness raising. It was not apparent if this was on a front-line basis or a more population based approach. Similarly, local memory services in **Northern Ireland** have responsibility for information provision after diagnosis.

**Ireland** and **Wales** committed (the former within primary care services), to the provision of a key worker/support worker who would co-ordinate each patient's care, including, information provision, continuity for the person and ensuring they were able to access supports and services. **England** did not specifically reference the role, but committed to ensuring that all people diagnosed received a similar type of support measured against national standards.

**England** similarly had a focus on the provision of information after a diagnosis had been made, though had a unique focus on informing people about research opportunities, specifically through its Join Dementia Research programme.

**Scotland** was more detailed in its commitment, continuing with the guarantee of one year of support from a Link Worker based on Alzheimer Scotland's "5 Pillars Model of PDS", for people diagnosed with dementia, whilst also proposing a new way of providing support (using the "8 Pillars Model" developed by Alzheimer Scotland) where a person's needs were more complex. The 12 month period of support would be made more flexible so that for those still requiring support after this time, the service would continue. The strategy also commits to exploring the provision of these services from primary care settings.

### Link/support workers and services

A number of the strategies contained different approaches to PDS services. Of those which included reference to some form of services, a similar theme emerged in the form of a link worker or specific service, going beyond basic

**Norway's** strategy covers similar detail to that of **Scotland**, outlining the importance of ensuring that people receive person-centred, coordinated support and advice after a diagnosis of dementia, proposing to develop and test different models of delivering PDS.

Conversely, **Malta** was distinct in its proposal to establish a new multidisciplinary team, the Dementia Intervention Team, managed by a Dementia Coordinator. This team would aid individuals with dementia and their relatives by providing information and care coordination (including psychological counselling, development of advance directives etc.).

### 5.3 Coordinated care in the community

This theme was one of the most commonly covered across all strategies and included the organisation and structure of services, how best they should be coordinated, as well as the move away from institutional-based care to community-based supports and services.

Such is the complexity of these issues and the breadth of approaches in each country, there was considerable overlap with other sections, including PDS, residential care etc. As those aspects have been covered in a separate subsection, they have not been included here, unless they relate to either the issue of coordination or the transfer of services away from institutional settings to community settings.

#### Coordination between services

Coordination between services was a recurring theme within this section, applying between not only health and social care sectors, but also at times between primary and secondary healthcare. Many of the strategies did not explore the detail of how their commitments would be operationalised, however, the information below captures some of the different components which were included.

A number of strategies focused on the need for multidisciplinary teams (MDTs) in supporting people with dementia throughout the course of the illness. **Flanders, Israel, Italy, Malta, Norway** and **Wales**, particularly emphasised team approaches to caring for people with dementia in community settings (including home-based care, intermediate care and, to a lesser degree residential facilities) drawing on the input across health and social care professions. The **Cypriot, Czech, Northern Irish, Portuguese, Spanish** (neurodegenerative) and **Swiss** strategies equally focused on the need for networks of services which variously included elements such as GP involvement, counselling, social services and day centres, to ensure that the person with dementia and their families received the appropriate level of support.

#### Other

The **Flanders** strategy contains a specific focus on the needs of people with early onset dementia, specifically in relation to the provision of high quality psychosocial support, as well as including aspects of choice and affordability. **Malta's** strategy also noted the distinct needs of younger persons with dementia following a diagnosis, but did not do so exclusively, as in the **Flanders** strategy.

In addition, this approach was contained within the strategies of **Flanders, Israel** and **Scotland**, however, with a single professional responsible for coordination and continuity of care. **Flanders** proposed creating dementia-specialist practitioners to coordinate home-based care services, **Israel** identified the need to create a new "nurse coordinator" role, with **Scotland** having a "Dementia Practice Coordinator" as part of its "8 Pillars Model", which creates a single practitioner to coordinate across health and social care services. **Finland's** system also noted the importance of case workers to coordinate support both for the person with dementia and the caregiver.

In addition, the **Northern Irish** and **Portuguese** strategies both identified care planning as a means of ensuring better coordination and continuity of care for the individual. The former specifically noted the use of shared assessments across health and social care as a means to achieving this aim.

The **English** strategy gives GPs a primary role in ensuring coordination and continuity of care for people with dementia, as part of a wider commitment to ensure that every person has access to a named GP. The **Portuguese** strategy also proposed a proximity model for the responsibility of care, though noted that this role could be carried out by people other than GPs. Whilst not necessarily providing a lead role, the **Czech** strategy and **German** strategic document also noted the importance in involving GPs in the coordination of care for people with dementia and their carers.

Specific coordination across organisational structures was a focus for some strategies including that of **Norway** which examined the integration of primary health and care. Similarly, **Northern Ireland** and **Wales** also acknowledged work around integrated boards with responsibility for health and social care to ensure better coordination of services, with the former placing emphasis on the commissioning of services to achieve this goal. On a similar theme, the **German** strategic document and the **Spanish** neurodegenerative

strategy both indicated that municipal and regional governments would take on greater responsibility in the provision of health care, with the former having a focus on rural areas, to better coordinate provision in their regions.

**Austria** and **Italy** were the only strategies to propose the development of quality standards in relation to integrated networks of care and support between providers and sectors.

**Germany** and **Italy** focused on the importance of information sharing as part of this process of coordination. The **German** strategic document focused on institutional information exchanges whilst also identifying the importance of information sharing between statutory organisations and peer support groups. As part of this, care and service providers committed to reducing unnecessary bureaucracy and creating more efficient care documentation. The **Italian** strategy more specifically focused on the need for local information structures to be accessible, which would improve transparency.

The **French** neurodegenerative strategy was broader in its aims with regards to the coordination of services for people with neurodegenerative conditions, however they were broadly consistent with those in the dementia-specific strategies. The strategy committed to ensuring a country-wide guarantee of access to appropriate care, with a focus on access to specialist centres and resources, as well as improved responses to individual needs.

## Community-based care and support

This section examines some of the measures and commitments within the strategies aimed at establishing, improving or supporting community-based care as the primary way of providing services and supports for people with dementia, their families and carers.

### General commitment

Some strategies contained only commitments towards the principle of community-based care and support. **Scotland's** strategy contained a high-level commitment to supporting people with dementia to stay in their own homes for as long as possible, focused on reducing delayed discharge and unscheduled bed days, and strengthening community care. As part of this, there was a commitment to disseminating learning from previous testing of a model of community-based support (the "8 Pillars Model"). Similarly, the **English** strategy committed to increasing the number of people with dementia being able to live longer in their own with a greater focus on independent living. The **Dutch** strategy also contains a focus on keeping people at home for as long as possible, with case management seen as the key to

ensuring high-quality and person-centred care provided by both professional and informal care.

In addition, the **Austrian** strategy contained a high-level principle of ensuring people with dementia were able to live in communities which promoted participation and autonomy to the greatest possible extent, with high-quality care guaranteed irrespective of where the person resides. A similar approach was present in the **Welsh** strategy which identified the need to ensure that health and social care pathways were in place to ensure services were in place to support people with dementia.

### Service specific

Of the strategies which addressed the issue of community based-supports, the majority focused on specific service offers or organisation of services. Similar approaches and themes have been grouped together in the following section.

## Home care/care at home

A number of commitments within the strategies concerned the provision of care at home/home care services in some capacity. The **Irish** strategy committed to examining how to most effectively use home care packages and respite care to allow people with dementia to continue living in their own homes and communities for as long as possible. The **Greek** strategy also places a responsibility on municipalities to create home care services which link with existing supports, services and primary care.

Some of the strategies specifically emphasise the importance of specialist dementia care at home. For example, the **Flemish** and **Maltese** strategies proposed the establishment of specialised support programmes, with a specific focus on high quality home care support. Similarly, the **Cypriot** strategy outlined the provision of specialist home care services which would encompass specialist nursing care, Allied Health Professional support etc. The **German** strategic document also committed specific funding from the long-term insurance to support 3,000 communities with mobile nursing care and grants for people living in communities.

The **Israeli** strategy proposed similar aims in terms of improving home care, however, its approach was slightly different as it committed to provision of more hours of care to patients requiring constant supervision and re-examine the assessments to take greater account of cognitive function within the assessment for support.

The **Norwegian** strategy commits to a three-year programme for developing and testing models for home care services intending to test different ways of working and

organising home care services, taking into account each family's situation, needs and resources.

## Day care/day services

The **Portuguese** strategy focuses on proximity responses, centred on both home care and day units, specialising on rehabilitation or maintenance programmes, specifically targeted at people with dementia. Similarly, the **Maltese** strategy focuses on increasing the number of day centres available for dementia management and care, whilst the **Norwegian** strategy also commits to extending the day services to accommodate the needs and wishes of people with dementia. Additionally, the **Israeli** strategy emphasised the importance of developing a “care package” for people with dementia, provided under its health insurance law, which would include day care centres.

Additionally, the **Danish** strategy contains a specific commitment on the need to provide counselling and activity centres for people with dementia and their carers, with funding also allocated to ensure involvement and support through social and physical activities. As part of this, the strategy also includes specific funds to increase the number of places offered in relief day care centres and more support for younger people with dementia.

## Community health

A small number of strategies outline the more clinical aspects of dementia management within community settings. For example, the **Danish** strategy outlined the need for interdisciplinary units for the outpatient surveillance and treatment of dementia within communities. Similarly, **Cyprus** proposed community-based monitoring of dementia from prevention through to treatment, including specialist supports through specific centres for nursing and Allied Health Professional input, with other care coordinated by “Dementia Management Consultants”. This mirrored the approach outlined in the **Portuguese** strategy which proposed the use of continuing care teams or community care units. Although proposing a network of services rather than a specific team, the **Swiss** approach is broadly consistent with a strong focus on ensuring coordination of services across both health and social care.

**Finland's** proposals were broadly in line with the proposals above, differing only insofar as caseworkers were expected to coordinate the provision of support, care and services for the affected individuals in partnership with a physician. In addition, the local authorities have responsibility for providing 24 hour care for people with dementia according to national guidelines, with a view to reducing the amount of

residential care and to increase the availability of community-based treatment alternatives.

The **Spanish** neurodegenerative strategy, focuses on the commissioning of rehabilitation and social services throughout the course of the disease, the creation of a directory of both generic and specialist services, as well as complete assessment and referrals made on individual needs. Uniquely, it also calls for the inclusion of a rehabilitation plan as part of individual care plans.

## Night services and respite

A number of strategies identified the need to provide respite services for carers of people with dementia. The **Luxembourg** strategy proposed provision of a number of “vacation beds” for people with dementia, whilst the **Maltese** strategy specifically highlighted the need for more institutional respite. The **Norwegian** strategy highlights that informal care programmes will be used to develop more flexible respite arrangements and measures for providing training and guidance to carers. As part of its 'teams around the individual' approach, the **Welsh** strategy commits to ensuring that families and carers can access respite care that meets their needs and those of the person living with dementia, proposing to review existing provision.

Additionally, the **Luxembourg** strategy committed to considering the specific needs of people with neurodegenerative illnesses in its roll-out of a ‘Night Guard’ service, following from previous testing, which had identified the need for such a service in the interests of people with dementia and the health and well-being of their carers. Similarly, **Malta** proposed development of night-time shelters in a number of localities that specifically cater for individuals with dementia and their caregivers.

The **Swiss** plan calls for the creation of flexible, financially affordable regional respite services for day and night care, oriented to specific needs of people with dementia, in a familiar environment (including short-term stays, holiday beds, day and night structures, as well as day and night services). Similarly, the **Israeli** strategy calls for some day care centres to serve as respite venues, both for planned visits and to respond to crisis situations.

It is notable that the **Cypriot** strategy is the only one to define the entitlement of carers to respite, setting out that carers should receive 20 days of respite per year from specialist centres which are able to support the person with dementia.

On this theme, the **Northern Irish** strategy is unique in its reference to commitment to ensuring that short breaks are available for people with dementia and their carers.



