



**Alzheimer's Disease
International**

IMPROVING DEMENTIA CARE WORLDWIDE

**IDEAS AND ADVICE
ON DEVELOPING
AND IMPLEMENTING
A NATIONAL
DEMENTIA PLAN**

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¹Trimbos Institute, the Netherlands Institute of Mental Health and Addiction, Utrecht

²VU University, EMGO+, Amsterdam

³School of Psychology, University of Queensland, Australia

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FOREWORD



Dementia, including Alzheimer's disease, is one of our biggest public health challenges. Today, over 35 million people worldwide live with the condition. This number is expected to double by 2030 and more than triple by 2050 to 115 million. As the prevalence of dementia increases around the world, so too will dementia care and support costs, that are estimated today to be US\$604 billion.

We're urging governments around the world to develop and implement National Dementia Plans because they are the single most powerful tool to transform national dementia care and support. Plans help governments ensure that health and social care systems are adequately structured and funded to ensure high-quality care and support is available to people living with dementia today, and in the future.

Currently, 11 countries around the world have developed and implemented National Dementia Plans, so there are already examples that governments wanting to develop their own can look to, and experiences that they can learn from.

Bupa, the largest international provider of specialist dementia care, and Alzheimer's Disease International (ADI), the global federation of Alzheimer's associations, have joined forces to publish, for the first time, a global report to help policy-makers. Our analysis provides an insight into the content of existing National Dementia Plans, advice on how to develop one, and also reviews the factors that might affect implementation.

We strongly advocate that every government, committed to improving dementia care, develops a National Dementia Plan. In pursuit of this we recommend politicians, civil servants and thought leaders to use this report as a source of information and inspiration on both what a plan should include and how it should be applied.



Stuart Fletcher
CEO
Bupa



Marc Wortmann
Executive Director
Alzheimer's Disease International

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RECOMMENDATIONS



Dementia remains one of the toughest challenges in healthcare. Despite scientific progress over the last 25 years, addressing dementia remains a national and international challenge.

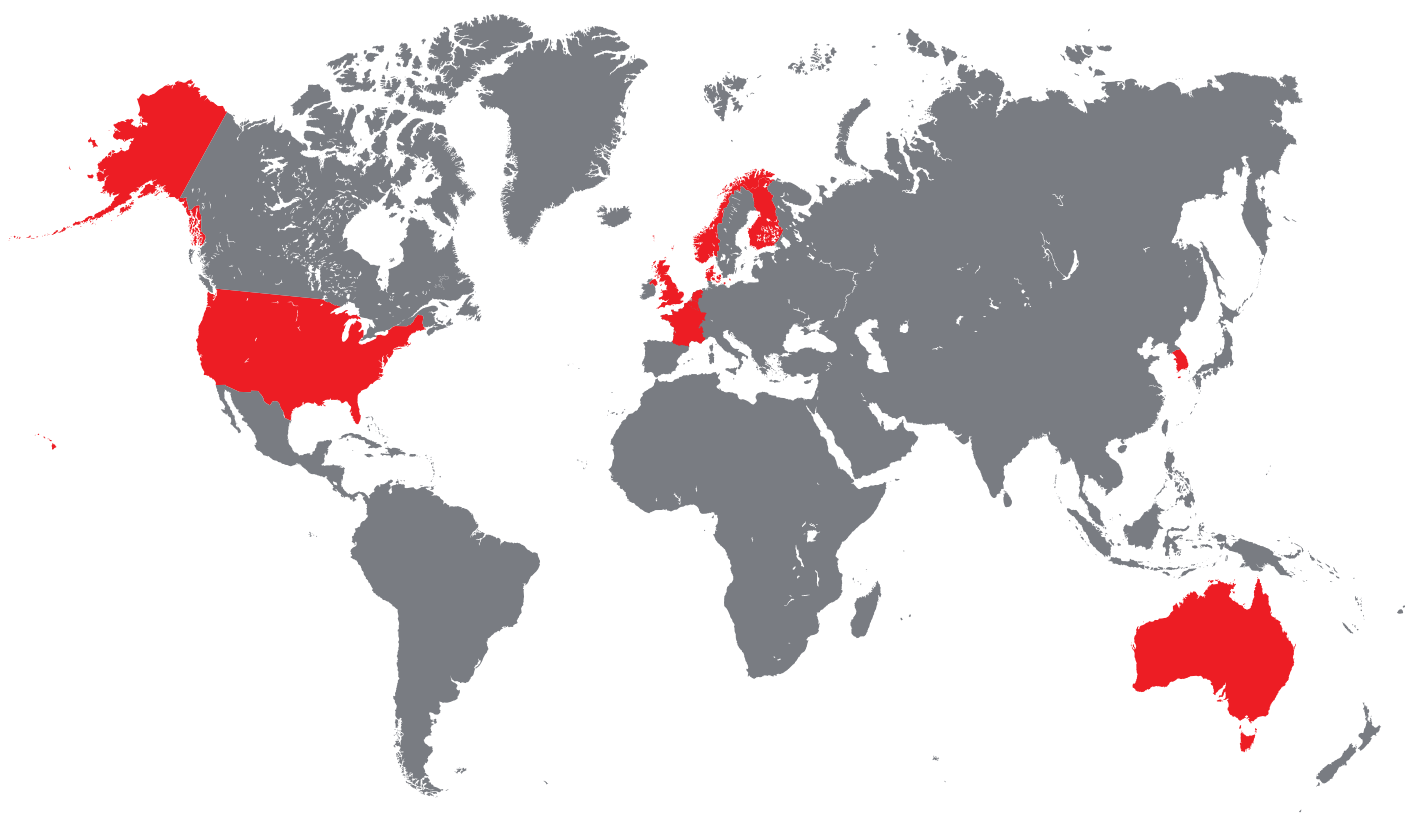
Stigma, denial and inadequate financial resources remain key barriers to proper treatment and care. Alzheimer's associations (advocacy groups for people with dementia and their care-givers), policy-makers, governments, providers, healthcare professionals and other stakeholders have started to search for appropriate, yet cost conscious, ways to meet the growing needs of people with dementia and their family, friends and carers. The development and implementation of National Dementia Plans, to close the gap between 'what we know' and 'what we do' in dementia care, can play a key role in meeting these goals.

A National Dementia Plan is the single most powerful tool to improve dementia care and support in any country. Currently, 11 countries around the world

– UK (England, Scotland, Wales and Northern Ireland), Australia, Denmark, Finland, France, South Korea, USA, Norway, the Netherlands, Luxembourg and Belgium – have developed, or are currently implementing, National Dementia Plans. This report has focused on reviewing National Dementia Plans in seven countries – Australia, France, the Netherlands, Norway, South Korea, the United Kingdom (England) and the United States.

These countries were chosen because they have the most information available about the plans and they are in different stages of implementation, which has been useful to provide different insights into challenges encountered at various stages. As other countries consider developing their own National Dementia Plans, we have examined the issues we believe should be addressed in a good plan.

We have also outlined how a plan should be developed, and discussed factors that might affect implementation, based on the execution of existing plans around the world.



- Countries with a National Dementia Plan
- Countries without a National Dementia Plan

Best practice: Content

From our international review, we identified ten areas that were typically identified and referenced in each plan, that we believe should feature in any future National Dementia Plan. These are:

1. Improve awareness and education
2. Improve (early) diagnosis and treatment
3. Improve support available at home
4. Strengthen support available to family care-givers
5. Improve residential/institutional care
6. Better integrate care pathways and the coordination of care
7. Improve training for healthcare professionals
8. Monitor progress
9. Commitment to research
10. Recognise the role of innovative technologies

Best practice: Development

We believe that there are seven important steps that should be taken when a National Dementia Plan is being developed. They are:

1. Agree a clear evidence base
2. Build a broad base of engaged people
3. Commit to draft the National Dementia Plan in a collaborative way
4. Set a timeframe, including key milestones
5. Agree resource, roles and responsibilities
6. Set up a system for monitoring and evaluation
7. Execute a high-profile launch

Best Practice: Implementation

Drawing on the national experiences of the seven plans we reviewed, we believe that there are seven factors that determine the effectiveness of a plan's implementation. They are:

1. Recognition of dementia as a public health priority
2. Leadership at a national level
3. People engagement
4. Involvement of all key stakeholders
5. Introducing a 'system of care' and a 'case management' approach
6. Committing funding
7. Effective monitoring, evaluation and update

THE IMPORTANCE OF FOCUS AND COMMITMENT

The National Dementia Plans discussed in this paper are all ambitious in their scope and objectives. While there is obviously more to be done to improve the quality of life of people with dementia and their care-givers, it cannot be done all at once. One of the challenges is to balance the need for change with the risk of setting too many targets. The experience of countries with National Dementia Plans reveals that it is better to focus on fewer targets that can be met in an agreed timeframe, rather than setting too many targets and achieving only a few.

It is also worth noting that improvements in dementia care will not, and should not, come to an end once a National Dementia Plan is concluded. Advances in dementia care only come to fruition with long-term commitment. A long-term approach is required to make dementia care and support, in its broadest sense, a success.

None of the current National Dementia Plans serve as a 'gold standard' because no one plan will work for another country. So the factors discussed in this report will need to be adapted to national, regional and local circumstances. Each country will require its own tailored plan, taking into consideration the specific needs of people living with dementia and their care-givers, and depending on the healthcare system structure, the services provided by healthcare professionals, and cultural and socio-economic factors.

We urge all governments to develop effective National Dementia Plans, using this report as a source of information and inspiration, both in terms of what a plan should include, how it should be developed and how it should be implemented.



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INTRODUCTION



DEMENTIA – A WORLDWIDE HEALTHCARE CHALLENGE

Dementia is a significant and increasing public health problem that impacts individuals, their family and friends, care-givers and society. Dementia is characterised by a combination of symptoms that affects thinking, orientation, comprehension, calculation, learning capacity, language, and judgment. It is often accompanied by a decline in emotional control or motivation, or a change in social behaviour. There are over 100 forms of dementia – the most common form is Alzheimer’s disease which accounts for between 60% and 70% of all cases. Other types of dementia include vascular dementia, fronto-temporal dementia and Lewy body disease.

