

Dementia in Europe Yearbook 2012



**National Dementia Strategies
(diagnosis, treatment and research)**

Including the Alzheimer Europe Annual Report 2011

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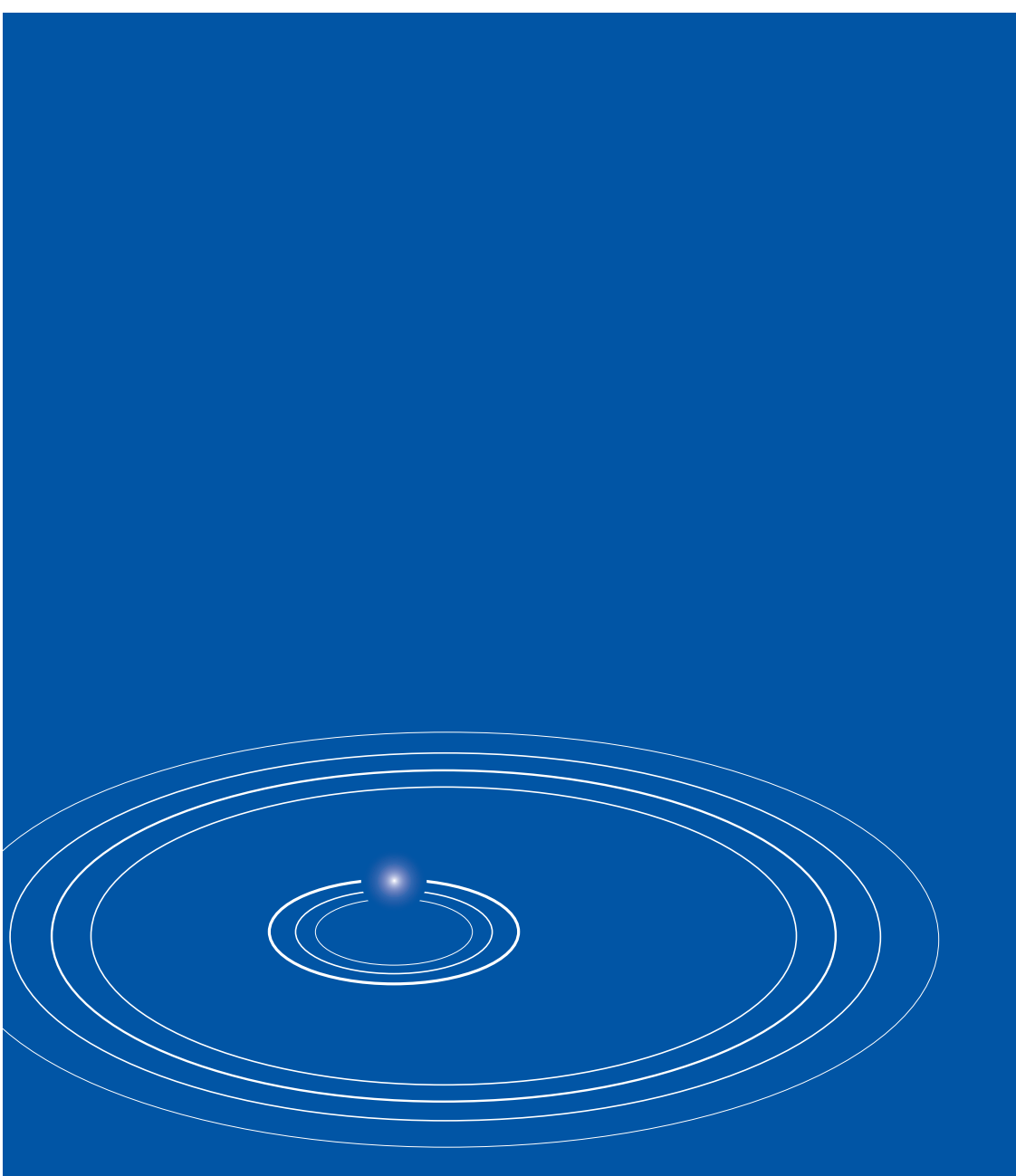
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Alzheimer Europe gratefully acknowledges the support it has received from the Alzheimer Europe Foundation for the publication of this Yearbook.

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Foreword



It gives me great pleasure to present this report on the development of national dementia strategies in Europe. The report contains information on the situation in 32 countries regarding the development of national dementia strategies focusing on three main topics, namely diagnosis, treatment and research. Of course, not all countries have such strategies as they are at different stages of development in relation to responding to the challenge that dementia poses.

National dementia plans all aim to address dementia but do so in different ways. We have decided to focus on the three above-mentioned topics in this report and in our next report to address more care-related issues such as the provision of care, the training of healthcare professionals and social care staff, support at home, in the community and in nursing homes, as well as issues linked to perceptions of dementia and dementia-friendly societies.

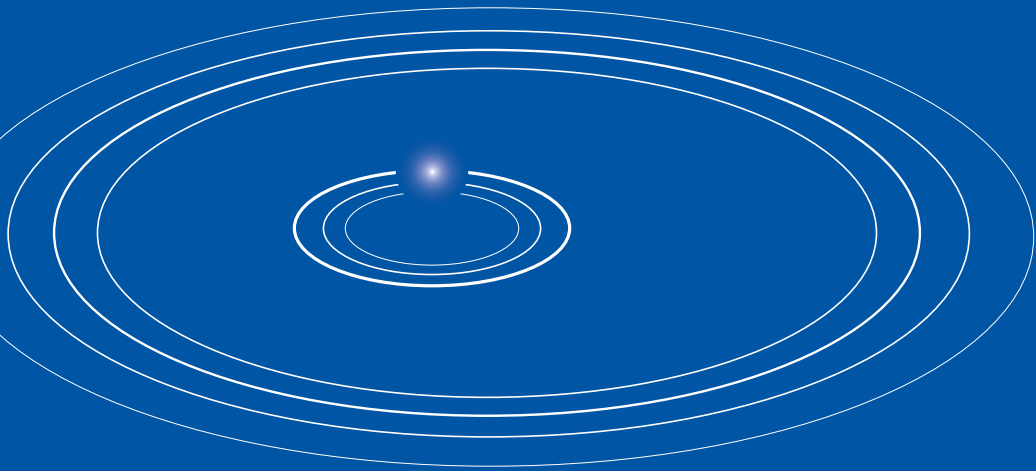
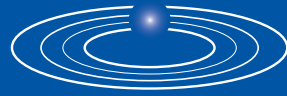
However, all countries have citizens with dementia who require timely diagnosis, treatment and support. This is essential to their quality of life and may help prevent premature entry into long-term residential care. It also represents a moral duty of each society towards people with dementia based on solidarity, beneficence, dignity and equity. Even countries which lack a national dementia strategy may have a system in place to diagnose dementia and organise treatment. Many are also involved in research at European level and/or fund research in their own country. Those countries which do have a strategy often have a timeframe within which to accomplish the goals they have set. Consequently, for each country, provisions relating to a national dementia strategy are described, followed by details of progress with their implementation. Wherever possible, details of how diagnosis, treatment and research are currently addressed at national level are provided.

It is hoped that this information will enable readers to compare how different countries have addressed these common issues and perhaps learn from the different solutions which have been attempted. As some countries are further along the process than others and have monitored their own progress, it is possible to benefit from their experience of success and of the obstacles they may have encountered along the way. Most, however, are in the early stages and many do not yet have a national dementia strategy.

Most of the reports were written by or with the assistance of Alzheimer Europe's member associations to whom we are immensely grateful. Some external experts also helped compile the reports. The names of all those who made it possible to produce this report are acknowledged at the end of each country report.

It is encouraging to see how far some countries have come in developing national strategies and how others are well on the way to doing so. Alzheimer Europe is closely monitoring this development and would be pleased to receive your comments and further information about developments within Europe.

Jean Georges
Executive Director
Alzheimer Europe



National Reports

1 Austria

1.1 Background information about the National Dementia Strategy

There is as yet no national dementia strategy in Austria.

1.2 Diagnosis, treatment and research

1.2.1 Issues relating to diagnosis

This is not addressed at national level.

1.2.1.1 *Which healthcare professionals are responsible for diagnosing dementia*

GPs are permitted to diagnose dementia and/or Alzheimer's disease and they do. The diagnosis can also be made by a specialist doctor (i.e. a neurologist, psychiatrist or geriatrician). GPs do not have set consultations times and there are no incentives to encourage timely diagnosis. They do not, for example, receive additional payment for special examinations to diagnose Alzheimer's disease.

1.2.1.2 *Type and degree of training of GPs in dementia*

GPs do not receive special training in dementia during their professional training to become a GP and continuing education is voluntary.

1.2.1.3 *Required tests to diagnose dementia*

There are no official guidelines, recommendations or tests which must be used in order to diagnose dementia and/or Alzheimer's disease. The MMSE and clock drawing tests are most commonly used.

1.2.2 Issues related to medical treatment

1.2.2.1 *The availability of medicines in general*

Austria keeps a list of pharmaceutical products for which expenses are covered by the healthcare system. Nevertheless, patients and carers need to cover part of the costs of medicines. This charge is currently set at EUR 5.15 per item prescribed. For infectious diseases and in cases of need, medicines may be free of charge.¹

1.2.2.2 *The availability of Alzheimer treatments*

All four AD drugs are available in Austria and are included on the list of pharmaceutical products that are covered by the healthcare system.

1.2.2.3 *Conditions surrounding the prescription and reimbursement of AD drugs*

Prescription is limited to specialist doctors and this applies to treatment initiation, as well as to continuing treatment decisions although continued treatment would be refunded

¹ European Commission (2012): MISSOC – Mutual information system on social protection: Social protection in the Member States of the European Union, of the European Economic Area and in Switzerland: Comparative tables

for six months if prescribed by a GP. For the prescription of acetylcholinesterase inhibitors, an MMSE is required. Treatment with acetylcholinesterase inhibitors is limited to people with an MMSE between 26 and 10, whereas treatment with memantine is reimbursed for patients scoring between 14 and 3 on this scale.

Medicines for people living alone and for people in nursing homes are also covered by the healthcare system. However, in the case of people with dementia living alone, there must be a carer who can ensure that the person with dementia takes the medication.

Bi-therapy with an acetylcholinesterase inhibitor and memantine is officially excluded from reimbursement in Austria, which means that patients would have to pay for one of the drugs except in well-founded cases (www.erstattungskodex.at).

Prescription and reimbursement	Donepezil	Rivastigmine	Galantamine	Memantine
Available	Yes	Yes	Yes	Yes
Reimbursed	Yes	Yes	Yes	Yes
Drug reimbursed if initially prescribed by	Specialist doctors	Specialist doctors	Specialist doctors	Specialist doctors
Continued treatment reimbursed if prescribed by	Specialist doctors or GPs but only for 6 months	Specialist doctors or GPs but only for 6 months	Specialist doctors or GPs but only for 6 months	Specialist doctors or GPs but only for 6 months
Required examinations	MMSE	MMSE	MMSE	MMSE
MMSE limits	26-10	26-10	26-10	14-3

1.2.3 Issues related to research

There are some research programmes but not on a national level. Austria is involved in the EU Joint Programme – Neurodegenerative Disease Research (JPND) but not in the Joint Action “Alzheimer Cooperative Valuation in Europe (ALCOVE)”.

1.3 Acknowledgements

Antonia Croy, President, Alzheimer Austria.

Roswitha Bartsch

2 *Belgium*

2.1 Issues relating to medical treatment

2.1.1 The availability of medicines in general

In Belgium, medical drugs are classified into different reimbursement categories.

Medicines in category A for serious illnesses are fully covered by the system and free of charge for the patient.

For medicines in category B (useful drugs), the patient is required to pay 25% up to a ceiling of EUR 11.30 to EUR 14.10 depending on the size of the box.

For medicines in category C (less useful drugs), the patient is required to pay 50% up to a ceiling of EUR 14.10. This percentage may go up to 60% or 80% for certain medicines in this group which fall under category CS (ease drugs) or Cx (for example: contraceptives).²

2.1.2 The availability of Alzheimer treatments

All four AD drugs are available in Belgium and are part of the reimbursement system.

2.1.3 Conditions surrounding the prescription and reimbursement of AD drugs

Belgium has a very strict treatment protocol for drugs to be reimbursed. Amongst other things, it limits the prescription of AD drugs to specialist doctors, both for treatment initiation and for treatment continuation. For the reimbursement of acetylcholinesterase inhibitors, treatment can be initiated for people with an MMSE score between 24 and 12. Treatment can be continued until an MMSE score of 10 has been reached. Equally, it is possible to prescribe acetylcholinesterase inhibitors to people with MMSE scores over 24, but such requests need to be further explained and documented as part of the diagnosis of Alzheimer's disease. Memantine can be prescribed to people with a score of between 15 and 3.

The Belgian system explicitly limits reimbursement to one class of drugs only, so that patients would not be able to receive bi-therapy under the system unlike some other European countries. According to the Ligue Nationale Alzheimer Liga, a significant number of patients and carers have to pay for their Alzheimer medicines, because their general practitioners failed to refer them to a specialist.

² European Commission (2012): MISSOC – Mutual information system on social protection: Social protection in the Member States of the European Union, of the European Economic Area and in Switzerland: Comparative tables

The reimbursement system does not impose any restrictions for the reimbursement of people living alone or in nursing homes.

Prescription and reimbursement	Donepezil	Rivastigmine	Galantamine	Memantine
Available	Yes	Yes	Yes	Yes
Reimbursed	Yes	Yes	Yes	Yes
Drug reimbursed if initially prescribed by	Specialist doctors	Specialist doctors	Specialist doctors	Specialist doctors
Continuing treatment reimbursed if prescribed by	Specialist doctors	Specialist doctors	Specialist doctors	Specialist doctors
Required examinations	Diagnostic protocol	Diagnostic protocol	Diagnostic protocol	Diagnostic protocol
MMSE limits	>10	>10	>10	15-3

2.2 Issues related to research

Belgium is involved in the EU Joint Programme – Neurodegenerative Disease Research (JPND) and is an associate member of the Joint Action “Alzheimer Cooperative Valuation in Europe (ALCOVE)”.

3 *Bulgaria*

3.1 **Background information about the National Dementia Strategy**

3.1.1 **Status and historical development of the National Dementia Strategy**

There is currently no National Dementia Strategy in Bulgaria.

3.1.2 **Involvement of the Alzheimer association (and/or people with dementia)**

Discussions are underway about the need for a National Dementia Strategy in Bulgaria and a model is being prepared to facilitate the development of such a strategy. A three-day roundtable was planned for the end of September in order to exchange experience and expertise in connection with the development of a National Strategy for dementia. Representatives from the Czech Republic and Macedonia were invited to the September round-table discussions. The executive authorities in Bulgaria/Ministry of Labour and Social Policy confirmed their participation but the Ministry of Health and Ministry of Finance did not appoint people to participate. This meeting was postponed and is now scheduled for the end of November 2012.

3.2 **Diagnosis, treatment and research**

3.2.1 **Issues related to timely diagnosis**

There are no measures at national level but the Bulgarian Alzheimer Association is working to improve awareness and understanding of dementia.

3.2.1.1 ***Which healthcare professionals are responsible for diagnosing dementia***

Whilst GPs are expected to recognise symptoms which might suggest dementia, their role is to refer people with suspected dementia to a specialist in diagnosis. In practice, in many places in the country doctors do not recognise the symptoms of dementia.

Neurologists and psychiatrists can also diagnose dementia and/or Alzheimer's disease. However, people usually only go to see a specialist when they are in the final stage of dementia.

GPs do not have a set consultation time. However, they are paid for consultations of 10 minutes regardless of the patient's age or diagnosis. Elderly patients and those with dementia are not given any extra time. There is no incentive for GPs to have longer consultation times as they would not receive additional payment for the extra time spent with the patient.

There are no incentives for GPs to improve or increase timely diagnosis.

3.2.1.2 *Type and degree of training of GPs in dementia*

In their professional training to become a GP, GPs have one module on neurology. The entire module on neurology lasts three months and incorporates two days' training in dementia. GPs are not under any obligation to take part in further courses or training once qualified.

3.2.1.3 *Required tests to diagnose dementia*

The MMSE test is generally used to diagnose dementia but its use is not obligatory and not all general practitioners are familiar with it or use it. There is no organised system for early diagnosis. The MMSE test is not included in the preventive work of GPs. Diagnosis is concentrated only in big cities with medical universities such as in Sofia, Plovdiv, Varna and Pleven. Specialists are obliged to administer certain tests in order to make a correct diagnosis. However, the equipment that they would need for this is only available in university hospitals.

3.2.2 *Issues related to medical treatment*

3.2.2.1 *The availability of medicines in general*

During the Communist government, the production and distribution of pharmaceutical drugs were the responsibility of the State. There has since been a transition to a market economy, whereby state-owned companies produce and distribute pharmaceuticals (Koulaksazov et al., 2003). Some have been privatised (Compassion Alzheimer Bulgaria, 2007).

The compulsory health insurance, which was introduced by the Health Insurance Act of 1998, gives people the right to certain medical treatment and drugs. The compulsory health insurance contribution is 8% of a person's income. It is divided between the employer and employee in the ratio of 60:40. The contributions are mandatory and are not linked to the expected cost of care.

Most drugs have to be purchased by individuals at market prices. However, certain drugs are partly or totally reimbursed by the National Health Insurance Fund (NHIF). A list of diseases for which drug treatment is reimbursable is drawn up by the NHIF taking into account principles accepted in the EU and recommendations made by the World Health Organisation. This list tends to include diseases which have a considerable social impact and those which are classed as a national health priority. In order to be refunded, a drug must:

- have marketing authorisation from the Bulgarian Drug Agency;
- be for the treatment of a disease which is included in the official list of diseases;
- be provided on prescription (by a specialist for certain diseases);
- not contain more than two active substances.

For drugs that are refunded, there are nevertheless three levels of reimbursement:

- 100% for drugs that are linked to diseases covered by the National Health Strategy (e.g. for severe and chronic illnesses),
- 75% for drugs of proven therapeutic efficacy for diseases not covered by the National Health Strategy (but with a social impact as defined by the Ministry of Health).
- 50% for all other drugs.

If refundable by the NHIF, this takes the form of a fixed amount which is deducted from the retail price. The patient must pay the difference.

Source of the above information on reimbursement: Datzova, 2003.

3.2.2.2 *The availability of Alzheimer treatments*

All AD drugs except memantine are available in Bulgaria.

3.2.2.3 *Conditions surrounding the prescription and reimbursement of AD drugs*

None of the AD drugs are amongst the drugs that are refunded. People with dementia therefore need to cover these costs themselves. However, since 2010 Aricept and Exelon have been refunded by the State if used during hospital treatment.

As a result of the long-term initiatives of the Bulgarian Alzheimer Association, Alzheimer’s disease is currently included in the list of diseases in Ordinance № 38 which determines the diseases for which the National Health Insurance Fund pays, either wholly or partially, for home treatment, drugs, medical devices and dietary foods for special medical purposes. However, the drugs for the home treatment of people with Alzheimer’s disease are not reimbursed and patients have to pay for all the drugs themselves. The Bulgarian Alzheimer Association is pursuing this issue.

Prescription and reimbursement	Donepezil	Rivastigmine	Galantamine	Memantine
Available	Yes	Yes	Yes	No
Reimbursed	No	No	No	No
Drug reimbursed if initially prescribed by	N/A	N/A	N/A	N/A
Continuing treatment reimbursed if prescribed by	N/A	N/A	N/A	N/A
Required examinations	None	None	None	None
MMSE limits	N/A	N/A	N/A	N/A

3.2.3 Issues related to research

Bulgaria is not involved in the EU Joint Programme – Neurodegenerative Disease Research (JPND) or the Joint Action “Alzheimer Cooperative Valuation in Europe (ALCOVE)”.

3.3 References

Datzova, B. (2003), *Health care reform and inequality of access to health care in Bulgaria*, United Nations Research Institute for Social Development.

Koulaksazov et al. (2003), *Health care systems in transition: Bulgaria*, European Observatory on Health Care Systems.

3.4 Acknowledgements

Irina Vasileva Ilieva, Bulgarian Alzheimer Society.

Lora Ivanova.

4 Croatia

4.1 Background information about the National Dementia Strategy

4.1.1 Status and historical development of the National Dementia Strategy

There is not yet a National Dementia Strategy in Croatia and there does not seem to be any interest within the current government in having one.

4.1.2 Involvement of the Alzheimer association (and/or people with dementia)

Alzheimer Croatia is developing a draft document which will eventually be submitted to the government.