## Housing

Housing is an area given attention by some strategies in two main ways: adaptations of existing houses in which people live and ensuring that future housing stock/developments are suitable for people with dementia. Both of these elements were present within the **Welsh** strategy. To a lesser extent, the **German** document also identified the need for housing stakeholders to be involved in the planning process of house building and urban planning, alongside health and social care service providers. Similarly, the **Northern Irish** strategy also sought to identify mutual priorities with housing partners.

The **Scottish** strategy refers to the government's own specific housing strategy for older people and how this will help ensure that older people are able to live in their own homes for longer.

## Other

Some elements within the strategies did not correspond to other strategies or did not fit in within the subsections above. As such, they have been included below.

Both the **Irish** and **Slovenian** strategies identified that both formal and informal social supports are crucial, with the need for self-help groups, advisory and information offices needing to complement the expansion of existing social services, with the former adopting a health promotion model.

The **Norwegian** strategy commits to creating a competency and innovation grant scheme for municipalities to strengthen municipal capacity and provide opportunities to develop sustainable, high-quality health and care services.

The **Irish** strategy also committed to the creation of a workstream on dementia care as part of its integrated care programme for older people, to provide leadership across all directorates. It also committed to the regulation of home and community care services for older people.

There was some reference within the **German** strategic document and the **Maltese** strategy about the need for greater use of "active citizenship" and volunteering as a means to improve supports for people with dementia and carers living within the community. The **Italian** strategic document similarly identified the need to sustain association and volunteer networks.

The **Irish** strategy considered, based on previous testing, the provision of "Dementia Advisors", a number of whom would be dedicated to the needs of people with early-onset dementia. On a related theme, the **Northern Irish** strategy also commits health trusts to working to develop regional care pathways for younger people with dementia.

Both the **German** and **Italian** strategic documents identified the needs around information provision and sharing as a crucial aspect of the provision of care. Specifically, the **Italian** strategy committed to creating a service charter providing information on available services in order to ensure the transparency of service offers, whilst the **German** document identified the need for information sharing between formal and informal services to be improved. On a similar theme, **Malta's** strategy proposed an updated directory of available dementia services to be distributed amongst healthcare professionals, individuals with dementia, their caregivers and family members.

The **German** strategic document also committed additional funding support for municipalities and rehabilitation providers to provide supports for carers, to keep people with dementia in their own homes for as long as possible.

The **Dutch** strategy also referred to an ongoing programme of work which aimed to improve care and support for people with dementia, through a focus on funding and organisational structures in relation to health insurers. Related to the funding of services, the **Swiss** strategy contained a specific commitment to guaranteeing the financial viability of needs-appropriate services for people with dementia, whilst also committing to reviewing the appropriateness of existing finance systems and how they compensate services necessary for dementia, including respite and counselling services.

## 5.4 Residential and long-term care

In some strategies, residential and long-term care were addressed distinctly, whereas other strategies addressed these issues as part of other subsections of this report (e.g. under 5.3 Coordinated care in the community). Issues covered within the strategies ranged from commitments to expand provision of services, definitions around quality and the use of restraints.

### Long-term services/specialist units

The **Greek** strategy set out its intention to establish a network of specialist dementia units (which will be specifically certified), linked to the classification of the person with dementia (received at the point of diagnosis). **Scotland** briefly refers to ongoing work in this area following a report

by a regulatory body, linked to its work on acute hospitals. On a related theme, the **Luxembourg** strategy proposed defining a formal framework and regulations on the use of restraints in long-term care settings.

The **Flemish** approach contains an integrated reference framework for the quality of care and life for people living with dementia, with an emphasis in residential care centres on social and person orientated, encouraging interaction between professional caregivers, the person with dementia, their family and friends.

The **Israeli** strategy contains high-level commitments in relation to long-term institutional services, one of which focused on the needs to develop information and consultation centres, accessible round the clock by telephone to help families access services and to provide responses in crisis situations. Similarly, for people with dementia who require 24-hour care, the **Norwegian** strategy commits to a programme of new buildings and modernisation of existing buildings which are dementia-friendly and incorporate small departments and housing collectives with space for community living and social activities.

Similarly, the **Swiss** strategy contains a broad commitment to promoting long-term in-patient nursing and care for people with dementia through the adaptation of existing infrastructure and care processes.

A slightly different approach was that of the **Northern Irish** strategy which framed the issue in terms of pathways, to ensure that health trusts were able to respond to crisis situations (involving people with dementia), including in relation to intermediate care.

## Residential homes/nursing homes

The **English** strategy contains a broad commitment that all hospitals and care homes should meet agreed criteria to become dementia friendly.

Both the **Irish** and **Flemish** strategies contain commitments in relation to the use of restraints in care homes, with the former implementing a national policy on the use of restraints and the latter requesting input from a bioethics advisory committee about the application of measures that restrict the liberty of people with dementia in residential care settings.

In relation to nursing homes, the **Maltese** strategy proposed to introduce recommendations and quality

measures to enhance patient-centred dementia management and care (including dementia-friendly design) in long-term nursing and residential care settings, in both public and private settings. These included ensuring buildings were dementia friendly in design, including secured open areas and development of meaningful activities for residents.

The **Irish** strategy committed to examining a range of long-term care options including new residential models, such as including housing with care, for people with dementia. Similarly, the **Maltese** strategy commits to developing new long-term housing units for individuals with dementia.

The **Norwegian** strategy commits to the development of a quality tool for all nursing homes, setting out criteria for good practice focused on management, organisation, professional practice, innovation and patient outcomes. Additionally, the **Northern Irish** strategy proposes developing standards in this area which will cover quality care, use of medications, links with community settings etc. which will also be included within the service specification to inform the commissioning of dementia services.

The **Scottish** strategy commits to specific work in this area, continuing the National Group on Dementia in Care Homes (established under the previous strategy) to ensure the ongoing modernisation of care homes takes account of the needs of people with dementia, including through the consideration of themed inspections by the national regulator.

## Other

The **German** strategic document focuses on its social health insurance system, specifically on revising criteria and procedures for rehabilitation needs for people with dementia. In addition, the Federal Government will develop and launch a long-term care fund to create demographic reserves.

It was again notable within this section that the **Flanders** strategy contained specific consideration of people with younger-onset dementia and whether dedicated workers for this group may be of value.

The **Northern Irish** strategy commits to working with a number of national partners and to developing environmental standards for all new facilities providing care solely or mainly for people with dementia, as well as assessing existing facilities used by people with dementia.

## 5.5 Acute/general hospitals

Many strategies had a specific focus on some of the health-care considerations related to dementia, with themes including the admission processes, the establishment of psychiatric services or accessibility issues for people with dementia. Some strategies, such as those of **Austria** and **Luxembourg** contain a broad commitment to improving the quality of care for people with dementia in general hospitals.

### Outpatient clinics/psychiatric services

A number of strategies placed a specific focus on psychiatric services for people with dementia, in one form or another.

The **Welsh** strategy set out that all general hospitals should have psychiatric liaison services, as well as ensuring the implementation of dementia-specific recommendations from professional clinical bodies.

The **Greek** strategy proposes the creation of clinics within every general hospital with the aim of providing integrated medical care to people with dementia, whilst noting that such services would need to link in with community-based services to improve access for people, including those in remote areas. Similarly, the **Slovenian** strategy proposes the creation of two state-led memory centres, with a network of regional memory centres, supporting and guiding the development of treatment for people with dementia at the national level.

The **Finnish** strategy took a similar approach committing to ensuring that hospitals or health catchment areas would have responsibility for establishing specialist medical care for people with dementia, as well as providing support to primary care.

The **Cypriot** strategy also committed to the creation of specialised memory clinics within hospitals, whilst also setting out the possibility of specific wards/beds for the long-term hospitalisation of people with dementia to monitor the progression of the condition.

The **Irish** strategy committed to ensuring that, where possible, in the circumstances where a person with dementia required acute admission to a psychiatric unit, a secure placement would be made in a suitable old age psychiatry unit.

### In-patient/admission/discharge

Of the strategies which focused on acute care, a number focused on the process of a person's admission to hospital and the care they received whilst within an acute setting.

Some strategies were primarily concerned with the process of admitting a person with dementia into an acute setting. For example, the **German** strategic document committed to identifying dementia promptly during or following admission to hospital, with hospitals informed in advance where transfers to acute settings were planned. The **Maltese** strategy similarly identified the importance of timely high-quality assessment of individuals presenting dementia symptoms in acute general hospitals.

On a similar theme, the **Northern Irish** strategy included an action for health trusts to review hospital bed provision for dementia assessment to harmonise provision across trusts, with an emphasis on developing assessment services in the community.

The **Irish** strategy committed to ensuring that hospitals take measures to encourage better recording and coding of a primary or secondary diagnosis of dementia to ensure better recording of admissions, re-admissions, lengths of stay and discharge.

The **Greek** approach is distinct insofar as it seeks the creation of special examination and treatment protocols for people in general hospitals, admission and the establishment of a doctor with overall coordination responsibility for dementia at every general hospital. Similarly, the **Swiss** strategy also contained a provision in relation to the development and implementation of recommendations and guidelines for acute care hospitals, with a focus on how adult-protection legislation would be embedded within decision-making processes.

Additionally, the **Swiss** strategy commits to the provision of services and crisis teams in community settings to reinforce expertise and safeguard quality of treatment, with the intention of fewer people with dementia being inappropriately admitted to hospital. Both the **Scottish** strategy and **German** strategic document committed to similar aims, including on delayed discharge, avoidable admissions and inappropriate long stays in hospital, with the latter committing to a national action plan, with the former committing to build on its acute work programme started under the second strategy.

Both the **Irish** and **Maltese** strategies also set out the need to ensure that people with dementia have a care plan developed during their hospital stay, addressing the dementia-specific supports and activities necessary to ensure appropriate care in, and timely discharge from, hospital.

## Dementia accessibility

A number of strategies additionally recognised that admission to hospital was often difficult for people with dementia and that there is a need for hospitals to adapt environments and practices to become more accommodating for people with dementia.

The **German** strategic document identified the need for specific provision to be made for people with dementia, including the structure of their day and activities, as well as allowing relatives the option to stay with the person with dementia if it is requested. Similarly, **Spain** also proposed similar approach for people with dementia both in hospital emergency rooms but also across the wider health system. On the latter point, the **Welsh** strategy also committed to applying the principles of “John’s Campaign<sup>8</sup>” in acute hospital settings.

The **Swiss** strategy focused on the promotion of dementia-appropriate care in acute care hospitals which included adapting both infrastructure and processes (including treatment, care and nursing, room design, staff and interface management). Similarly, the **Irish** strategy commits to hospitals prioritising the assessment of social and environmental supports to meet the needs of people with dementia and their carers.

Focused more on the design and decor of hospitals, the **Danish** strategy included a commitment to initiating pilot projects in selected regions and hospitals. Similarly, the **English** national dementia strategy contains a high level commitment to ensuring that all hospitals and care homes meet agreed criteria to become dementia friendly.

This approach was also found within the **Irish** strategy which committed to the development of guidelines on dementia-friendly ward specification (including safe walking spaces and the use of colour, lighting, signage, orientation cues etc.), which would be taken into account at the design stage of all refurbishments and new builds.

As well as securing an agreement from the **German** Hospital Federation regarding the incorporation of dementia friendly room design, the **German** strategic document also commits to the development of information brochures for patients and relatives about the challenges in acute settings.

## Other

The **Irish** strategy contained specific commitments which were not found in other strategies, including the creation and implementation of a dementia and delirium care pathway implemented at a local level in each acute hospital. Similar to the **Greek** strategy, the **Irish** strategy also proposes the assignment of a senior clinician within each hospital to lead the development, implementation and monitoring of the pathway.

Additionally, the **Irish** strategy is the only one which specifically addresses the needs of people with dementia who go through Emergency Departments and Acute Medical Units, proposing to develop a specific pathway.