Almost 35.6 million people were affected by dementia worldwide in 2010. This number will nearly double every 20 years, to 65.7 million in 2030 and 115.4 million in 2050. Each year, another 7.7 million new cases will be registered, implying one new case every four seconds. More than half of all people with dementia worldwide (58%) currently live in low and middle-income countries, with this figure expected to rise to 71% by 2050. The number of people with dementia will increase at least four times by 2050, compared to 2010, in Latin America (except for the Southern part), Northern Africa, the Middle East and Oceania (see Table 1).

Table 1 Total population over 60, crude estimated prevalence of dementia (2010), estimated number of people with dementia (2010, 2030 and 2050) and proportionate increases (2010 – 2030 and 2010 – 2050) by GBD world region

GBD REGION	OVER 60 POPULATION (MILLIONS)	CRUDE ESTIMATED PREVALENCE (%)	NUMBER OF PEOPLE WITH DEMENTIA (MILLIONS)			PROPORTIONATE INCREASES (%)	
	2010	2010	2010	2030	2050	2010 – 2030	2010 – 2050
ASIA	406.55	3.9	15.94	33.04	60.92	107	282
Australia	4.82	6.4	0.31	0.53	0.79	71	157
Asia Pacific High Income	46.63	6.1	2.83	5.36	7.03	89	148
Oceania	0.49	4.0	0.02	0.04	0.10	100	400
Asia, Central	7.16	4.6	0.33	0.56	1.19	70	261
Asia, East	171.61	3.2	5.49	11.93	22.54	117	311
Asia, South	124.61	3.6	4.48	9.31	18.12	108	304
Asia, Southeast	51.22	4.8	2.48	5.30	11.13	114	349
EUROPE	160.18	6.2	9.95	13.95	18.65	40	87
Europe, Western	97.27	7.2	6.98	10.03	13.44	44	93
Europe, Central	23.61	4.7	1.10	1.57	2.10	43	91
Europe, East	39.30	4.8	1.87	2.36	3.10	26	66
THE AMERICAS	120.74	6.5	7.82	14.78	27.08	89	246
North America, High Income	63.67	6.9	4.38	7.13	11.01	63	151
Caribbean	5.06	6.5	0.33	0.62	1.04	88	215
Latin America, Andean	4.51	5.6	0.25	0.59	1.29	136	416
Latin America, Central	19.54	6.1	1.19	2.79	6.37	134	435
Latin America, Southern	8.74	7.0	0.61	1.08	1.83	77	200
Latin America, Tropical	19.23	5.5	1.05	2.58	5.54	146	428
AFRICA	71.07	2.6	1.86	3.92	8.74	111	370
North Africa / Middle East	31.11	3.7	1.15	2.59	6.19	125	438
Sub-Saharan Africa, Central	3.93	1.8	0.07	0.12	0.24	71	243
Sub-Saharan Africa, East	16.03	2.3	0.36	0.69	1.38	92	283
Sub-Saharan Africa, Southern	4.66	2.1	0.10	0.17	0.20	70	100
Sub-Saharan Africa, West	15.33	1.2	0.18	0.35	0.72	94	300
WORLD	758.54	4.7	35.56	65.69	115.38	85	225

Table 1 (ADI 2010 World Alzheimer Report: estimated global prevalence data)

Dementia is one of the major causes of disability and dependency among older people. It accounts for 11.9% of the years lived with disability due to a non-communicable disease (WHO, 2008). Most people with dementia live at home, but there are significant variations across countries as well as between urban and rural areas (Table 2). For example, in Asia and Central and Latin America, almost all people with dementia live at home, especially in rural areas.

Table 2 Estimated proportion of people with dementia that are living at home (%) Source: ADI survey (unpublished)

COUNTRY	URBAN AREAS	RURAL AREAS	COUNTRY	URBAN AREAS	RURAL AREAS
ASIA			EUROPE		
Armenia	50 - 59%	50 - 59%	Belgium	50 - 59%	70 - 79%
China	70 - 99%	80 - 94%	Croatia	80 - 89%	95 - 99%
India	90 - 94%	95 - 99%	Cyprus	70 - 79%	95 - 99%
Japan	60 - 79%	70 - 79%	Germany	50 - 59%	60 - 69%
Jordan	95 - 99%	95 - 99%	Greece	80 - 89%	95 - 99%
Pakistan	100%	100%	Ireland	60 - 69%	60 - 69%
Nepal	100%	100%	Israel	80 - 89%	80 - 89%
Singapore	90 - 99%	100%	Italy	50 - 59%	50 - 59%
Sri Lanka	70 - 99%	95 - 100%	Macedonia Former Yugoslav Rep. of	50 - 59%	90 - 94%
Thailand	80 - 89%	95 - 99%	Netherlands	60 - 69%	70 - 79%
Turkey	70 - 79%	90 - 94%	Poland	80 - 89%	95 - 99%
AFRICA			Romania	80 - 89%	100%
Egypt	100%	100%	Serbia	95 - 99%	100%
Mauritius	80 - 89%	80 - 89%	Slovakia (Slovak Republic)	80 - 89%	90 - 94%
Nigeria	80 - 89%	90 - 94%	Slovenia	40 - 49%	60 - 69%
South Africa	90 - 94%	100%	Sweden	50 - 59%	50 - 59%
Zimbabwe	70 - 79%	95 - 99%	Switzerland	60 - 69%	50 - 59%
THE AMERICAS			United Kingdom	50 - 94%	50 - 94%
Argentina	50 - 89%	70 - 94%	AUSTRALASIA		
Aruba	80 - 89%	80 - 89%	Australia	50 - 69%	50 - 69%
Bahamas	95 - 99%	95 - 99%			
Bolivia	70 - 94%	90 - 99%			
Brazil	70 - 94%	90 - 99%			
Dominican Republic	90 - 94%	95 - 99%			
Honduras	95 - 99%	100%			
Jamaica	70 - 79%	70 - 79%			
Mexico	80 - 99%	95 - 100%			
Peru	90 - 94%	95 - 99%			
Puerto Rico	70 - 79%	70 - 89%			
Venezuela	90 - 94%	95 - 99%			
United States	70 - 79%	80 - 89%			

Table 2 (ADI 2010 World Alzheimer Report: estimated proportion of people with dementia that are living at home)

Dementia is one of the toughest challenges in healthcare and presents a looming threat to our financial and social systems across the developed and developing world.

There is an urgent need for policies to be agreed and implemented. For this reason, the World Health Organization, as well as ADI and Bupa, recommends that every country should have a National Dementia Plan.



THE SOCIETAL IMPACT OF DEMENTIA

Dementia has a profound impact on people living with the condition, their family and friends, and society at large. The direct and indirect economic costs for dementia are estimated to be higher than the costs of any other major disease. In 2010, the estimated worldwide cost of dementia was US\$604 billion – this includes the cost of informal care, direct cost of social care in the community or long-term care facilities, and direct medical costs. Direct medical costs represent only a small part of the total costs of dementia – the most substantial contributors, in almost equal share, are the costs of informal care and the direct costs of social care (World Alzheimer Report, 2010).

If the cost of dementia care worldwide was represented as a country, it would be the world's 18th largest economy, ranking between Turkey and Indonesia. The cost of dementia was also compared to annual revenues of multi-national companies – if dementia was a company, in 2010 it would have been the world's largest by annual revenue exceeding Wal-Mart (US\$414 billion).

Dementia has far-reaching and often underestimated consequences for informal care-givers (family members, friends and neighbours providing unpaid care), in terms of quality of life, health and loss of income. For example, care-givers often need to reduce work and leisure activities; providing informal care

to people with dementia does not only result in serious feelings of burden and guilt, but also has a detrimental impact on care-givers' mental and physical health (Pinquart & Sörensen, 2003; 2007; Schulz & Martire, 2004). It is estimated that one in four care-givers suffer from depression (Cuijpers et al., 2005) and informal care-givers have a higher mortality risk compared to the general population (Schulz & Beach, 1999).

TACKLING GAPS IN DEMENTIA DIAGNOSIS, TREATMENT AND CARE

Although there is broad agreement that people with dementia deserve a diagnosis and access to treatment, care and support that is right for them, there is no uniform pathway to diagnose and treat dementia. Research carried out by ADI and the International Psychogeriatric Association (IPA) showed that this holds true both globally and in Europe.

“...people with dementia deserve a diagnosis and access to treatment, care and support that is right for them.”

An ADI survey, that examined diagnosis, care and support in 67 countries, focused on the availability and reimbursement of dementia drugs (donepezil, rivastigmine, galantamine, memantine) and showed that there were substantial differences and inconsistencies between countries (ADI, 2006).

In 64% of the countries, people with dementia had to meet specific criteria in order to be prescribed the medication and in about half of the countries, people with dementia had to pay for medication out-of-pocket.