4.2 Diagnosis, treatment and research

4.2.1 Issues relating to diagnosis

4.2.1.1 *Which healthcare professionals are responsible for diagnosing dementia*

GPs may diagnose dementia. Sometimes they do and sometimes they prefer to refer patients with suspected dementia to a specialist (a neurologist or psychiatrist) for diagnosis. It is up to the GP to decide. It is not a problem to see a specialist quickly (within a few days). For younger people, it is sometimes considered preferable to hospitalise them for diagnostic purposes. In such cases, an agreement is made to do all the tests and evaluations at the same time rather than have the person return for different tests over a period of time. The hospitalisation costs are covered as everyone in Croatia has insurance for this.

The duration of GP consultations is about 10 minutes. This is an average rather than obligatory length of time. A GP is free to spend more time with a particular patient but this would reduce the amount of time available for other patients. People sometimes have to return several times before a diagnosis can be made based on the gradual accumulation of the necessary details. There are no incentives for GPs to improve or increase timely diagnosis.

4.2.1.2 *Type and degree of training of GPs in dementia*

Over the last ten years, Alzheimer Croatia has tried to educate GPs. It is now more common to hear about dementia in the medical faculties. The Alzheimer association also tries to educate the population through events held on World Alzheimer's Day.

GPs only receive a few hours' training in dementia during the courses on neurology and psychiatry which are part of the professional training to become a GP. They are obliged to undergo continuing education in order to prolong their licence to practice as a GP. However, they can choose the courses they wish to attend in order to obtain the necessary points to prolong their licences and only a minority of GPs choose courses on Alzheimer's disease or old age psychiatry.

4.2.1.3 *Required tests to diagnose dementia*

The most commonly used tests for the diagnosis of dementia are the MMSE and the clock drawing test. However, a GP will usually not diagnose dementia without first sending the person to a psychologist and for a CT test. The ICD-10 criteria must be fulfilled in order to make a diagnosis of dementia and/or Alzheimer’s disease.

4.2.2 *Issues relating to medical treatment*

4.2.2.1 *The availability of medicines in general*

In Croatia there is a list of medical drugs which are reimbursable.

4.2.2.2 *The availability of Alzheimer treatments*

Alzheimer drugs are not on the list of reimbursable drugs. However, one month ago (i.e. in September 2012), it was declared that memantine would soon be partially reimbursed if prescribed by a specialist (a neurologist or psychiatrist). Whilst these drugs may be relatively inexpensive in some countries, for Croatian people they remain too expensive and the average family cannot afford to buy AD drugs.

4.2.2.3 *Conditions surrounding the prescription and reimbursement of AD drugs*

Once the GP has received all the test results, s/he makes a diagnosis and prescribes an AD drug if appropriate. However, the drug which is on the reimbursement list (namely, memantine) must be prescribed for the first time by a specialist (neurologist or psychiatrist) in order to be reimbursed. GPs can prescribe AD drugs but patients have to pay for them. If a patient has been referred to a specialist, the specialist makes the diagnosis and can make the first and future prescription of AD drugs. There are no restrictions on the prescription or reimbursement of AD drugs for people living alone or in nursing homes.

Prescription and reimbursement	Donepezil	Rivastigmine	Galantamine	Memantine
Available	Yes	Yes	No	Yes
Reimbursed	No	No	No	Yes, partially (20%)
Initial drug reimbursed if prescribed by	N/A	N/A	N/A	Specialists (neurologist or psychiatrist)
Continuing treatment reimbursed if prescribed by	N/A	N/A	N/A	GP
Required examinations	None	None	None	Must be moderate to severe stage
MMSE limits	None	None	None	None

4.2.3 Issues relating to research

Research is carried out mainly in university hospitals, faculties and institutes. There is a special institute called the Croatian Institute for Brain Research. The main types of research are basic, clinical and translational for which most of the funding comes from the government. Research in the social sciences is not so prominent. Alzheimer Croatia would like to see social science research into dementia being promoted and for carers and people with dementia to be more involved. It also recognises the need to attract more experts in psycho-social research to the field of dementia.

Croatia is not involved in the EU Joint Programme – Neurodegenerative Disease Research (JPND) or the Joint Action “Alzheimer Cooperative Valuation in Europe (ALCOVE)”.

4.3 References

Mimica N, Presečki P. (2010). How do we treat people with dementia in Croatia. *Psychiatra Danubina*, 22(2), 363-366.

Mimica N, Presečki P. (2010). Current treatment options for people with Alzheimer’s disease in Croatia. *Chemico-Biological Interactions*, 187, 409-410.

www.alzheimer.hr.

4.4 Acknowledgements

Ninoslav Mimica, MD, PhD, Professor of psychiatry, President of Alzheimer Croatia.

5 Cyprus

5.1 Background information about the National Dementia Strategy

5.1.1 Status and historical development of the National Dementia Strategy

A National Dementia Strategy is currently being developed in Cyprus.

5.2 Treatment and research

5.2.1 Issues relating to medical treatment

5.2.1.1 *The availability of medicines in general*

Pharmaceutical products are provided by the pharmacies of hospitals/institutions³. There is a list of drugs which can be prescribed and patients fall into one of two categories which determine how much they have to pay for those drugs. This list is regularly updated. The first category covers people who are entitled to receive medical drugs free of charge. This includes patients suffering from certain chronic diseases and people who are on Public Assistance as well as their dependants. The second category covers people who are entitled to a reduced rate based on the level of their income. The people in the second category must pay 50% of the cost. In addition, there is a co-payment system which applies to approximately 100 medicinal products which are provided by private pharmacies. For these drugs, patients must pay a pre-determined amount for each medicinal product.

5.2.1.2 *The availability of Alzheimer treatments*

All four AD drugs are available in Cyprus. The availability and part reimbursement of AD drugs has been improved in Cyprus due to the successful lobbying of the Cyprus Alzheimer Association.

In 2000, the Cyprus Alzheimer Association requested the Minister of Health to provide free medication in state hospitals for AD patients. This request was granted and subject to the annual tender legislation procedures, one medication out of three (i.e. donepezil, rivastigmine or galantamine) is provided free of charge. This may be a different one each year. Memantine is not included in the annual tender.

5.2.1.3 *Conditions surrounding the prescription and reimbursement of AD drugs*

Every year, the three companies which produce donepezil, rivastigmine or galantamine need to make a bid-tender so that the government can determine which is offering the lowest price. That drug is then purchased by the government and made available in state hospitals where patients can then obtain it free of charge provided that it has been prescribed by their GP. All people with Alzheimer's disease are entitled to attend hospital. They need to pay a minimal fee for registration.

³ European Commission (2011): MISSOC – Mutual information system on social protection: Social protection in the Member States of the European Union, of the European Economic Area and in Switzerland: Comparative tables

A few years later, the Cyprus Alzheimer Association requested that a 40% subsidy be given as compensation for the other two AD drugs (which patients would have to purchase themselves). This was the case until 2012 when, due to the economic crisis, the subsidy was reduced to 25%.

Due to this tender system, nearly every year a different AD drug is provided free of charge in hospitals. Patients who use one of those which are not free for the current year have to buy it privately and are subsequently only reimbursed for 25% of the cost.

Memantine had not yet obtained Community-wide marketing authorization when the original agreement was made with the Minister of Health to make AD drugs available and to establish a system of reimbursement. Consequently, it is not part of the tender agreement and is only ever reimbursed at the rate of 25%.

Prescription and reimbursement	Donepezil	Rivastigmine	Galantamine	Memantine
Available	Yes	Yes	Yes	Yes
Reimbursed	Free or 25% reimbursed	Free or 25% reimbursed	Free or 25% reimbursed	25%
Initial drug reimbursed if prescribed by	GP	GP	GP	GP

5.2.2 Issues relating to research

Cyprus is not involved in the EU Joint Programme – Neurodegenerative Disease Research (JPND) but is a Collaborator in the Joint Action “Alzheimer Cooperative Valuation in Europe (ALCOVE)”.

5.3 Acknowledgements

Noni Diakou, Cyprus Alzheimer Association.

6 *Czech Republic*

6.1 **Background information about the National Dementia Strategy**

6.1.1 **Status and historical development of the National Dementia Strategy**

The Czech Alzheimer Society lobbied many branches of the government to set up a National Dementia Strategy. The government finally agreed to create one in 2010.

6.1.2 **Involvement of the Alzheimer association (and/or people with dementia)**

The Czech Alzheimer Society has been very active from the very beginning. It repeatedly addressed the Prime Minister in 2009 and also Ministers of Health and the Minister of Labour and Social Affairs etc. In October 2010, the Government of the Czech Republic decided that an “Alzheimer Plan” would be developed. Ministries of Health, Social Affairs, Education (which is responsible for research) and Justice were ordered to prepare a concept to enable the Government to proceed with the preparation of the National Dementia Strategy (Plan Alzheimer).

The Czech Alzheimer Society asked for the collaboration of many professionals and prepared a list of suggested priorities for the future Dementia Strategy based on discussion with physicians (neurologists, GPs, geriatricians and psychiatrists), family caregivers and people with dementia, lawyers, social workers, nurses etc. Officers from the Ministry of Health (responsible for the conception of the Strategy) also participated in these discussions. After a difficult political situation lasting two years, the conception was accepted by the Government of the Czech Republic in October 2012. It was decided to invite a group of interested persons including specialists to prepare the National Dementia Strategy. It is presumed that the Czech Alzheimer Society (and also new Alzheimer Foundation) will play an important role in this process.

The Czech Alzheimer Society continues to support the Strategy with media campaigns for better awareness. These campaigns are also targeted at municipalities.

6.2 **Diagnosis, treatment and research**

6.2.1 **Issues relating to diagnosis**

6.2.1.1 ***Which healthcare professionals are responsible for diagnosing dementia***

GPs are expected to carry out basic screening of cognitive functions, but this is not specified in any guidelines. There are principles of care in guidelines that were prepared by an expert group of GPs, neurologists, psychiatrists and geriatricians including representatives of the Czech Alzheimer Society. GPs should also make a basic diagnosis and then refer patients to a specialist for a full diagnosis. This could be a neurologist, psychiatrist or geriatrician.

Dementia is not still a care priority for general practitioners. They have to focus in their practice on many other difficult problems. Therefore, they often underestimate the importance of the timely diagnosis of dementia.

6.2.1.2 *Type and degree of training of GPs in dementia*

The Czech Alzheimer Society, together with the School of Long-term Care Medicine of the Postgraduate Medical Institute, organises courses for GPs and for physicians working in long-term care settings. A course on dementia has become part of postgraduate specialisation training for GPs. GPs therefore receive three hours of theoretical training in dementia during their postgraduate specialist education. A range of voluntary courses are also available.

6.2.1.3 *Required tests to diagnose dementia*

The MMSE test is used in the diagnosis of dementia. This is necessary if AD drugs are to be prescribed. GPs are not obliged to use this for their initial basic diagnosis. They might but it is sufficient that they refer patients to specialists based on their clinical impression.

As mentioned earlier, a group of psychiatrists, neurologists and geriatricians, including members of the Czech Alzheimer Society, published recommended guidelines for the diagnosis and treatment of dementia, both generally and also in general practice.

6.2.2 *Issues relating to medical treatment*

6.2.2.1 *The availability of medicines in general*

In the Czech Republic, medicinal products are classified into three categories and reimbursement varies from 0 to 100%. The first category is fully covered and includes the cheapest effective preparations of all essential products. For medicines in the second or third category, patients need to either partly or fully co-finance the costs of the medicines. There is nevertheless a regulatory charge of CZK 30 (EUR 1.17) for every drug prescribed irrespective of whether it is partly or fully reimbursed by the public health insurance system. The regulatory charge is waived in certain cases which include people living in homes for disabled people or for older people (if their “minimum income remainder” is less than CZK 800 (EUR 31) or if they have been proved to be in material need.⁴

6.2.2.2 *The availability of Alzheimer treatments*

All four AD drugs are available in the Czech Republic and are part of the reimbursement system.

6.2.2.3 *Conditions surrounding the prescription and reimbursement of AD drugs*

The Czech Republic limits reimbursement of AD drugs to prescriptions filled in by specialists (neurologists, psychiatrists and geriatricians) both for initiation and continuation decisions of these treatments. Furthermore, acetylcholinesterase inhibitors are limited

⁴ European Commission (2012): MISSOC – Mutual information system on social protection: Social protection in the Member States of the European Union, of the European Economic Area and in Switzerland: Comparative tables

to patients with an MMSE score between 20 and 13 and memantine to patients with an MMSE score between 16 and 6. There are no formal reimbursement restrictions for people living alone or in nursing homes. However, these people are disadvantaged by the system which governs the funding of nursing homes. These do not exist as a combination of health and social care but are divided between systems of health and social care. In the first group, budgetary restrictions often reduce the use of these drugs. With the second type of care, there are many restrictions for prescribing physicians and access to specialists is very limited. Therefore, in these institutes cholinesterase inhibitors and memantine are very rarely prescribed and not according to the real needs of patients.

Not all specialists are willing to prescribe drugs so the Czech Alzheimer Society carries out memory days to offer free screening of cognitive disorders. People can be referred directly to specialists. By carrying out these memory days, the Association has significantly increased the number of people who can be treated because GPs cannot prescribe AD drugs, whereas specialists can.

Prescription and reimbursement	Donepezil	Rivastigmine	Galantamine	Memantine
Available	Yes	Yes	Yes	Yes
Reimbursed	Yes	Yes	Yes	Yes
Initial drugs reimbursed if prescribed by	Specialist	Specialist	Specialist	Specialist
Continuing treatment reimbursed if prescribed by	Specialist	Specialist	Specialist	Specialist
Required examinations	MMSE	MMSE	MMSE	MMSE
MMSE limits	20-13	20-13	20-13	16-6

6.2.3 Issues relating to research

Research is located mainly in universities and in some institutes. Mostly research in basic science is carried out by the Czech Academy of Sciences. There is also some interesting research being carried out in memory and neurological departments as well as research into genetics. A new comprehensive research centre is under construction. Also, the Czech Republic has some studies in dementia being carried out in university medical facilities in the departments of neurology, psychiatry, geriatrics and humanities. In the faculty of humanities, the focus is on research into long-term care and into the provision and management of services. There is also on-going research being carried out by neurologists and geriatricians who have the ability to foster new research. The new palliative society and the specialisation by doctors in long-term care also give rise to new research.

There are some minor agencies which provide funding for research but the main source is from the grant agency of the Czech Republic which provides funding for basic research and the Ministry of Health grant agency which provides funding for applied research.

International research is funded by the Ministry of Education, Youth and Sport. However, the whole system of research funding in the Czech Republic is based on regular public competition and therefore it is difficult to comply with the terms of the JPND. This results in a split between the funding allocated which has proved problematic and a case in point is the funding for Joint Programming. It remains unclear whether the Czech funding is for international collaboration or for national projects. There have been lengthy discussions on this issue which have led to delays and missed deadlines. The Czech Republic is not very involved in international projects, which tend to focus on big themes from Western Europe. It has been joining forces with other interested parties from Central and Eastern European countries with the aim of jointly applying for international research grants on dementia. It is very important to the Czech Republic and other EU countries as well.

The Czech Republic is involved in the EU Joint Programme – Neurodegenerative Disease Research (JPND) and is a Collaborator in the Joint Action “Alzheimer Cooperative Valuation in Europe (ALCOVE)”.

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6.4 Acknowledgements

Iva Holmerová, Chairperson, Czech Alzheimer Society, Vice Chairperson of the management board of the Czech Alzheimer Foundation

7 *Denmark*

7.1 Background information about the National Dementia Strategy

7.1.1 Status and historical development of the National Dementia Strategy

In 2009, work was started under the auspices of the Ministry for Social Security and the Ministry for Health and Internal Affairs with the aim of establishing how people with dementia were treated both medically and socially.

A working group was set up by the Ministries and there was participation from “Danish Regions” (which are responsible for the hospital sector and GPs), and “Danish municipalities (KL)” which are responsible for social care. The Finance Ministry also participated in this group.

Several meetings were held in smaller groups to describe the field as thoroughly as possible and to find out what the obstacles are for the future development in this field.

This work resulted in 14 recommendations, which were put forward to the Danish Parliament in December 2010 and agreed on as focus points for the following years.

7.1.2 Duration of the National Dementia Strategy

The National Dementia Strategy runs from 2011 to 2014.

7.1.3 How the National Dementia Strategy is funded

A total of approximately Euro 4.1 million was allocated to the National Dementia Strategy.

7.1.4 Provisions or procedure for implementing the Strategy

The Plan has recommendations in many fields as indicated by the participation of three different ministries and other stakeholders. Each is responsible for the implementation of different parts of the strategy.

7.1.5 Procedure for monitoring progress made in achieving the goals set

There is no formal procedure to monitor the progress of the plan in achieving the goals set.

7.1.6 Involvement of the Alzheimer association (and/or people with dementia)

The Danish Alzheimer Association was involved in the drafting of the 14 recommendations mentioned above. However, in 2010 there was a conference on creativity in awareness raising campaigns which was inspiring but the Danish association was not invited to take part in the drafting of such campaigns. This was not part of the National Dementia Strategy as it took place before the Strategy. A new campaign is being organised as part of the Strategy but it has not yet been implemented.

7.1.7 Alzheimer association's overall assessment of the National Dementia Strategy

The Alzheimer Association was involved in discussions about patients' rights and support for family carers such as Alzheimer cafés and respite care in care homes and at home.

7.2 Diagnosis, treatment and research

7.2.1 Issues relating to diagnosis

7.2.1.1 *Timely diagnosis in the National Dementia Strategy*

Work is in progress under the auspices of the Danish National Health Board to issue "National clinical guidelines for Dementia". The guidelines will cover the issue of establishing the diagnosis. Two basic questions will be addressed: 1. Does this patient have cognitive problems (and if so) 2. what is the underlying cause?

The relevant diagnostic procedures will be described. A group of professionals will finish their work on this within a few months. The Danish Alzheimer Association is represented in the group.

The guidelines will serve as "best practice" for all the hospitals involved in diagnosing and treating people with dementia. All hospitals are expected to comply with the guidelines.

7.2.1.2 *Which healthcare professionals are responsible for diagnosing dementia*

In order to be refunded for AD drugs, people with suspected dementia must have a CT scan which is carried out by a specialist (a radiologist). In order to see the specialist, they must first consult a GP which means that GPs are an essential part of the diagnostic process. Sometimes, older people are diagnosed with dementia without the diagnostic processes described in the clinical guidelines having been followed. This may happen, for example, when the GP thinks that nothing can be gained from medical treatment.

There are also dementia coordinators and nurses who are employed by local communities and are responsible for ensuring that people with dementia receive the support they need. Each locality has at least one dementia coordinator.

GPs do not have a fixed consultation time but most have consultation modules of 10 minutes. Some allow patients to book a block of two modules (i.e. one after the other). However, GPs would only be paid for one consultation. They would receive extra payment for carrying out an MMSE and for having consultations with the patient's relatives.

7.2.1.3 *Type and degree of training of GPs in dementia*

The amount and content of training in dementia which GPs receive as part of their professional training to become a GP differs from one faculty to the next. Also, dementia is part of the curriculum for diseases in old age. It is therefore not possible to calculate the exact number of hours as such teaching is part of that for other subjects.

In Copenhagen, for example, dementia is part of the curriculum in neurology, which is compulsory for all medical students. All students have to attend a two-hour lecture on dementia. This is followed by 1 month in a neurological department where bedside education in dementia can be given, either in the ward or in an outpatient clinic.

In Aarhus, a one-hour lecture in dementia is provided, followed by two weeks in a neurological department including one day in the outpatient clinic.

In Odense, there is a two-hour lecture in dementia, followed by two or three hours towards the end of the study.

Postgraduate education is not compulsory for Danish GPs. However, the Danish Association of General Practitioners (DSAM) has produced an E-learning programme in dementia which doctors are free to use.

7.2.1.4 *Required tests to diagnose dementia*

A CT scan must be carried out and assessed by a specialist.

7.2.2 *Issues relating to medical treatment*

7.2.2.1 *Issues related to medical treatment in the National Dementia Strategy*

The issue of medical treatment will be part of the clinical guidelines. There will be recommendations on the appropriate medical treatment for the different types of dementia.

Another workgroup under the Ministry of Social Security is trying to find ways to improve the treatment of people with dementia who are difficult to treat because of BPSD. This work will probably tackle the issue of how, as far as possible, to avoid the use of psychotropic drugs.

7.2.2.2 *The availability of medicines in general*

In Denmark, medicines on a special list (essentially all prescription medicines) are covered up to a certain degree depending on the overall total expenditure on medicines of a patient during a year.

If the total expenditure on medicines in a year does not exceed DKK 890, the patient covers 100% of the drug costs.

For total expenditure on medicines of between DKK 890 and DKK 1,450, the patient covers 50% of the costs.

For total expenditure on medicines of between DKK 1,450 and DKK 3,130, the patient covers 25% of the costs.

For total medicines expenditure above DKK 3,130, the patient covers 15% of the costs.