## 5.6 End of life and palliative care

A considerable number of strategies specifically identified that the needs of people with dementia at the End of Life and Palliative Care were distinct and require specific consideration. In a number of the strategies, the care and support of a person with dementia was linked or addressed by the same section; as a result, we have included commitments regarding advanced dementia within this section.

Both **France** and **Malta** commit in broad terms to improving the provision of end of life and palliative care for people, with the latter including a specific reference to ensuring adequate pain relief.

### Care, support and advanced planning

The **Welsh** strategy’s “teams around the individual” approach is also referenced in this section, particularly in relation to the importance of making advanced decisions and ensuring an agreed palliative care pathway is in place. The **Norwegian** strategy also focuses on the need for specialist team to provide such treatment, committing to establishing competence networks of nurses working on palliative care.

The **Flanders** strategy follows a similar approach in relation to the development of dementia-specific early care planning guidelines, linked to quality indicators, whilst also

<sup>8</sup> John’s Campaign is a UK-wide campaign which seeks to give carers greater ability to support the person with dementia whilst they are in hospital or care facility.

committing to coordination between dementia centres of excellence and palliative care networks to encourage early care planning.

The **Israeli** strategy contains a focus on the need for advanced and early planning (both through advanced health care directives or proxy decision maker), whilst also recognising the need for the provision of home care or home hospice care from multidisciplinary staff to deliver good quality palliative care. This recognition of other locations is reflected in **Germany's** strategic document which includes the need for the development of offers of palliative care both at home and in inpatient facilities, with a particular focus on dementia.

The **Flanders** strategy is distinct in its commitment to the use of an application (intended for use by care organisations), titled "before I forget", which encourages people to discuss their wishes throughout their life which can then inform care at the end of life.

The **Spanish** neurodegenerative strategy recognised the need to support both the person with the condition and carers at the advanced phase of illness and at the end of life. Specifically, the strategy calls for palliative support to be offered in the person's own home or at a hospital level, with the service based on the needs of the person.

## Institutions

Both the **Cypriot** and **Greek** strategies are focused on institutional delivery of palliative and end of life care. The former specifically focused on the creation of two new palliative care facilities which aimed to improve to services as well as reducing inefficient resource use in general hospitals. As with other countries, **Greece** will also use develop specific care guidelines to guarantee the quality of care provided for people with dementia at the end of life. Similarly, the **Cypriot** strategy proposes upgrading and investing in existing institutions (e.g. nursing homes) to provide better quality care at the end of life.

## 5.7 Treatment and medication

In addition to other aspects of the health and social care system addressed, many strategies also included aspects related to the clinical treatment, management and medication often used for people with dementia.

## Carers and families

**Israel** and **Malta** both include specific commitments around the need to ensure that families are informed about the progression of the person with dementia at the end of life and adequately supported (e.g. through psychological services). On a related theme, the **Welsh** strategy acknowledges the need for appropriate bereavement services to be available to ensure the needs of families and carers of people with dementia are met. As well as highlighting the need for coordinated and person-centred care, the **English** strategy also commits to ensuring bereavement support for carers and a right to stay for relatives when a person with dementia is near the end of life, either in hospital or in a care home.

## Models and frameworks

The high level commitment within the **Scottish** strategy is to ensure that more people get timely access to good quality palliative and end of life care. As part of it, there is a commitment to test a new model of support of people with advanced dementia (which builds on previous models of community-based care), whilst also seeking to examine specific improvements in palliative and end of life care for people with dementia as part of the government's existing national work.

The **Finnish** strategy commits local authorities and joint authorities to establishing local clinical pathways for people with dementia which includes good palliative and end of life care, with services provided in line with national recommendations. Similarly, both the **Northern Irish** and **Portuguese** strategies contain high-level commitments to ensure that palliative care is developed in line with existing national frameworks and organisations which have responsibility for palliative and end of life care.

On this theme of utilising existing structures and frameworks, the **Slovenian** strategy commits to improving the provision of palliative and end of life care, noting the European Association for Palliative Care guidance around the issues of anticipatory care planning, maintenance of function, as well as involvement of carers and family members.

## Pharmacological interventions

The over-prescription and use of anti-psychotic medications was a key focus for a number of strategies. For example, the **Welsh** strategy commits to ensuring that health boards provide access to evidence-based psychosocial and

pharmacological interventions, as well as responding to the recommendations of a parliamentary inquiry. On this latter point, the **Irish** strategy also commits to the national health executive developing guidance on the appropriate management of medication for people with dementia, in particular on psychotropic medication management.

The **Danish** strategy commits to reducing the consumption of anti-psychotic medicines amongst people with dementia by five percent before 2025, with funding committed for the monitoring and reviewing of prescribing. Similarly, the **English** strategy commits to a reduction in the inappropriate prescribing of antipsychotic medication, including a reduction in the variation across different parts of the country.

Both the **Cypriot** and **Portuguese** strategies commit to ensuring that people with dementia have access to both pharmacological and non-pharmacological interventions to treat and manage the symptoms of people with dementia depending on appropriateness. Similarly, the **Czech** strategy commits to ensuring that both non-pharmacological and pharmacological disease treatments are compensated by public health insurance, with consistent standards of treatment between neurology, psychiatry and geriatrics. The Maltese strategy commits to the inclusion of all approved medications for the treatment of Alzheimer's disease in the government formulary list. Additionally, the **Israeli** strategy specifically commits to the expansion of drug therapy to delay disease progression and addressing the accompanying symptoms as needed.

The **German** strategic document included improving information on diagnostic options as well as on pharmacological and non-pharmacological treatments, offering the right support and assistance. Partners committed to exploring how to reduce restrictive measures by both pharmacological and physical means. This includes a Federal Government commitment to funding research into reducing pharmacological interventions, as well as clinical guidance being issued by national medical associations. Similarly, the **Slovenian** strategy committed to the development of recommendations to ensure interdisciplinary services to adequately treat the person with dementia in line with their symptoms, including the provision, monitoring and review of dementia-specific medications.

Following on from the latter point, the **Maltese** strategy also proposes that people with dementia should have their medications reviewed every six months, alongside cognitive screening measures. In relation to this, the strategy calls for stronger regulation over the use of antipsychotics in individuals with dementia, through policies whereby justification for starting antipsychotics would be clearly documented. Similarly, **Northern Ireland** highlights the need for medications for dementia to be prescribed appropriately, with medication reviews as an integral part of the

care management process and a range of interventions available to people with dementia and their carers.

The **Scottish** strategy commits to commissioning and publishing a renewed study on trends in the prescribing of psychoactive medications for people with dementia.

Whilst the **French** neurodegenerative strategy was more broad in its commitment to ensuring that high quality treatment was available across all areas, the **Spanish** neurodegenerative strategy primarily focused on pharmacological interventions, committing to ensuring the availability of relevant medications, as well as establishing recommendations on their use across primary and secondary healthcare. As part of this, it also committed to establishing communication mechanisms between different professional teams regarding medications management.

## Non-pharmacological interventions

The **Greek** strategy proposes to establish a network of 30 day care centres by 2020, operated and funded by a mixture of public, private and non-profit sector organisations. The commitment has been included here to reflect its position within the **Greek** strategy; the model proposed focuses on treatment and rehabilitation for people with dementia, with a multidisciplinary team (including psychologists, nurses, occupational therapists and social workers) of working within the centres, linking into local memory clinics, with their doctors covering the medical needs which may arise.

Similarly, **Italy** focuses on the promotion of appropriate interventions (particularly within residential settings) through the development of guidelines and consensus documents regarding the main preventive and care priorities and monitoring these through agreed quality indicators.

The **Israeli** strategy also focuses on increasing referrals to non-medical treatment, such as psychosocial intervention and the treatment of behavioural and psychological symptoms of dementia. Similarly, the **English** strategy has a focus on ensuring that where a person with dementia's needs are complex, skilled assessment and care ensures that the person is not subject to inappropriate care or inappropriately prescribed medication.

## Other

The **Finnish** strategy gave responsibility to local authorities and hospital to ensure that waiting times are observed at all stages of the clinical pathway of people living with dementia, with access to rehabilitation provided on equal terms to other patient groups. As part of this, these authorities will have responsibility for setting up and introducing

clinical pathways for treating people with memory disorders and dementia.

In addition to pharmacological interventions, the **Spanish** neurodegenerative strategy highlighted the need to provide additional services for people with moderate symptoms to prevent falls and manage other symptoms.

The **Luxembourg** strategy provides a broad commitment to establishing national standards which guarantee the quality of medical care of people with dementia in line with international standards.

The **Maltese** strategy contains a commitment to remove age limits for the access to all services for individuals with dementia and make sure that the needs of individuals with early onset dementia are met.

The **Scottish** strategy also commits to reviewing whether there is a need for a review of national clinical guidelines on specific elements of clinical dementia treatment. Along similar lines, the **Northern Irish** strategy commits to conducting an audit of interventions available for dementia care across all settings, including nursing and residential care.

## 5.8 Training and workforce development

For most strategies, the need to improve the knowledge, skills and training of professionals across the disciplines in health and social care was seen as a central component of delivering high quality care and support to people with dementia. This included in relation to the diagnostic and treatment processes, as well as the provision of care and support in both institutional and community settings. However, the delivery of training programmes (either through continuous professional development or at the time of initial training) was not the only method to develop the workforce; other methods such as the creation of nationwide-posts were proposed and have been included below.

### Interdisciplinary training

The majority of strategies highlighted the need for training across health and social care, with some focused on the location or nature of the care, rather than the specific practitioner or role.

For example, the **Portuguese** strategy focuses on the need for practitioners across institutional settings (including residential and acute settings) to be skilled, to support better diagnosis, treatment, care and nursing for people with dementia. As part of this, the strategy identifies the need for expansion of dementia-specific training. Similarly, the **Swiss** strategy notes the need for high quality care services throughout the entire course of the condition, with dementia-specific professional skills being a key focus.

The **Norwegian** strategy, by comparison, focuses on specific programmes (“Dementia ABC Education Programme” and the “Psychosocial Intervention Programmes”), committing to develop and implement this resource amongst municipal health and care personnel. Similarly, the **Scottish** strategy commits to the continuation of the Promoting Excellence Framework (launched as part of **Scotland’s** first national dementia strategy) resource for health and social care practitioners.

On a similar theme, the **Welsh** strategy had a considerable focus on its “Good Work” approach, including producing cross-sector training resources, training practitioners to recognise the early signs of dementia and ensuring all public-facing NHS staff have training in dementia. In addition, the strategy also identified the need to train practitioners who could initiate conversations on serious illness. Furthermore, the **English** strategy suggests that all healthcare staff will receive training appropriate to their role, with the hospital regulator seeking evidence of a newly established “care certificate” as part of their inspection regime.

The **Northern Irish** strategy also committed to the development of a training and development plan across primary, community and secondary care, as well as in both statutory and non-statutory sectors, to improve knowledge and skills of professionals providing care to people with dementia.

The **Czech** and **Israeli** strategies identify the need to support and develop education for professionals, with the former indicating that this will be measured through the number of physicians, nurses and social services staff completing specific modules and training programmes, as part of continuous professional development.

The **Maltese** strategy similarly, proposes inter-disciplinary training for all professionals through continuous professional development (CPD), across settings, including focuses on non-pharmacological interventions, establishing accredited online platforms for dementia and creating dementia-specific end of life training for health and social care professionals. Similarly, the **Slovenian** strategy focuses on integrating existing health professional training and CPD to support people with dementia, including neuroleptic and other non-pharmacological interventions.

The **Danish** strategy commits resources to cross-sectorial and inter-disciplinary courses to evaluate their existing course programmes concerning dementia and to produce

knowledge based manuals for social and healthcare practice. Additional resources are also committed to improving practice-oriented skills in municipalities and regions.

**Norway's** strategy was more specifically focused, examining its "learning networks" which share and spread good practice on medical/healthcare follow-up for people with dementia with complex needs who receive home care services.

The **French** neurodegenerative strategy contained a significant focus on continuing education and training of health and social care professionals to improve services for people affected by a neurological condition.