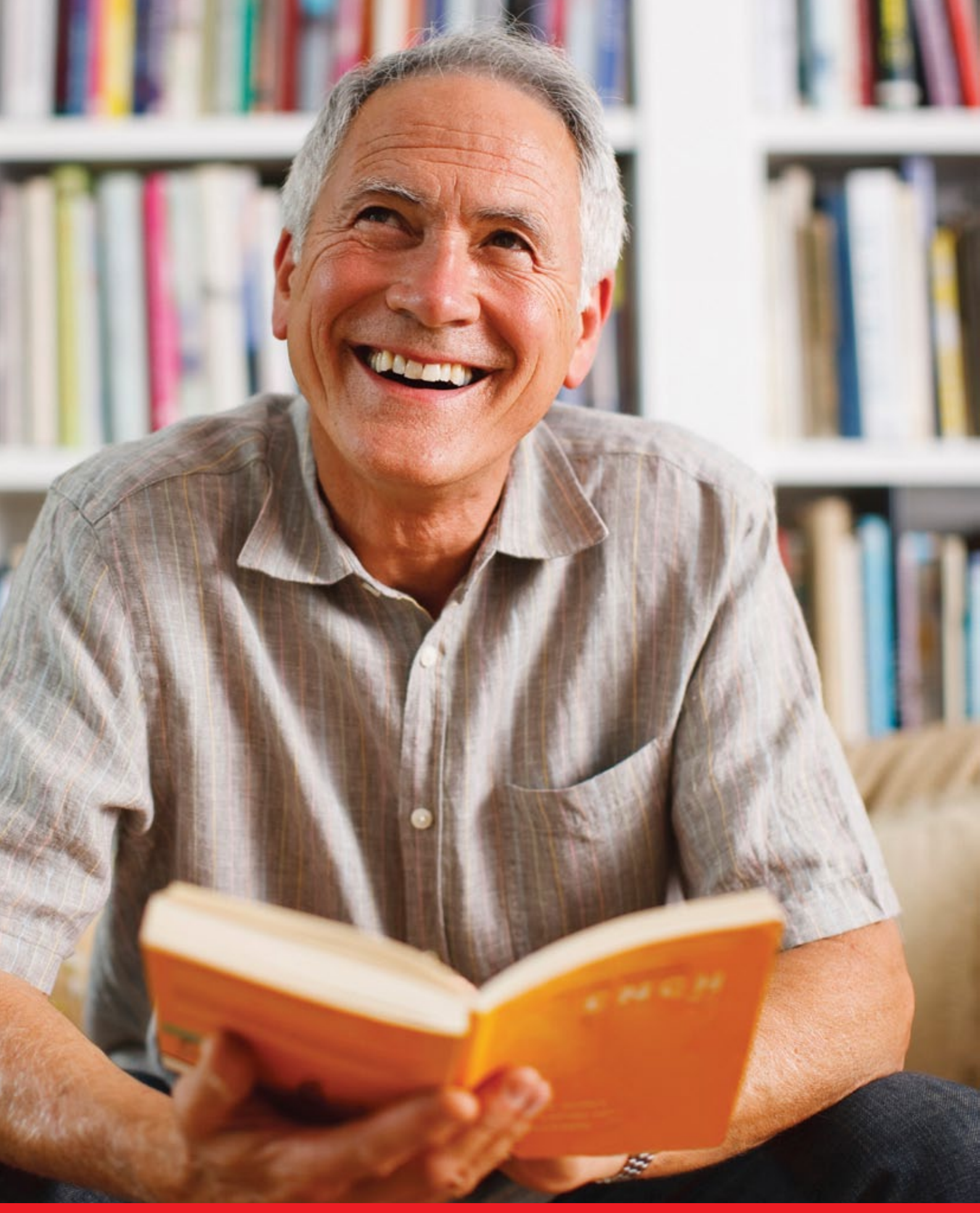
In addition, the IPA's qualitative research showed that international guidelines were found to have little or no influence on the procedures for diagnosis and treatment at the local level. Instead, local culture, political realities, and local resources influenced all aspects of dementia care and support.

For example, whereas in Germany, France and Spain, a primary care physician diagnoses and prescribes treatment, in Italy only 500 centres could provide a diagnosis (IPA, 2007). Also, while in the UK the cost of care was tracked against annual budgets at the physician, hospital and regional levels, in Italy the cost of care was counted against a fixed care budget for the primary care physician (not the specialist that prescribed the treatment), while in Spain arrangements were administered regionally.



4

CONTENT



WHAT A NATIONAL DEMENTIA PLAN SHOULD COVER

INTRODUCTION

National Dementia Plans need to be based on the country-specific situation and context and methods. Approaches to improve national dementia care ought to correspond with, and address, challenges encountered in each country (WHO, 2008).

Challenges faced in dementia care will differ from country to country due to differences in the structure of the healthcare system and in the quality of the care provided by healthcare professionals and providers. Other factors, such as the availability of funding and the commitment of stakeholders to improve care, will also influence the choice of key areas to prioritise. However, the existing national plans around the world can serve as useful templates. For an overview of the seven plans we reviewed, please see Appendix 3.

TEN KEY ELEMENTS

National Dementia Plans generally take a multiple stakeholder approach, stressing the importance of patient-focused initiatives and shared responsibility. In most cases, both governmental representatives and advocacy groups were involved in the development of national plans or strategies, however, their role did vary. For example, the French plan relied heavily on governmental input, while for the Dutch plan, national advocacy group Alzheimer Netherlands played a crucial role.

The areas identified in most plans draw on actions and interventions with a good evidence base to substantiate their effectiveness, but also allows for innovative initiatives, and adaptation at local level, taking into account local circumstances. All the plans recognise that changes in dementia care and support require organisational and attitudinal changes, and that a team approach to implementation is required. At the same time, mechanisms of implementation differ, so does the level of involvement of governments in the process. For example, in Europe the

French National Dementia Plan is focused on legislation, regulation, standard setting and monitoring, while the English National Dementia Plan is more focused on stimulating and facilitating problem solving and consumer participation.

The review of seven National Dementia Plans revealed some overlap in the core elements and contents within them.

We identified 10 core areas that were identified in most of the plans as ways to improve care and support. These can be found in the table below and are explained in more detail on the following pages.

Recommended content for a National Dementia Plan

- 1** *Improve awareness and education*
- 2** *Improve (early) diagnosis and treatment*
- 3** *Improve support available at home*
- 4** *Strengthen support available to family care-givers*
- 5** *Improve residential/institutional care*
- 6** *Better integrate care pathways and the coordination of care*
- 7** *Improve training for healthcare professionals*
- 8** *Monitor progress*
- 9** *Commitment to research*
- 10** *Recognise the role of innovative technologies*

RECOMMENDATION 1 IMPROVE AWARENESS AND EDUCATION

All plans in this review recognise that there is a stigma associated with dementia but acknowledge that promoting a better understanding can help address this. In order to reduce discrimination and possible social exclusion, and to promote an early or timely diagnosis and access to subsequent care, several actions are required in a dementia plan, varying from information dissemination and educational awareness campaigns, to setting up a national helpline (like France did) and website with information and advice at a local level. Some plans went as far as to organise regional conferences (for example, France) to raise awareness of dementia and even develop a framework to monitor public knowledge and attitudes through population surveys.

RECOMMENDATION 2 IMPROVE (EARLY) DIAGNOSIS AND TREATMENT

A diagnosis is important because it enables access to treatment, care and support. The national plans we examined put forward initiatives focused on improving the pathway to care and support for people living with dementia. Actions vary from creating memory clinics or units, to the creation of a specific, new service for early diagnosis, and training of specialists to provide a rapid assessment and accurate diagnosis. The plans we examined also promote partnership with other sectors to enable a multi-disciplinary, team approach to dementia care and support. Some plans propose that an 'Alzheimer's disease information card' is made for each patient (France, for example), to be used as a tool for sharing information between health care professionals and other relevant parties and in connection with developing a new payment system. In regard to treatment, the dementia plans we examined paid specific attention to reducing the use of anti-psychotic drugs, which all countries should consider.

RECOMMENDATION 3 IMPROVE SUPPORT AVAILABLE AT HOME

The plans we reviewed required the setting up of programmes to engage and stimulate dementia patients, to improve the availability of leisure activities available to them, and generally support them to live a meaningful daily life. For example, the national plans we reviewed acknowledged that assessments of housing adjustments, rehabilitation and cognitive stimulation in the home are important for people living with dementia.

RECOMMENDATION 4 STRENGTHEN SUPPORT AVAILABLE TO FAMILY CARE-GIVERS

The role of family care-givers is widely recognised by all stakeholders, and is acknowledged as a key factor to contributing to the quality of life of people with dementia and to improving their chances to stay at home for as long as possible. National plans enabled the set up of dedicated support groups or schools for family care-givers, reinforcing and improving support at home and creating several types of respite care services.

RECOMMENDATION 5 IMPROVE RESIDENTIAL/ INSTITUTIONAL CARE

The actions that are formulated in each plan vary from country to country. They range from setting up or identifying specific units for different patient groups (such as people with dementia presented with behavioural challenges, young people with dementia or others), to requirements to transform long-term care facilities into specialist facilities or to develop leadership for dementia care within bigger care homes. National plans also define recommended care pathways and either outline or introduce inspection systems that monitor quality of care.

RECOMMENDATION 6 BETTER INTEGRATE CARE PATHWAYS AND THE COORDINATION OF CARE

Plans we reviewed attempt to define coordinated care options that will meet people's wishes and needs at various stages of dementia. There is also a focus to assign single points of contacts or single coordinators in an attempt to improve the coordination between all parties involved in delivering care to each person. The aim of this is to facilitate easy and better access to treatment, care and support at various points in the journey. However, the roles and responsibilities of coordinators or advisers differ between countries – for example they may focus on all cases or complex cases only, and they may provide support in the area of care after diagnosis or also in the period before or during diagnosis.

RECOMMENDATION 7 IMPROVE TRAINING FOR HEALTHCARE PROFESSIONALS

This includes the formulation of core competencies for professionals involved in delivering dementia care, continuous education and training, and the development of career pathways or specification by commissioners of necessary dementia training for service providers. Training covers a range of settings, including hospitals.

RECOMMENDATION 8 MONITOR PROGRESS

This includes monitoring activities and collecting information on patient characteristics, epidemiological data and care quality indicators.

RECOMMENDATION 9 COMMITMENT TO RESEARCH

Several plans give explicit and extensive attention to research. In France, for example, four years after the adoption of the National Dementia Plan, more than €165 million has been allocated for research for the funding of 143 research projects for which 138 new researchers were recruited. Norway also focuses on research as a key focus area in its dementia plan.

RECOMMENDATION 10 RECOGNISE THE ROLE OF INNOVATIVE TECHNOLOGIES

Innovative technologies, such as technology for adapting housing with regard to the cognitive impairment of people with dementia and telecare for the support of people with dementia and their care-givers.

OTHER AREAS FOR ACTION

The ten areas mentioned above were consistent themes in the plans that we reviewed, but it is also worth noting that there were other important topics covered in some of the plans that other countries can learn from and/or use. There are three areas in particular:

- The setting up of networks for people with dementia and their care-givers;
- End-of-life care; and
- Ethical considerations recognising the fundamental rights of people with dementia and to ensure ethical decision making in dementia care.

5

DEVELOPMENT



A GUIDE TO DEVELOPING A NATIONAL DEMENTIA PLAN

Each country requires its own tailored National Dementia Plan, taking into consideration the specific needs of people living with dementia and their care-givers, and depending on the healthcare system structure, the services provided by healthcare professionals, and cultural and socio-economic factors.

Below we have outlined some helpful pointers that could help steer governments as they consider the development of a national plan. This step by step guide is broken down into two specific phases:

initiation phase and **implementation** phase.

INITIATION PHASE: DEVELOPMENT OF THE POLICY DOCUMENT

In order to initiate the development of a National Dementia Plan, the objectives or targets need to be formulated and a consortium of relevant key stakeholders needs to be set up. To do this, policy-makers should do the following:

RECOMMENDATION 1 AGREE A CLEAR EVIDENCE BASE

Assess the current situation concerning dementia in your country, the burden of disease and the current services available at different levels and types of care (the whole care chain from public health to palliative care and focused at different domains of functioning – physical, mental, social and financial).