Nevertheless, for cases where there is a well-documented need for extensive and permanent treatment, the reimbursement rate can go up to 100% of the part of the total co-payment which is in excess of DKK 3,655 (approx. EUR 492).

Finally, in special cases the health service can contribute to medicines not on the list or contribute fully to medicines for people who are dying⁵.

7.2.2.3 *The availability of Alzheimer treatments*

All AD drugs are available in Denmark and are part of the reimbursement system. Reimbursement is dependent on prior authorisation by the Danish Medicines Agency according to the following procedure.

7.2.2.4 *Conditions surrounding the prescription and reimbursement of AD drugs*

An application for reimbursement has to be sent to the Danish Medicines Agency and any doctor can apply for reimbursement for a patient. Nevertheless, reimbursement is only granted if a specialist in neurology, psychiatry or geriatrics has made the diagnosis.

For patients with mild to moderate dementia a CT (or MR scan) of the brain has to be performed first. The physician also has to state that causes other than Alzheimer’s disease are excluded. The system does not provide upper or lower MMSE limits for treatment with different AD drugs, but reimbursement is dependent on a clinical grading. Reimbursement for donepezil, rivastigmine and galantamine is only granted to patients in mild to moderate stages and memantine to patients in moderate to severe stages.

The application has to be renewed every 12 to 15 months. Renewal of reimbursement of memantine depends on a statement by the physician that a continuous effect in the individual patient is still observed. There are no restrictions as to the access of people living alone or in nursing homes to available AD treatments.

Prescription and reimbursement	Donepezil	Rivastigmine	Galantamine	Memantine
Available	Yes	Yes	Yes	Yes
Reimbursed	Yes	Yes	Yes	Yes
Initial drug reimbursed if prescribed by	Specialist	Specialist	Specialist	Specialist
Continuing treatment reimbursed if prescribed by	No restrictions	No restrictions	No restrictions	No restrictions
Required examinations	Diagnostic protocol	Diagnostic protocol	Diagnostic protocol	Diagnostic protocol
MMSE Limits	None	None	None	None

5 European Commission (2012): MISSOC – Mutual information system on social protection: Social protection in the Member States of the European Union, of the European Economic Area and in Switzerland: Comparative tables

7.2.3 Issues relating to research

The issue of research is only very briefly addressed in the National Dementia Strategy. However, it was decided to allocate money for “National Knowledge Centre for Dementia” which is initiating scientific research, both in the clinical field and in basic science subjects. At the same time, the Centre runs a range of courses for doctors, nurses, carers and other people with an interest in dementia.

The National Knowledge Centre has set up a network between all memory clinics in Denmark. Jointly they should have the capacity to carry out investigative research. A big project has started known as “ADEX” which is about exercise in people who have been recently diagnosed with dementia but who are still in good health. It is difficult to estimate how much money the government allocates to dementia research as the Knowledge Centre encompasses more than dementia research.

Denmark has a bio-bank and there are a lot of projects running in the psychosocial field. These projects face the same challenges as in other countries in that often, once they are completed, nothing is done with them. In order to prevent the projects just “disappearing”, the dementia strategy includes a provision that the Ministry of Social Security should collect all the information from these projects in order to establish good practices and to try to make the results available.

In Denmark, everyone has a number which consists of their birthdate and four digits. It is unique for each person and everyone must have one. This enables a diagnostic registry to be kept whereby each diagnosis is registered in a central register. Requests can be made for specific searches to be made (e.g. for the number of people diagnosed with dementia). The last four numbers are erased for anonymity.

Denmark is involved in the EU Joint Programme – Neurodegenerative Disease Research (JPND) but not in the Joint Action “Alzheimer Cooperative Valuation in Europe (ALCOVE)”. It is a prominent partner in the JPND project about biomarkers.

There are some Alzheimer research funds from a special fund called “The Alzheimer Research Fund” but these are very small and just cover the costs of a few PhD projects or contribute to them. The fund should be used to promote new PhD students and recruit new PhD students for future work. The PhD projects running at the moment include 1. Downs syndrome and Alzheimer’s disease, and 2. Dementia and pain. There was a study on ethnic minorities which resulted in an approved thesis.

7.3 Acknowledgements

Anne Arndal, Chair, Danish Alzheimer Association.

8 Estonia

8.1 Issues relating to medical treatment

8.1.1 The availability of medicines in general

Prescription drugs are generally reimbursed if they are on the “positive list”. People pay a subscription fee of approx. EUR 3.20 for pharmaceutical drugs reimbursed at 50% and a prescription fee of approx. EUR 1.27 for those reimbursed at a higher level of either 75% or 100%. The Health Insurance Fund pays up to EUR 12.79 for drugs reimbursed at the level of 50% and up to the reference price for those reimbursed at a higher level. The level of 75% reimbursement is increased to 90% for certain groups of people. This includes people who are disabled or retired. Over-the-counter drugs are not generally reimbursed⁶.

8.1.2 The availability of Alzheimer treatments

All four AD drugs are authorised for use in Estonia.

8.1.3 Conditions surrounding the prescription and reimbursement of AD drugs

With the exception of Exelon (Donepezil), they are part of the reimbursement system and reimbursed at 50%.

Prescription and reimbursement	Donepezil	Rivastigmine	Galantamine	Memantine
Available	Yes	Yes	Yes	Yes
Reimbursed	No	Yes	Yes	Yes

8.2 Issues relating to research

Estonia is not involved in the EU Joint Programme – Neurodegenerative Disease Research (JPND) or in the Joint Action “Alzheimer Cooperative Valuation in Europe (ALCOVE)”.

6 European Commission (2012): MISSOC – Mutual information system on social protection: Social protection in the Member States of the European Union, of the European Economic Area and in Switzerland: Comparative tables

9 *Finland*

9.1 Background information about the National Dementia Strategy

9.1.1 Status and historical development of the National Dementia Strategy

The Alzheimer Society of Finland insisted on a National Memory Strategy for Finland by collecting over 14,000 names on a petition in 2010. The Finnish Ministry of Social Affairs and Health started the development process for National Memory Strategy in December 2010 by setting up a working group consisting of 18 professionals including a representative from the Alzheimer Society of Finland. The Strategy went through a commentary round in November 2011 and was released on 5 May 2012.

The English translation for the Finnish National Memory Strategy 2012-2020 is in process.

9.1.2 Duration of the National Dementia Strategy

The Strategy is valid from 2012 to 2020. It involves recommendations for policymakers. The actual implementation plan will be in liaison with a vast National Development Programme for Social Welfare and Health Care (Kaste) with the National Institute for Health and Welfare. The implementation plan is in process.

9.1.3 How the National Dementia Strategy is funded

The development of the Strategy was funded by the Finnish Ministry of Social Affairs and Health. However, there is no mention in the Strategy of the funding for the various measures proposed.

9.1.4 Provisions or procedure for implementing the Strategy

The funding of the implementation plan is still to be determined.

9.1.5 Procedure for monitoring progress made in achieving the goals set

The same as mentioned above.

9.1.6 Involvement of the Alzheimer association (and/or people with dementia)

The Alzheimer Society of Finland had one representative in the working group. There were no people with dementia involved. The Alzheimer Society of Finland recommended regional forums on the matter to ensure that people with dementia would be heard.

9.1.7 Alzheimer association's overall assessment of the National Dementia Strategy

The Alzheimer Society of Finland is pleased to see the Strategy taking a firm stance on brain health and the prevention of memory-related diseases. Rehabilitation – in addition to good care, is also one of the four basic principles, and the right for self-determination is pinpointed as well. These are important aspects concerning the well-being and the quality of life of people with dementia.

The Society is now expecting a strict policy for the implementation and monitoring of the Strategy, including firm time schedules and details of the organisations in charge.

9.2 Diagnosis, treatment and research

9.2.1 Issues relating to diagnosis

9.2.1.1 *Timely diagnosis in the National Dementia Strategy*

A significant proportion of people with dementia are still not diagnosed, which leads to the excessive use of social and health services and is also extremely costly to society. That is why public and occupational healthcare professionals have to recognise early memory problems and direct people to memory examinations when required. The aim is to diagnose dementia and start medical treatment and good care and rehabilitation as early as possible. The investment in the good expertise of social and healthcare professionals is needed.

9.2.1.2 *Which healthcare professionals are responsible for diagnosing dementia*

In Finland, there is a memory nurse in every municipality whom older people can consult should they have concerns about their memory. These nurses are fully trained to administer the MMSE and if they detect a problem, they can make a report which the person can then take to the doctor. The municipalities are obliged to provide such a service and the memory nurse can visit people in their own homes.

9.2.1.3 *Required tests to diagnose dementia*

CT or MRI scans are often carried out and MMSE used. These are not obligatory but often used as part of the thorough examination carried out by specialists which are necessary if the AD drugs are to be reimbursed.

9.2.1.4 *Issues related to medical treatment in the National Dementia Strategy*

As stated above, one of the aims in the National Dementia Strategy is to start medication early and to ensure that healthcare professionals have the sufficient expertise.

9.2.1.5 *The availability of medicines in general*

In Finland, medicines are generally reimbursed at a level of 42% of the cost of medicines. Nevertheless, for serious and chronic conditions, the reimbursement system lists a number of medicines for which the reimbursement can be 72% of the cost or a refund of 100% of costs exceeding EUR 3 per product. Should the total pharmaceutical expenses of an individual exceed EUR 675.39 in a year, the excess of EUR 1.50 per product prescribed is refunded⁷.

9.2.1.6 *The availability of Alzheimer treatments*

All AD drugs are available in Finland and are part of the reimbursement system.

⁷ European Commission (2012): MISSOC – Mutual information system on social protection: Social protection in the Member States of the European Union, of the European Economic Area and in Switzerland: Comparative tables

9.2.1.7 Conditions surrounding the prescription and reimbursement of AD drugs

The reimbursement system does not provide a list of specific examinations to be carried out, but for Alzheimer treatments to be reimbursed a diagnosis of Alzheimer's disease must be established by a specialist who carries out a thorough examination which often includes a CT or MRI scan. There are no upper or lower MMSE limits for treatment with different AD drugs. Any doctor can prescribe Alzheimer treatments, but to be reimbursed, the prescription must be accompanied by a statement from a specialist doctor. There are no restrictions as to the access of people living alone or in nursing homes to available Alzheimer treatments. In open wards, the normal reimbursement continues, whereas for formal institutional care, the institution covers the cost of these medicines.

Prescription and reimbursement	Donepezil	Rivastigmine	Galantamine	Memantine
Available	Yes	Yes	Yes	Yes
Reimbursed	Yes	Yes	Yes	Yes
Initial drug reimbursed if prescribed by	Statement needed from a specialist	Statement needed from a specialist	Statement needed from a specialist	Statement needed from a specialist
Required examinations	None	None	None	None
MMSE limits	None	None	None	None

9.2.2 Issues relating to research

Research and the competence of social and health care professionals is one of the four basic principles of the Strategy. Multidisciplinary and coordinated research is seen essential to combat the challenge that dementia builds on public health services and economy.

We have and need high-quality, versatile and nationwide research. Research on brain health, diagnostics and care services has already helped to develop new innovations, but we still need more on the psychosocial support and the possibilities of technology for the people with dementia. We also need to ensure that research results are rapidly transformed into action especially in the public healthcare services, so that practice is evidence based.

Finland is involved in the EU Joint Programme – Neurodegenerative Disease Research (JPND) and is an Associate partner in the Joint Action “Alzheimer Cooperative Valuation in Europe (ALCOVE)”.

9.2.3 Any additional medical or scientific issues covered in the National Dementia Strategy

The Strategy has four basic principles:

- 1) Brain health is a life-long theme

Everyone needs to take care of their own brain health throughout life, but it has to be taken into consideration in every sector of the society, for example in social and health services and in education and community planning.

2) Memory-related diseases touch us all – attitudes matter

The negative and discriminative attitudes towards dementia have diminished the well-being of people with dementia. The attitudes need to be shifted in order to people with dementia living a meaningful life as an equal member of the society.

3) Good care pays off

The goal is to have a solid chain of social and health services, which are planned and coordinated. Medical treatment and rehabilitation support living at home. Palliative care is also being taken into account.

4) Strengthening the research and expertise

9.3 Acknowledgements

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10 France

10.1 Background information about the National Dementia Strategy

10.1.1 Status and historical development of the National Dementia Strategy

Three main stages can be identified in the development of a National Dementia Strategy in France resulting in three successive plans. A detailed article on these three plans has been written by Marie-Jo Guisset-Martinez (2012). A few points are mentioned here. The first plan stemmed from a report written by Girard and Canestri in 2000 in which the problem of stigma was highlighted and the need to develop a dedicated strategy to address dementia. Four key issues were highlighted as needing particular attention. These focused on problems related to diagnosis, the lack of services, inadequate coordination within the healthcare sector and the provision of information to the public (Guisset-Martinez, 2012). A set of recommendations by Girard (2001) led to the adoption by the French Ministry of Health of the “Programme of people suffering from Alzheimer’s disease and related disorders”. This was the first national Alzheimer plan which ran from 2001 to 2004 and covered the implementation of a network of memory consultants, the creation of day care centres and measures to improve the quality of residential care for people with cognitive impairments.

The second plan was launched in 2004 with the aim of building on the progress made during the first plan. According to Guisset-Martinez (2012), it is difficult to assess how successful this was as there was no specific budget allocated to it. Nevertheless, 2007 was the year in which Alzheimer’s disease was declared a major national cause (*Alzheimer Grande Cause Nationale*).

The third plan resulted from the work of a national expert committee led by Professor Joël Ménard (Guisset-Martinez, 2012). This committee organised a nation-wide consultation involving working groups, interviews and audits with family carers, advocacy groups, service providers, professional bodies and academic and research experts. The report was presented by Prof. Ménard to the President of the French Republic in 2007 accompanied by a series of recommendations. The third plan was launched in 2008. It has 11 objectives and 44 measures.

10.1.2 Duration of the National Dementia Strategy

The three plans cover a period of time stretching from 2001 to 2012, namely 2001 – 2004, 2004 – 2007 and 2008 – 2012.

10.1.3 How the National Dementia Strategy is funded

The third Alzheimer plan had an initial budget of EUR 1.6 billion.

10.1.4 Provisions or procedure for implementing the Strategy

The “Plan Alzheimer Mission” was set up to evaluate the implementation of the plan and to oversee the use of funding for the achievement of the objectives of the plan.

10.1.5 Procedure for monitoring progress made in achieving the goals set

A National Steering Committee was set up to monitor the achievements and barriers to the achievement of the actions outlined in the third plan.

10.2 Diagnosis, treatment and research

10.2.1 Issues relating to diagnosis

10.2.1.1 *Timely diagnosis in the National Dementia Strategy*

Measure 8 of the third plan addressed the preparation and implementation of a system for disclosing the diagnosis and providing counselling. The objective was to improve the conditions surrounding the disclosure of the diagnosis and the provision of support thereafter. This was to be achieved by drafting and validating a reference system for communicating the diagnosis and for the associated support (which was published in November 2009); establishing training for the professionals concerned, implementing a system of disclosure in specialist units and implementing measures for disclosure and support with primary care doctors.

A working group was set up to draft the arrangements which would be validated by a consensus group working with the HAS (*Haute Autorité de Santé*). A reference system was to be produced and specific training created along with an adaptation of pricing where necessary. The arrangements were due to be implemented within and outside hospitals between 2009 and 2012.

In order to make and disclose the diagnosis, as well as to provide support, the HAS has taken the following measures:

- A first recommendation in March 2008 on the diagnosis and care of people Alzheimer’s disease and related disorders;
- a guide for doctors on long-term medical conditions in May 2009, which permits people with dementia to have 100% of their care for this condition covered;
- a recommendation on the disclosure of the diagnosis and support in November 2009.

These documents were distributed by the “Caisse Nationale d’Assurance Maladie” to 40,000 doctors in December 2010.

In April 2012, the HAS and the ANESM (the national agency for the evaluation and quality of social and medico-social establishments and services) also elaborated a summary of the measures for support: linked to the disclosure of the diagnosis, the development of a care plan, support at home and within care establishments. A plan for support to be effective from the moment that a diagnosis is made and which creates a link between

doctors and the MAIA (*Maison pour l'Autonomie et l'Intégration des malades d'Alzheimer*) has been elaborated:

- the tool for communication between specialists and GPs was published in October 2011 (annex 5 of the Communication of 20 October 2011 regarding the organisation of the diagnosis and the follow-up of people with Alzheimer's disease and related disorders);
- a long consultation at home in the presence of the carer was decided upon (inscription in the convention of general practitioners - CNAMTS (*Caisse nationale de l'assurance maladie des travailleurs salariés*) – signed on 26 July 2011) and became operational at the beginning of 2012;
- a tool for doctors elaborated by the INPES (*Institut national de prévention et d'éducation pour la santé*) called "*Repères pour votre pratique. Maladie d'Alzheimer – Réaliser une visite longue*" (guidelines for your practice. Alzheimer's disease – carrying out a long visit). This is a guide to carrying out a meeting in order to better discern the situation of the patient and his/her carer.

Another measure which should affect timely diagnosis was the creation of more memory units, particularly in areas not yet covered. This was measure 11 of the third plan. There were 366 memory units in 2006 located in short-stay institutions throughout the country and it was envisaged in the third plan to create a further 38 memory units for which EUR 6.68 million was set aside for this task. In 2010, an additional 21 units had been created (Official Press Release, 2010).

In 2008, there were 25 CMRRs (memory resource and research centres) in 23 regions of France which provided diagnosis in the most complex cases and for the earliest forms of dementia. Measure 12 of the third plan envisaged the creation of new centres to be set up in Auvergne, Corsica and Limousine. EUR 1.14 million was set aside for the creation of these new centres. The centres in Auvergne and Limousine were set up in 2008 and the one in Corsica was planned for 2011 (Official website update, 2010). In addition, a national reference centre for young people with Alzheimer's disease (i.e. under the age of 60) was set up in February 2009. This has a network of contacts all over France who are able to provide specific advice.

As some of the memory units were particularly busy, it was considered necessary to provide them with more funds so as to reduce the time taken to obtain a specialist memory assessment and guarantee the quality of the service provided, particularly with regard to the disclosure of the diagnosis. This resulted in allocating additional resources (amounting to EUR 12.3 million in total) to 122 approved memory units. Eventually, 202 centres were given additional support. The success of this measure was estimated as being satisfactory in 2009 with the average waiting time being an average of 51 days and 4 out of 5 people receiving an appointment in less than three months (Official Press Release, 2010).

Other measures linked in the plan to improving access to diagnosis and care pathways include the creation of an Alzheimer's disease information card for each patient and experimentation with new payment terms for health professionals.

10.2.1.2 Which healthcare professionals are responsible for diagnosing dementia

GPs are authorised to carry out a pre-diagnosis before orientating patients towards specialists in memory centres or to independent specialists such as neurologists, geriatricians or psychiatrists. GPs cannot make the initial prescription of AD drugs unless they have obtained qualifications in geriatrics in which case they would have become geriatricians.

The specialists who are mainly responsible for diagnosing dementia are neurologists, geriatricians and, to a lesser extent, psychiatrists.

GPs do not have set consultation times for the pre-diagnosis of dementia. Consequently, they would not receive additional payment for a longer consultation. However, since 2012 they can carry out one long consultation per year for each person with dementia and his/her carer. GPs receive a higher payment for this compared to their standard consultations.

10.2.1.3 Type and degree of training of GPs in dementia

GPs receive initial training followed by a module in geriatrics plus 12 additional hours of practice which include the use of tests.

Continued education exists but is not obligatory. The Regional Union of Healthcare Professionals (*Union Régionale des professionnels de santé*) has been offering for some time now training by doctors for GP practices.

10.2.2 Issues relating to medical treatment

10.2.2.1 Medical treatment in the National Dementia Strategy

Measure 15 of the third plan is to improve the correct use of medical drugs. The objective is described as being "to improve the quality of practice and the use of psychotropic drugs in this disease". This was to be achieved by:

- drafting clinical practice recommendations about sedation for behavioural problems in difficult situations and on how to handle behavioural problems;
- by drafting and circulating programmes to evaluate and improve professional practice in the effective use of medication, including psychotropic drugs, in elderly patients including those with Alzheimer's disease.

A working group was to be set up to draft those recommendations in 2008 with implementation planned in 2009. The recommendations of the HAS on the diagnosis and care of people with Alzheimer's disease and related disorders were published in March 2008. In May 2011, these recommendations were withdrawn for formal legal reasons

(*des raisons juridiques formelles*). This caused some disturbance amongst both patients and professionals. The Commission for Transparency, which was in charge of evaluating AD drugs for the HAS, concluded on 27 October 2011 that AD drugs had limited therapeutic benefit and recommended limiting their prescription to one year, renewable subject to strict conditions being fulfilled. In November 2011, the HAS therefore published a new recommendation on the diagnosis and care of people with Alzheimer's disease and related disorders in order to bring up to date its chapter on medical treatment according to the new declaration of the Commission for Transparency. Moreover, the recommendations for the management of acute confusion in elderly people of disturbing behavioural symptoms were published in May 2009.