The **Spanish** neurodegenerative strategy proposed a comprehensive and integrated approach between the different levels of health and social systems. It further places responsibility on each of the autonomous communities to create a training plan for professionals working with people with neurodegenerative conditions, primarily focused on continuous professional development.

### GPs/primary care

The **Welsh** strategy placed a focus on GPs, encouraging them to complete an additional component within its enhanced mental health service programme, reviewing and updating the dementia awareness DVD for GPs, as well as reviewing primary care practices to ensure they are dementia friendly. Additionally, the **Maltese** strategy commits to providing training opportunities for GPs in relation to the diagnosis, referral, disclosure and management of dementia.

On a similar theme, the **Flanders** strategy commits to investment in the cooperation initiatives for primary healthcare and its dementia expertise centre, to raise awareness among professionals and informal caregivers about young-onset dementia.

### Secondary care settings

The **German** strategic document noted the intention of the German Medical Association to develop specialist training for the treatment of patients with dementia, whilst the **Greek** strategy committed to accelerated training programmes for a small number of existing clinicians, such as neurologists, through its proposed centres of excellence to become specialist dementia doctors.

Similarly the **Slovenian** strategy indicates that clinicians in general hospitals should undergo regular training on the quality of care for dementia patients, whilst the **Luxembourg** strategy commits to evaluating the need for

continuous specialist training for professionals working in long-term institutional settings to ensure better care.

### Nursing

The **German** strategic document also noted the intention of the Federal Government to reforming the law around nurse training, to establish a common basic training profile as well as creating an expert commission to inform the curriculum, ensuring counselling is included within the teaching.

Similarly, the **Slovenian** strategy committed to the introduction of additional educational programs for nurses with specialist knowledge in the field of neurodegenerative diseases, especially dementia.

### Allied health professionals (AHPs)/therapeutic interventions

The **Danish** strategy commits and allocates funds for training and physical activities related to rehabilitation, specifically to support training schemes and packages to ensure consistency in rehabilitation programmes.

Following on from work undertaken as part of its second national strategy (including the creation of a national dementia AHP consultant), the **Scottish** strategy commits to the implementation of the subsequent AHP framework which was developed, outlining how AHPs can support people with dementia, including in relation to falls preventions, rehabilitation etc. The **Welsh** strategy follows a similar approach, proposing to develop a national AHP post to provide advice and support to health boards and local authorities to improve services.

The **Norwegian** strategy highlights the creation of a national competence centre on culture, health and care to develop and disseminate therapeutic methods and ways of working in milieu therapy, with educational programmes on milieu therapy and the integrated use of music and singing designed for employees in general and dementia-specific care services.

### Social care

The **Israeli** strategy specifically identifies the need to develop specialist training for homecare workers that provides them with the knowledge, skills and tools to address stressed behaviours of people with dementia, as well as providing the appropriate tools to provide meaningful occupation. This was also the approach of the **Maltese** strategy, though it focused on the training needs of day care staff.



The **English** strategy continued this theme to an extent, though support was focused on ensuring that social care staff working with adults and older people were able to identify the early signs and symptoms of dementia and helping people with the condition to access high quality care and support.

As part of its commitment to the provision of dementia support workers, the **Welsh** strategy commits to reviewing their role and to ensuring they are trained to an appropriate occupational level.

### Vocational training (i.e. academic/institutional-based training)

Some strategies identified the need for training around dementia to be a fundamental aspect of vocational training for health and social care practitioners (i.e. before they qualify and begin to practice). Other strategies proposed centres of excellence which would provide training for highly specialist practitioners.

The **Welsh** strategy commits to embedding its “Good Work” principles for new vocational qualifications for health and social care. Similarly, the **Flanders** strategy commits to a continued focus on the education and follow-up training of dementia-skilled workers.

The **Finnish** strategy commits to ensuring that education authorities and organisations ensure that basic, further and supplementary social welfare and health care training includes elements related to brain health promotion, detecting memory disorders in their early stages, treating and rehabilitating patients, providing palliative and end-of-life care and supporting people with dementia and their families.

The **Greek** strategy commits to ensuring dementia is included within the undergraduate training of relevant disciplines (including medicine, nursing, pharmacy and biology). However, it also proposes the development of ‘centres for excellence’ in dementia (public or private) which will train 18 core specialists, as well as engaging in clinical research.

The **Irish** strategy focuses on engaging with professional and academic organisations to develop provision of dementia-specific training, including CPD, professional peer-led support, education for GPs and nursing home staff.

The **Portuguese** and **Maltese** strategies both commit to ensuring the inclusion of units on medical, social, psychological and economic aspects of dementia for students in health/social care training programmes within academic institutions within both undergraduate and post graduate courses. The latter also commits to ensuring that all

dementia training programmes delivered outside academic institutions are accredited.

The **Slovenian** strategy commits to the inclusion of dementia within all secondary education programmes for professions which involve regular direct contact with older people, as part of undergraduate and graduate education programmes, as well as standardising basic knowledge on dementia at a clinical level through for CPD.

The **Luxembourg** strategy contains a proposal in relation to the country’s Ministries of Education and Vocational Training, Higher Education and Research for Cooperative Work to revise the initial training curriculum in the health domain (particularly in relation to geriatric health), including utilising or adapting international standards.

The **Cypriot** strategy identifies the need to empower health-care professionals with training in advanced techniques and skills, particularly around prevention, diagnosis and care. It is expected that this will be carried out through specialised centres and the establishment of specialist masters courses in ‘dementia and gerontology’. It is also proposed to strengthen the training of nursing students, as well as creating an elective course in dementia.

### Non-clinical/care professions

The **Welsh** strategy also identifies the need to ensure training for staff who work with people who have a higher risk of developing dementia (such as those working in learning disabilities, substance misuse, ambulance and prison services), as well as for housing staff. Similarly, the **Czech** strategy proposes the education of workers in education and the public sector, including teachers, police, administrators etc. to raise basic awareness. **Finland’s** approach was similar, though had a specific focus on the promotion of brain health, training professionals across different sectors (e.g. sports, culture and education).

### Ethics in practice

Both the **Maltese** and **Norwegian** strategies propose building ethical competence in municipal health and social care services, with the former linking this to quality and professional development and with the latter focused on decision-making and the personhood of persons with dementia. The **Portuguese** strategy also commits to examining both the ethical and legal aspects required within professions which offer support for people with dementia.

The **Swiss** strategy also notes the need to anchor ethical guidelines through the promotion and implementation of existing guidelines, respecting individual rights, especially

regarding the law on the protection of adults and to avoid risk situations in care structures.

## Quality assessment and leadership

The **German** strategic document notes that partners have committed to ensuring that multi-professionalism and workforce strategies are in place to ensure sufficient numbers of staff, providing high quality care, with the skills body seeking to improve qualitative and quantitative personnel assessment procedures.

The **Italian** strategy places importance on the evaluation of outcomes and of professionals responsible for the delivery of services. As part of the promotion of training across disciplines, the strategy proposes promoting systematic audit activities to enhance self-assessment of professionals and improve clinical practice. On a related theme, the **Norwegian** strategy notes the needs for a greater number of managers and improved leadership skills which resulted in the development of a national leadership training programme targeted at managers in municipal health and care services.

## Other

Some measures related to the training and development of the workforce included other commitments which were either unique to their strategies or took an approach which did not correspond to the themes above.

The **Welsh** strategy committed to ensuring that people with dementia, their families and carers were involved in the development and delivery of dementia education and training, as well as focusing on how health and social care staff appropriately include carers in the care process. It also proposed ensuring that unpaid carers received access to training.

On the theme of carers, the **Czech Republic** commits to ensuring the education and offer of accredited training courses of unpaid carers (on par with social care assistants), citing the potential European Structural Funds (ESF) funding to provide this. Similarly, the **Austrian, Swiss and Northern Irish** strategies acknowledge the need to strengthen the skills of relatives and unpaid carers as does the **Portuguese** strategy which commits to considering a comprehensive training programme for both formal and informal carers. Similarly, the **Norwegian** strategy commits to continuing work (started under its previous strategy) to establish educational programmes and dialogue groups for family members of people with dementia.

**Finland** places responsibility on municipal authorities to advise and support local authorities by providing training and compiling statistics about health and well-being, to ensure that social welfare and health professionals have the skills to promote brain health so they may identify cognitive impairments and refer people as appropriate. The strategy also commits to developing national targets for the skills that professionals working with individuals with memory disorders and dementia must have.

On the matter on manpower within the workforce, the **Israeli** strategy commits to increasing resources to train manpower in the community and in hospitals. Similarly, the **Maltese** strategy focuses on ensuring there are sufficient numbers of trained health and social care workforce, including for memory services.

The **Greek** strategy, in addition to its development of centres of excellence and specialist training for clinicians, also calls for the establishment of 10 clinical fellowships per year and five research scholarships per year with the aim of creating specialist clinical and research practitioners in the field of dementia.

The **English** and **Maltese** strategies, alongside the **German** strategic document, commit to ensuring that professionals are trained and educated to identify, prevent and manage stressed and distressed behaviours in people with dementia.

The **Dutch** dementia strategy commits to the development of a specific database with evidence-based recommendations and information for professionals on how people with dementia may continue to live longer and more safely at home, with online resources available and professionals able to share good practice examples. The **English** strategy also follows a similar approach, committing to develop a clear evidence base for what works in training on dementia for health and social care staff, which would be used to develop education and training programmes.

The **Norwegian** strategy is the only one to specifically commit to the further development of competence-building measures in the area of end-of-life palliative treatment and care through the development of an educational programme on palliative treatment for people with dementia, as part of its Dementia ABC education programme.

## 5.9 Personal accounts



I used to take care of my father, who also had Alzheimer's disease (AD), therefore the symptoms and cognitive decline were familiar; I was more aware of changes that appeared out of the blue.

Minor problems with memory and orientation convinced me that something was going on. For example, if I had to drive my car into unknown destinations or just parked a few blocks away, I was totally lost, frustrated and in distress. I really doubted that age would affect my functioning, so I decided to find an explanation for my change of behaviour.

My starting point was Spominčica-Alzheimer Slovenia. I arranged for a meeting with Štefanija L. Zlobec, president of Spominčica, who kindly invited me to an informative session. When I told my GP about changes that started to influence my daily routine, she immediately gave a green light for neurological consultation. I went through various diagnostic tests, which clarified that I might have Mild Cognitive Impairment (MCI) or mild dementia. However, the MRI scan surprisingly showed things were fine. In my heart I felt this could not be true. With my neurologist, I decided on a lumbar puncture which identified 2 or 3 biomarkers and I got the diagnosis of AD at my 64. The neurologist prescribed dementia medication, which I still use daily.

On one hand the time after diagnosis was a shock. But on the other hand I felt relief. I knew what is wrong with me, the fear was taken away and I was aware what dementia really meant. Since then, I planned everyday activities with a lot of enthusiasm. I still wanted to be the same as before, active and sociable.

I have wonderful friends. They accepted my small inconveniences as a normal part of my life. They pay a lot of attention to me, never leave me alone and always ensure I am safe, no matter where I am. They are friends everyone would wish for.

Since my diagnosis I have become very active at public campaigns about dementia in Slovenia. My story shows that people around you have less preconceptions if they know exactly what kind of disease you have. Hence it is important to say out loud that you have dementia, be part of groups (such as EWGPWD) and involved in European projects or clinical trials to share your feelings, thoughts and wishes about how you would like to be treated by others.

**Tomaž Gržinič** is a member of the European Working Group of People with Dementia (EWGPWD) and president of the Slovenian Working Group of People with Dementia. This account has been translated by Alenka Virant, who supports Tomaž.

The third Scottish National Dementia Strategy was launched in June 2017. It includes 21 commitments, all to be delivered by June 2020.

The Scottish Dementia Working Group (SDWG) was part of the 'Dementia Dialogue' events and were also represented on the National Expert Advisory Group in the development of this strategy, ensuring that the voices of those living with dementia are heard. The group also has regular meetings with the Minister for Mental Health where they provide feedback on issues raised by the general membership and local groups.