The assessment should identify the gaps in the care for people with dementia and their family care-givers and what is needed to overcome them.

The findings of the assessment should be presented to people with dementia and their care-givers, who should be given the opportunity to provide feedback and engage from the beginning with the process.

RECOMMENDATION 2 BUILD A BROAD BASE OF ENGAGED PEOPLE

Build a consortium or a working group involving key stakeholders who should prepare the National Dementia Plan. For this, firstly identify key stakeholders and determine their interest, importance and influence over the development and implementation of a national plan.

The make-up of this group ought to include representatives for people with dementia and their family care-givers, alongside healthcare professionals, care providers, policy-makers, companies or industry. It might be helpful in the long run to consider involvement of a broader range of stakeholders from the private sector that could contribute to the development and (co-) funding of innovative treatment, products, technologies, or environmental designs to support people with dementia and their care-givers.

RECOMMENDATION 3 COMMIT TO DRAFT THE NATIONAL DEMENTIA PLAN IN A COLLABORATIVE WAY

The National Dementia Plan that is drafted by the consortium should be based on the national assessment (step 1 above) and international guidance. It should also be developed so that targets are formulated in a specific, measurable, attainable, relevant and time-bound manner.

Once the plan is written, it is important to conclude this phase by ensuring there is broad support for the new plan. This might be achieved by actively involving all key stakeholders and making them feel responsible and accountable for its implementation (see phase below).

INITIATION PHASE: DESIGNING IMPLEMENTATION STRATEGIES

National Dementia Plans need to be accompanied by a concrete plan for how to implement it, with an appropriate level of detail. To achieve this, the below steps could be followed:

RECOMMENDATION 4 SET A TIMELINE, INCLUDING KEY MILESTONES

At the beginning of the implementation phase, a timeline that outlines key milestones for delivering the plan's priorities should be developed. This should be regularly reviewed to check that implementation is on track.

RECOMMENDATION 5 AGREE RESOURCE, ROLES AND RESPONSIBILITIES

At this point, a human resource strategy is needed to ensure the necessary level of staff is available to execute the plan. Staff implementing the plan must have the necessary knowledge, skills and competencies to fully execute the plan.

Roles and responsibilities of various stakeholders (be that different departments or groups on the consortium) should also be agreed at this point. As with the initiation phase, a failure to adequately plan greatly reduces the chances of successfully achieving the goals outlined in the plan.

RECOMMENDATION 6 SET UP A SYSTEM FOR MONITORING AND EVALUATION

A system of effective monitoring and evaluation should be put in place to review and improve the impact of the national plan. These should include data on appropriateness, effectiveness, efficiency, quality, accessibility, impact on collaboration, sustainability and outcomes. Policy-makers should be aware that different stakeholders may have different views on the progress of specific targets because they have different priorities and represent different interests and groups.

RECOMMENDATION 7 EXECUTE A HIGH-PROFILE LAUNCH

The beginning of the implementation phase should have the support of a high ranking official or personality championing the plan, in addition to other key stakeholders. This might be a Prime Minister, President or senior Minister. Such top-level leadership – launched publicly – mobilises ambition, not only for setting the strategic direction for a plan, but also to facilitate effective implementation and ensure stakeholders keep their promises and assist with delivery.



6

IMPLEMENTATION



FACTORS THAT AFFECT THE IMPLEMENTATION OF A NATIONAL DEMENTIA PLAN

The development of National Dementia Plans is an important first step to improving national dementia care and support. Progress has been made with 11 countries having developed and implemented plans, but execution remains a challenge. While a number of other countries, such as Mexico and Peru, are considering developing their own National Dementia Plans, it is important to understand the factors that can facilitate effective implementation of such plans. Drawing on the national experiences of the seven plans we reviewed, we believe that there are seven factors that determine the effectiveness of a plan's implementation. They are:

1. Recognition of dementia as a public health priority;
2. Leadership at a national level;
3. People engagement;
4. Involvement of all key stakeholders;
5. Introducing a 'system of care' and a 'case management' approach;
6. Committing funding; and
7. Effective monitoring, evaluation and update.

1. RECOGNITION OF DEMENTIA AS A PUBLIC HEALTH PRIORITY

Placing dementia within the context of a country's overall public health agenda and recognising it as a public health priority is essential. Our analysis reveals that policy-makers' focus has typically been at the middle and latter stages of the dementia journey, which is understandable given that diagnosis tends to be towards a person's end of life. However, we believe that a more holistic, public health approach should be taken, that ensures there is adequate support at earlier stages too, for example by investing in earlier diagnosis and signposting and in universal and selective prevention.

A public health approach is important for several reasons: not only for keeping the general population as healthy as possible, but also for maintaining and improving the quality of life of people with dementia and their care-givers and to delay or prevent, and therefore make more appropriate, institutional (such as hospital or care home) placement.

Lessons can also be drawn from the development and successful adoption of policy in other areas of health, notably tobacco control or HIV/AIDS. For example, with the adoption of the WHO Framework Convention on Tobacco Control (WHO FCTC), tobacco control has become the first public health issue to be regulated by an international legal binding treaty. In the field of HIV/AIDS, the last 12 years has brought about remarkable achievements including a reduction in the incidence of HIV infection by more than 25% between 2001 and 2009 in 33 countries.

In addition, antiretroviral therapy has been made available to more than 6.6 million people in low-and middle-income countries, which is a 16-fold increase since 2003 (WHO, 2011b).

For dementia, to keep the population as healthy as possible, it is also important to tackle risk factors that might lead to decreases in prevalence rates of dementia. Research shows that several preventable risk factors for Alzheimer's disease are the same as for other diseases, such as diabetes, midlife hypertension, midlife obesity, smoking, depression, cognitive inactivity or low educational attainment, and physical inactivity. Tackling such risk factors and promoting behavioural changes to prevent the lifetime risk of dementia does require investment from governments.

“...investing in earlier diagnosis and signposting.”

THE PUBLIC HEALTH APPROACH IN NATIONAL DEMENTIA PLANS

All of the National Dementia Plans reviewed for this report take a public health approach, and stress its importance. The plans address, although to a greater or lesser extent, the need to raise awareness of dementia among the general population and among professionals, the need for better understanding of the condition, for earlier diagnosis, for better information and treatment, for improving care pathways, and for better community support for people with dementia and their care-givers at an early stage.

Recommendation

Governments should take a public health approach to dementia and recognise it as a priority issue.

2. LEADERSHIP AT A NATIONAL LEVEL

In general, a mandate from the national government is critical. This might include the involvement of the Ministry of Health, ideally at ministerial level, but also the involvement of higher level politicians, such as a Prime Minister or President. Such top-level leadership mobilises ambition, not only for setting the strategic direction for a plan, but also to facilitate effective implementation and ensure stakeholders keep their promises and assist with delivery. Senior government leadership and involvement can also facilitate a multi-sectoral approach and interdependent working between different ministries or departments.



Example from France

In France, the personal involvement of the President was seen as crucial to generating

political pressure for the implementation of the French national plan. The French plan is linked to the government's official website and every six months during the implementation of the plan (2008 - 2012) the President was personally briefed on the plan's progress and implementation which stimulated other stakeholders to deliver on their own commitments.



Example from England (United Kingdom)

Similar to France, there has been leadership from the top of

government. This is illustrated by the recent launch of the "Prime Minister's Challenge on Dementia: Delivering major improvements in dementia care and research by 2015". This document outlines the government's commitment "to go further and faster on dementia, by making life better for people with dementia and their carers, and supporting the research that will ultimately help us slow, stop and even prevent the condition". The document calls for strengthening the organisation of local champion groups, and setting up mechanisms for regular reports to the Prime Minister through relevant ministers in the Department of Health. The Prime Minister's personal involvement has generated media interest which is likely to have helped increase awareness of action that is taking place in England.

Recommendation

A Prime Minister, President or senior Minister should personally champion and be involved in the development and implementation of a National Dementia Plan.

3. PEOPLE ENGAGEMENT

Since people living with dementia are the ultimate beneficiaries of any National Dementia Plan, their involvement, and that of their care-givers, in shaping any plan is essential. The ultimate aim of seeking their input is to make the health and social care system more user friendly, and more accessible and acceptable for all. The following examples show the role people with dementia and their family care-givers can play in the development, implementation and evaluation of a National Dementia Plan.



Example from England (United Kingdom)

In England, it was largely recognised that a national plan to improve dementia care would only be sustainable in the long-term if it was in line with the needs of people with dementia and their care-givers. Their input was collected through consultations organised by the Alzheimer's Society as part of a nationwide listening and engagement exercise. One of the most consistent messages that emerged from this consultation process was that receiving a diagnosis was important for those involved. Therefore, contrary to the belief that it might be better not to tell people with dementia about the nature of their illness because there is no cure and a diagnosis can create anxiety, a clear message that came through was that people living with dementia want to know they have it, so they have time to plan for the years ahead. Another important message received from people with dementia and their care-givers was that they needed support and advice on how to engage with services and how to identify and access appropriate care, based on their specific needs and circumstances. These were considerations taken into account when the English plan was written.



Example from the Netherlands

In the Netherlands, one of the aims of the national plan was to adapt the health system to fulfil the needs and preferences of people with dementia and their care-givers. People with dementia and their care-givers were therefore consulted on the key challenges they were confronted with and on most appropriate solutions for overcoming them. Through regional consultations that were carried out by volunteers of Alzheimer Netherlands, people with dementia and their carers identified 14 problem areas, out of which three were prioritised: 'What is going on, and what can help'; 'It is too much for me'; and 'Miscommunication with healthcare providers'. Findings from the consultations set the regional agendas and fed directly into the development of the national plan. The active involvement of people with dementia, family care-givers and national and regional representatives from advocacy group Alzheimer Nederland, is seen as one of the key success factors for the development and implementation of the dementia care in the Netherlands.



Example from France

The French plan is probably the most comprehensive in terms of seeking regular feedback. It incorporates service users' and carers' perspectives and feedback to form part of the plan's formal evaluation process. Regular surveys are conducted to seek service users' feedback.

Recommendation

People with dementia and their care-givers should be consulted before a National Dementia Plan is developed in order to identify a number of key areas to address.