A warning indicator measuring the exposure of people with Alzheimer's disease to neuroleptics was set up by the HAS. A reduction in the use of neuroleptics at national level has been noted of 16.9% to 15.5% between 2007 and 2010. This indicator is not being followed in the MAIA territories, at regional level, at national level and at European level (as a joint action with ALCOVE). It will also be retained as a quality indicator in care homes.

10.2.2.2 The availability of medicines in general

France has different reimbursement levels for medicines depending on the efficacy of the medicines and the seriousness of the disease or symptoms. Patients may have to contribute between 0% and 85% towards the cost of medication depending on the recognition of the medical service provided plus a flat-rate co-payment of EUR 0.50 per package of medicine with a limit of EUR 50 per year per person⁸.

10.2.2.3 The availability of Alzheimer treatments

All four AD drugs are available.

10.2.2.4 Conditions surrounding the prescription and reimbursement of AD drugs

All AD drugs are available in France and are fully reimbursed at 100% through the reimbursement system. However, full reimbursement has recently been called into question.

There are no specific examinations which are specified by the reimbursement system, but reimbursement of acetylcholinesterase inhibitors is limited to people with Alzheimer's disease with an MMSE score ranging between 26 and 10 and memantine to patients with an MMSE score below 15.

The French system requires the initial treatment decision and prescription to be carried out by a specialist (a neurologist, psychiatrist or geriatrician), whereas continuing treatment prescriptions can be filled in by GPs as well. There are no restrictions as to the access of people living alone or in nursing homes to available AD treatments.

⁸ European Commission (2012): MISSOC – Mutual information system on social protection: Social protection in the Member States of the European Union, of the European Economic Area and in Switzerland: Comparative tables

France Alzheimer clarified that although the market authorisation for all four products is for Alzheimer’s disease, the French system also has a system of temporary authorisations (*“autorisations temporaires d’utilisation”*) for diseases for which no treatment is available. Under that system, some people with Lewy body dementia, vascular dementia and Parkinson’s disease dementia also have access to these treatments.

Prescription and reimbursement	Donepezil	Rivastigmine	Galantamine	Memantine
Available	Yes	Yes	Yes	Yes
Reimbursed	Yes	Yes	Yes	Yes
Initial treatment decision	Specialist (neurologist, psychiatrist or geriatrician)	Specialist (neurologist, psychiatrist or geriatrician)	Specialist (neurologist, psychiatrist or geriatrician)	Specialist (neurologist, psychiatrist or geriatrician)
Continuing treatment decision	Specialist or GP	Specialist or GP	Specialist or GP	Specialist or GP
Required examinations	None but reimbursement depends on MMSE score	None but reimbursement depends on MMSE score	None but reimbursement depends on MMSE score	None but reimbursement depends on MMSE score
MMSE limits	26 - 10	26 -10	26 - 10	Below 15

10.2.3 Issues relating to research
10.2.3.1 Research in the National Dementia Strategy

Objective 7 of the third plan was to make unprecedented efforts in research. The following 13 measures (as numbered in the plan) were designed to achieve this objective:

- 21. Creating a foundation for scientific cooperation to stimulate and coordinate scientific research: This was created in June 2008 with public and private funding.
- 22. Developing clinical research into Alzheimer’s disease and improving the evaluation of non-drug therapies. Each year the Fondation Plan Alzheimer launches calls for clinical research projects.
- 23. Providing doctoral and post-doctoral grants: In the period 2008-2010, 146 theses on Alzheimer’s disease were identified and 36 post-doctoral studies financed. The survey was renewed in November 2012.
- 24. Creating new assistant surgeon and hospital teaching assistant positions: Calls for applications have been made since 2008 which led to the appointment of new heads of clinics/assistants.
- 25. Promoting research in human and social sciences: Every year, the Fondation Plan Alzheimer launches calls for research projects in the human and social sciences. Seventeen projects have been selected between 2009 and 2012.
- 26. Providing support for research groups working on innovative approaches: There were four calls for project in 2012 and four in 2010.

27. Providing support for methodological research groups in human and social sciences: In May 2010 a methodological group was set up.
28. Creating a body of research into automatic image processing: In June 2010, a centre for the acquisition and computerised treatment of images was established.
29. Studying large patient populations (cohorts) with long-term monitoring: A cohort (3C) stretching back over 10 years and involving 6,000 subjects aged 75 and over is being followed up. However, there is a risk of not reaching the objective for 2012.
30. Organising a high-speed genotyping project: Considerable progress has been made. Two new genes affecting susceptibility were identified (CLU and CRI), the study was replicated in the United States of America and in 2011 the International Genomic Alzheimer Project was launched involving 30,000 people with Alzheimer's disease and 60,000 controls.
31. Exploiting the genome sequencing of the microcebe (which is a lemur): Between 2009 and 2011, ten projects were financed at a cost of EUR 3 million.
32. Promoting training in clinical epidemiology (in order to increase the number of doctors taking part in research protocols): 637 people have been trained since 2009 and a further 189 have completed e-training courses.
33. Developing links between public research and industry: A DIU (*Diplôme interuniversitaire*) has been created and congresses organised involving the private and public domains as well as enquiries into the ongoing clinical studies.

By 2010, 61 research projects had received funding (total amount EUR 30 million). The studies covered basic, clinical and therapeutic research, as well as research into new technologies and human and social science research. In addition, 54 new researchers were recruited over two years.

10.2.3.2 European involvement in research

France is involved in the EU Joint Programme – Neurodegenerative Disease Research (JPND) and is an Associate partner in the Joint Action “Alzheimer Cooperative Valuation in Europe (ALCOVE)”.

10.3 References

Guisset-Martinez, M-J. (2012), Three Alzheimer plans in France (2008-2012). In Innes, A., Kelly, F. and McCabe, L., *Key issues in evolving dementia care: international theory-based policy and practice*, London, Jessica Kingsley, pp.122-136.

10.4 Acknowledgements

Judith Mollard, Expert Psychologist, Association France Alzheimer

Fanny Gaspard, Public Policies Executive, Association France Alzheimer.

11 Germany

11.1 Background information about the National Dementia Strategy

11.1.1 Status and historical development of the National Dementia Strategy

The Ministry for Families, Senior Citizens, Women and Youth (BMFSFJ) gave an order to a research institute to evaluate national dementia plans in other countries. In a workshop with various experts the results of the research report were discussed. Most of the experts held the opinion that Germany also needed a dementia strategy. The secretaries of state of BMFSFJ and the Ministry for Health (BMG) arranged for another meeting to build a “national alliance for people with dementia”. It took place on 21 June 2012. On 19 September 2012, the fields of actions for this Alliance were adopted. The work should consist of a cooperative process between the actors of the Alliance

11.1.2 Involvement of the Alzheimer association (and/or people with dementia)

The German Alzheimer Association is involved in all these events. It was one of the actors that took the initiative to discuss the necessity of a National Dementia Plan in writing a letter to the German chancellor asking for such a plan. The German Alzheimer association thinks that a National Dementia Plan for Germany is necessary to coordinate the activities in several fields and to provide standards in medical treatment and care.

11.2 Diagnosis, treatment and research

11.2.1 Issues relating to diagnosis

11.2.1.1 Which healthcare professionals are responsible for diagnosing dementia

GPs are allowed to diagnose and prescribe medication without the need to refer to a specialist. In some areas, especially in rural areas, there are not many specialists. Consequently, it can take about three to five months to see a specialist (e.g. a psychiatrist or neurologist).

Whilst it is up to the GP how long s/he takes to see a patient, it can sometimes be a problem because the money the GP receives per visit is fixed in that it is based on a contract between the healthcare insurance and the doctor's association. From the point of view of the German Alzheimer Association, people go too late to the doctor and when they do go it is not because of a memory problem but for a different reason.

11.2.1.2 Required tests to diagnose dementia

Consensual guidelines have been drawn up by the national medical and scientific associations concerning the diagnosis and treatment of Alzheimer's disease. These include the S3-guidelines of the Deutsche Gesellschaft für Psychiatrie, Psychotherapie und Nervenheilkunde (DGPPN) and the Deutsche Gesellschaft für Neurologie (DGN) and the Guidelines of the Deutschen Gesellschaft für Allgemeinmedizin (DEGAM).

The guidelines lay down the tests which need to be done and in which cases a CT should be carried out. Their implementation would represent great progress, also concerning early diagnosis. Unfortunately, for different reasons the guidelines don't seem to be considered very important in daily practice.

11.2.2 Issues relating to medical treatment

11.2.2.1 General issues related to treatment

Since 2004 the Institute of Quality and Economy of the Health System (IQWiG) has been evaluating the efficiency of medical and non-medical therapies of Alzheimer's disease. It does not evaluate the extent to which medical treatment is provided to those who need it.

11.2.2.2 The availability of medicines in general

In Germany, patients generally pay 10% of the cost of medicines with a minimum contribution of EUR 5 per product and a maximum contribution fixed at EUR 10⁹. Nevertheless, the system also makes exceptions for children and hardship cases for whom no contributions are required.

For some products, the system sets fixed prices. If the cost of the product exceeds this fixed price, a patient is required to also cover the difference in addition to the set prescription charge.

11.2.2.3 The availability of Alzheimer treatments

All AD drugs are available in Germany and are part of the reimbursement system.

11.2.2.4 Conditions surrounding the prescription and reimbursement of AD drugs

There are no specific examinations which are required for medicines to be reimbursed nor does the system provide upper or lower MMSE limits for the treatment with different AD drugs. There are no restrictions as to the access of people living alone or in nursing homes to available Alzheimer treatments. The German system does not limit treatment initiation or continuation decisions to specialist doctors. The German Alzheimer Association underlines that due to the introduction of medicines budgets for individual doctors, some doctors are less inclined to prescribe Alzheimer treatments.

⁹ European Commission (2011): MISSOC – Mutual information system on social protection: Social protection in the Member States of the European Union, of the European Economic Area and in Switzerland: Comparative tables

Prescription and reimbursement	Donepezil	Rivastigmine	Galantamine	Memantine
Available	Yes	Yes	Yes	Yes
Reimbursed	Yes	Yes	Yes	Yes
Initial drug reimbursed if prescribed by	No restrictions	No restrictions	No restrictions	No restrictions
Continuing treatment reimbursed if prescribed by	No restrictions	No restrictions	No restrictions	No restrictions
Required examinations	None	None	None	None
MMSE limits	None	None	None	None
People living alone	No restrictions	No restrictions	No restrictions	No restrictions
People in nursing homes	No restrictions	No restrictions	No restrictions	No restrictions

11.2.3 Issues related to research

The Ministry for research 2009 started to build up the German centre for neuro-degenerative diseases (DZNE) and supports it with EUR 66 million per year. The centre is situated in Bonn and coordinates the cooperation with several other university institutes all over Germany.

Research into Alzheimer’s disease and other forms of dementia is carried out in the medical, biological, psychological, epidemiological and other departments of several universities, Max Planck Institutes and other institutions. In Witten/Herdecke care science is carried out as a part of the DZNE.

Germany is involved in the EU Joint Programme – Neurodegenerative Disease Research (JPND) but not in the Joint Action “Alzheimer Cooperative Valuation in Europe (ALCOVE)”.

11.3 Acknowledgements

Sabine Jansen, Executive Director, Deutsche Alzheimer Gesellschaft e.V. Selbsthilfe Demenz.

Hans-Jürgen Freter, Vice Executive Director, Deutsche Alzheimer Gesellschaft e.V. Selbsthilfe Demenz.

12 Greece

12.1 Background information about the National Dementia Strategy

12.1.1 Status and historical development of the National Dementia Strategy

There is no approved national dementia strategy in Greece. A plan has been developed and submitted to the Greek parliament by the Greek Federation of Alzheimer's Disease and Related Disorders. The Federation also presented a petition with the signatures of more than 15,000 people who supported its campaign for a national dementia strategy to the Mayor of Athens and representatives from the Ministry of Health in September 2010.

12.1.2 Involvement of the Alzheimer association (and/or people with dementia)

See above.

12.2 Diagnosis, treatment and research

12.2.1 Issues relating to diagnosis

12.2.1.1 Which healthcare professionals are responsible for diagnosing dementia

GPs may make a diagnosis of dementia or refer patients to a specialist for diagnosis. Some GPs are well trained in making such a diagnosis, others less so. It is mainly neurologists and psychiatrists, and to a much lesser extent geriatricians, who diagnose dementia and/or Alzheimer's disease.

GPs do not have fixed consultation times and the time that they can dedicate to each patient is very limited. It is difficult to spend more time with patients with dementia. Some GPs manage very well in the limited time available but they are few in number.

There are no specific incentives to improve or increase timely diagnosis by GPs. Some pharmaceutical companies have helped the Greek Federation of Alzheimer's Disease and Related Disorders to train GPs but the GPs have to find the time to participate in these training courses.

12.2.1.2 Type and degree of training of GPs in dementia

GPs do not receive official training in dementia as part of their professional training to become a GP. However, Prof. Magda Tsolaki was invited to give three one-hour lectures at the hospital. This was not part of a national plan to educate GPs about dementia but nevertheless provided a minimum of 1 to 3 hours' training in dementia for those GPs who attended. Continuing education is not yet obligatory for GPs in Greece.

12.2.1.3 Required tests to diagnose dementia

Established criteria, cognitive and functional tests, and a test for depression are used in the diagnosis of dementia. However, there are no specific recommendations or guidelines that must be followed and there are no obligatory tests.

12.2.2 Issues relating to medical treatment

12.2.2.1 The availability of medicines in general

Until today, the Greek system provides for different levels of participation of patients to the cost of medicines¹⁰. As a general rule, patients should pay 25% of the cost of medicines prescribed by a doctor. Nevertheless, for certain diseases such as Parkinson's disease or Crohn's disease, this contribution from patients is reduced to 10%. Similarly, the contribution is reduced to 10% for retired people receiving the minimum pension. Finally, for certain chronic conditions such as cancer or diabetes, medicines are fully covered.

12.2.2.2 The availability of Alzheimer treatments

All four AD drugs are available to patients in Greece and are part of the reimbursement system.

12.2.2.3 Conditions surrounding the prescription and reimbursement of AD drugs

Greece requires the initial treatment decision to be taken by a neurologist or psychiatrist, but does not have any restrictions for continuing treatment decisions which can be made by any practitioner. GPs cannot write the initial prescription for AD drugs. In practice, some GPs do make the initial prescription as this is inadequately controlled.

Greece does not require any specific diagnostic examinations to be carried out, nor does the system provide upper or lower treatment limits. The Greek system reimburses medicines for people living alone or in nursing homes.

Prescription and reimbursement	Donepezil	Rivastigmine	Galantamine	Memantine
Available	Yes	Yes	Yes	Yes
Reimbursed	Yes	Yes	Yes	Yes
Initial drug reimbursed if prescribed by	Neurologist or psychiatrist	Neurologist or psychiatrist	Neurologist or psychiatrist	Neurologist or psychiatrist
Continuing treatment reimbursed if prescribed by	No restrictions	No restrictions	No restrictions	No restrictions
Required examinations	None	None	None	None
MMSE limits	None	None	None	None

¹⁰ European Commission (2012): MISSOC – Mutual information system on social protection: Social protection in the Member States of the European Union, of the European Economic Area and in Switzerland: Comparative tables

12.2.3 Issues relating to research

Current research programmes in Greece include, amongst others:

- (a) European projects: (BIOMARK-APD, NILVAD, Pharmacog, LLM, Dem@care (the last two are based on new technologies),
- (b) National projects: (1) The Collaboration for Cognitive problems (En-NOHSHS) which has six partners which have good ideas for diagnosis, prevention and management of dementia with new technologies. (2) "Excellence" The best CV of the principal investigator (robotics, sports science and tele-education of caregivers).
- (c) Doctoral theses (PhD): (1) Virtual reality in the diagnosis of Alzheimer's disease; (2) The ability of expression of patients' wishes with Alzheimer's disease; (3) Helicobacter of pylori and Alzheimer's disease; (4) Driving and Alzheimer's disease; (5) Non pharmacological management of BPSD;. (6) The retinal thickness in patients with Alzheimer's disease.
- (d) Research programmes in the day care centres - different non pharmacological interventions.

Greece is involved in the EU Joint Programme – Neurodegenerative Disease Research (JPND) and is an Associate member of the "Alzheimer Cooperative Valuation in Europe (ALCOVE)".

12.3 Acknowledgements

Magda Tsolaki MD, PhD, Neuropsychiatrist, Theologist, Professor, Aristotle University of Thessaloniki, Chair of Greek of Federation of Alzheimer Disease.

13 Hungary

13.1 Issues relating to medical treatment

13.1.1 The availability of medicines in general

In Hungary, in-patient medicines are free of charge. Some pharmaceutical drugs are subsidised by the National Health Insurance Fund (Egészségbiztosítási Pénztár) at various levels of reimbursement. This amounts to 100% of the price for certain chronic diseases and patients just have to pay a packing fee of HUF 300 (approx. EUR 0.95). Elderly people with low income and disabled persons can receive a special card which gives them a right to free medicines¹¹.

13.1.2 The availability of Alzheimer treatments

Except for galantamine, AD drugs are available in Hungary

13.1.3 Conditions surrounding the prescription and reimbursement of AD drugs

The available AD drugs are part of the reimbursement system (50% reimbursement). Prescriptions both for treatment initiation and for treatment continuation need to be filled in by specialist doctors. There are no restrictions as to the access of people living alone or in nursing homes to available Alzheimer treatments but continuous treatment must be guaranteed.

Since 1999, there have been several national guidelines for the diagnosis and treatment of Alzheimer's disease. The 2006 guideline was accepted by the Ministry of Health and prescribes a number of diagnostic examinations (MMSE, Laboratory tests and either a CT or MRI scan).

Since 2003, special dementia centres have been instituted (at the time of print, the number of these centres was 84) which are led by neurologists or psychiatrists. Physicians of these centres have the right to prescribe donepezil, rivastigmine and memantine with reimbursement.

Prescription and reimbursement	Donepezil	Rivastigmine	Galantamine	Memantine
Available	Yes	Yes	No	Yes
Reimbursed	Yes	Yes	No	Yes
Initial drug reimbursed if prescribed by	Specialist	Specialist	Specialist	Specialist
Continuing treatment reimbursed if prescribed by	Specialist	Specialist	Specialist	Specialist

11 European Commission (2012): MISSOC – Mutual information system on social protection: Social protection in the Member States of the European Union, of the European Economic Area and in Switzerland: Comparative tables

Prescription and reimbursement	Donepezil	Rivastigmine	Galantamine	Memantine
Required examinations	According to guidelines	According to guidelines	According to guidelines	According to guidelines
MMSE limits	26-10	26-10		18-0

13.2 Issues relating to research

Hungary is involved in the EU Joint Programme – Neurodegenerative Disease Research (JPND) and is a Collaborator in the Joint Action “Alzheimer Cooperative Valuation in Europe (ALCOVE)”.

14 Ireland

14.1 Background information about the National Dementia Strategy

14.1.1 Status and historical development of the National Dementia Strategy

According to the Chair of the Alzheimer Society of Ireland, the initial impetus for the launch of the Irish Dementia Strategy came from Alzheimer Europe's Paris Declaration. In 2006, the Irish association began lobbying MPs and influencers to make dementia a national priority.

This initial effort was not successful. However, a TV documentary about the poor living conditions of people with dementia provoked public reaction and restarted the debate. This was helped by an Irish Minister speaking out about the difficulties of caring for his wife, who was living with dementia. In addition, the Irish association received a grant that was used to fund a major communications campaign.

The national Irish dementia strategy is due to be launched in 2013.

14.1.2 Involvement of the Alzheimer association (and/or people with dementia)

The Alzheimer Society of Ireland campaigned with other NGOs in the age sector with a single voice.

14.2 Diagnosis, treatment and research

14.2.1 Issues relating to diagnosis

14.2.1.1 Which healthcare professionals are responsible for diagnosing dementia

GPs can diagnose dementia, prescribe medication (which would be refundable) and make repeat prescriptions. They can also refer patients to specialists if they see fit. Referrals would be made to a psychiatrist of old age or a geriatrician. Neurologists do not generally deal with cases of dementia.

GPs have fixed consultation times of 15 minutes. It is possible to book a "double appointment" (i.e. 30 minutes) for which patients would be charged accordingly. Some GPs operate a discretionary policy around this, especially if they know the patient.

14.2.1.2 Type and degree of training of GPs in dementia

GPs receive one month's training in psychiatry and one month in neurology. Dementia is discussed in both of these areas, but it is not treated as a separate issue. All GPs are obliged to do CPD (continuous professional development) and have to obtain a certain number of points (calculated in hours) per year in order to retain their registration. The main trainer of GPs is the Irish College of General Practitioners (<http://www.icgp.ie/>). There are no incentives for GPs to improve or increase timely diagnosis.