The SDWG wrote the foreword to the third strategy and has continued to monitor how dementia services have developed in line with the commitments of the previous two strategies. Two of the commitments in the strategy focus on post diagnostic support, which has been a priority of the SDWG for the last two years. The commitments mark a move towards a more flexible and person centred approach. This goes beyond the one year guarantee with the opportunity for those diagnosed early to be supported by a named Link Worker for longer than 12 months if necessary. The period of post diagnostic support will be flexible and open ended and led by the person with dementia and their carers. The strategy also commits to testing post diagnostic services in primary care settings in a number of locations.

These are ambitious changes which may take some time to deliver and get right but ultimately these commitments support SDWG's vision of *“effective and person centred support to enable people with dementia to live well and have choice and control over their future”*.

**Scottish Dementia Working Group** – Carol Hargreaves is the Vice-Chair of this group and sits on the European Working Group of People with Dementia (EWGPWD).

## 6. Informal carers

With the exception of some brief references in other sections (e.g. in relation to training for unpaid carers in section 5.8 or some brief references to respite in section 5.3), there are comparatively few references to carers. Where reference to carers was made, it was often vague or incorporated as part of the service offer for people with dementia. The majority of the strategies, in some form,

recognised the importance of involving carers in the decision-making process and in the process of caring for the person with dementia.

This section will only deal with commitments which are specific to carers and which were not addressed under previous sections.

### 6.1 Support for informal carers

#### Assessment

The **Welsh** strategy contained a number of measures aimed at supporting carers of people with dementia, mostly outlined in other sections of this document. One commitment which underpins all of the measures is the commitment to ensure that carers will be offered an assessment of their own needs and, if eligible, a support plan will be developed with them. Similarly, the **Irish** strategy commits to ensuring that the carer assessment enables the provision of more targeted supports for carers. The **Northern Irish** strategy also commits to the implementation of a carer's assessment tool for those caring for people with dementia.

On a similar theme, the **Flemish** dementia strategy identifies that care plans must focus on the role of unpaid carers outlining the support required to allow them to do this role and define the cooperation between informal and professional care. As part of this, the strategy committed to developing "psycho-education" tailored to informal caregivers with the aim of increasing the capacity and quality of life of the informal caregiver.

#### Information and services

The **Danish** strategy includes a specific commitment to fund the development and distribution of a national toolbox of courses for relatives. Similarly, the **Maltese** strategy commits to the development of an online guide to dementia for carers and family members.

The **German** strategic document has a significant focus on help and support for familial carers, with partners committing to evaluate and improve the quality of support and assistance available for carers, including counselling, peer support networks and information provision. The Federal

Government, Länder and municipalities also committed to providing information on assistance and benefits to improve take up by carers. As part of this, the Federal Government committed to providing legal reform to allow for a better work/caring balance and the Länder committed to expanding low-threshold care services. The statutory social insurance system will develop a concept for preventing the deterioration of physical and mental health which can come from a caregiving role.

The **Finnish** strategy commits to ensuring that local and joint authorities must cooperate with the third sector to ensure that carers of people with dementia are supported, including having access to support to adjust to the situation and information about the condition. In addition to a case worker who oversees support for the affected person, goal-orientated peer support groups will be provided for informal carers.

The **Italian** strategy includes action points on monitoring health conditions and quality of life of carers of people with dementia, including through the promotion of informal supports. Similarly, the **Israeli** strategy identifies the need for the development and delivery of services specifically for carers, to maintain their social and emotional well-being including support groups and family therapy, providing information and support as needed by the individual.

The **Greek** strategy proposes a number of ways in which carers of people with dementia can be supported to maintain both their physical and mental well-being. This includes the provision of information and training, including through staffed information centres in care facilities. The strategy also calls for the creation of a helpline for carers.

The **English** strategy groups together support for carers of people with dementia, committing to ensuring that they

are aware of and offered the opportunity for respite, education, training, emotional and psychological support so that they feel able to cope with their caring responsibilities and to have a life alongside caring.

**Scotland's** strategy contains a high level outcome in relation to ensuring that carers are encouraged to be involved throughout the duration of the illness, whilst also ensuring that the carers' own needs are identified and addressed.

As part of the assessments referred to above, the **Northern Irish** strategy makes provision for health trusts to support carers through various means (including education and services) in line with their needs. The strategy also identifies the need for shared peer support networks for carers. In relation to decision-making, the strategy commits to trusts involving carers in planning for a patient's discharge from hospital and intermediate care.

The proposed care pathway within the **Portuguese** strategy includes components for carers of people with dementia, which includes family/carer orientated supports, such as counselling and emotional support.

The **Spanish** neurodegenerative strategy focuses on the physical and mental well-being of carers, including identifying the need for a specific assessment for the needs of carers (with ongoing reviews of needs throughout the duration of the illness), as well as offering of supports, services as required.

## Training

The **Cypriot** and **Spanish** (neurodegenerative) strategy included a specific focus on delivering workshops for primary carers focused on skills, knowledge and coping mechanisms to carry out a caregiving role, whilst also including emotional support. Similarly, the **Maltese** strategy proposed training for caregivers, which would include a focus on stress management and communication, delivered by dementia professionals. Similar commitments are also made as part of broader measures in the **English**, **Northern Irish** and **Portuguese** strategies (see section 5.8).

## Financial assistance

The **Flanders** strategy proposed the automatic granting of compensation to both people with dementia and their carers through the Flemish Social Protection. Similarly, the **Czech** strategy proposed establishing new financial aid for carers, in addition to supporting economically active carers.

## Other carers strategies/policies

The **Irish** strategy notes that it has a separate strategy for carers, whilst also noting that previous training needs analyses carried out had highlighted the need for training courses for carers of people with dementia.

Similarly, the **Scottish** strategy notes that primary legislation had been introduced which would provide more support to unpaid carers with the aim of improving their health and well-being, including through guaranteeing assessments of their needs and the provision of information and advice.

## Other

The **Greek** strategy also calls for an annual caregivers day to raise awareness of the position of unpaid carers.

The **French** neurodegenerative strategy makes a broad commitment to provide support for carers who care for members of their own family.

The **Spanish** neurodegenerative strategy commits to providing bereavement support for carers whose loved-one has died.

The **Israeli** strategy included a focus on ensuring that carers were aware of their legal rights, including the right to take six days of absence per year to care for a spouse or older parent, with a commitment to increase the number of leave days permitted to care for a family member. On a related theme, the **English** strategy commits to ensuring that more employers have carer friendly policies and practices to enable more carers to continue to work and care.

## 6.2 Personal accounts



Ireland's National Dementia Strategy, while welcome in principle, is not providing changes on the ground.

Supports are at an all-time low in Ireland and, particularly if you are living in a rural area, services and supports are non-existent. Rural and social isolation are major issues for both carers and people with dementia.

We need more joined up initiatives – getting all groups working together to build awareness, give support and human contact to all effected.

As a former primary carer for my mum, the most difficult part of caring was the isolation and loneliness that came with the winter afternoons, dark at 3.30pm – probably raining – West of Ireland and no one would be calling or checking in on us until next morning when a formal carer would call for 20 minutes to help get mum up, showered and dressed.

My mum was non-verbal for her final year – while we communicated perfectly well, I would love to have heard her voice. The silence at times was deafening as human contact is vital for all of us to flourish and remain productive citizens.

Having been in a position to care for my mum, it was the most rewarding thing I have done and would love to see early diagnosis, signposting to various supports/services if available and more families empowered to care for their loved one in their homes, which is where the majority of us want to remain.

**Carmel Geoghegan** was the primary carer of her mother and is the founder of Dementia Ireland. She is supporter to Helen Rochford-Brennan (Chair of EWGPWD).



In 2009, my father passed away, and perhaps with the emotional shock my mother experienced, she began to experience a pre-dementia (slight cognitive deficit). Later came the diagnosis of Alzheimer's disease. My mother and I had to readjust our lives and face the stigma of an incapacitating and limiting disease.

I changed my personal life, I stopped having a social life and I decided to face and fight against the stigma of dementias, because I soon learned that what does not kill us gives us more strength. My mother had to be cared for and she needed an informal carer, and that role fell on me, my aunty and sister.

I have tried to be active in defending all the rights of people with dementia and their family caregivers. The work of my mother in the EWGPWD (European Working Group of People with Dementia) has allowed us to have a more comprehensive view of the reality of our country, especially when compared with other European countries and in recent years, my mother and I have been very active and involved in many actions that relate to the struggles experienced by people with dementia and their informal caregivers.

The provision of informal care has too heavy a cost for those who do it. The impacts are economic, physical and psychological. There is a huge risk of poverty, abandonment of employment, isolation, breakdown of relationships and social life, depression, exhaustion and stress.

There is scarcity of formal care, home care services and other services are few and make the family responsible for care, overburdening them and, in a certain way, disempowering the state and the family. The informal caregiver is not guaranteed their right to rest, nor the possibility of reconciling care and professional life. There is no social or monetary support, nor the recognition of care for the purposes of career contributory.

Because this is a theme in particular, I have, along with my mother, been fighting for an Informal Caregivers Statute, because it is opportune that something is done on this theme for all of us.

**Nélida Aguiar** former carer for her father, current carer/supporter for her mother, Idalina Aguiar (member of EWGPWD) from Portugal.

## 7. Prevention, dementia-friendly communities and public awareness

Many strategies dealt with the issues of prevention, dementia-friendly communities and public awareness in similar ways, primarily focusing on improving public awareness of the condition both as a means to recognise the disease and its symptoms (thus supporting timely diagnosis) but also to reduce societal stigma associated with the condition.

There are some overlaps with other areas, including workforce development (section 5.8), particularly in relation to awareness raising/training for non-health workers. In keeping with other sections of this report, where an issue could fall under multiple sections, its location has been determined by its location within its respective strategy.

### 7.1 Prevention of dementia

The prevention aspects contained within the strategies were primarily, though not exclusively, focused on primary prevention<sup>9</sup>, with secondary and tertiary prevention mentioned to a lesser degree. It is the case that many of the services and supports contained in other areas of the strategies constitute preventative measures to some degree, however, very few of the strategies identified those measures as such.

#### Primary prevention

The **English** and **Welsh** strategies both commit to a number of actions to ensure that the public people understand the steps they can take to reduce their risk, or delay the onset, of dementia, including ensuring risk reduction messages are included in relevant public health policies and programmes, as well as ensuring people with dementia receive advice about changes they could make to improve their general health and well-being.

The **Irish** strategy follows a similar approach addressing both population and individual level prevention. The national focus includes targeting high risk populations, including people with intellectual disabilities, with the strategy proposing to manage individual tobacco and alcohol use, as well as the physical activity of the person with dementia, within their care plans.

The **Flanders** strategy focuses on existing prevention organisations incorporating dementia into their campaigns and messaging, linking this to legislation on

health prevention. This was organised in collaboration with a number of other countries (**Germany, Luxembourg, Netherlands** and **Norway**) to develop the “SaniMemo-riX” resources.

The **Israeli** strategy committed to implementing a programme and disseminating findings in relation to prevention following a clinical consensus conference.

The **Greek** strategy focuses on work required across health, social care, local authorities and non-profit organisations to raise awareness of prevention and risk factors. The Greek strategy is unique in its commitment to the introduction of annual screening programmes around risk factors.

The **Northern Ireland** strategy provides detailed information on the area of prevention, addressing a number of areas including the promotion of healthy lifestyles and avoidance of risk factors. The strategy is unique insofar as it is the only one which references and gives consideration to initiatives that may reduce serious head injuries.

The **Luxembourg** strategy committed to carrying out a primary prevention campaign focused on active ageing and good health by maintaining social contacts. There was a specific focus on the role of carers and their health, raising awareness of respite, as well as means of primary and secondary prevention.