4. INVOLVEMENT OF ALL KEY STAKEHOLDERS

Stakeholders represent different sectors, background and priorities so it is important to involve a wide range of stakeholders in the development and implementation of any National Dementia Plan to ensure that all areas of care and support are adequately covered in a plan.

Apart from people living with dementia and care-givers themselves, there are a range of other stakeholders that should be involved. These include:

1. **Healthcare professionals**, such as nurses, physicians and psychologists;
2. **Organisations where healthcare is provided**, such as health centres, community care, mental healthcare, and long-term care facilities; and
3. **Healthcare companies or industry**, such as pharmaceutical companies and companies that produce medical devices.

It may also be relevant to include regional and local governments, healthcare financiers such as insurance companies, employers, and also the media (WHO, 2008).

If a key partner is not involved, serious problems may rise. As one of the national coordinators interviewed for this report explained: “Those who are not with you, are against you”.



Example from South Korea

In South Korea, the ‘War on Dementia’ plan was jointly

developed by neurology/psychiatry associations, the Ministry of Health & Welfare, nurses’ associations, the Alzheimer’s Association, South Korea, and the media.



Example from Norway

The Norwegian dementia plan stresses the importance of a multiple stakeholder

approach. It requires that models of care are developed and tested jointly by the specialist and municipal health services. The plan also calls for collaboration between local authorities and specialist health service providers in evaluation and diagnosis, interdisciplinary advising and guidance, and the sharing of expertise and follow-up to patients.



Example from France

It is worth noting that the person responsible for coordinating the

French plan is a civil servant within the Ministry of Finance, who does not report to any of the Ministries involved in the project. This set up protects the independence of the plan’s coordinator. Thus while not having previous professional connection with stakeholders involved in the implementation of the plan, and being perceived as an ‘outsider’, the coordinator can bring together stakeholders that might otherwise hesitate to work together.



Example from the US

The development of the US national plan was a consultative

process involving 24 different departments and agencies. The plan also took into account other national strategies and processes (such as those on chronic care) to ensure they are aligned and support each other.



Example from England (United Kingdom)

The English National Dementia Plan was initiated by the UK

Department of Health and was developed with the contribution of many experts and key stakeholders. A National Clinical Director for Dementia has been appointed to provide leadership for the implementation of the national strategy, which includes overseeing engagement with relevant parties and increasing their support for the plan.

The “Prime Minister’s Challenge on Dementia” emphasises the importance of involvement from a range of partners across the health and social care sectors, the research and industry sector, and broader society. It explains that a consultative and collaborative approach is required for dementia care and support to be improved.

Three so-called ‘champion groups’ were set up to bring together leading organisations and interest groups, to support the delivery of the commitments and to mobilise wider engagement. Each group includes between 10–15 members drawn from key sectors, including health and social care, industry and the voluntary sector.

Recommendation

A wide range of stakeholders should be involved in the development of a National Dementia Plan to ensure it is comprehensive and all encompassing. This will also support a collaborative, and therefore more impactful and effective, delivery.

5. INTRODUCING A SYSTEM OF CARE AND A CASE MANAGEMENT APPROACH

The overall quality of a healthcare system is more than the sum of the quality of separate services within it: it depends on good coordination at all levels.

Poor coordination often results in poor patient outcomes, and the quality of care for a patient depends as much on how the services connect with each other as it does on how well the patient is treated within each service (WHO, 2008).

The same is true for dementia care itself. Many dementia services operate in isolation, with no integration mechanisms. People with dementia and their family care-givers often receive little support with transition from one service to another, and with coordination of care while living at home. Therefore, it is important that National Dementia Plans endorse a 'system of care' approach.

Similar to the management of other chronic conditions, care coordination with a single point of contact is a key factor for improving dementia care and support. According to the national coordinators interviewed for this report, ensuring coordination between, and access to, different components and services along the care pathway is a crucial aspect that determines the success of a national plan's implementation. A case-manager or adviser could help coordinate a care pathway.



Example from the Netherlands

The Dutch Dementia Strategy (2008-2011) stressed the importance of a coordinated approach to care. Health Care Insurance (Zorgverzekeraars Nederland), Alzheimer Netherlands and the Ministry of Health worked together on the Coordinated Dementia Care Programme (ketenzorg dementie), the aim of which was to produce demand-led, coordinated care programme, to ensure the integration of services. A key aspect of this was the setting up of a case management system, whereby case managers were assigned to people living with dementia to answer questions they may have, address their specific care needs, and direct and guide them to information, care and counselling.

Recommendation

There should be a focus on integration of services and adequate support for people and their carers to navigate the system.



Example from France

The second objective of the French plan is focused on coordinating services with all stakeholders involved. It set up single entry points, called Maison pour l'autonomie et l'intégration des maladies Alzheimer (MAIA), which are essentially places where people can go to get information and agree where in the local area they can access treatment, care and support. By the end of 2011, 55 MAIA were installed across France, and the goal is to reach 500 in 2014. At a MAIA, a care coordinator is appointed to the person with dementia and their family. Each coordinator is responsible for implementing the recommendations from the memory clinic and can be consulted during the whole care process. Under the Plan, the health needs of people with dementia are assessed annually.



Example from England (United Kingdom)

In England, a dementia adviser has been introduced to facilitate easier access to appropriate care, support and advice for those diagnosed with dementia and their carers. Dementia advisers are different from case managers. Their role is to act as a single point of contact for people with dementia and their carers, who can identify problems and facilitate engagement with local specialist services.

6. COMMITTING FUNDING

Adequate dementia care requires proper funding from different sources (e.g. health, social welfare), covering different components, such as:

- **Prevention and early detection:** this includes population based interventions, such as public awareness raising and lifestyle interventions to prevent risk factors, to interventions aimed at mainstreaming dementia care into overall health promotion and disease prevention services. The latter includes building capacity in primary care, screening programmes and to targeting interventions for defined groups (e.g. prevention of common mental health problems among carers of people with dementia);
- Funding for **healthcare:** covering medication, hospital and outpatient care, memory services, as well as training of health professionals;
- Funding for **social care:** covering support for home care and other social care support, such as transportation, food, community-based activities (aimed at increasing the period of living at home, and delaying institutionalisation) and residential or nursing homes; and
- Funding for **other issues such as monitoring and continual improvement:** for users and carers satisfaction monitoring, for assessments of quality of hospital and residential care, funding for innovation and research that can lead to improvements in treatment and care. It is also important that funding is allocated for coordination and regular evaluation of national plans.

Funding should be sustainable and reliable (WHO, 2012). It should be noted that views of the National Coordinators interviewed for this report on how money should be allocated and spent did vary. Some were convinced that more money needs to be put into the system to improve the quality of care while others were more focused on better spending current resources. For those with the former view, they argued that more funding is needed to develop more flexible, innovative respite solutions for family care-givers, develop more memory clinics or more trained professionals in residential care. These sorts of solutions will be increasingly necessary as the number of people with dementia increases.

In contrast, for people who believe current resources should be better spent, they focused on tapping into resources from the general healthcare system. They noted that in resource-poor settings, where expanding the existing services would not be feasible, reorganising the care system, for example by changing the place where services are provided or by whom they are provided, could help (see also Ovreitvit, 2008).

Examples

The amount of funding allocated to implement National Dementia Plans varies widely between countries. For example, France has allocated more than €1.6 billion over five years whereas the first Dutch Ministry of Health earmarked only €2.4 million for its National Dementia Plan. The UK's allocation can be found below, while the Australian plan received AUD 320 million over five years.

None of the National Dementia Plans reviewed for this report clarified how funding for dementia initiatives would continue after the plans come to an end. We recommend this ought to be factored in towards the end of a plan's evaluation period.

Recommendation

Sufficient funding should be allocated to ensure the effective implementation of a National Dementia Plan. Funding should be sustainable and reliable, rather than solely on a project basis.



Examples of new funding allocations in England, as per 2012 Prime Minister's policy implementation document

Increased diagnosis rates through existing checks for over-65s

- Financial rewards for hospitals offering quality dementia care. From April 2012, £54m will be available through the Dementia CQUIN (Commissioning for Quality and Innovation) payment framework to hospitals offering dementia risk assessments to all over-75s admitted to their care. From April 2013, this will be extended to the quality of dementia care delivered. Also, for April 2013 access to all CQUIN rewards will be dependent on delivering support for carers in line with the National Institute for Health and Care Excellence/ Social Care Institute for Excellence guidelines.
- An Innovation Challenge Prize of £1m. NHS staff can win up to £1m for innovative ideas for transforming dementia care.
- There will be better support for carers. The NHS is required to work closer than ever before with local carers' organisations and councils to agree plans, pool their resources, and make sure that carers get the support and break they deserve and that young carers do not take on excessive or inappropriate caring roles. An additional £400m has been made available to the NHS between 2011 and 2015 to provide carers with breaks from their caring responsibilities to sustain them in their role.

Creating dementia friendly communities that understand how to help

- Government will work with the Alzheimer's Society to develop local Dementia Action Alliances to bring together people with dementia, their carers and key organisations, funded by £537,000 from the Department of Health over three years.

Better research

- More than doubling overall funding for dementia research to over £66m by 2015. The combined value of the NIHR, MRC and ESRC funding for research into dementia will increase from £26.6m in 2009/10 to an estimated £66.3m in 2014/15.
- Major investment in brain scanning MRC will make a major additional investment in dementia research using the BioBank. MRC anticipates piloting the brain scanning of a subset of this national cohort, with a view to rolling out to 50-100,000 participants.
- £13m funding for social science research on dementia (NIHR/ ESRC) including £3m for public health research.
- £36m funding over 5 years for a new NIHR dementia translational research collaboration to pull discoveries into real benefits for patients. Four new NIHR biomedical research units in dementia and biomedical research centres which include dementia themed research will share their considerable resources and world leading expertise to improve treatment and care.

- The MRC will spend over £3m in supporting the UK brain bank network, which connects all the UK brain banks for the benefit of donors, researchers and future patients This includes £500k a year to improve the process for donation of brain tissue by meeting the costs of collecting brain tissue through the NHS, so smoothing the pathway to donation.
- Up to £9m of DH funding will be made available for research into 'living well with dementia' and the delivery of dementia care.
- The world-leading MRC Laboratory of Molecular Biology (LMB) is moving to its new £200m facilities in Cambridge in the autumn. Within this, the Neuroscience Research Division has been provided with an expanded budget of £29m over the next three years, with a major part of its research dedicated to dementia/neurodegeneration.
- The NIHR has also just completed a first-ever themed call for proposals in dementia research. Some £17m will be committed to new research projects through this call, exceeding original expectations. The 18 projects to be funded range from work on better diagnosis to improving care in a wide range of settings, from individual's own homes, through residential care to specialist hospitals.