14.2.1.3 Required tests to diagnose dementia

As long as a drug is approved (by the Irish Medicine’s Board) and prescribed by a doctor, it qualifies for the medical card (an almost-free medicine scheme) and the drug payment scheme (the patient pays a ceiling price regardless of the cost of the drug and the state pays the balance). There is no diagnostic process involving obligatory tests that has to be adhered to in order for the drugs to be made available under either scheme, largely because there is no one national diagnostic process. There are recommended criteria but no national guidelines for the diagnosis of dementia.

14.2.2 Issues relating to medical treatment

14.2.2.1 The availability of medicines in general

People with full eligibility must pay EUR 0.50 per prescribed item up to an amount of EUR 10 per family per month. Drugs prescribed for the treatment of a specified long-term illness are free of charge. Under the Drug Payment Scheme, no individual or family is required to pay more than EUR 120 per month for approved prescribed medicines and medical devices¹².

14.2.2.2 The availability of Alzheimer treatments

All AD drugs are available in Ireland and are part of the general system described above.

14.2.2.3 Conditions surrounding the prescription and reimbursement of AD drugs

There are no specific examinations which are required for medicines to be made available to patients, nor does the system provide upper or lower MMSE limits for the treatment with different AD drugs. There are no restrictions as to the access of people living alone or in nursing homes to available Alzheimer treatments. Finally, prescriptions can be filled in by any doctor and are not limited to specialists, be it for treatment initiation or continuation decisions.

Prescription and reimbursement	Donepezil	Rivastigmine	Galantamine	Memantine
Available	Yes	Yes	Yes	Yes
Reimbursed	Yes	Yes	Yes	Yes
Initial drug reimbursed if prescribed by	No restrictions	No restrictions	No restrictions	No restrictions
Continuing treatment reimbursed if prescribed by	No restrictions	No restrictions	No restrictions	No restrictions
Required examinations	None	None	None	None
MMSE limits	None	None	None	None

12 European Commission (2011): MISSOC – Mutual information system on social protection: Social protection in the Member States of the European Union, of the European Economic Area and in Switzerland: Comparative tables

14.2.3 Issues relating to research

Ireland is involved in the EU Joint Programme – Neurodegenerative Disease Research (JPND) but not in the Joint Action “Alzheimer Cooperative Valuation in Europe (ALCOVE)”.

14.3 Acknowledgements

Maurice O’Connell, The Alzheimer Society of Ireland, Chief Executive Officer

Grainne McGettrick, The Alzheimer Society of Ireland, Research and Policy Officer

15 *Italy*

15.1 **Background information about the National Dementia Strategy**

15.1.1 **Status and historical development of the National Dementia Strategy – details needed**

The Italian Ministry of Health has created a 10-point working document aimed at the future development of a National Dementia Strategy similar to that of France. The document has been held up for many months at the level of the Conferenza Stato-Regione (the official meeting that deals with the relationship between the State and the Regions) because of the problem in Italy that healthcare is managed by the regions. Each region in Italy has its own model of healthcare.

15.1.2 **Involvement of the Alzheimer association (and/or people with dementia)**

Alzheimer Uniti Onlus Italy has participated in many technical groups of the Ministry of Health involved in the development of a strategy and some of its fellow associations have actively participated in the development of their own regional plans.

15.2 **Diagnosis, treatment and research**

15.2.1 **Timely diagnosis in the future National Dementia Strategy**

Timely diagnosis is one of the 10 points addressed in the working document mentioned earlier aimed at the future development of National Dementia Strategy. The 10 points are still only a recommendation but the exact phrase regarding timely diagnosis is: "Optimization of the diagnostic process and upgrading of the social welfare process."

15.2.2 **Issues relating to diagnosis**

15.2.2.1 ***Which healthcare professionals are responsible for diagnosing dementia***

There are about 500 UVAs (Alzheimer Evaluation Units) in Italy. These are specialist services for the diagnosis and treatment of Alzheimer's disease and other forms of dementia. GPs can diagnose dementia privately but not officially. If the GP suspects Alzheimer's disease or dementia, the GP then sends the person to a UVA, as described above.

Geriatricians, neurologists and psychiatrists can diagnose dementia and/or Alzheimer's disease. It is the geriatricians, neurologists and sometimes (but not often) the psychiatrists who are responsible for each Alzheimer Evaluation Unit.

GPs do not have a fixed consultation time. They can decide for themselves how much time to spend with each patient. There are no incentives for GPs to improve or increase timely diagnosis.

15.2.2.2 Type and degree of training of GPs in dementia

All medical students study dementia whilst at medical school but those who specialise in geriatrics or neurology study it in greater depth. Continuing education is an obligation for GPs. GPs and all doctors must be re-accredited through official courses. Each course carries a number of credits and a doctor must obtain a certain number of credits per year.

15.2.2.3 Required tests to diagnose dementia

The criteria of the NINCDS-ADRDA must be used in order to diagnose dementia and/or Alzheimer's disease.

15.2.3 Issues relating to medical treatment**15.2.3.1 The availability of medicines in general**

Medicines in Italy are included in one of two groups:

Group A is for medicines termed essential or for serious diseases and are free of charge. However, in the case where there is a generic form available but the patient prefers a brand name, the patient pays the difference.

Group C is for other medicines for which the full costs must be borne by the patient.

Each region has its regional tax ("ticket") on medicines and the rate varies from region to region. However, the tax is waived for people over 65 years of age or for those with an income below EUR 35,000 per year or for a person with an officially recognised disability.

15.2.3.2 The availability of Alzheimer treatments

The AIFA (Italian Medicines Agency), as the national authority responsible for drug regulation, has authorised current medical treatments for dementia. All AD drugs are therefore available in Italy. Each region has autonomy over healthcare matters.

15.2.3.3 Conditions surrounding the prescription and reimbursement of AD drugs

In order to be reimbursed for AD drugs in Italy, the drug must be included on the specified list (please see above). However, this list is continually changed by the government. Moreover, the health system has been split into around 20 regions and each operates differently.

Treatment with acetylcholinesterase inhibitors is available for people with an MMSE score between 26 and 10. Memantine is available for people with an MMSE score between 18 and 10.

There are no specific restrictions as to the access of people living alone or in nursing homes to available Alzheimer treatments.

Prescription and reimbursement	Donepezil	Rivastigmine	Galantamine	Memantine
Available	Yes	Yes	Yes	Yes
Reimbursed	Yes	Yes	Yes	Yes
Initial drug reimbursed if prescribed by	UVA	UVA	UVA	UVA
Continuing treatment reimbursed if prescribed by	UVA	UVA	UVA	UVA
Required examinations	Clinical Diagnosis	Clinical Diagnosis	Clinical Diagnosis	Clinical Diagnosis
MMSE limits	15-10	15-10	15-10	18-10

15.2.4 Issues relating to research

Italy is involved in the EU Joint Programme – Neurodegenerative Disease Research (JPND) and is an Association member of the Joint Action “Alzheimer Cooperative Valuation in Europe (ALCOVE)”.

Research is one of the 10 points addressed in the working document mentioned earlier aimed at the future development of National Dementia Strategy. As mentioned above, the 10 points are only a recommendation but the exact phrase is: “Development of clinical guidelines and promotion of scientific research.”

15.3 Acknowledgements

Professor Luisa Bartorelli, Geriatrician and President of Alzheimer Uniti Onlus.

16 *Jersey*

16.1 **Background information about the National Dementia Strategy**

16.1.1 **Status and historical development of the National Dementia Strategy**

The Jersey Health and Social Services Department (HSSD) signed up to the equivalent of the UK National Dementia Strategy in October 2009. An initial meeting was held between the department and Jersey Alzheimer's Association but very little has been done since then.

However, the Jersey HSSD is in the process of putting together an Outline Business Case to present to the Government for increased funding for dementia care. It incorporates a lot of the points which were covered in the National Dementia Strategy and will probably supersede it. As the initial document signed by the HSSD may be different to that which is finally implemented, it will be referred to hereafter as "the Plan".

16.1.2 **Duration of the National Dementia Strategy**

The initial goal of the Plan was to transform the way that people with dementia and their carers are cared for in the next five years. However, as stated above, nothing has been done since the signing of the document in 2009.

16.1.3 **How the National Dementia Strategy is funded**

There is no specific funding for the Plan.

16.1.4 **Provisions or procedure for implementing the Strategy**

Nothing specific has been agreed.

16.1.5 **Procedure for monitoring progress made in achieving the goals set**

Nothing has been agreed.

16.1.6 **Involvement of the Alzheimer association (and/or people with dementia)**

Jersey Alzheimer's Association was instrumental in drawing up the Plan and getting it adopted by HSSD. The implementation of the Plan was to be a joint project between Jersey Alzheimer's Association and HSSD.

16.1.7 **Alzheimer association's overall assessment of the National Dementia Strategy**

The Jersey Alzheimer's Association considers the Plan, as drawn up by them, good.

16.2 Diagnosis treatment and research

16.2.1 Issues relating to diagnosis

16.2.1.1 *Timely diagnosis in the National Dementia Strategy*

In the Plan, there are three recommendations which are specifically related to the issue of timely diagnosis:

Recommendation 1: Increased public and professional awareness of dementia.

According to Jersey Alzheimer's Association, poor public and professional awareness about dementia is one of the most significant problems to overcome. People currently wait up to three years before seeking help after symptoms first develop. A long-term programme of public education is needed in order to arrive at a situation whereby people know what dementia is and that help is available. It must also ensure that when people ask for help, doctors and social workers are in a position to know what can be done. It was also stated that public and professional awareness and understanding of dementia should be improved and the stigma associated with it addressed. Individuals should be informed of the benefits of timely diagnosis and care, the prevention of dementia should be promoted, and social exclusion and discrimination should be minimised.

Recommendation 2: good quality early diagnosis and intervention for all

The third recommendation states that all people with dementia should have access to a pathway of care that delivers:

- a rapid and competent specialist assessment;
- an accurate diagnosis that is sensitively communicated to the person with dementia and their carers; and,
- immediate treatment, care and support following diagnosis.

It is further stated that the system must have the capacity to see everyone with dementia. The development of specialist memory services is proposed, including consultants, social care workers and the voluntary sectors to ensure effective diagnosis and access to ongoing information and support.

Jersey Alzheimer's Association points out that people with dementia are often told that forgetfulness is just a natural part of ageing or are wrongly diagnosed with depression. Sometimes they have to go back to the doctor three or four times before they are referred on for help, or there is no developed diagnostic service available. When a diagnosis is made it is often made inappropriately. The development of memory assessment services, which can act as a hub for diagnosis and access to information and advice, would be a significant and positive development in dementia care.

Recommendation 3: good quality information for those with dementia and their carers throughout the course of their care.

The Plan proposes that this could be in the form of an information prescription on diagnosis where people are given information about local services and support available.

Jersey Alzheimer's Association points out that people with dementia and their families want to have good information about their condition and what they can expect. They also want to take control of their lives by having information about what sources of help are available. Improving access to information will significantly improve the current situation. Such information should be available in paper and electronic versions as well as by phone.

16.2.1.2 Which healthcare professionals are responsible for diagnosing dementia

GPs usually raise the possibility of dementia and refer people on to the Memory Clinic for further investigation. Diagnoses of dementia and/or Alzheimer's disease are therefore usually made by the Memory Clinic.

GPs have consultation times of 10 – 15 minutes but these can be extended at the discretion of the GP in the case of dementia. Multiple appointments are also an alternative. All GPs are encouraged to use 6CIT screening tool which is quick and evidence based.

There are as yet no incentives for GPs to improve or increase timely diagnosis.

16.2.1.3 Type and degree of training of GPs in dementia

GPs receive training in dementia through psychiatry/medical attachments as a student/junior doctor.

Continuing education is an obligation for GPs. There is an appraisal system in place to help doctors identify deficiencies and opportunities for further learning.

16.2.1.4 Required tests to diagnose dementia

GPs are encouraged to perform a battery of blood tests before referral to identify any underlying cause. More sophisticated psychometric tests are the province of specialists.

16.2.2 Issues relating to medical treatment

16.2.2.1 The availability of medicines in general

Pharmaceutical products are free at the point of delivery for Jersey residents.

16.2.2.2 The availability of Alzheimer treatments

All four AD drugs are available. They are all prescribed as generics.

16.2.2.3 Conditions surrounding the prescription and reimbursement of AD drugs

Certain tests are expected to be performed by GPs in the first instance and then more sophisticated tests are performed by specialists once patients have been transferred. There are no strict cut-off scores on the MMSE and people who live alone as well as those living in nursing homes receive AD drugs if indicated. As AD drugs are free at the point of delivery, the issue of reimbursement for initial or continuing treatment does not arise.

Prescription and reimbursement	Donepezil	Rivastigmine	Galantamine	Memantine
Available	Yes	Yes	Yes	Yes
Reimbursed	N/A	N/A	N/A	N/A
Initial drug reimbursed if prescribed by	N/A	N/A	N/A	N/A
Continuing treatment reimbursed if prescribed by	N/A	N/A	N/A	N/A
Required examinations	Assessment in Memory Clinic	Assessment in Memory Clinic	Assessment in Memory Clinic	Assessment in Memory Clinic
MMSE limits	No strict limits	No strict limits	No strict limits	No strict limits

16.2.3 Issues relating to research

Jersey is not involved in the EU Joint Programme – Neurodegenerative Disease Research (JPND) or in the Joint Action “Alzheimer Cooperative Valuation in Europe (ALCOVE)”.

16.3 References

National Dementia Strategy drawn up by the Jersey Alzheimer’s Association.

16.4 Acknowledgements

Kim Averty, Honorary Secretary of the Jersey Alzheimer’s Association.

17 Latvia

17.1 Issues relating to medical treatment

17.1.1 The availability of medicines in general

Pharmaceutical drugs are reimbursed on the basis of the type, character and severity of diseases at either 100%, 75% or 50%. Those which are eligible for reimbursement are included on “the positive list” and further divided into three categories (A, B and C)¹³. List A contains clusters of interchangeable pharmaceutical products and the reference price for each cluster is that of the cheapest product based on the form, dosage and package size. List B contains products which are not interchangeable and List C contains products which are considered expensive (e.g. treatment exceeding LVL 3,000 (EUR 4,288) a year). The reimbursement of pharmaceuticals products is also possible if a person’s disease is not included in the list of diagnoses for which reimbursement would be possible but their life would be endangered without that particular drug. The reimbursement of pharmaceutical drugs cannot exceed LVL 10,000 (EUR 14,292) per person per 12 months.

17.1.2 The availability of Alzheimer treatments

All four AD drugs are available but none of them are part of the reimbursement system.

17.1.3 Conditions surrounding the prescription and reimbursement of AD drugs

Prescription and reimbursement	Donepezil	Rivastigmine	Galantamine	Memantine
Available	Yes	Yes	Yes	Yes
Reimbursed	No	No	No	No

17.2 Issues relating to research

Latvia is not involved in the EU Joint Programme – Neurodegenerative Disease Research (JPND) but is an Associate member of the Joint Action “Alzheimer Cooperative Valuation in Europe (ALCOVE)”.

13 European Commission (2012): MISSOC – Mutual information system on social protection: Social protection in the Member States of the European Union, of the European Economic Area and in Switzerland: Comparative tables

18 Lithuania

18.1 Issues relating to medical treatment

18.1.1 The availability of medicines in general

Medicines in Lithuania are fully covered for children under 18, persons with group 1 disability and for hospital treatment. 50% of the price of medicines is covered for old-age pensioners, persons with group 2 disability and other persons entitled to a social insurance protection¹⁴.

The Lithuanian system prescribes reimbursement levels for medicines for specific diseases on a special list for which reimbursement can be 50%, 80%, 90% or 100% depending on the disease.

18.1.2 Conditions surrounding the prescription and reimbursement of AD drugs

In Lithuania, only donepezil and memantine are part of the reimbursement system. People with an MMSE score between 20 and 0 can qualify for the reimbursement of donepezil. There are no restrictions in Lithuania for the reimbursement of these treatments for people living alone or in nursing homes.

Prescription and reimbursement	Donepezil	Rivastigmine	Galantamine	Memantine
Available	Yes	No	No	Yes
Reimbursed	Yes	N/A	N/A	Yes
Required examinations	MMSE	N/A	N/A	
MMSE limits	20-0	N/A	N/A	

18.2 Issues relating to research

Lithuania is not involved in the EU Joint Programme – Neurodegenerative Disease Research (JPND) but is an Associate member of the Joint Action “Alzheimer Cooperative Valuation in Europe (ALCOVE)”.

¹⁴ European Commission (2011): MISSOC – Mutual information system on social protection: Social protection in the Member States of the European Union, of the European Economic Area and in Switzerland: Comparative tables

19 Luxembourg

19.1 Background information about the National Dementia Strategy

19.1.1 Status and historical development of the National Dementia Strategy

Discussions between the Ministry of Health and the Ministry of Family and Integration have commenced in order to develop a national dementia strategy for Luxembourg. The development of a "*plan démence*" (dementia plan) became an integral part of the coalition agreement.

19.1.2 Involvement of the Alzheimer association (and/or people with dementia)

Working groups have been set up and the national Alzheimer association (Association Alzheimer Luxembourg) will take part in the discussions.

19.2 Diagnosis, treatment and research

19.2.1 Issues relating to diagnosis

19.2.1.1 Which healthcare professionals are responsible for diagnosing dementia

GPs are permitted to diagnose dementia and/or Alzheimer's disease, as are all medical doctors in Luxembourg. GPs do not have set consultation times and can therefore allocate as much time as they wish to their patients.

19.2.1.2 Type and degree of training of GPs in dementia

It is not possible to study to become a GP in Luxembourg. GPs who work in the country have therefore all completed their medical training elsewhere. The type and amount of training in dementia received by GPs therefore varies from one individual to another.

19.2.1.3 Required tests to diagnose dementia

CT or MRI and MMSE are used in the diagnosis of dementia. Such tests are not obligatory but they are essential for a person to be refunded for AD drugs.

19.2.2 Issues relating to medical treatment

19.2.2.1 The availability of medicines in general

Medicines in Luxembourg can fall under one of four different reimbursement systems:

- Normal reimbursement of medicines amounts to 80%,
- Preferential reimbursement is 100%,
- Reduced reimbursement is 40% and.
- Certain medicines are not reimbursed.¹⁵

¹⁵ European Commission (2011): MISSOC – Mutual information system on social protection: Social protection in the Member States of the European Union, of the European Economic Area and in Switzerland: Comparative tables

19.2.2.2 The availability of Alzheimer treatments

In Luxembourg, all AD drugs are available.

19.2.2.3 Conditions surrounding the prescription and reimbursement of AD drugs

AD drugs are part of the normal reimbursement system and are reimbursed at 80%. Reimbursement is nevertheless dependent on prior approval by the medical control unit of the Social Security Ministry. Any doctor can fill in this application for reimbursement, but specific information needs to be provided in order to determine whether a patient fulfils the DSM IV definition of Alzheimer’s disease. In practice, most applications are filled in by neurologists or psychiatrists. A reimbursement decision is made for six months only, after which a follow-up examination is necessary and treatment continuation is possible.

Treatment with acetylcholinesterase inhibitors is for people with MMSE scores between 26 and 10 and memantine for MMSE scores below 15.

There are no restrictions in Luxembourg for the reimbursement of these treatments for people living alone or in nursing homes.

Prescription and reimbursement	Donepezil	Rivastigmine	Galantamine	Memantine
Available	Yes	Yes	Yes	Yes
Reimbursement	Yes	Yes	Yes	Yes
Initial drug reimbursed if prescribed by	No restrictions	No restrictions	No restrictions	No restrictions
Continuing treatment reimbursed if prescribed by	No restrictions	No restrictions	No restrictions	No restrictions
Required examinations	Diagnostic protocol	Diagnostic protocol	Diagnostic protocol	Diagnostic protocol
MMSE limits	26-10	26-10	26-10	< 15

19.2.3 Issues relating to research

Luxembourg is involved in the EU Joint Programme – Neurodegenerative Disease Research (JPND) and is a Collaborator in the Joint Action “Alzheimer Cooperative Valuation in Europe (ALCOVE)”.

19.3 Acknowledgements

Dr Carine Federspiel, Directrice Médicale, ZithaSenior Centrale, Luxembourg.