The **Spanish** neurodegenerative strategy focuses on primary prevention and the elimination of the factors associated

<sup>9</sup> For the purposes of this document, **primary prevention** is considered as interventions aimed at those targeted before health effects occur, **secondary prevention** as interventions which aim to identify diseases in the earliest stages and **tertiary prevention** as interventions which manage the disease after diagnosis to slow or stop disease progression.



with the appearance of neurodegenerative diseases. Specifically, it proposes the promotion of healthy lifestyles as a means of preventing or delaying the development of some neurodegenerative diseases, through community and inter-sectoral programmes (e.g. in schools, health education etc.) as well as through the promotion of occupational health programmes.

## Prevention of associated risk

The **Norwegian** strategy provides a greater focus on the prevention of risks associated with dementia, such as an increase in falls, with a target of a 10 % reduction in the number of hip fractures by 2018 through training and development of quality indicators, home visits and the patient safety programme. As part of this, the strategy commits to developing new guidelines to assist municipalities in developing preventive and health-promoting measures for older people, including recommendations on models for preventive home visits and health-promoting services.

The **Northern Irish** strategy indicates consideration will be given to further development of secondary prevention targets to its dementia indicator. Additionally, it proposes developing referral pathways for genetic testing services for people likely to have genetic risk factors for developing dementia. Finally, national services commit to ensuring that a range of provision is developed to help people preserve function.

The **French** neurodegenerative strategy focuses on tertiary preventative measures, and as part of this, underlining the role of individuals and the carer or family member closest to them in managing the illness, primarily through therapeutic education.

## Links to existing prevention strategies

The **Norwegian** strategy distinguishes between primary and secondary prevention, looking at both risk factors for developing dementia but also minimising the effects of the condition once it has developed. As part of this, the strategy focuses on the overlap in preventing dementia and other non-communicable diseases (NCDs), which is reflected in Norway's NCD strategy (which is linked to the World Health Organization's target of reducing premature mortality by 25%).

The **Finnish** strategy commits, by 2020, to ensuring that brain health promotion has been factored into all sectors of

society. This includes dedicated funding supporting activities promoting brain health, including all public bodies having responsibility for providing support and information about brain health, as well as NGOs publishing information. Additionally, joint municipal authorities will have responsibility for updating their health care provision plans to incorporate brain health.

The **Italian** strategy also notes the need to promote both primary and secondary prevention of dementia. It noted that dementia had been included within the country's first national prevention plan and was under consideration as part of the ongoing development of the revised plan. In a similar approach, the **Irish** strategy notes that, at a national level, there is overlap in reducing dementia through addressing risk factors and the strategy on physical activity.

The **Norwegian** strategy commits to the creation of a separate strategy for older people with a view to promoting activity through employment, voluntary work, participation in the local community, social life and physical activity, with more emphasis given to health promotion and the ways communities can strengthen individual's functional capacity. Separately, there is reference within the strategy to a white paper which is being drawn up in relation to substance misuse.

The **English** strategy proposes its measures within the context of a healthy ageing campaign and access to tools such as a personalised risk assessment calculator.

## Focus on the role of practitioners

The **Northern Irish** strategy incorporates elements of prevention whilst specifically outlining the role of certain practitioners. Primary care professionals have a prominent role in this regard, targeting different population groups, including middle aged and older people, people with existing conditions which put them at risk and people with an existing diagnosis. Primary care professionals are expected to offer lifestyle advice, monitor, review and treat modifiable factors, and play a central role in the ongoing care of people who have been diagnosed with the condition. As part of this, the strategy notes that consideration will be given to the addition of primary prevention targets for dementia.

Similarly, the **Czech** strategy placed the focus of prevention onto healthcare professionals, noting the need for changes to the training of GPs and the professional development of pharmacists.

## 7.2 Dementia-friendly communities/Dementia Friends

This section is primarily focused on actions and commitments proposed within strategies which relate to the creation of “dementia-friendly communities”, “Dementia Friends” programmes or other community-based actions which aimed to allow people with dementia to stay in their communities for longer.

In some cases, there was significant overlap with other sections, e.g. awareness raising amongst non-health/social care professionals, under section 5.8 (workforce development). As with other sections, the placement of items reflects their placement within the strategy from which it was taken.

### Dementia-friendly communities (DFCs)

The **Welsh** strategy contained a number of proposed actions to improve public understanding about dementia. A key focus of the strategy is to work with the third sector and people with lived experience, expanding initiatives such as Dementia Friends, dementia supportive communities and organisations, and the creation of a “dementia-friendly generation”.

Additionally, the strategy commits local authorities and health boards to working with local communities and third sector organisations to encourage them to open their services to people with dementia, their families and carers, whilst ensuring the needs of people living with dementia are considered as part of the planning processes.

The **Italian** strategy aimed to improve the quality of life of persons with dementia and their families by supporting empowerment of people with dementia and a reduction in stigma associated with the condition, including ensuring people living in communities can be part of service planning.

The **German** strategic document contains a commitment from local authorities and municipalities improving the provision of accessible amenities and services. Similarly, the **Luxembourg** strategy commits to promoting the social inclusion of people with dementia and their families.

The **Danish** strategy aims to ensure that all 98 municipalities become dementia friendly. Resources allocated to this area include local and national activities to develop DFCs and information campaigns. In addition, the strategy includes a commitment to increase the level of dementia friendly housing, making assisted living housing more suitable for people with dementia and instituting a national labelling system for housing that is suitable for people with dementia.

Similarly, the **Flanders** strategy also commits to supporting municipalities to become more dementia-friendly.

The **Slovenian** strategy includes a commitment to promote activities of local communities to raise awareness and help combat stereotypes about dementia, providing educational content for relatives of people with dementia and informal carers.

The **Finnish** strategy focuses on improving societal attitudes towards brain health, memory disorders, dementia and people with dementia. The approach includes the creation of an online resource providing information about symptoms, memory disorders, dementia, research, treatment and rehabilitation. Similarly the **Flanders** strategy proposes a dementia-friendly “widget” for use on municipality websites.

The **English** strategy has a strong focus on dementia-friendly communities, with a number of actions to implement its objective. This includes working with the formal standards body and third sector to formalise dementia-friendly criterion with different levels for attainment. Businesses will be encouraged to become dementia-friendly and develop Dementia-Friendly Charters, tied into dementia awareness training. In addition, public, private and third sector organisations will be encouraged to be more engaged with local dementia alliances.

The **Spanish** neurodegenerative strategy commits to increasing the knowledge and awareness of the population about neurodegenerative diseases, including possible preventable factors, possibilities of rehabilitation, resources and services. Additionally, the strategy promotes cross-sectoral working (including patient organisations) to encourage participation and involvement in supporting people with these conditions.

### Dementia Friends/other training

The **English** strategy commits to the Alzheimer’s Society delivering an additional three million Dementia Friends in England and turning Dementia Friends into a global movement. Additionally, “Dementia Friends Champions” will be offered support to take new opportunities and action, for example through dedicated volunteering networks.

The **Dutch** strategy commits to creating a society which is more dementia-friendly, with a specific programme (“Samen dementievriendelijk”) inspired by dementia projects in other countries, to improve societal understanding about how the public can help people with dementia and their carers.

It offers a free online training course for the general public and 10 tailored online training courses for specific businesses, such as the banking, hospitality and retail sectors.

The **Norwegian** strategy proposes a three year programme of low-level educational courses for the public and service sectors to help improve understanding and openness about dementia amongst society. Similarly, the **Swiss** strategy proposes sector-specific materials for people likely to come into contact with people with dementia every day.

The **Irish** strategy commits the national health organisations to consider how best to promote better understanding of, and sensitivity to, dementia among staff of frontline public services. This point is also included within the **Slovenian** strategy.

The **Finnish** strategy proposes to build the components of a memory-friendly Finland, with targeted work at schools promoting the brain health and the importance of treating individuals with respect. The **English, German and Welsh** documents all propose similar approaches to ensure better intergenerational understanding of dementia, through the provision of materials and resources for schools and further/higher education settings in the case of **England**.

## Transport

The **Welsh** strategy also notes that transport planners and operators should consider the needs of people living with dementia in the development of their services, with a commitment within the strategy to develop and undertake awareness training amongst transport workers.

The **Scottish** strategy makes a broader commitment around the national transport organisation examining what can be done to better support people with dementia to ensure transport is accessible.

## Befriending/social isolation/loneliness

The **Finnish** strategy places responsibility on the third sector to work with local authorities to provide people with dementia and their families with opportunities to engage in social activities, access to peer support and information to help them cope with day to day life.

The **German** strategic document notes the commitment of the Federal Government to funding around 500 local alliances as help networks, 450 multi-generational centres as a starting point of caring communities and 300 contact points for older people to enable independent living. Related to this work, it notes the promotion of neighbourhood contact centres for older people to encourage and facilitate participation in their communities.

The **Norwegian** strategy has a considerable focus on the reduction of loneliness of people with dementia. It proposes to address this through voluntary work, through cooperation of public and private sectors, with the development of local strategies. Additionally, cooperation with the voluntary sector will be promoted through technology and expanded day activities.

The **Scottish** strategy contains a high level commitment to ensure more dementia-friendly and dementia-enabled communities, organisations and initiatives, with a specific commitment to working with partner organisations to explore the potential to promote and support increased participation in dementia befriending.

The **Cypriot** strategy commits to the establishment of dementia cafés similar to those in the UK or the Netherlands to support the socialisation and peer support of people with dementia and their carers, as well the provision of practical advice and emotional support.

The **French** neurodegenerative strategy prioritises mitigating personal and social consequences on everyday life for people with neurodegenerative conditions. In addition, the strategy identifies the need to help people with such conditions live within respectful, integrated and voluntary societies, prioritising social connections and combating isolation.

## Other

The **German** strategic document also addresses the issues of accessibility, both in terms of physical environments, and information and literature which were seen as barriers to participation.

## 7.3 Public awareness campaigns

This section is specifically focused on raising awareness of dementia and other measures aimed at destigmatising the condition. There is some overlap with section 7.2 (dementia-friendly communities) in terms of the intention of both,

however, as there was considerable difference in approach, they have been distinguished within this document.

## Encouraging timely diagnosis

The **Northern Irish** and **Welsh** strategy includes a high level outcome about the importance of ensuring that people are aware of the early signs of dementia, the importance of a timely diagnosis and have an understanding of where they can go to get help. Similarly, the **Greek** strategy commits to running public-facing information campaigns which both challenge stigma and encourage people to seek an earlier diagnosis.

The **Maltese, Portuguese** and **Slovenian** strategies propose similar approaches for information campaigns focused on increasing awareness and understanding of dementia and encouraging help seeking behaviour, as well as providing information about the condition, risk factors and preventive measures, the value of early diagnosis and the availability of support services.

## Reducing stigma

The **Austrian, Cypriot, Czech, Finnish, Flanders, German, Irish, Israeli, Italian, Maltese, Northern Irish, Portuguese, Slovenian** and **Swiss** documents all focus on the need to change the societal understanding and awareness of dementia, with the primary aim of reducing the stigma and negative perceptions associated with the stigma associated with dementia through the use of information or public awareness campaigns in some form. It was also common amongst these strategies to include the need to raise awareness amongst public-facing professions.

The **French** neurodegenerative strategy commits to raising awareness of such illnesses and the effects on the day to day lives of people with the condition and their carers, with the specific aim of reducing stigma. As part of this, the strategy also focuses on how to ensure people are able to stay in their own homes and within their communities.

Additionally, **Flanders** focused on the need to encourage people with dementia to continue to participate in their

community, with a specific 'Forget Dementia, Remember the Person' campaign as part of the commitment.

As part of its campaign, the **German** strategic document proposes to include information to improve people's knowledge of diagnosis and treatment, with partners involved in the development of the document agreeing to coordinate efforts around World Alzheimer's Day (21<sup>st</sup> September) to raise awareness.

In relation to this area, the **Czech** strategy commits to developing and applying a methodology to assess the stigmatisation experienced by people with dementia.