7. EFFECTIVE MONITORING, EVALUATION AND UPDATE

Our review of National Dementia Plans and discussions with national co-ordinators showed the key role of monitoring systems and evaluation processes. Essentially, collecting data and evaluating progress can act as a key trigger to prompt governments to do more, and monitoring quality of care in different care settings can lead to investment in new models of care and improvements in the quality of care in other settings.

Systems did vary from country to country – some were very specific while others were broadly defined; some took a top down approach while other were bottom up.

Monitoring improvements in dementia care needs to focus not only on disease prevalence, incidence and mortality (although they are important indicators), but also on the following areas:

- The quality of life of people with dementia and of their family care-givers;
- Quality of treatment and care at home and in institutional settings; and
- Social integration.

While all the national plans we reviewed required monitoring and evaluation to be embedded in the implementation process, setting up such complex monitoring systems has been challenging. One of the challenges in mental health monitoring that applies to dementia care, is that the validity of data collected is often questioned. Service users, carers and professionals attach different meanings to outcome measures in mental health, and often the measurements made by these groups differ significantly. In addition, professionals often lack incentives to collect data because results are rarely fed back into their practice.



Example from France

The French plan's evaluation process is very clear, with most of the 44 measures or targets within it having a specific objective and tangible measure. To monitor the progress of each measure, a so-called 'fiche de suivi' (template to monitor progress) is filled in once every month. This template captures actions undertaken and results achieved, but also planned upcoming tasks, their deadlines, estimated costs and anticipated outcomes.

It is worth noting that every month stakeholders meet at the French Department of Finance to review the previous month's monitoring report and discuss work planned for the upcoming six months. The monitoring framework is supported by a three page summary report that is circulated in advance of these meetings. A key learning from this process is that because all stakeholders are in the room – including representatives from different Ministries – if any actions, responsibilities or accountabilities are unclear, from the monitoring framework or supporting three page report, they can be discussed and clarified before the meeting concludes. Stakeholders did not like this rigorous reporting progress but it helped prevent any confusion and drove forward progress.



Example from England (United Kingdom)

The National Dementia Strategy and its implementation

documents cover monitoring and evaluation at a range of levels and collects input from service users and clinicians. The 2010 document produced by the National Dementia Strategy Implementation Team on the quality outcomes for people with dementia illustrates the person-centred approach of the Strategy, and can be found below as an example of best global practice.

Quality outcomes for people with dementia in England

By 2014, all people living with dementia in England should be able to say:

- *I was diagnosed early*
- *I understand, so I make good decisions and provide for future decision making*
- *I get the treatment and support which are best for my dementia, and my life*
- *I am treated with dignity and respect*
- *I know what I can do to help myself and who else can help me*
- *Those around me and looking after me are well supported*
- *I can enjoy life*
- *I feel part of a community and I'm inspired to give something back*
- *I am confident my end of life wishes will be respected. I can expect a good death*

Source: Department of Health Quality outcomes for people with dementia: building on the work of the National Dementia Strategy, 2010



Example from Australia

The 2005 - 2010 Dementia Initiative was evaluated in 2009.

The analysis examined two areas:

- What effect the Dementia Initiative had on consumers; that is, people with dementia and their carers?; and
- What added value was given to current dementia care in Australia as a result of the activities funded by the Dementia Initiative?

A report was produced that presented an evaluation of the Initiative using a set of 8 performance indicators: appropriateness, effectiveness, efficiency, quality, accessibility, impact on collaboration, sustainability and outcomes. The report combined brief reviews and in-depth evaluations.

Recommendation

A system to monitor and evaluate progress should be put in place to review and improve the impact of a National Dementia Plan.

7

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APPENDIX 1: METHODOLOGY

OBJECTIVE

The objective of this report is to provide an insight into overlapping content of National Dementia Plans, and to review factors that affect their implementation, using comparative experiences in countries that have already developed and adopted plans. In order to enhance dementia care and support worldwide, and to improve the quality of life and autonomy of people with dementia and their carers, this paper aims to further encourage the development of new National Dementia Plans in countries that do not already have them. It also aims to support effective implementation of current action plans around the world.

The report aims to provide practical advice on the “how-to” of turning government and policy-makers’ commitments into real action. The target audiences are therefore governments and other policy-makers in health and social care as well as representatives of national Alzheimer associations around the world who are typically involved in drafting as well as executing National Dementia Plans.

CONTEXT

This report has been prepared for Alzheimer Disease International (ADI) and Bupa, and is based on an earlier unpublished version that was written for the WHO Regional Office for Europe. It contains a number of references to preceding international reports that focus on health and social systems’ responses to dementia, the economic impact of dementia, and National Dementia Plans themselves.

A key report that has supported the development of this report, is the WHO/ADI report ‘Dementia: a public health priority’, published in 2012, that provides an in-depth epidemiology review and examines the impact of dementia, the roles of National Dementia Plans and legislation and ethical issues and considerations. It also reflects on the role of health and social care systems, the needs for support of dementia care-givers, and the needs for raising awareness and public understanding of dementia as a condition. This report was also developed with the support and advice of an extensive group of national and international experts.

Several other reports on National Dementia Plans have been published or are currently being developed. Examples include the 2012 ADI paper focused on early detection, access to diagnosis, and stigma reduction; the Alzheimer Europe Magazine on current status of National Dementia Plans around Europe (Alzheimer Europe, 2011); and the 2011 Alzheimer’s Australia paper on dementia plans, with a brief comparison between different plans, looking at the policy context, the focus and funding of the plans, development of the base of evidence, and the consultative process for their development (Alzheimer’s Australia, 2011). Finally, a 2011 review of dementia plans from all over the world was also used (Rosow et al., 2011). An upcoming paper that has also informed this review is being prepared by the Research Triangle Institute, and for the National Alzheimer’s Project Act (NAPA) Advisory Council.

METHODS

This review has focused on National Dementia Plans in seven countries – Australia, France, the Netherlands, Norway, South Korea, the United Kingdom (England) and the United States. These countries were chosen because they have the most information available about the plans and they are in different stages of implementation, which has been useful to provide different insights into challenges encountered at various stages.

Three methods were used to prepare this paper:

- Policy review of National Dementia Plans in selected countries;
- An international literature review; and
- Interviews with key stakeholders involved in National Dementia Plans.

The international literature review was informed by the reports and papers mentioned above.

It is worth noting that some countries have more substantial experience of dementia policy development and implementation – for example, for France, we looked at the third dementia plan; for the Netherlands, we used findings from the evaluation of the first dementia plan, while we also reviewed the next plan. The English National Dementia Plan will end in 2014 and the Norwegian one in 2015.

APPENDIX 2: DEVELOPMENTS IN DEMENTIA POLICY

THE BACKGROUND: UNIVERSAL BASIC PRINCIPLES

In the last decade, dementia care and support has received increasing attention, in part due to the intensive advocacy work undertaken by ADI, Alzheimer Europe (AE), and national Alzheimer associations. In 2004, the Kyoto declaration initiated by ADI was agreed upon, that put forward 10 overall recommendations regarding dementia:

1. Provide treatment in primary care;
2. Make appropriate treatments available;
3. Give care in the community;
4. Educate the public;
5. Involve communities, families and consumers;
6. Establish national policies, programmes and legislation;
7. Develop human resources;
8. Link with other sectors;
9. Monitor community health; and
10. Support more research.

The Kyoto declaration was followed in 2006 by the Paris Declaration that was initiated by Alzheimer Europe. This went further and defined priorities in four areas: public health; research and medical; care and social support; and legal and ethical approaches.

Building on these declarations, ADI formulated six principles that should be adopted to make Alzheimer's disease and other dementias a global priority:

1. Promote awareness and understanding of the disease;
2. Respect the human rights of people with the disease;
3. Recognise the key role of families and carers;
4. Provide access to health and social care;
5. Stress the importance of optimal treatment after diagnosis; and
6. Take action to prevent the disease, through improvements in public health.

Furthermore, an Action Plan was prepared by ADI, with the expectation that countries would implement, within the limits of their resources, 11 key actions:

1. Provide public information about the symptoms, treatment and course of the disease;
2. Reduce stigma by promoting understanding and awareness;
3. Provide training and tools to healthcare professionals (including social workers) and family care-givers, to encourage early assessment, diagnosis, appropriate care, and access to optimal treatment;
4. Provide access to primary and secondary health care services, responsive to the needs of people with dementia;

5. Promote access to a range of options for long-term care that prioritize maintenance of independence, home and community-based care and support for family carers.
6. Make all care environments, including (acute) hospitals and long term care institutions, safe places for people with the disease;
7. Encourage the fullest possible participation of those living with the disease, in the life of their communities and in decisions about their care;
8. Ensure a standard of living adequate for health and well being, including food, clothing, housing and medical care for people with the disease;
9. Provide a legislative framework to regulate and protect the rights of those people with dementia who lack the capacity to manage their everyday lives;
10. Fund awareness programs to promote greater understanding that the risk of the disease can be reduced; and
11. Prioritize research into Alzheimer's disease and other dementias.

Building on the above, Bupa and ADI then developed a joint Global Dementia Charter, 'I can live well with dementia', that outlines the core fundamentals of best practice dementia care and support. Launched in April 2013, Bupa and ADI announced a call to action for governments around the world to develop and implement effective National Dementia Plans, to allow the 10 points in the Charter to become a reality. This report contributes to that campaign.

WORLDWIDE NATIONAL PLANS

Currently only 11 countries – UK (England, Scotland, Wales and Northern Ireland), Australia, Denmark, Finland, France, South Korea, USA, Norway, the Netherlands, Luxembourg and Belgium – have formal National Dementia Plans that have been adopted by their governments. It should also be noted that some countries have moved towards a second plan or phase of implementation. Further details on these plans can be found in Appendix 3, including information on the following:

1. Title of the plan and timeframe it covered;
2. Overall priorities and specific objectives;
3. Monitoring mechanisms; and
4. Funding allocated for implementation.