20 *Malta*

20.1 Background information about the National Dementia Strategy

20.1.1 Status and historical development of the National Dementia Strategy

The development of a National Dementia Strategy started with the setting up of the Malta Dementia Strategy Group in May 2009 (please see below). This resulted in a report comprising ten recommendations following consultation with healthcare experts and various stakeholders organised by the Malta Dementia Strategy Group. Stakeholders came from five groups, namely education, professional bodies, long-term care service providers, acute and intermediate service providers and the community. The community consisted of the Maltese Dementia Society, the general public, representatives from the Catholic Church and local council representatives. Following the consultation with stakeholders, the general public were invited to provide further feedback by means of a widely publicised questionnaire which could be filled in anonymously and was available on Internet or by post. 613 completed questionnaires were received and analysed. For details of the findings, please see Scerri (2012).

The Malta Dementia Strategy Plan is in its final stages of completion and its publication falls within the remit of the Malta Ministry of Health, the Elderly and Community Care. It is intended to include measures aimed at improving the quality of life of individuals with dementia, their caregivers and relatives. These measures are expected to be implemented between the years 2012 and 2020.

20.1.2 Involvement of the Alzheimer association (and/or people with dementia)

The Malta Dementia Society has been involved from the very beginning. Members of the Malta Dementia Society Management Committee formed the core of the Malta Dementia Strategy Group of experts entrusted to devise a series of recommendations that would provide a comprehensive strategic framework that would lay the ground for the final plan. Indeed, the General Secretary of the Malta Dementia Society acted as Chairperson for the Strategy Group. The document containing the recommendations as well as ways with which these could be achieved was presented to the central health authorities in January of 2010.

20.2 Diagnosis, treatment and research

20.2.1 Issues relating to diagnosis

20.2.1.1 *Timely diagnosis in the planned National Dementia Strategy*

In Malta, the majority of individuals with dementia are not diagnosed early on in the disease process. This is mainly because there is not enough awareness of the early symptoms that characterise the condition both among the general public as well as healthcare professionals. Most of these individuals are cared at home leading to significant caregiver burnout (Innes et al., 2011). The inaccurate notion that dementia symptoms are part of normal ageing is still prevalent and this leads to a delay in seeking medical advice.

The Dementia Plan envisages the need for timely diagnosis and support. This can be achieved by increasing awareness about the condition at all levels, drawing up a referral pathway and adequate protocols for diagnosis, increasing the number of dementia specialists and providing support to patients and caregivers following diagnosis.

The Dementia Society of Malta advocates that every individual with suspected dementia should have the opportunity of timely diagnosis through the utilisation of specialised services such as those offered by the Memory Clinic and upon diagnosis to have a long-term care plan drawn up.

20.2.1.2 Which healthcare professionals are responsible for diagnosing dementia

All medical professionals in Malta have the authority to diagnose dementia. Dementia can therefore be diagnosed by a GP or a specialist. However, GPs' consultation times, in most cases, are brief and usually do not exceed ten minutes. GPs' times are not fixed by appointment and depend on GPs' discretion. Specialists usually have longer appointment times but charge significantly higher fees compared to GPs.

The duration of each appointment is not fixed but is solely at GPs' discretion.

Currently there are no incentives that improve timely diagnosis.

20.2.1.3 Type and degree of training of GPs in dementia

GPs do not receive a great deal of training on dementia during their medical studies (i.e. more than 10 hours during their undergraduate training).

Currently, professional undergraduate training on dementia does not exceed ten hours in total during the 5-year medical course. In the past, it used to be much less. Specialised training programmes in family medicine include a 2-month part-time post in geriatrics where GP trainees have the opportunity to experience ageing and dementia on a 'hands-on' basis. Training mostly focuses on the medical model.

There is no obligation for continuing education. However, seminars and talks on subjects of interest are organised by local associations of family doctors usually in collaboration with the pharmaceutical industry. Attendance at these gatherings is usually rewarded by CPD (continuing professional development) points. Dedicated websites are also available (<http://mcfcd.org.mt>, <http://www.thesynapse.net>).

20.2.1.4 Required tests to diagnose dementia

There are no official guidelines yet concerning tests which must be used in order to diagnose dementia and/or Alzheimer's disease. Diagnostic tools are therefore at the GP's discretion although the MMSE is perhaps the most popular. The National Plan envisages the setting up and adoption of a protocol for diagnosis to be used in governmental-run healthcare settings.

20.2.2 Issues related to medical treatment

20.2.2.1 *Medical treatment in the planned National Dementia Strategy*

In the recent past, Malta was one of two countries in the European Union that did not provide any sort of financial assistance for AD medication. Indeed, this was one of the ten recommendations that were included in the document drawn up by the Malta Dementia Strategy Group and presented to the authorities in January 2010. Such recommendation is also included in the final Plan. Although the latter has not yet been published, the central health authorities felt that such situation needed to be rectified. As a result, in March of 2012, dementia was included in Schedule V of the Malta Social Security Act which lists a number of chronic conditions to which free medication should be available by the government health services (<https://ehealth.gov.mt/download.aspx?id=6853>).

The National Plan recommends that free entitlement to AD medication only occurs following diagnosis by specialists in governmental-run healthcare settings. GPs would still be able to prescribe them but it would be an out-of-pocket expense for patients. This was done to ensure that diagnosis is conducted by specialists rather than GPs who, in most cases, do not have the necessary training in diagnosing dementia.

20.2.2.2 *The availability of medicines in general*

The government supplies medicines free of charge to all in-patients in government hospitals and for three days following discharge. Otherwise they are supplied on a means-tested basis. There are two schedules under the Social Security Act Cap. 318 to grant free medicines:

Schedule II (referred to as the Pink Card), entitles households with low total income (means tested) to medicines listed in the Government Formulary, subject to completion of certain requirements (e.g. hospital consultant's signature in the case of certain medicines). A Pink Card can also be issued for people with tuberculosis, leprosy or poliomyelitis and their after effects. People with diabetes can also benefit from this schedule.

Schedule V (referred to as the Yellow Card), entitles people with diseases listed under the fifth schedule of the Social Security Act for free medicines for that condition irrespective of financial position. These include many chronic diseases such as malignancy, chronic cardiovascular and respiratory disease, collagen disease, endocrine diseases, schizophrenia and others. The list has recently (February 2012) been updated and includes dementia.

For more information on medicines entitlement in Malta refer to: https://ehealth.gov.mt/HealthPortal/strategy_policy/pharm_pol_mon/med_entitle_unit/schedule_v.aspx.

20.2.2.3 *The availability of Alzheimer treatments*

All four AD drugs are available in Malta and can be purchased through out-of-pocket payments. Dementia has recently been included in the Schedule V list and AD drugs should be available free of charge after being included in the national formulary. However, a drug protocol would have to be drawn up first which stipulates which patients are

entitled to the drugs, based on the level of cognitive impairment, the type of dementia etc. Consequently, inclusion in the Schedule V does not necessarily mean that the drugs are provided for free immediately.

Free treatment is expected to continue following approval by the specialist. The latter will also be responsible for discontinuation of treatment.

20.2.2.4 Conditions surrounding the prescription and reimbursement of AD drugs

Prescriptions can be made both by specialists and family doctors. Assessment and diagnostic tools vary but most healthcare professionals make use of the MMSE. MMSE limits have not yet been determined but should be indicated in the planned drug protocol.

An MRI scan is not obligatory although most individuals suspecting dementia and attending the Memory Clinic are usually prescribed imaging, depending on the situation.

There are no restrictions on the prescription of AD drugs to people who live alone or are in residential care.

Prescription and reimbursement	Donepezil	Rivastigmine	Galantamine	Memantine
Available	Yes	Yes	Yes	Yes
Reimbursed (expected to be free in the near future)	(No)	(No)	(No)	(No)
Initial drug reimbursed if prescribed by	No restrictions on prescription but not refunded	No restrictions on prescription but not refunded	No restrictions on prescription but not refunded	No restrictions on prescription but not refunded
Continuing treatment reimbursed if prescribed	No restrictions on prescription but not refunded	No restrictions on prescription but not refunded	No restrictions on prescription but not refunded	No restrictions on prescription but not refunded
Required examinations	MMSE is the preferred tool	MMSE is the preferred tool	MMSE is the preferred tool	MMSE is the preferred tool
MMSE limits.	Not yet determined	Not yet determined	Not yet determined	Not yet determined

20.2.3 Issues relating to research

Dementia research in Malta is mostly conducted on a personal level. Researchers in this particular field of study are few and financial resources limited. Most of the published research comes from the University of Malta, the only tertiary education establishment in the Maltese islands. There is international collaboration in several areas of dementia research spanning molecular and cellular aspects of the disease process as well as its impact on the Maltese society. The forthcoming Dementia Plan envisages the need for

training and research in dementia also in view of the fact that the number of elderly individuals is expected to rise significantly in the coming years.

Malta is not involved in the EU Joint Programme – Neurodegenerative Disease Research (JPND) but is a Collaborator in the Joint Action “Alzheimer Cooperative Valuation in Europe (ALCOVE)”.

20.3 References

Innes A, Abela S and Scerri C. (2011). The organisation of dementia care by families in Malta: The experiences of family caregivers. *Dementia* 10(2): 165-184.

Scerri C. (2012). Challenges of developing a dementia strategy: the case of Malta. In: A. Innes, F. Kelly and L. McCabe, *Key issues in Evolving Dementia Care: International Theory-based Policy and Practice*. London: Jessica Kingsley, pp. 150-172. ISBN 978-0-470-19510-9.

20.4 Acknowledgements

Charles Scerri, General Secretary of the Malta Dementia Society and Senior Lecturer at the Faculty of Medicine & Surgery, University of Malta.

21 *Netherlands*

21.1 **Background information about the National Dementia Strategy**

In the past, Alzheimer Nederland (the Dutch Alzheimer Society) initiated and participated in two national programmes to improve dementia care. The first was the National Dementia Programme, a four-year programme (2005-2008). Alzheimer Nederland coordinated with the Ministry of Public Health, Welfare and Sport and the Netherlands Institute for Care and Welfare (Vilans) a programme for regional providers of care, welfare and the treatment of dementia to improve dementia care from a client's perspective. It was a bottom-up programme. The participation of regional networks of care providers was voluntary. The results were impressive: 90% of the country participated with 206 improvement projects fitting the needs of patients and families. Providers of care, welfare and treatment worked together with volunteers from the Alzheimer Nederland. Alzheimer Nederland collected the wishes and demands of families of patients in 160 focus groups and by means of a survey amongst caregivers (N=1500). Nevertheless, more incentives were necessary to integrate help for people with dementia and their families from the beginning until the end of the dementia. The budget for the first National Dementia programme was EUR 2.82 million.

Therefore, in 2008 the second programme started: 'Purchasing integrated dementia care'. What was new about this programme was the participation of the national umbrella organisation representing the healthcare insurance companies (ZN) in the Netherlands. The goal was to provide and purchase integrated support including case management. A purchase guide was developed with a description of the "ideal region" for people with dementia and families from the beginning until the end of the dementia, based on the clients' perspective. ZN made guidelines to finance the integrated care. Care providers who developed integrated dementia care, including case management, received an extra budget. Again, volunteers participated as patients' advocates, being spokespeople for people with dementia and their families in the region. At the end of the programme (end of 2011) 90% of the country participated in purchasing integrated dementia care. Alzheimer Nederland organised the evaluation (focus groups and questionnaire) of the programme from a client perspective. The annual budget for purchasing integrated care during the four-year programme was around EUR 10 million. For 2013, EUR 15.5 million has been allocated to purchase integrated dementia care.

From January 2011 until May 2012, the national standard for dementia care was developed. This is the first national integral standard on dementia and it includes welfare, care, treatment and housing standards which meet the wishes of patients and their families. It encompasses all professional guidelines, best practises and evidence-based interventions. Alzheimer Nederland was project leader. In total, 28 branch organisations and associations of professionals in dementia care were involved. From 2012, the standard will be used to purchase integrated care in 85 dementia care networks. Case management for people with dementia is a crucial part of the national standard.

In the summer of 2011, Alzheimer Nederland, VUmc Alzheimer Centre and the national umbrella organisation of medical university hospitals (NFU) took the initiative for a new national plan. The new national plan is called the “Delta Plan Dementia”. The name “Delta Plan” was chosen as it reflects the increase in the numbers of people with dementia in a similar way to the expected flood of 1953. After the flood, a national strategy was formed to fight a possible new flood. Embankments along the coast and dikes in river areas were built and great pieces of land were reclaimed.

21.1.1 Status and historical development of the National Dementia Strategy

At the start of the initiative, several national companies were invited to support and take part in the coalition. Rabo Bank, Achmea (the biggest health insurance company) and PGGM (a leading Dutch pension administrator with its roots in the healthcare and social work sector) were the first to join. A first meeting was organised at the Ministry of Health, Welfare and Sports with attendance of three directors (long-term care, treatment and public health) of the ministry. The Delta Plan Dementia was presented with a strong focus on scientific research and two other elements: a national e-health platform for patients, carers and professionals and a national patient registry to improve the quality of diagnostics, treatment and care. The total amount of money requested is EUR 200 million.

After the initial meeting other companies expressed their interest such as Philips, Nutricia, CZ (another health insurance company), KPMG (consultancy), Vital Valley (computer technology) as well as the national confederation of industry and employers (VNO-NCW) and the national organisation of health research and development (ZonMw). They together formed a steering committee which in the past months worked out the plan in terms of a project plan, business case, requested budgets and so on. It was envisaged to present the plan to the Minister in May 2012. However, in April the government fell and new elections were organised for September. The plan will be presented to the minister after the formation of a new government.

21.1.2 Duration of the National Dementia Strategy

The Delta Plan Dementia will last for 8 years. We think it will start after the new government has given its financial commitment for the plan. In December, a meeting with the Minister (Ms Edith Schippers, Labour Party, also minister in the last period) and State Secretary (Mr Martin van Rijn, Socialist Party, former CEO of PGGM) is scheduled. The Minister has declared her interest in the Delta Plan in the parliament. The newly appointed State Secretary was chairman of the steering committee of Alzheimer Nederland's initiative.

21.1.3 How the National Dementia Strategy is funded

Funding is intended to come both from public sources (government and national research funds) and private sources. Alzheimer Nederland will invest a part of its budget for scientific research. It will draw up a communication and marketing plan to raise funds together with the parties involved in the Delta Plan.

21.1.4 Provisions or procedure for implementing the Strategy

Alzheimer Nederland formed a broad alliance of public and private parties. Umbrella organisations are informed on a regular basis and will be involved in setting up the research programme and developing the e-health platform and national registry. Alzheimer Nederland also involved Vilans (the Netherlands Institute for Care and Welfare) which has access to regional networks of care providers.

21.1.5 Procedure for monitoring progress made in achieving the goals set

Each element of the Delta Plan has a separate project plan and will be organised by the participants in the way which seems best. Each element will be led by a project leader who will be appointed by a steering group. Progress is monitored by the steering group on a monthly basis.

21.1.6 Involvement of the Alzheimer association (and/or people with dementia)

Alzheimer Nederland was one of the parties which took the initiative to develop the plan. The Delta Plan fits completely with the strategic plan of Alzheimer Nederland which was recently set up for the period 2012 to 2015. In the context of the new strategic plan, a research agenda was developed with the involvement of people with dementia, family caregivers, lay people and scientists. The development took three quarters of a year and involved focus groups and interviews. This research agenda will be followed in the Research Programme that is part of the Delta Plan. This serves as an excellent base for the further participation of people with dementia and family caregivers in the research field. Alzheimer Nederland has been invited by the other parties to take a leading role in the Delta Plan Dementia.

21.1.7 Alzheimer association's overall assessment of the National Dementia Strategy

As mentioned, the Delta Plan Dementia fits very well within the strategic plan of Alzheimer Nederland. Alzheimer Nederland's aim is to spend EUR 20 million on research in 2020 (in 2011 about EUR 2 million was spent. The DPD supports our ambition to find solutions for both the patients of today as well as the patients of the future.

21.2 Diagnosis, treatment and research

21.2.1 Issues relating to diagnosis

21.2.1.1 *Which healthcare professionals are responsible for diagnosing dementia*

GPs may diagnose dementia but should refer patients to a basic memory clinic in case of comorbidity, behavioural problems, psychiatric problems, severe system problems and/or refusal of care. In general, neurologists and geriatricians diagnose patients in memory clinics assisted by geriatric nurses and/or psychologists. In some cases, referral to a specialist memory clinic is necessary because of the complexity and/or necessity of specific diagnostic equipment.

GPs can charge for double consultation time and diagnostic tests in the case of dementia. Patients must ask for an extended consultation. Such requests are not always granted. There is no further incentive for GPs to improve or increase timely diagnosis.

21.2.1.2 *Type and degree of training of GPs in dementia*

GP's receive almost no professional training in dementia in their basic education. Therefore, the association of GPs has started a programme to train GP's in the care of frail older people including people with dementia. This will result in a growing number of GPs having a specialisation in the care of frail older people.

GPs have a obligation for continuing education in general to update their knowledge.

21.2.1.3 *Required tests to diagnose dementia*

GPs and specialists each have a set of guidelines which are slightly different for each group. The guideline for GPs was recently published (NHG Standard, July 2012). A new guideline for specialists is announced for the end of 2013. Although guidelines are well known, they are not always followed. There is also a national care dementia standard which encompasses all professional guidelines and tries to address inconsistencies between different guidelines. Alzheimer Nederland developed the national care standard which was finished in May 2012. The care standard guides health insurance companies to contract regional dementia care.

21.2.2 *Issues relating to medical treatment*

21.2.2.1 *The availability of medicines in general*

The health insurance system in the Netherlands is a mixture of private and public insurance schemes. In 2006, there was a huge change in the system. Hospital and GP care, drugs and other short-term care are now insured by private insurance companies, within the framework of public rules about acceptance, settlement of bad risks and price. Long-term care is still part of public insurance.

Only pharmaceutical products with a marketing authorisation are added to a positive list by the health ministry.

Products with a reference price are listed in annex 1a. If a reference price cannot be allocated to a product it will be placed in annex 1b. When deciding about the reimbursement of products in annex 1b the therapeutic value of the product is considered. If the therapeutic value of a product is low, it will not be considered eligible for reimbursement. Some drugs in the positive list are classified into annex 2. These drugs are reimbursed only if certain criteria are fulfilled. The criteria could be, for example, that the prescription must be written by a specialist physician.

21.2.2.2 *The availability of Alzheimer treatments*

With the exception of donepezil, AD drugs are available in the Netherlands and are part of the reimbursement system. Since these drugs are on annex 2 of the positive list, cer-

tain criteria need to be fulfilled prior to reimbursement. Treatment with acetylcholinesterase inhibitors is for people with MMSE scores between 26 and 10 and memantine for MMSE scores between 14 and 3.

There are no restrictions in the Netherlands for the reimbursement of these treatments for people living alone. Although there are no restrictions in theory for the access of people in nursing homes, Alzheimer Nederland stresses that reimbursement remains problematic, since the cost of treatment would need to be covered by the budgets of the nursing home and may thus be dependent on a positive decision of the home in question.

21.2.2.3 Conditions surrounding the prescription and reimbursement of AD drugs

GPs and specialists can both make the initial and follow-up prescriptions of AD drugs but the initial prescription would only be reimbursable if made by a specialist.

Prescription and reimbursement	Donepezil	Rivastigmine	Galantamine	Memantine
Available	No	Yes	Yes	Yes
Reimbursed	N/A	Yes	Yes	Yes
Initial drug reimbursed if prescribed by	N/A	Specialist	Specialist	Specialist
Continuing treatment reimbursed if prescribed by	N/A	No restrictions	No restrictions	No restrictions
Required examinations	N/A	Diagnostic protocol	Diagnostic protocol	Diagnostic protocol
MMSE limits	N/A	26-10	26-10	14-3

21.2.3 Issues relating to research

Alzheimer Nederland was founded in 1984 and the statutes laid down provisions to optimise research. However, it took until 2000 to actually allocate money and effort to research. Initially Alzheimer Centres for research were launched in university hospitals, in Maastricht (2000), Amsterdam (2001), Nijmegen (2005) and Rotterdam (2012) respectively. This means that in half of the university hospitals an Alzheimer Centre has been founded. Since 2010, Alzheimer Nederland has been organising a call for proposals. The first call had a focus on diagnostics. In 2011, the theme of the annual call was “psycho-social interventions”. In 2012, the theme was “origins of the disease”. In 2011, Alzheimer Nederland also launched a fellowship programme which enables researchers to travel to other countries and then return and practice what they had learned. Currently, Alzheimer Nederland is the biggest non-profit organisation for research in the field of dementia in the Netherlands.

It is not possible for the State to say how much it spends on dementia research. Alzheimer Nederland estimates this figure to be around EUR 10 million, but this is for research into brain, cognition and frail older people programmes, not specifically on dementia itself.

In 2011, the Society drew up a common research agenda with patients, carers, scientists and lay people. The same issues were identified by each group: 1. diagnostics, 2. origins of the disease, 3. psychosocial interventions, 4. medical interventions, 5. prevention, and 6. care research. In the context of the JPND initiative, the Society also carried out an inventory on the strengths of dementia research and the results suggest that basic research was not considered as good but research on genetics, imaging and bio-markers, clinical research, and the establishment of a brain bank, psychological interventions and technical innovation (e-health and housing) all ranked as good.