The **Norwegian** strategy proposes a campaign focused on both reducing physical and social barriers in society which prevent people with dementia from participating on an equal footing, with patient organisations involved in the development of the campaign.

The **Austrian** and **Swiss** both focus on health literacy focused on raising population awareness, reducing stigma, targeting information for people with dementia and their carers, whilst also targeting working age people who may be at higher risk of developing the condition. Additionally, the former also proposes the development of a code of good practice for media information related to dementia.

## Other

The **Maltese** strategy was the only one which made specific reference to promoting the work of the Maltese Dementia Society and other non-government organisations working in the field of dementia.

The **Israeli** strategy acknowledges the need to work with civil society to develop information resources which are societally and culturally appropriate.

## 7.4 Personal account



I continue to assume my role as ambassador in dementia. In spite of the disease that obscures my memory, I insist on proving that it is possible to live with dementia and help to convey the message of an inclusive society.

On the international day of friendship (30 July 2018), the campaign “Friends in Dementia”, promoted by Alzheimer Portugal, was launched and several friends joined this campaign.

The main objective of this campaign is to increase the understanding about dementia in our country and to invite all citizens to actively engage in improving the daily lives of people with dementia.

This initiative aims to combat the lack of knowledge and stigma associated with dementia, as well as raising awareness on the subject in Portugal. It also aims to help citizens understand how dementia affects people, help change behaviour, and make society more friendly with people with dementia.

To launch this campaign, which aims to change the way our country thinks, acts and talks about dementia, Alzheimer Portugal has promoted in 21 Portuguese beaches and cities in all districts of Portugal, the Madeira Archipelago (where I live) and the Azores, where employees and volunteers from the Association presented the initiative and invited people to join.

“Friends in Dementia” is an initiative of Alzheimer Portugal and counts on the High Sponsorship of the President of the Republic and the support of a wide range of reference partners.

**Idalina Aguiar** is a member of the European Working Group of People with Dementia (EWGPWD) from Portugal.

## 8. Research

Research was an area of significant focus for a number of strategies, with recognition across strategies that there was need for further research across all disciplines including in relation to disease pathology, epidemiology and development of interventions and cures (including drug

development). This section has been divided into two main sections, reflecting broader commitments towards supporting research in specific areas and those which were more focused on routine data collection and epidemiological work.

### 8.1 Support for research

#### Practice and service provision

A number of strategies examined the way in which research could be used to make a difference in to professional practice or the delivery of services for people with dementia, their families and carers.

For example, the **Cypriot** strategy commits to greater support in relation to the prevention of the condition (including risk factors) as well as the application of such research in the provision of services.

Comparatively, the **Portuguese** strategy primarily views research in the context of measurement and evaluation of different elements within the strategy, highlighting that whilst there is a need for greater research in basic and clinical research into dementia, there is also a need for research into services and policies. This was also the case within the **Welsh** strategy which included evaluation of its 'teams around the individual' approach as well as committing to ensuring research informs and shapes practice.

Similarly, **Flanders** proposes to ensure that research transforms into practice through better utilisation of information websites. The **Finnish** strategy also proposes an online portal to spread good practice and evidence. In addition, the **Swiss** strategy also commits to the linking of research and practice through an online platform logging research projects and findings on dementia.

Both the **English** and **Welsh** strategies identify the need for greater research into the day-to-day practical issues which affect people with dementia, their carers and families in managing the condition. Additionally, the **English** strategy commits to more research being conducted and disseminated in care homes, as well as a greater focus on research to inform effective service models and interventions.

The **English** strategy has a considerable focus on risk factors related to dementia, committing to a cure or disease-modifying therapy to be on track to exist by 2025 and an understanding of the interactions of genetic risk with comorbidities and environmental triggers that exacerbate

disease progression. In addition, it contains a commitment related to prevention, including measures such as biomarkers for the stratification of disease and monitoring of disease progression, through imaging, molecular, cognitive and behavioural studies.

The **Finnish** strategy also has a considerable focus on research, with national health and research organisations having responsibility for producing information on the costs, effectiveness and quality of services used by people with dementia. The national body (along with public sector and third sector bodies) also has responsibility for other research areas, including developing national criteria and indicators for the quality control and supervision of care and services, the promotion of brain health among the population and producing evidence to inform the development of services which support people with dementia, their families and carers.

The **Austrian** strategy took a similar approach to improving the quality of care through dementia research, primarily through focusing on the causes of dementia and the needs of people with dementia as well as, communicating the recent state of research on dementia, identifying the gaps in information and data, and undertaking coordinated research to close the gaps.

The **Norwegian** strategy commits its national research body to establishing three new cross-disciplinary 10-year programmes, focused on services research, practice-based clinical research and prevention research.

Additionally, the **Swiss** strategy commits to ensuring research informs practice, supporting the trend of approaches to the treatment, care and nursing of people with dementia being scientifically evaluated to ensure quality of care, transferring research findings into practice through the establishment of a dialogue between researchers and professionals.

The **Maltese** strategy commits to establishing research initiatives in non-pharmacological interventions aimed at cognitive stimulation and behavioural management. In

addition, it commits to carrying out research to assess the unmet needs of older adults with dementia, their families and carers, as well as creating a multidisciplinary group of experts in dementia to ensure practice is informed by an evolving evidence base.

The **Spanish** neurodegenerative strategy included an extensive list of research priorities including, among other themes, prevention, disease management, clinical practice, interventions, disease pathology, diagnosis and epidemiology. Specifically, the strategy identifies the need to involve scientific and professional societies related to neurodegenerative diseases in the planning and evaluation of services. As well as, committing to promoting interdisciplinary research lines.

The **French** neurodegenerative strategy also includes a focus on research into the prevention of conditions (both in preventing their appearance and slowing their progression). It also proposes strengthening the cohorts dedicated to neurodegenerative conditions, coordination of research priorities to identify new biomarkers of neurodegenerative conditions and understanding them using system models to identify therapeutic targets and initiate clinical trials.

## Opportunities for research participation

Some strategies included elements on how to encourage more people with dementia and carers to take part in research related to dementia.

The **Welsh** and **Maltese** strategies commit to creating more opportunities for people with and affected by dementia to participate, be involved and engage with research activity. The **Israeli** strategy makes a similar commitment, whilst also acknowledging the need to include minority groups and other sub-groups in dementia research.

The **English** strategy highlighted a specific online platform (Join Dementia Research) for connecting researchers with people who were interested in participating in dementia research. Specifically, it aims to have 25% of people diagnosed with dementia registered, with 10% participating in research. Additionally, national research programmes will be encouraged to have stronger elements of patient and/or public involvement.

## Research infrastructure/resources

Of the strategies which contained references to dementia research, a key priority for the majority was the need to ensure that sufficient infrastructure and resource is in place to allow for high quality research to take place. This covered a number of areas including, among others, the

number of researchers available to carry out research, the dedicated funding available for research or the physical infrastructure to allow research to take place.

The **Flanders** strategy committed to addressing the imbalance between global academic performance norms and practical relevance as it was noted that this had the potential to diminish the impact of dementia care.

The **Cypriot** strategy identified that there was little funded research taking place across all disciplines, noting that some was taking place as a result of collaboration between the national Alzheimer's association and, private and state universities. However, the strategy identifies the need for dedicated resources from the state to allow and encourage research to take place. Similarly, the **Greek** strategy highlights the need to build research capacity within the country, with proposed annual or bi-annual research programmes established; the strategy identifies that national and supra-national funding sources will be required to achieve this.

The **Israeli** strategy also identified the need for specific research funding and committed to providing funds for research on issues related to dementia from the funds designated for research within its health insurance legislation. The **Norwegian** strategy also committed to including funding for care research and building care research infrastructure as part of its services research programme.

The **Northern Irish** strategy sets out actions for improving dementia research within the country, including a commitment to national support from the health and social care research organisation for the clinical research network, as well as supporting researchers in preparing submissions to the US National Institutes of Health or to funding bodies. On the latter point, the **Czech** strategy similarly commits to support researchers and targeting bids for funding.

The **Scottish** strategy also commits to supporting clinical and non-clinical research in **Scotland**, including supporting linkages to the UK-wide research institute, linking policy and research and providing support to national dementia research networks.

The **English** strategy contains a commitment to double funding for dementia by 2025, with increased investment in dementia research from pharmaceutical, biotech devices and diagnostics sectors. In addition, government research bodies will support initiatives aimed at building interdisciplinary/professional work in health and care research for dementia.

The **Slovenian** strategy focuses on building the capacity of dementia research within the country across areas of basic science, health economics and clinical practice. As part of this, it commits to establishing national multidisciplinary

networks of experts on dementia, regional centres for spreading good practice and national banks for brain tissue and cerebrospinal fluid. Similarly, the **Spanish** neurodegenerative strategy identifies the need to boost the activity of biobanks by encouraging brain tissue donation and biological samples by people with neurodegenerative diseases.

On a related theme of establishing research infrastructure, the **Danish** strategy commits to making its national knowledge centre for dementia permanent, allowing for work on e-learning courses, future research and knowledge sharing to continue. It additionally identifies the need for better data in the field of dementia with funding allocated to further develop the **Danish** Clinical Quality Data-base for Dementia to construct a cross-sectorial quality data base, including municipal data. The **Finnish** strategy commits to examining the potential for establishing a national network of centres of expertise, in addition to working with funding bodies to ensure basic research into dementia continues.

The primary focus of the **Dutch** strategy is on different components of dementia research within the country, including the development and implementation of interventions and care models. Its specific “Memorabel” research programme involves health, voluntary and academic partners, providing funding for research on four themes: cause and mechanism of the disease; diagnosis; treatment and prevention; and efficient care and support. Alzheimer Nederland also supports basic research through an innovative research programme which is also part of the **Dutch** dementia strategy.

## International/European-level research

Some of the strategies looked beyond their respective domestic contexts to identify work ongoing at an EU or international level.

This is apparent in the **English** strategy, which contains a number of commitments, including to establish an international dementia institute in England. Additionally, the strategy commits to the expansion of the global dementia research agenda, filling research gaps identified by the World Health Organization (WHO) and the Organisation for Economic Co-operation and Development (OECD).

The **English** and **Scottish** strategies both make reference to the UK’s role in advancing care and support for people with dementia through Scotland’s leadership of the second EU Joint Action on Dementia (2016–2019). The **Norwegian** strategy notes its leadership of the quality of residential care work stream in the Joint Action. The **Scottish** strategy also highlights the Scottish Government’s role in working with the International Consortium for Health

Outcomes Measurement (ICHOM) in developing global standards for measuring and reporting on outcomes for people with dementia.

The **Maltese** and **Greek** strategies both identify the need for each country to increase participation in EU and international projects related to dementia research.

The **French** neurodegenerative strategy included a focus on better national coordination of neurodegenerative research, the establishment and implementation of a research structure, identifying sites of international importance and facilitating cooperation (particularly in a European context).

The **Greek** strategy specifically identifies collaborations such as the Joint Programme on Neurodegenerative Diseases (JPND). Three other countries highlight the JPND programme within their strategies, with the **Czech** and **Slovenian** strategies highlighting it as examples of research collaboration in which they believe they should be involved, with the **Dutch** strategy highlighting that the “Memorabel” research programme was a part of this work.

## Other

Some strategies contained other commitments around research infrastructure which either were not in common with other strategies or distinct from the main themes previously identified. As a result, these have been included below.

Both the **English** and **Flanders** strategies identified that subsidised research should be open access. Related to this, was the **Austrian** commitment to ensure that research findings were disseminated to policy and decision-makers, the public and people with dementia. Similarly, the **French** neurodegenerative strategy highlighted the need to communicate research with the general public.

The **Welsh** strategy was the only one to commit to encouraging research that uses public health approaches to consider the inequalities experienced by people with dementia.

The **Danish** strategy committed to a new national research strategy specifically for dementia, with specific funding allocated for this purpose.

The **Greek** strategy proposed using incentives in the form of prizes for clinical and basic research as a means of promoting interest in the field. Although not proposing incentives or rewards, the **English** strategy also identified the need to promote dementia research as a career opportunity among researchers.