APPENDIX 3: OVERVIEW OF NATIONAL DEMENTIA PLANS AND SUPPORTING POLICIES

AUSTRALIA

TITLE	The Dementia Initiative - Making Dementia a National Health Priority
PERIOD COVERED	2005 - 2010. While the Initiative was discontinued and not replaced by a new one, in August 2012, the Australian Health Ministers recognised dementia as the ninth National Health Priority Area.
PRIORITIES/ MEASURES	<p>The Dementia Initiative focused on 3 priority areas. For each priority, a set of measures for progress were defined:</p> <ol style="list-style-type: none"> 1. Dementia - A National Health Priority, involved additional research, improved care initiatives, and early intervention programmes. <p>Measures:</p> <ul style="list-style-type: none"> - increased the level of knowledge, understanding and evidence in relation to assessment and care, risk reduction and prevention, treatment, management and support to improve the quality of life of people with dementia and their carers; - improved partnerships and networks between researchers, health and aged care service providers, consumers and other stakeholders; - consolidated dementia research, encouraged national and international collaboration, and funded further research; - expanded early intervention services and developed awareness strategies to encourage prevention and early intervention; and - assisted people with dementia to remain in their own homes longer, with appropriate evidence based assessment, treatment, support and care. 2. Extended Aged Care at Home Dementia (EACHD) involved 2,000 dementia-specific Extended Aged Care at Home places. <p>Measure:</p> <ul style="list-style-type: none"> - Provide coordinated and managed packages of care to frail older people with dementia who experience behaviours of concern. 3. Training to Care for People with Dementia Program involved additional dementia-specific training for up to 9,000 aged care workers, and up to 7,000 carers and community workers. <p>Measures:</p> <ul style="list-style-type: none"> - help people with dementia and their carers to enhance their quality of life by improving the dementia care skills of health and aged care workers; - improve the knowledge and understanding of health, aged care and community workers in caring for people with dementia; - help promote dementia care as a desirable and valued career option; - support family carers to reduce the burden of caring for a person with dementia by improving their skills; - promote the delivery of best dementia care practices and encourage innovative and flexible approaches to dementia care; - enhance the level of confidence of health and aged care workers in caring for people with dementia; and - strengthen networks between aged care providers, researchers and training organisations to promote sustainability of dementia care training.

**MONITORING
PROGRESS**

A comprehensive evaluation of the Dementia Initiative was carried out in 2009, using the following key performance criteria:

- Appropriateness (is it what people want and need?)
- Effectiveness (did it make a difference?)
- Efficiency (was it worth it?)
- Quality (was it any good?)
- Accessibility (could people use it?)
- Impact on collaboration (did services work together?)
- Sustainability (long-term outlook?)
- Outcomes (what was the end result?)

**PLANNED
BUDGET**

The plan had the budget of AUD 320 million over 5 years. Funding was not continued under 2011 – 12 Federal Budget.



AUSTRALIA

TITLE	National Framework for Action on Dementia
PERIOD COVERED	2006 - 2010. A new National Framework for Action on Dementia covering the period 2013 - 2017 is currently being developed.
PRIORITIES/ MEASURES	<p>The Framework identified 5 priority areas for action, and identifies a set of outcomes to be achieved under each of them:</p> <p>Priority Area 1</p> <p>Care and Support services that are flexible and can respond to the changing needs of people with dementia, their carers and families.</p> <p>Outcomes: Effective, appropriate, quality and accessible care is provided:</p> <ul style="list-style-type: none">• Across all settings and geographical locations.• Focusing on person-centred planning.• Through involving carers and family members.• Allowing seamless transition for people with dementia between the different types of care. <p>Priority Area 2</p> <p>Access and Equity to dementia information, support and care for all people with dementia, their carers and families regardless of their location or cultural background.</p> <p>Outcomes</p> <ul style="list-style-type: none">• All people with dementia, their carers and families should be able to obtain quality services that suit their needs, when they need them, regardless of where they live, their health status, their age, their cultural background, or financial and social circumstances. <p>Priority Area 3</p> <p>Information and Education that is evidence-based, accurate and provided in a timely and meaningful way.</p> <p>Outcomes</p> <ul style="list-style-type: none">• People with dementia, their carers and families can easily access appropriate information, education and support services.• The community is aware and understands dementia and how to assist people with dementia, their carers and families.• Information sharing between jurisdictions is effective. <p>Priority Area 4</p> <p>Research into prevention, risk reduction and delaying the onset of dementia as well as into the needs of people with dementia, their carers and families.</p> <p>Outcomes</p> <ul style="list-style-type: none">• Research is directed to the cause, cure and care of dementia.• Research is translated into practice and is promoted and available to those who need it.• Research findings are promoted more broadly in the community. <p>Priority Area 5</p> <p>Workforce and Training strategies that deliver skilled, high quality dementia care.</p> <p>Outcomes</p> <ul style="list-style-type: none">• A skilled and informed workforce is available to care for and support people with dementia, their carers and families.

MONITORING PROGRESS	Responsibility for monitoring is done by the Australian Health Ministers Advisory Council (AHMAC) and the Australian Health Ministers Conference (AHMC). The NFAD was reviewed in 2011.
PLANNED BUDGET	No information available.

FRANCE

TITLE	The French National Plan
PERIOD COVERED	2008 - 2013
PRIORITIES/ MEASURES	<ol style="list-style-type: none"> 1. Improving quality of life for patients and carers <ul style="list-style-type: none"> - Objective 1: Increasing support for carers - Objective 2: Strengthening coordination between all actors involved - Objective 3: Enabling patients and their families to choose support at home - Objective 4: Improving access to diagnosis and care pathways - Objective 5: Improving residential care for better quality of life for Alzheimer's disease sufferers. - Objective 6: Recognising skills and developing training for health professionals 2. Knowledge for action <ul style="list-style-type: none"> - Objective 7: Making unprecedented efforts in research - Objective 8: Organising epidemiological surveillance and follow up 3. Mobilising around a social issue <ul style="list-style-type: none"> - Objective 9: Providing information for general public awareness - Objective 10: Promoting ethical considerations and an ethical approach - Objective 11: Making Alzheimer's disease a European priority <p>The Plan details 44 measures to be undertaken under these 11 objectives.</p>
MONITORING PROGRESS	The Plan details evaluation mechanisms and responsible implementers for each measure under the Plan's objectives. An implementation report is produced every 6 months. An overall evaluation report for the period 2008 - 2012 has been published in June 2013.
PLANNED BUDGET	1.6 billion Euros

THE NETHERLANDS

TITLE	National Dementia Programme
PERIOD COVERED	2004 - 2008
PRIORITIES/ MEASURES	<ol style="list-style-type: none"> 1. Creating a coordinated range of care options that meet the client's needs and wishes; 2. Delivering sufficient guidance and support for people with dementia and their carers; 3. Measuring the quality of dementia care annually. <p>This National Dementia Programme covered 14 problem areas, as follows:</p> <ol style="list-style-type: none"> 1. What is going on and what can help? 2. Anxious, angry and confused 3. Alone in the care 4. Avoiding contacts 5. Physical care 6. Danger 7. And also health problems 8. Loss 9. It is too much for me 10. Losing control 11. In good times and bad times 12. Miscommunication with health care professionals 13. Resistance to institutional placement 14. Monitoring progress
MONITORING PROGRESS	This Programme has been evaluated through surveys of regional representatives of Alzheimer Nederland, as well as through surveys of wishes and needs of family care-givers of people with dementia. Additionally, project leaders in pilot locations were interviewed, and pilot projects reviewed.
PLANNED BUDGET	2.4 million Euros

TITLE	Dementia Care Plan
PERIOD COVERED	2008 - 2011
PRIORITIES/ MEASURES	<ol style="list-style-type: none"> 1. Creation of a coordinated range of care options that meet the client's needs and wishes 2. Provision of sufficient guidance and support for people with dementia and their carers 3. Monitoring of the quality of dementia care annually
PLANNED BUDGET	No additional funds have been budgeted for the implementation of this plan.

In April 2013, the Dutch Ministry of Health announced that it would invest 32.5 million Euros for a next plan: the Delta Plan Dementia. This plan is an innovative public-private partnership that focuses on the patient and the patient of tomorrow today. It will consist of:

- A national healthcare portal with information exchange, networking and e-health care for people with dementia, carers and professionals
- A national registry with information on diagnosis, treatment and care to improve the quality of care
- Research that focuses on prevention, treatment and cure of dementia and care innovation and efficient care.

NORWAY

TITLE	Dementia Plan
PERIOD COVERED	2007 - 2015
PRIORITIES/ MEASURES	<ol style="list-style-type: none"> 1. Day Programmes 2. Living facilities better adapted to patient needs 3. Increased knowledge and skills (information, education, new expertise and research) <p>The plan outlines 5 strategies for addressing challenges of dementia care:</p> <ol style="list-style-type: none"> 1. Quality development, research and planning 2. Capacity growth and raising skills and knowledge 3. Improving collaboration among professions and medical follow-up 4. Active care 5. Partnerships with families and local communities
MONITORING PROGRESS	The plan details long-term strategy and outcome targets for 2015 and a four-year action programme. Regional authorities are to produce annual evaluation reports on the implementation of national strategy and effectiveness of actions taken.
PLANNED BUDGET	In the 2011 - 12 budget 1.1 billion Kroner in total was committed to the Dementia Plan.

SOUTH KOREA

TITLE	War on Dementia
PERIOD COVERED	2008 - 2013. The implementation was carried out in two phases: 2008 - 2010 and 2011 - 2013.
PRIORITIES/ MEASURES	<p>The plan focuses on 3 priorities.</p> <ol style="list-style-type: none"> 1. Lower the lead time to the treatment of disease through early diagnosis. 2. Service infrastructure is planned to expand, in particular, to train dementia specialists. 3. Lift the care-givers' burden, the state to become, in essence, an extended family of the individual. <p>The first two priorities are to be implemented in the first phase, while the third priority is to be implemented in the second phase of the plan.</p>
MONITORING PROGRESS	<p>According to Alzheimer's Association Korea, progress has been reported in some of the priority areas, namely in early diagnosis and prevention, treatment, infrastructure and public awareness. The plan specifies a number of indicators to track progress, such as:</p> <ul style="list-style-type: none"> • establish public health centre from the current 50% to national coverage. • build a comprehensive National Dementia Centre and install a replica in the four big regional hospitals • train six thousand (6,000) specialists by 2012. • increase the eligibility of long-term care insurance by increasing the recipient limit by twenty thousand (20,000) persons each year. <p>So far no evaluation report on the implementation of the plan has been published.</p>
PLANNED BUDGET	Total funding for this Plan is estimated at 6.46 trillion won.