The Delta Plan Dementia is close to the JPND research agenda. Contributions by the government into JPND will be organised with the Delta Plan Dementia. The Netherlands is involved in the EU Joint Programme – Neurodegenerative Disease Research (JPND) and is a collaborator in the Joint Action “Alzheimer Cooperative Valuation in Europe (ALCOVE)”. However, Alzheimer Nederland itself feels it is not involved in the way it should be.

21.3 Acknowledgements

Marco Blom, Director Scientific Research.

Julie Meerveld, Manager Advocacy.

22 *Norway*

22.1 Background information about the National Dementia Strategy

22.1.1 Status and historical development of the National Dementia Strategy

In 2006, the Norwegian government issued Report nr 25 (2005–2015) to the Parliament – Care plan 2015. Dementia was one of the elements in focus in this strategy and in 2007, the Ministry of Health and Care Services launched the Dementia Plan 2015 as a sub-plan to Care Plan 2015. The Dementia Plan 2015 includes a 4-year action plan. In 2011, the action plan was revised.

22.1.2 Duration of the National Dementia Strategy

The Dementia Plan officially started in 2007 and runs until 2015.

22.1.3 How the National Dementia Strategy is funded

The Dementia Plan 2015 is funded by the Norwegian government. Unfortunately, in the first years of the plan period, the funding was limited. From 2012, the government granted NOK 200 million (approx. EUR 262,000). The main grant was given to establish day programmes in the municipalities. NOK 15,000 was aimed at establishing carer support and educational programs in the municipalities. After 18 months, 72% of all Norwegian municipalities provide an educational or support program for family carers.

22.1.4 Provisions or procedure for implementing the Strategy

The national government uses both law and grants to meet the goals set in the Dementia Plan 2015. The main executor is the municipalities.

22.1.5 Procedure for monitoring progress made in achieving the goals set

“Ageing and Health”, the Norwegian Centre for Research, Education and Service Development, was assigned by the Ministry of Health and Care Services to monitor and report on status. The last report was made in 2011 and shows that although some progress has been made, a lot of challenges still remain.

22.1.6 Involvement of the Alzheimer association (and/or people with dementia)

The Norwegian Alzheimer Association was involved in the development as an advisor to the government. Regarding implementation, the Norwegian Alzheimer Association has received some financial support for its dementia help-line and for its information efforts, training for primary carers and support groups organised by the local branches. The Norwegian Alzheimer Association is also an important lobbyist for implementation of the national strategies, mainly for the Parliament.

22.1.7 Alzheimer association's overall assessment of the National Dementia Strategy

The Norwegian Alzheimer Association regards the Dementia Plan as a description of best practice for public dementia care and services. If Norway manages to meet all the goals set in the plan, dementia care will be satisfactory. However, the Norwegian Alzheimer Association acknowledges that there is still a long way to go before all the goals set by the action plan are met.

22.2 Diagnosis, treatment and research

22.2.1 Issues relating to diagnosis

22.2.1.1 *Timely diagnosis in the National Dementia Strategy*

The Dementia Plan acknowledges that approximately 50% of all users in nursing homes with sure signs of dementia have not been diagnosed. In the Dementia Plan, it is stated that this is partly due to lack of expertise in the health and care services. It is further claimed that the solution is to increase knowledge and improve skills through various training programmes.

Models for evaluating and diagnosing people with dementia are to be developed in partnership with specialists and municipal health services. This will include the development of routines to ensure collaboration between local authorities and specialist health services with regard to evaluation, diagnosis, interdisciplinary advice and guidance, the sharing of expertise and improved follow-up of people with dementia.

22.2.1.2 *Which healthcare professionals are responsible for diagnosing dementia*

Dementia can be diagnosed by a GP or a specialist. GPs normally have 15 to 20 minutes' consultation time. They can, however, plan a longer time and organise multiple consultations, which is recommended when diagnosing dementia. There are some guidelines regarding the use of questionnaires and the assessment but no incentives linked to diagnosis.

22.2.1.3 *Type and degree of training of GPs in dementia*

According to the Norwegian Board of Health and Norwegian Medical Association (2000), medical training is offered by the universities of Oslo, Bergen, Tromsø and Trondheim. Courses, which lead to a degree in medicine, normally last six years and are followed by 18 months' compulsory preliminary internship (turnustjeneste). This consists of a set period working in hospitals and a set period working for a municipal health service. General medicine is one of 42 medical specialties. However, it is not mandatory to specialise in general medicine in order to become a GP in Norway. Those who do train for this specialty can, to a large extent, choose the areas of medicine on which they would like to focus. The mandatory parts of the specialist training are fairly general, covering issues such as communication, research and quality etc. GPs therefore need to be aware of and search for the knowledge needed for their practice.

Specialists in general practice have to recertify every 5 years. However, it is not necessary to be a specialist in general medicine to be a “fastlege”. A “fastlege” is a GP who has a list of patients who have registered through their municipality to have him/her as their regular GP. The GP then prioritises those patients and receives a fixed compensation per listed patient (Overland et al., 2008).

22.2.1.4 Required tests to diagnose dementia

The MMSE is used to diagnose dementia. This is recommended by the Ministry of Health and Care Services. There are a few recommendations covering the diagnosis of dementia. Links to the recommendations (which are in Norwegian) are listed below:

<http://www.aldringoghelse.no/ViewFile.aspx?itemID=2806> (recommended diagnostic tool for use at residents in living institutions).

<http://www.aldringoghelse.no/ViewFile.aspx?itemID=1481> (recommended diagnostic tool for GPs).

<http://www.aldringoghelse.no/ViewFile.aspx?itemID=1492> (recommended diagnostic tool for dementia teams e.g. specialized healthcare professionals in municipalities).

22.2.2 Issues relating to medical treatment

22.2.2.1 Medical treatment in the National Dementia Strategy

The issue of medical treatment is scarcely addressed in the Dementia Plan 2015. It states a need for better routines and more knowledge in the municipal health and care services. The importance of milieu therapy and treatment is acknowledged as a development programme.

22.2.2.2 The availability of medicines in general

The Norwegian system differentiates between important and less important medicines.

For less important medicines, the patient pays the full cost, even if they have been prescribed by a doctor. Nevertheless, under certain conditions, it is possible for patients to claim a refund of 90% of all costs exceeding NOK 1,600 (approx. EUR 205)¹⁶.

For drugs on the important medicines list, patients are required to pay 38% of the cost. This only applies to the cost of drugs up to a ceiling of NOK 520 (approx. EUR 67) for a three-month period. The part not paid by the patient is paid by the National Insurance by means of a direct settlement with the pharmacies. Pensioners in receipt of a minimum pension or disability pension do not need to pay cost-sharing charges for important medicines and nursing articles.

¹⁶ European Commission (2011): MISSOC – Mutual information system on social protection: Social protection in the Member States of the European Union, of the European Economic Area and in Switzerland: Comparative tables

22.2.2.3 The availability of Alzheimer treatments

All four AD drugs are available in Norway.

22.2.2.4 Conditions surrounding the prescription and reimbursement of AD drugs

Memantine is not on the list of important medicines and is thus not reimbursed. Nevertheless, the Norwegian Alzheimer's association explains that it is possible for doctors to fill out a form for memantine indicating that the drug is important and needs to be taken over a long period of time. In such cases, memantine can be partially reimbursed with a part of the costs borne by the patient. The other three AD drugs are reimbursable. Norway does not limit the prescription of AD drugs to specialist doctors, since the rules only state that the physician must have an interest in and knowledge about dementia. A diagnosis of Alzheimer's disease and an MMSE score over 12 are the only requirements for the reimbursement of acetylcholinesterase inhibitors. Also, the Norwegian system reimburses medicines for people living alone or in nursing homes.

Prescription and reimbursement	Donepezil	Rivastigmine	Galantamine	Memantine
Available	Yes	Yes	Yes	Yes
Reimbursed	Yes	Yes	Yes	It depends
Initial drug reimbursed if prescribed by	No restrictions	No restrictions	No restrictions	Restrictions
Continuing treatment reimbursed if prescribed by	No restrictions	No restrictions	No restrictions	
Required examinations	MMSE	MMSE	MMSE	
MMSE limits	> 12	> 12	> 12	
People living alone	No restrictions	No restrictions	No restrictions	No restrictions
People in nursing homes	No restrictions	No restrictions	No restrictions	No restrictions

22.2.3 Issues relating to research

22.2.3.1 Research in the National Dementia Strategy

The Dementia Plan 2015 acknowledges the need for and importance of research. A dedicated research programme has been established under the direction of the Research Council of Norway but with limited funding and only regarding care related research.

Nevertheless, R & D projects were implemented during the period of 2007 to 2010 by the Norwegian Directorate for Health with a grant of NOK 5 million each, focusing on younger people with dementia, people with dementia from minority language backgrounds, people with dementia from the Sami population and the treatment of people with dementia with challenging behaviour living in residential care (Engedal, 2010).

22.2.3.2 Any additional medical or scientific issues covered in the National Dementia Strategy

The Dementia Plan describes several. The government wishes to develop dementia care as an integrated and continuous chain of measures. The services need to be adapted to the individual's functioning level and service need. This includes day care programmes (e.g. considered a main challenge in Norwegian care), support and guidance for family care givers and care staff, support groups, systematic information efforts to the public and boosting of the quality and frequency of nursing homes.

In addition to public funding, the Norwegian Alzheimer Association collect funding for PhDs and running costs related to dementia research. In 2012, 4 PhDs are underway.

Norway is involved in the EU Joint Programme – Neurodegenerative Disease Research (JPND) and is a Collaborator in the Joint Action “Alzheimer Cooperative Valuation in Europe (ALCOVE)”.

22.3 References

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Overland, R., Overland, S., Johansen, K.N. and Mykletun, A. (2008), *Verifiability of diagnostic categories and work ability in the context of disability pension award: A survey on “gate-keeping” among general practitioners in Norway*, *BMC Public Health*, 8, 137.

22.4 Acknowledgements

Anne-Kjersti Toft, Political Advisor, National Alzheimer Association

May-Hilde Garden, Dementia Advisor, National Alzheimer Association

23 Poland

23.1 Background information about the National Dementia Strategy

23.1.1 Status and historical development of the National Dementia Strategy

A National Dementia Strategy has been developed by the Alzheimer Coalition and presented to the Ministry of Health which promised to set up a working group which would accept the Strategy. Such a group has not been set up yet. It is hoped that it will materialise this year.

23.1.2 Involvement of the Alzheimer association (and/or people with dementia)

The initiative to develop and formulate the National Dementia Strategy (National Alzheimer Plan) came from the Alzheimer Coalition which was established by the Polish Alzheimer's Association. The Coalition consists of representatives of the Polish Agreement for Cooperation of the Polish Alzheimer's NGOs, coordinated the Polish Alzheimer's Association, and the Polish Alzheimer's Society which groups specialists (medical professions and researchers).

23.2 Diagnosis, treatment and research

23.2.1 Issues relating to diagnosis

23.2.1.1 *Timely diagnosis in the planned National Dementia Strategy*

In the project of the National Dementia Strategy, the Polish Alzheimer's Association has included a demand for an obligatory examination (MMSE) of cognitive functions for all people who are over 60. Such examination should be possible during a visit to a GP and this would hopefully result in the first signs of dementia being detected as early as possible and thus make timely diagnosis easier.

23.2.1.2 *Which healthcare professionals are responsible for diagnosing dementia*

There are no legal barriers in the State Regulation Concerning Basic Health Services issued by the Minister of Health which would prevent GPs from diagnosing dementia. There is no list of diseases either which should be diagnosed by specialists only.

In Poland, some GPs who suspect dementia treat patients themselves while others refer patients to specialists. The specialists who can diagnose dementia and/or Alzheimer's disease are neurologists, psychiatrists and geriatricians.

GPs use screening tests like the MMSE and the clock drawing test to assess dementia provided that they possess the relevant knowledge and that such tests are available. Often, GPs diagnose dementia just on the basis of the consultation with the patient and/or family. Often, they do not attempt to diagnose a particular disease, like Alzheimer's disease, and undertake treatment simply because they have no right to order an examination like a CT scan or psychological examination. Only a specialist can decide on that. Also, there

is a fear that in the absence of a consultation with a specialist, the patient will not be entitled to purchase the drugs at a lower price with reimbursement from the state. If a GP prescribes drugs without a consultation with a specialist, the patient has to pay 100% as otherwise the GP would have to refund the cost of the treatment. Consequently, in practice, GPs either diagnose dementia and do not refer the patient to specialists or diagnose dementia but send the patient to a specialist for a more detailed, accurate diagnosis.

There is no set consultation time in any regulations or agreements with medical staff. The duration of the consultation may differ according to the size of the clinic and the number of patients registered in it. Patients usually have an appointment for 15 minutes but on average they have ten-minute consultations. This depends on how many patients have appointments on a particular day, the season (i.e. there are more patients with colds in winter) and whether the doctor devotes any of his/her free time. Patients with pain, fever or something urgent do not need to have an appointment and have to be treated as if it were an emergency.

The consultation time can be extended but there is no regulation on this, so it just depends on the GP and the number of patients s/he has to consult on a particular day.

The National Health Service pays GPs who work in out-patient clinics, taking into account the total number of patients registered in a particular clinic but not how much work each GP does, how many patients s/he consults each day or how many diagnostic tests s/he carries out. The higher the number of older patients registered in a particular out-patient clinic, the more money the clinic receives. This is insufficient to serve as an incentive to GPs to devote more time to patients with dementia and thereby improve or increase timely diagnosis.

23.2.1.3 *Type and degree of training of GPs in dementia*

GPs are trained in different types of dementia, differential diagnostics and treatment during their first year at medical school and while attending neurology, psychiatry and internal disease lectures, seminars or classes during their six-year medical studies, as well as during their work in hospitals after completing studies.

During their studies at Warsaw Medical University, for example, they have in the third year, in addition to other subjects, 125 hours devoted to internal medicine and 45 hours of classes in laboratory diagnosis. In the fourth year, they have 161 hours on internal medicine and 60 hours on genetics, then 90 hours on neurology in the fifth year and finally, 120 hours on psychiatry and 30 hours on geriatrics in the sixth year. There is a general opinion, amongst GPs and specialists, that there are not enough hours on dementia in the training programme of medical students at Polish medical universities.

As with other doctors, GPs are obliged to develop their knowledge and skills and to obtain 200 points for continuing education in the four years which follow their qualification as a medical doctor. This is regulated by the Ministry of Health Regulation of 2004

on the ways to fulfil this duty to continue professional training. For example, a doctor can receive five points for his/her membership and involvement in a researchers' association/society or the same number of points for attending a conference.

23.2.1.4 Required tests to diagnose dementia

There are some guidelines issued by the Family Doctors' Collegium as well as by researchers' associations. There are no official guidelines from the National Health Service or Ministry of Health on diagnosing dementia. The Polish Alzheimer's Association has published and distributed a leaflet addressed to GPs with information prepared by leading specialists in the diagnosis and treatment of dementia outlining steps which should be taken when a GP suspects dementia. However, as in other specializations, there is no requirement for GPs to follow any guidelines to diagnose dementia and/or Alzheimer's disease as recommendations in Poland are not obligatory for doctors. As diagnostic guidelines and tests are not available at every out-patient clinic, GPs usually refer patients with memory problems to specialists.

23.2.1.5 Medical treatment in the planned National Dementia Strategy

A demand has been made for full accessibility of drugs used in AD treatment. The drugs should be available free of charge or with 70% reimbursement.

23.2.1.6 The availability of medicines in general

Medicines in Poland can fall under one of three different reimbursement systems:

- For basic medicines, patients pay a fixed price of PLN 3.25 (approx. EUR 0.82) to PLN 5.00 (approx. EUR 1.27) as determined by the Minister of Health,
- For special additional medicines, patients pay 30% to 50% of the cost,
- For all other medicines, patients pay the totality of the cost.

Hospital medicines are free of charge.¹⁷

23.2.1.7 The availability of Alzheimer treatments

In Poland, all AD drugs are available, but only donepezil and rivastigmine are part of the reimbursement system. Recently, generic versions of donepezil have become available in Poland and reimbursement is limited to those generic versions.

23.2.1.8 Conditions surrounding the prescription and reimbursement of AD drugs

Treatment with acetylcholinesterase inhibitors is for people with MMSE scores between 26 and 10 and memantine for MMSE scores below 14. There are no restrictions in Poland for the reimbursement of these treatments for people living alone or in nursing homes. Also, prescriptions can be made by any doctor whether for treatment initiation or treatment continuation.

¹⁷ European Commission (2011): MISSOC – Mutual information system on social protection: Social protection in the Member States of the European Union, of the European Economic Area and in Switzerland: Comparative tables

Prescription and reimbursement	Donepezil	Rivastigmine	Galantamine	Memantine
Available	Yes	Yes	Yes	Yes
Reimbursed	Only generic	Yes	No	No
Initial reimbursed if prescribed by	No restrictions	No restrictions	No restrictions	No restrictions
Continuing treatment reimbursed if prescribed by	No restrictions	No restrictions	No restrictions	No restrictions
Required examinations	No restrictions	No restrictions	No restrictions	No restrictions
MMSE limits	26-10	26-10	N/A	<10

23.2.2 Issues relating to research

It is stated in the planned National Dementia Strategy that research studies in medicine and social consequences of AD should be developed as well as promoted and financed by the state. Poland is involved in the EU Joint Programme – Neurodegenerative Disease Research (JPND) but not in the Joint Action “Alzheimer Cooperative Valuation in Europe (ALCOVE)”.

23.2.3 Additional medical or scientific issues

The planned National Dementia Strategy includes research into community issues and other social and legal issues connected with living with dementia, as well as studies into the public awareness of dementia.

23.3 Acknowledgements

Alicja Sadowska, Chair, Polish Alzheimer’s Association.

Mirka Wojciechowska, Board member, Polish Alzheimer’s Association

Katarzyna Broczek, MD, Geriatrics Clinic at Warsaw Medical University.

24 Portugal

24.1 Background information about the National Dementia Strategy

24.1.1 Status and historical development of the National Dementia Strategy

In October 2009, Alzheimer Portugal prepared a document “Plano Nacional de Intervenção Alzheimer” which reflects what some other countries already have. Inspired by the French Alzheimer Plan, Alzheimer Portugal formulated the main ideas which it felt a national plan should include. This document was delivered to the members of the Portuguese parliament. Five of them attended and participated in a round table at a conference hosted by Alzheimer Portugal where this issue was the main topic.

A year later, two proposals were discussed and approved by the Parliament. Unfortunately, these were only recommendations to the government which stepped down a short time after. Consequently, the proposals were never implemented and a National Dementia Strategy has not yet been adopted.

At the moment, because of the economic crisis, dementia is not one of the political priorities.

24.1.2 Involvement of the Alzheimer association (and/or people with dementia)

Alzheimer Portugal is not just involved in the development of a National Dementia Strategy. It is the organisation leading the advocacy on this issue.

24.2 Diagnosis, treatment and research

24.2.1 Issues relating to diagnosis

24.2.1.1 *Timely diagnosis at national level*

Last year, the government launched an initiative to establish national guidelines (Normas) in different clinical situations. One of these guidelines addresses diagnostic and therapeutical issues in patients with cognitive decline or dementia. The process of public consultation is about to end, and the final guideline will soon be published. The draft document can be accessed at:

<http://www.dgs.pt/ms/8/paginaRegisto.aspx?back=1&id=21604>

24.2.1.2 *Which healthcare professionals are responsible for diagnosing dementia*

GPs may diagnose dementia and prescribe AD drugs but these drugs would not be refundable. Consultations are generally for 20 minutes and cannot be extended. Neurologists and psychiatrists can also diagnose dementia and/or Alzheimer's disease. According to the Portuguese Alzheimer association, there is a problem concerning the dialogue between GPs and specialists as the specialists do not always provide feedback to the GPs. This may affect GPs' motivation to make an initial referral. This dialogue needs to be

enhanced in order to ensure that the person who goes to the specialist to get medication with reimbursement is motivated to then return to the GP. There are no specific measures to improve timely diagnosis.

24.2.1.3 *Type and degree of training of GPs in dementia*

Information was not available on the amount of training in dementia that GPs receive in their professional training to become a GP. Continuing education is an obligation for GPs (i.e. ad hoc courses to update their knowledge).

24.2.1.4 *Required tests to diagnose dementia*

Guideline #53 DGS - Abordagem Terapêutica das Alterações Cognitivas is used to diagnose dementia.