## 8.2 Routine data collection and prevalence studies

A number of strategies identified the lack of existing data in relation to the use of health and social care services or the prevalence of dementia within their countries as barriers to planning services and supports to meet the needs of people living with dementia.

### Routine data collection

The **Irish** strategy specifically refers to the need for data collected as part of its assessment tool to be used within dementia research to inform the provision of dementia care. This was similar to the **Swiss** strategy which identified the need for national data on the structure of care services and their uptake, noting that at the cantonal level, such data are crucial to long-term management and care planning, as well as the quality of care services.

The **Greek** strategy identifies the need for collection of more robust and reliable data to inform care and treatment of people with dementia. Similarly, the **Czech** strategy identifies the need for epidemiological surveillance and monitoring in order to plan health and social services.

The **German** strategic document commits the Federal Government to overseeing nationwide health monitoring working alongside the Robert Koch Institute, including supporting the establishment of a national cohort of 200,000 people with the Helmholtz Association, as well as improving the collection of routine data for use in research.

The **Israeli** strategy commits to formulating an agenda for research that will focus on gaps in available data including in relation to the epidemiology of dementia,

organisation of services and the socio-economic implications of the disease.

### Prevalence/incidence of dementia

The **Scottish** strategy commits to commissioning work to assess dementia prevalence, and considering which model applies best, noting that the use of the EUROCODE methodology did not align with other UK statistics, meaning estimates of the number of people with dementia varied considerably. Additionally, the **Norwegian** strategy also committed to commissioning a study on the prevalence of dementia.

Both the **Israeli** and **Swiss** strategy commit to considering the feasibility of establishing a monitoring system which would include the incidence and prevalence of dementia. The **Swiss** strategy further outlines that for medium and long-term care planning and management, there is a need for dementia to be better reflected in existing health statistics to determine demand for services. Similarly, the **English** strategy commits to ensuring that all commissioning bodies have access to improved local and national prevalence data to inform the commissioning and provision of services, primarily in relation to diagnosis and post diagnostic support services.

The **Slovenian** strategy commits to the establishment and maintenance of incidence and prevalence data on dementia, with a national anonymised registry, with responsibility sitting with the national public health body. Similarly, the **Italian** strategy commits to implementing epidemiological surveillance, in addition to supporting and coordinating national research in public health. The **Maltese** strategy also commits to supporting epidemiological research into the care and management of dementia.

## 9. Other themes

There were a number of elements within the strategies which did not fit in with other themes within the Yearbook, either through being unique to that strategy or simply by virtue of falling outwith the scope of the sections above.

### 9.1 Technology/living aids

Technology was a recurring theme throughout the strategies, however, the proposed approaches and utilisation of technology mean it did not, as a coherent theme, fit within other sections. Whilst in some cases the strategies identified its use in enhancing care and support, other strategies examined other uses such as the dissemination of information.

The **German** strategic document included a commitment for municipal counselling centres to provide information on technology as a means of improving quality of life in old age.

The **Finnish** strategy placed a specific responsibility on joint authorities for providing access to high-quality daily living aids and ensuring that aids and technology are utilised to improve the function and activity of people with dementia. Similarly, both the **Maltese** and **Israeli** commit to the promotion and development of technology to support both the person with dementia and the caregiver.

The **Irish** strategy commits to considering the use of assistive technology as a means of support, whilst the **Northern Irish** strategy similarly committed its national public health body to commission a literature review on the cost effectiveness of assistive technologies in supporting people with dementia.

The **English** strategy commits to research in relation to assistive technologies and assisted living, and how these can best be used to help people living with dementia to live well. The strategy also commits to establishing a national online resource to enable people with dementia and carers to access assistive technology.

The **Scottish** strategy commits the Scottish Government to implementing a specific technology charter for people with dementia (drawn up in collaboration with a number of partners, including Alzheimer Scotland). As part of this, cohorts of professionals will be trained to have specific expertise in this area.

Both the **Portuguese** and **Cypriot** strategies identify the importance of access to new technologies within the context of their strategies, particularly in relation to the exchange of information and communication.

The **Luxembourg** strategy identified the need to have accessible information and documentation that was available to the public and committed to using new technologies and means of communication as a way to achieve this.

### 9.2 Dementia and equalities

Some strategies addressed the issue of dementia and equalities (i.e. matters relating to minority communities) the context of other aspects of their strategies. As such, this section includes only those sections which addressed the matter in its own right.

The **Welsh** strategy identifies the additional challenges faced by minority communities, including Lesbian, Gay, Bisexual and Transgender (LGBT) and Black and Minority Ethnic (BME) communities, as well as people with visual impairments. As part of this, the document acknowledges the need for services and resources to be accessible and useful for everyone. Similarly, the **Flanders** strategy commits to carrying out work to examine the perception of

dementia within minority ethnic communities and find ways of focusing on engaging at a neighbourhood level.

The **Norwegian** strategy addressed a similar issue within its specific context, committing to disseminating knowledge and information to all municipalities in relation to people with a Sami or minority language background who develop dementia. The strategy also highlights a grant scheme for municipalities to strengthen professional and service development within services for people with disabilities.

On a similar theme, the **Scottish** strategy commits the Scottish Government to implementing the findings from a dementia and inequalities report commissioned as part

of the second dementia strategy, specifically examining challenges faced by persons within the LGBT, BME and learning disability communities. The **Northern Irish** strategy commits health trusts to ensuring that people with learning disabilities and dementia are supported both

by specialist services and dementia services in line with their needs. As part of this, it commits specialist dementia diagnostic and support services to make necessary reasonable adjustments to enable full access by people with learning disabilities.

### 9.3 Helplines

The **Welsh** strategy commits to reviewing and promoting the Welsh dementia helpline as a key source of information. Similarly, **Flanders** commits to supporting its own dementia

helpline, whilst further identifying the need to make professionals aware of its existence and to use data from the helpline used to create targeted information initiatives.

### 9.4 Quality improvement

The **Flanders** strategy committed to the development of dementia-specific quality indicators and studies to be included within the ongoing Flemish indicator project. On the same theme, the **Cypriot** strategy identifies the need to implement a quality programme for services provided

across all stages of the illness including prevention, diagnosis and treatment. As part of this, priority will be given to the development and use of quality indicators. More broadly, the **French** neurodegenerative strategy includes a commitment to reinforce the quality and safety of care.

### 9.5 Miscellaneous

Both the **Scottish** and **Flanders** strategies highlight specific programmes of work underway with their respective police forces, incorporating specific measures for people with dementia who go missing.

The **Danish** strategy contains a commitment to review, in collaboration with the Ministry for Children and Social Affairs, current regulations within law on the use of force. It also commits to the creation of an annual dementia award to an employee that has made a specific effort in the field of dementia.

The **English** strategy commits to ensuring that an increased number of NGOs are involved in the work of the Global Alzheimer's and Dementia Action Alliance.

The **Cypriot** and **French** strategies both include small-scale commitments in relation to dementia and work. The **Cypriot** strategy commits to greater support for people with early dementia in their workplace and to support carers in their own work, through the development of specific work programmes, whilst allowing for more flexibility for caregivers. Similarly, the **French** strategy commits to mitigating the economic consequences of the illness and helping to maintain the career of younger people with a neurodegenerative condition.

The **Czech** strategy identifies the need to set rules in relation to the medical assessment on the competence to drive in older people.

## 10. Conclusions

Drawing together the information presented within this report, it is important to consider that the information presented is a reflection of the content of the strategies; it does not provide further insight into the experience of living with the condition, the nature of services or the extent to which policy is being implemented in each country.

Despite this, it is still useful to be able to reflect on the themes and approaches which are present within the strategies. We see that the greatest number of commitments and content largely relate to the provision of health and social care services for people with dementia, including around care coordination, diagnosis, treatment and the training of practitioners. Aside from these service-focused commitments, awareness raising amongst the public and improved infrastructure and resources around research were areas of significant focus for many of the strategies.

Although there are considerable differences between countries (in terms of the sizes of population, economic position or structures/operation of the healthcare systems), this prioritisation of issues remained broadly consistent for most strategies.

Prevention was an area acknowledged and dealt with by some strategies, although mainly on primary prevention linked to awareness raising. Although some strategies differentiated between types of prevention, most did not. However, it was true that many did not identify interventions (e.g. services providing therapeutic interventions) as forms of secondary or tertiary forms of prevention.

It was disappointing there was not a greater focus on carers within the strategies. Whilst most included the matter to some extent, it was often as an addition to the service

offer for the person with dementia, without identifying the distinct needs of carers in their own right. However, it was positive that a number of strategies recognised that informal carers need training and support if they are to carry out a caregiving role.

Additionally, we would have welcomed more strategies including a focus on human rights and legal matters for people with dementia. Where present, it was welcome to see references to international agreements such as the European Convention on Human Rights (ECHR) and United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), underlining the rights of people with dementia, especially in relation to the need for people to be involved in their own care and support, as well as in broader policy and decision-making processes.

It was interesting to note some strategies begin to consider technology in relation to dementia, although no consensus was evident; whilst many recognise its role in supporting daily living, others identified it as a means for greater information provision.

We hope this yearbook provides a useful overview of the approach of dementia strategies of the countries that have them, highlighting some of the policy convergence which exists across Europe, identifying potential areas of future focus, whilst also acting as a useful resource for those countries working towards the development of their own strategies. The table on the following page provides a high-level overview of the content of all the strategies covered in the document, providing a broad indication of the most common themes addressed within European dementia strategies.

Table 2: National dementia strategies at a glance

	Implementation <sup>10</sup>	Human rights	Legal matters	Diagnosis	PDS	Coordinated care	Residential & long-term	Acute & hospitals	End-of-life	Treatment & medication	Training & workforce	Support for carers	Prevention	DFCs	Public awareness	Research infrastructure	Routine data	Technology
Austria				✓		✓		✓			✓	✓			✓	✓		
Belgium (Flanders)	✓	✓		✓	✓	✓	✓		✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Cyprus	✓	✓		✓		✓		✓	✓	✓	✓	✓		✓	✓	✓		✓
Czech Republic	✓			✓		✓				✓	✓	✓	✓		✓	✓	✓	
Denmark	✓			✓		✓		✓		✓	✓	✓		✓		✓		
Finland	✓	✓		✓	✓	✓		✓	✓	✓	✓	✓	✓	✓	✓	✓		✓
France		✓		✓		✓			✓	✓	✓	✓	✓	✓	✓	✓		
Germany	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓		✓	✓		✓	✓
Greece	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓		✓	✓	✓	
Ireland	✓		✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Israel	✓		✓	✓	✓	✓	✓		✓	✓	✓	✓	✓		✓	✓	✓	✓
Italy	✓			✓		✓				✓	✓	✓	✓	✓	✓		✓	
Luxembourg	✓	✓	✓	✓	✓	✓	✓	✓		✓	✓	✓	✓	✓				✓
Malta	✓		✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓		✓	✓	✓	✓
Netherlands						✓								✓			✓	
Norway	✓	✓	✓	✓	✓	✓	✓		✓		✓	✓	✓	✓		✓	✓	
Portugal	✓			✓		✓			✓	✓	✓	✓			✓	✓		✓
Slovenia	✓	✓	✓	✓	✓	✓		✓	✓	✓	✓			✓	✓	✓	✓	
Spain		✓	✓	✓		✓		✓	✓	✓	✓	✓	✓	✓		✓		
Switzerland	✓	✓		✓		✓	✓	✓		✓		✓		✓	✓	✓	✓	
UK (England)	✓	✓		✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓		✓	✓	✓
UK (N. Ireland)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓		✓	✓		✓
UK (Scotland)	✓	✓		✓	✓	✓	✓	✓	✓	✓	✓	✓		✓		✓	✓	✓
UK (Wales)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓		

<sup>10</sup> Implementation refers to whether the strategy outline implementation or governance measures – it does not refer to the status of implementation of the strategy.

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