UNITED KINGDOM (ENGLAND)

TITLE	Living well with dementia: A National Dementia Strategy
PERIOD COVERED	2009 - 2014
PRIORITIES/ MEASURES	<p>Improved awareness, earlier diagnosis and intervention, and a higher quality of care.</p> <p>Objectives (with a determined timeframe, and accountability specified):</p> <ol style="list-style-type: none"> 1. Improving public and professional awareness and understanding of dementia. 2. Good-quality early diagnosis and intervention for all. 3. Good-quality information for those with diagnosed dementia and their carers. 4. Enabling easy access to care, support and advice following diagnosis. 5. Development of structured peer support and learning networks. 6. Improved community personal support services. 7. Implementing the Carers' Strategy. 8. Improved quality of care for people with dementia in general hospitals. 9. Improved intermediate care for people with dementia. 10. Considering the potential for housing support, housing-related services and telecare to support people with dementia and their carers. 11. Living well with dementia in care homes. 12. Improved end of life care for people with dementia. 13. An informed and effective workforce for people with dementia. 14. A joint commissioning strategy for dementia. 15. Improved assessment and regulation of health and care services and of how systems are working for people with dementia and their carers. 16. A clear picture of research evidence and needs. 17. Effective national and regional support for implementation of the Strategy.
MONITORING PROGRESS	<p>Performance assessment: NHS and local authorities</p> <ul style="list-style-type: none"> - the Self-Assessment Survey (SAS) completed by all councils in England; - the experience of people who use social care and their carers; - the National Indicator Set, and data from national returns; - regulatory activity; - service inspection evidence, judgements and monitored progress against action plans; - joint inspection improvement review activity; - other inspection activity with relevance to social care services; - routine business meetings and annual review meetings as part of a continuous dialogue around council performance; - progress against agreed improvement/action plans; and - delivery of relevant Local Area Agreement (LAA) targets and any other local targets underpinned by the Joint Strategic Needs Assessment implementation plan.

MONITORING PROGRESS (CONTINUED)	<p>Outcome indicators: By 2014, all people living with dementia in England should be able to say:</p> <ul style="list-style-type: none">- I was diagnosed early- Those around me and looking after me are well supported- I can enjoy life- I understand, so I make good decisions and provide for future decision making- I am treated with dignity and respect- I feel part of a community and I'm inspired to give something back- I get the treatment and support which are best for my dementia, and my life- I know what I can do to help myself and who else can help me- I am confident my end of life wishes will be respected. I can expect a good death <p>In addition, 11 recommendations were formulated to reduce the use of antipsychotic drugs to the level where benefit will outweigh risk and where can be assured that patients are being managed safely and effectively.</p>
PLANNED BUDGET	£ 150 million

UNITED KINGDOM (ENGLAND)

TITLE	Improving care for people with dementia
PERIOD COVERED	2013 – 2015
PRIORITIES/ MEASURES	<ol style="list-style-type: none"> 1. Increase diagnosis rates <ul style="list-style-type: none"> • Making sure that doctors give 65 to 74 year olds information about memory services as part of the NHS health check programme, and refer them for assessment if they need it • Making £1 million available for innovative NHS projects to increase diagnosis rates through the Innovation Challenge Prize for Dementia • Launching a new toolkit to help GPs provide better support 2. Health and care services – to improve health and care services for people with dementia, by March 2013: <ul style="list-style-type: none"> • Every hospital in England was asked to commit to becoming dementia-friendly • £54 million for hospitals delivering quality dementia care by offering dementia risk assessments to all 75 year olds admitted to their care • Dementia information was made available on the Our Health South West website available nationally, so people have a better understanding of the services available in their local area <p>Other:</p> <ul style="list-style-type: none"> • Care homes and services are asked to sign up to the Dementia Care and Support Compact, which sets out new standards for dementia care • Provide £50 million of funding to adapt wards and care homes for people with dementia • Provide dementia training resources for health and care workers • Help to fund a £300 million programme to build or renovate housing for people with long-term conditions, including dementia • Provide £400 million to help fund breaks for carers 3. Dementia-friendly communities <ul style="list-style-type: none"> • Raising awareness and working with different organisations to create dementia-friendly communities 4. Dementia research <ul style="list-style-type: none"> • Annual funding of dementia research will be increased to around £66 million by 2015 to increase scientific knowledge of dementia - and potentially make new treatments possible
MONITORING PROGRESS	The monitoring of progress of the Dementia Challenge is overseen by three groups of ‘champions’. The latest report was published in May 2013.
PLANNED BUDGET	Information not available.



UNITED STATES

TITLE	National Plan to address Alzheimer's Disease
PERIOD COVERED	2012 – 2015
PRIORITIES/ MEASURES	<p>The plan is centered around 5 goals. For each goal, a set of strategies is defined, and corresponding actions.</p> <p>Goal 1: Prevent and Effectively Treat Alzheimer's Disease by 2025</p> <ul style="list-style-type: none"> - Strategy 1.A: Identify Research Priorities and Milestones - Strategy 1.B: Expand Research Aimed at Preventing and Treating Alzheimer's Disease - Strategy 1.C: Accelerate Efforts to Identify Early and Presymptomatic Stages of Alzheimer's Disease - Strategy 1.D: Coordinate Research with International Public and Private Entities - Strategy 1.E: Facilitate Translation of Findings into Medical Practice and Public Health Programs <p>Goal 2: Enhance Care Quality and Efficiency</p> <ul style="list-style-type: none"> - Strategy 2.A: Build a Workforce with the Skills to Provide High-Quality Care - Strategy 2.B: Ensure Timely and Accurate Diagnosis - Strategy 2.C: Educate and Support People with AD and Their Families upon Diagnosis - Strategy 2.D: Identify High-Quality Dementia Care Guidelines and Measures Across Care Settings - Strategy 2.E: Explore the Effectiveness of New Models of Care for People with AD - Strategy 2.F: Ensure that People with AD Experience Safe and Effective Transitions between Care Settings and Systems - Strategy 2.G: Advance Coordinated and Integrated Health and Long-Term Services and Supports for Individuals Living with AD - Strategy 2.H: Improve Care for Populations Disproportionally Affected by Alzheimer's Disease and for Populations Facing Care Challenges <p>Goal 3: Expand Supports for People with Alzheimer's Disease and Their Families</p> <ul style="list-style-type: none"> - Strategy 3.A: Ensure Receipt of Culturally Sensitive Education, Training, and Support Materials - Strategy 3.B: Enable Family Care-givers to Continue to Provide Care while Maintaining Their Own Health and Well-Being - Strategy 3.C: Assist Families in Planning for Future Care Needs - Strategy 3.D: Maintain the Dignity, Safety and Rights of People with Alzheimer's Disease - Strategy 3.E: Assess and Address the Housing Needs of People with AD <p>Goal 4: Enhance Public Awareness and Engagement</p> <ul style="list-style-type: none"> - Strategy 4.A: Educate the Public about Alzheimer's Disease - Strategy 4.B: Work with State, Tribal, and Local Governments to Improve Coordination and Identify Model Initiatives to Advance Alzheimer's Disease Awareness and Readiness across the Government - Strategy 4.C: Coordinate U.S. Efforts with Those of the Global Community

PRIORITIES/ MEASURES (CONT)	Goal 5: Improve Data to Track Progress <ul style="list-style-type: none">- Strategy 5.A: Enhance the Federal Government's Ability to Track Progress- Strategy 5.B: Monitor Progress on the National Plan
MONITORING PROGRESS	The plan includes a set of milestones linked to the actions required under the strategies for meeting the goals. A federal agency has been assigned responsibility for each provision of the Plan to ensure the provision is implemented.
PLANNED BUDGET	Information is not available on the overall amount for the implementation of the Plan.

For further information on any of the above plans, please visit www.alz.co.uk/alzheimer-plans.





ABOUT BUPA

- Bupa's purpose is longer, healthier, happier lives.
- A leading international healthcare group, we serve over 14 million customers in more than 190 countries.
- We offer personal and company-financed health insurance and medical subscription products, run hospitals, provide workplace health services, home healthcare, health assessments and chronic disease management services. We are also a major international provider of nursing and residential care for elderly people.
- With no shareholders, we invest our profits to provide more and better healthcare and fulfil our purpose.
- Bupa employs more than 62,000 people, principally in the UK, Australia, Spain, Poland, New Zealand and the USA, as well as Saudi Arabia, Hong Kong, India, Thailand, China and across Latin America.

For more information, visit bupa.com

About Bupa's social care services around the world

- Bupa cares for more than 30,000 people in more than 460 care homes and retirement villages in the UK, Spain, Australia, New Zealand and Poland.
- Bupa is the largest international provider of specialist dementia care, caring for more than 19,000 residents with dementia.
- In the UK, Bupa Care Services looks after more than 17,900 residents in almost 300 care homes.
- In Australia, Bupa Care Services Australia currently operates 60 care homes caring for 5,300 residents.
- In New Zealand, Bupa Care Services New Zealand cares for more than 4,600 people in 48 homes, 21 care villages and seven rehabilitation sites and also provides telecare services via a personal alarm network.
- In Spain, Bupa (Sanitas Residencial) cares for around 4,400 residents in 40 care homes.
- In Poland, Bupa (LUXMED) has a large care home in Warsaw.

For more information, visit bupa.com/dementia

ABOUT ADI

- ADI is the international federation of 79 Alzheimer associations around the world.
- It is in official relations with the World Health Organization and has consultative status with the United Nations.
- ADI's vision is an improved quality of life for people with dementia and their families throughout the world.
- ADI believes that the key to winning the fight against dementia lies in a unique combination of global solutions and local knowledge. As such, it works locally, by empowering Alzheimer associations to promote and offer care and support for people with dementia and their carers, while working globally to focus attention on dementia and campaign for policy change from governments.
- Alzheimer's Disease International: The International Federation of Alzheimer's Disease and Related Disorders Societies, Inc. is incorporated in Illinois, USA, and is a 501(c)(3) not-for-profit organisation.

For more information, visit alz.co.uk