24.2.2 *Issues relating to medical treatment*

24.2.2.1 *The availability of medicines in general*

The level of reimbursement depends on the type of illness and whether a person is a pensioner on a low income (i.e. an annual total income not exceeding 14 times the minimum wage). The level ranges from 15% to 95%. Medicines are refunded at 95% if their retail price is equal to or higher than the average retail price of the five cheapest medicines on the market.

Generic medicines can be paid in full by the State for beneficiaries whose income does not exceed a set amount and provided that certain conditions are met¹⁸.

24.2.2.2 *The availability of Alzheimer treatments*

All four AD drugs are available to patients in Portugal and are part of the reimbursement system.

24.2.2.3 *Conditions surrounding the prescription and reimbursement of AD drugs*

AD drugs are classified as level C drugs and the State covers 40% of their costs if prescribed by a neurologist or psychiatrist. It does not require any specific diagnostic examinations to be carried out, nor does the system provide upper or lower treatment limits.

AD drugs prescribed by a GP are not refundable. However, generic drugs are available in Portugal, which are relatively inexpensive, which means that for many people, this is not a problem.

The Portuguese system reimburses medicines for people living alone or in nursing homes.

¹⁸ European Commission (2011): MISSOC – Mutual information system on social protection: Social protection in the Member States of the European Union, of the European Economic Area and in Switzerland: Comparative tables

Prescription and reimbursement	Donepezil	Rivastigmine	Galantamine	Memantine
Available	Yes	Yes	Yes	Yes
Reimbursed	Yes	Yes	Yes	Yes
Initial drug reimbursed if prescribed by	Specialist	Specialist	Specialist	Specialist
Continuing treatment reimbursed if prescribed by	Specialist	Specialist	Specialist	Specialist
Required examinations	None	None	None	None
MMSE limits	None	None	None	None

24.2.3 Issues relating to research

The national agency which finances research in Portugal is the Fundação para a Ciência e Tecnologia (FCT). There is no national specific research programme for Alzheimer’s disease or dementia. Research projects on this topic may be financed but are in competition with other scientific areas. Furthermore, FCT supports national researchers involved in European projects on neurodegenerative disorders, like the Joint Programming on Neurodegenerative Disorders (JPND). Alzheimer Portugal emphasises the need for funding for research to be part of any future national dementia strategy for Portugal.

24.2.4 Additional medical or scientific issues

Progress has been made in modern technologies in Portugal just like the recent possibility to use PET PiB.

Portugal is involved in the EU Joint Programme – Neurodegenerative Disease Research (JPND) but not in the Joint Action “Alzheimer Cooperative Valuation in Europe (ALCOVE)”.

24.3 Acknowledgements

Maria do Rosário Zincke dos Reis, Chair of Alzheimer Portugal and Honorary Treasurer of Alzheimer Europe.

Celso Pontes, Coordinator of the Scientific Committee of Alzheimer Portugal

Alexandre de Mendonça, Member of the Scientific Committee of Alzheimer Portugal

António Leuschner, Psychiatrist.

25 *Romania*

25.1 Background information about the National Dementia Strategy

25.1.1 Status and historical development of the National Dementia Strategy

In February 2012, the National Alzheimer Alliance was created and this was the first step in lobbying for a National Dementia Strategy. The Romanian Alzheimer Society was the main actor in this fight.

25.1.2 Involvement of the Alzheimer association (and/or people with dementia)

The Romanian Alzheimer Society has elaborated a manifesto which contains the action plan for a National Dementia Strategy and has already gathered 3,000 signatures in support of it.

Letters were sent to national policy makers asking them to establish an intergovernmental department/commission to work on this issue.

A lot of family members as well as people with dementia are also involved. They signed the declaration in which it is stated that there is an urgent need for a National Dementia Strategy and this was accompanied by a request for action.

25.2 Diagnosis, treatment and research

25.2.1 Issues relating to diagnosis

25.2.1.1 *Which healthcare professionals are responsible for diagnosing dementia*

There are huge difficulties in obtaining an early diagnosis. GPs are not permitted to diagnose dementia and do not have set consultation times to evaluate people with cognitive impairment. There is a reimbursement system based on 15-minute consultations irrespective of the age or condition of the patient. GPs can be reimbursed for twenty consultations per day.

Psychiatrists, neurologists and geriatricians are permitted to diagnose dementia and/or Alzheimer's disease. As with GPs, specialists have fixed reimbursements for consultations so there is no difference in the duration of the consultation or in the level of reimbursement that specialists receive for dealing with different conditions. There are currently no incentives to improve timely diagnosis.

25.2.1.2 *Type and degree of training of GPs in dementia*

In their professional training to become a GP, the curriculum contains a one-month period of training in psychiatry during their three years' residency. Dementia is amongst the list of topics covered.

Continuing education is an obligation for GPs although courses on the diagnosis and management of patients with dementia are not mandatory. However, courses on this subject were provided during the information campaign for GPs and at conferences and congresses, many of which were carried out by the Romanian Alzheimer Society in major cities in Romania.

25.2.1.3 Required tests to diagnose dementia

The National Health Insurance approved guidelines that are in existence in Romania which prescribe a series of examinations that need to be carried out when making a diagnosis. These include neuropsychological tests, CT or MRI scans and laboratory tests.

The current "Guidelines for Dementia Diagnosis and Treatment" were published in 2009 with the approval of the Health Ministry. These guidelines were developed by neurologists and psychiatrists and undertaken by all the specialist doctors involved in the diagnosis and treatment of dementia (neurologists, psychiatrists, geriatricians).

25.2.2 Issues relating to medical treatment

25.2.2.1 The availability of medicines in general

Pharmaceutical products are reimbursed at different levels based on which category they have been allocated to. The National House for Health Insurance reimburses medical drugs on the following basis:

List A: 90% of the reference price covered.

List B: 50% of the reference price covered.

List C: C1 - 100% of the reference price covered; C2 – full price for drugs for HIV/AIDS and tuberculosis; C3 – 100% of reference price for certain group including people who are totally or partially unable to work¹⁹.

25.2.2.2 The availability of Alzheimer treatments

Medical treatment at national level is free of charge and it belongs to a National Plan concerning pharmacological treatment for chronic diseases and is still applicable, on C1 list 100% of reference price covered.

All AD drugs are available and reimbursable in Romania. Unlike other countries, donepezil is also indicated for the treatment of vascular dementia and can be reimbursed in those cases as well.

Although there are no restrictions for people living alone or for people living in nursing homes, the Romanian Alzheimer Society does report difficulties for these people in accessing medication due to a lack of social support available.

¹⁹ European Commission (2011): MISSOC – Mutual information system on social protection: Social protection in the Member States of the European Union, of the European Economic Area and in Switzerland: Comparative tables

25.2.2.3 Conditions surrounding the prescription and reimbursement of AD drugs

Treatment initiation and treatment continuation are restricted to specialists (neurologists or psychiatrists). For AD drugs to be reimbursed, the series of tests mentioned earlier need to be carried out and included in a medical report.

Until recently, the system did not prescribe any upper or lower treatment limits either, but in some areas of the country, the Romanian Alzheimer Society reports that health insurance offices have restricted reimbursement to people with Alzheimer's disease with an MMSE score over 10.

Prescription and reimbursement	Donepezil	Rivastigmine	Galantamine	Memantine
Available	Yes	Yes	Yes	Yes
Reimbursed	Yes	Yes	Yes	Yes
Initial drug reimbursed if prescribed by	Psychiatrist, neurologist and geriatrician	Psychiatrist, neurologist and geriatrician	Psychiatrist, neurologist and geriatrician	Psychiatrist, neurologist and geriatrician
Continuing treatment reimbursed if prescribed by	Psychiatrist, neurologist and geriatrician	Psychiatrist, neurologist and geriatrician	Psychiatrist, neurologist and geriatrician	Psychiatrist, neurologist and geriatrician
Required examinations	Diagnostic protocol	Diagnostic protocol	Diagnostic protocol	Diagnostic protocol
MMSE limits	Over 10	Over 10	Over 10	Over 10

25.2.3 Issues relating to research

Romania is involved in the EU Joint Programme – Neurodegenerative Disease Research (JPND) but not in the Joint Action “Alzheimer Cooperative Valuation in Europe (ALCOVE)”.

25.3 Acknowledgements

Gabriela Cirstescu, Executive Director, Romanian Alzheimer Society

Maria Moglan, Romanian Alzheimer Society

26 Slovakia

26.1 Issues relating to medical treatment

26.1.1 The availability of medicines in general

Pharmaceutical drugs are either free of charge or partially refunded depending on whether they are on a special list. On average, patients pay 10-14% of the cost of drugs. There are no special groups which receive a higher level of reimbursement. However, older people and disabled people on a low income are not expected to pay more than EUR 30 to EUR 40 per quarter for pharmaceutical products²⁰.

26.1.2 The availability of Alzheimer treatments

All four AD drugs are available. Unlike in other countries, memantine is available for people with mild to moderate Alzheimer’s disease and not severe Alzheimer’s disease. People who live alone or in nursing homes have access to the AD drugs.

26.1.3 Conditions surrounding the prescription and reimbursement of AD drugs

The AD drugs are part of the reimbursement system. In order to be eligible for a refund, patients must have been prescribed the drugs by a specialist doctor. This also applies to repeat prescriptions. An MMSE should be carried out.

Prescription and reimbursement	Donepezil	Rivastigmine	Galantamine	Memantine
Available	Yes	Yes	Yes	Yes
Reimbursed	Yes	Yes	Yes	Yes
Initial drugs reimbursed if prescribed by	Specialist doctor	Specialist doctor	Specialist doctor	Specialist doctor
Continuing treatment reimbursed if prescribed by	Specialist doctor	Specialist doctor	Specialist doctor	Specialist doctor
Required examinations	MMSE	MMSE	MMSE	MMSE
MMSE limits	24-13	24-13	24-13	24-13

26.2 Issues relating to research

Slovakia is involved in the EU Joint Programme – Neurodegenerative Disease Research (JPND) and is an Associate member of the Joint Action “Alzheimer Cooperative Valuation in Europe (ALCOVE)”.

20 European Commission (2012): MISSOC – Mutual information system on social protection: Social protection in the Member States of the European Union, of the European Economic Area and in Switzerland: Comparative tables

27 *Slovenia*

27.1 **Background information about the National Dementia Strategy**

27.1.1 **Status and historical development of the National Dementia Strategy**

In 2010, the Ministry of Health of Slovenia formed a taskforce to prepare the first official document about dementia at national level. The taskforce consisted of dementia experts, representatives of Alzheimer Slovenia, members of other non-profit organisations and government officials. This taskforce evaluated the current state of dementia care and completed its task by the end of August 2011.

The two major conclusions of the first national document about dementia were the need to establish a National Dementia Centre and that the National Dementia Centre should develop a National Dementia Strategy in collaboration with all other interested parties. These conclusions were approved by the National Board of Psychiatrists and the National Board of Neurologists. The National Board of General Physicians appeared initially reserved with regard to this idea since they worried that an excess burden of dementia care would fall upon them. However, they eventually realised that within the National Dementia Strategy their role in dementia care would be reduced and become more transparent.

In September 2012, this programme, derived from the conclusions of the first national document about dementia and approved by the National Boards of Psychiatrists, Neurologists and General Physicians, was proposed to the Advisory Board of the Ministry of Health of Slovenia. Unfortunately, it was not approved due to disagreement from a small group of neurologists who had requested increased funding for their own, largely research-based, dementia programme and who failed to recognise that this programme was in their own interests. As a result, the programme proposing the development of the National Dementia Strategy was rejected instead of being approved and appropriately funded. An considerable amount of work will be needed to get the programme finally approved.

27.2 **Diagnosis, treatment and research**

27.2.1 **Issues relating to diagnosis**

27.2.1.1 *Which healthcare professionals are responsible for diagnosing dementia*

GPs diagnose dementia but a formal diagnosis of diseases causing dementia is made primarily by psychiatrists and neurologists. GPs have set consultation times of less than 10 minutes per patient. This could be extended and this is something that will be proposed in the National Dementia Strategy and will require negotiations with the insurance companies. Meanwhile, GPs are paid on the basis of a ten-minute consultation and would not receive any additional payment for any extra time spent with a patient.

There are currently three incentives in the planned National Dementia Strategy to improve or increase timely diagnosis. The first is to improve the education of GPs, the second to better integrate dementia screening tests into GPs' environment and the third to introduce a comprehensive dementia care programme into GPs' daily practice.

27.2.1.2 Type and degree of training of GPs in dementia

There are no formal requirements or organised training in dementia for GPs. Whilst there are meetings and workshops where GPs can learn about dementia, the lack of formal requirements and organised dementia training at national level is a major drawback with regard to their understanding of dementia care.

27.2.1.3 Required tests to diagnose dementia

Many tests are used to diagnose dementia ranging from the MMSE, the clock drawing test to longer, more complex tests such as the ACE-R. In theory, such tests should be used during the initial diagnosis and then every six months to monitor the efficacy of treatment and to prevent complications. However, there is no data on the number of doctors who do this. It is possible that many do not and consequently, this should be better monitored.

27.2.2 Issues relating to medical treatment

27.2.2.1 The availability of medicines in general

Pharmaceutical products are divided into three lists classed as positive, interim and negative²¹:

- Products in the positive list are 75% reimbursed and 100% in the case of children and some other categories;
- Pharmaceutical products in the intermediate list are reimbursed at 10%;
- Pharmaceutical products in the negative list must be paid for by the patient.

It is possible to take out a voluntary insurance to cover co-payments. For pharmaceutical products not contained in the lists, the full cost must be borne by the patient. All drugs used during hospital treatment are free.

27.2.2.2 The availability of Alzheimer treatments

All four AD dementia drugs are available in Slovenia and there are no restrictions for people with dementia living alone or in nursing homes.

27.2.2.3 Conditions surrounding the prescription and reimbursement of AD drugs

AD drugs are prescribed by a psychiatrist or neurologist. There are no restrictions for continuing treatment decisions. A diagnosis of Alzheimer's disease and an MMSE score between 10 and 26 are required for reimbursement of AD drugs. Nevertheless, the Slovenian Alzheimer association also explains that for patients with an MMSE over 26,

²¹ European Commission (2012): MISSOC – Mutual information system on social protection: Social protection in the Member States of the European Union, of the European Economic Area and in Switzerland: Comparative tables

reimbursement is possible if further more extensive neuropsychological tests show the cognitive decline of a patient which is consistent with Alzheimer’s disease.

Prescription and reimbursement	Donepezil	Rivastigmine	Galantamine	Memantine
Available	Yes	Yes	Yes	Yes
Reimbursed	Yes	Yes	Yes	Yes
Initial drug reimbursed if prescribed by	Psychiatrist or Neurologist	Psychiatrist or neurologist	Psychiatrist or neurologist	Psychiatrist or neurologist
Continuing treatment reimbursed if prescribed by	No restrictions	No restrictions	No restrictions	No restrictions
Required examinations	MMSE	MMSE	MMSE	MMSE
MMSE limits	26-10	26-10	26-10	Below 10

27.2.3 Issues relating to research

Slovenia is involved in the EU Joint Programme – Neurodegenerative Disease Research (JPND) but not in the Joint Action “Alzheimer Cooperative Valuation in Europe (ALCOVE)”, although it would like to be, but an invitation has never been extended.

27.3 Acknowledgements

Stefanija Lukič-Zlobec, Member of Alzheimer Slovenia – Spomincica, Dipl. OEDC, Employed at the Ministry of Finance

Gorazd Bernard Stokin, Assistant Professor of Neurology, MD, PhD, University Psychiatric Hospital and Division of Neurology, University Medical Centre Ljubljana

28 Spain

28.1 Background information about the National Dementia Strategy

28.1.1 Status and historical development of the National Dementia Strategy

Spain does not have a national dementia strategy. Led by the Spanish Alzheimer Federation (CEAFA), the “Alzheimer’s Alliance” (which includes a cross-section of national organisations such as Spanish Societies of Neurology, Geriatrics, Primary Attention and the Foundation Pasqual Maragall) aims to ensure that a National Alzheimer Strategy is implemented. The Alliance was due to have a formal meeting with the Health Ministry to discuss a national plan, but the meeting was delayed due to forthcoming national elections in November 2011.

28.2 Treatment and research

28.2.1 Issues relating to medical treatment

28.2.1.1 *The availability of medicines in general*

Patients must pay 40% of the price of pharmaceutical products but for certain products there is a reduction of 90% with a maximum limit of EUR 2.64. However, certain groups of people do not have to make any payment. This includes pensioners, people receiving inpatient hospital care and people over the age of 65 with limited resources²².

28.2.1.2 *The availability of Alzheimer treatments*

All four AD drugs are available in Spain.

28.2.1.3 *Conditions surrounding the prescription and reimbursement of AD drugs*

AD drugs are part of the reimbursement system. Treatment initiation and continuation is limited to specialists and the reimbursement system requires specialists to carry out an MMSE of patients. Reimbursement with acetylcholinesterase inhibitors is limited to people with Alzheimer’s disease with an MMSE score of 23 and below and with memantine for an MMSE score of 17 and below. There are no restrictions for people living alone or in nursing homes.

22 European Commission (2012): MISSOC – Mutual information system on social protection: Social protection in the Member States of the European Union, of the European Economic Area and in Switzerland: Comparative tables

Prescription and reimbursement	Donepezil	Rivastigmine	Galantamine	Memantine
Available	Yes	Yes	Yes	Yes
Reimbursed	Yes	Yes	Yes	Yes
Initial drug reimbursed if prescribed by	Specialist doctor	Specialist doctor	Specialist doctor	Specialist doctor
Continuing treatment reimbursed if prescribed by	Specialist doctor	Specialist doctor	Specialist doctor	Specialist doctor
Required examinations	MMSE	MMSE	MMSE	MMSE
MMSE limits	23 and below	23 and below	23 and below	17 and below

28.2.2 Issues relating to research

Spain is involved in the EU Joint Programme – Neurodegenerative Disease Research (JPND) and is an Associate member of the Joint Action “Alzheimer Cooperative Valuation in Europe (ALCOVE)”.

29 *Sweden*

29.1 **Background information about the National Dementia Strategy**

29.1.1 **Status and historical development of the National Dementia Strategy**

The National Dementia Strategy of the Swedish National Board of Health and Welfare from 2010 is the first national guidelines for care in dementia within the field. The guidelines emphasise evidence-based and evaluated treatments and methods of care for people with dementia and for support for their next of kin. During the development of the guidelines the focus was on community care and primary health care. The guidelines concern both private and public care. A number of experts participated in this work. The scientific information and conclusions of the Swedish Council of Technology Assessment in Health Care were important in this respect.

The purpose of the National Dementia Strategy for Sweden is that it should support decision makers in communities, county councils and regions in governing healthcare and social services through open and systematic priorities. One part of the guidelines is targeted mainly at decision makers and management boards within health and medical care, and intended to support leaders within all levels of the health and medical care and social care sectors. Other parts of the guidelines are directed mainly toward unit managers, nurses with medical responsibilities and other health and care personnel.

The National Board of Health and Welfare adjudges that the recommendations are central preconditions to enable these guidelines, in overall terms, to deliver the desired result. Recommendations may be resource-intensive and entail for example the need for investments in staff and competence.

29.1.2 **Duration of the National Dementia Strategy**

The National Board of Health and Welfare considers that Health and Medical Care and Social Services should follow up, at least once a year, medication treatment, cognition, functional capacity, general state of health, behavioural changes and support those inputs agreed upon.

Indicators for nursing care in special dementia living units were introduced in 2012. The guidelines will be revised when the results of new research become available. This is a continuous process.

The National Board of Health and Welfare considers that the recommendation reduces the costs of health and medical care and social services in the longer term.

29.1.3 **How the National Dementia Strategy is funded**

The National Dementia Strategy is funded by the government. The National Board of Health and Welfare considers that the effect of the recommendations on basic and

extended examinations will be that the number of examinations will increase by about 7,000 per year at a cost of around SEK 41–59 million (about one per mille of the total costs for dementia-type illnesses). An increase in the quality of dementia examinations is expected to contribute towards more adequate care and a reduced need for emergency measures (e.g. hospitalisations), and should not lead to an increase in total costs.

29.1.4 Provisions or procedure for implementing the Strategy

It is possible to apply to the Swedish National Board of Health and Welfare for financial support to implement the guidelines. This will lead to an initial increase in costs but in the long run the guidelines are expected to lead to savings.

Information about the guidelines has been widely disseminated throughout Sweden by representatives of the Swedish National Board of Health and Welfare. The guidelines are to be integrated into practice. As part of this procedure, the Alzheimer Society of Sweden is involved in training dementia nurses.

29.1.5 Procedure for monitoring progress made in achieving the goals set

Every person diagnosed with dementia should be registered in the Swedish National Dementia Registry. The National Board of Health and Welfare has drawn up different indicators for the follow-up of medical care, long-term care and welfare of persons with dementia illnesses. Of these, it is possible to monitor six through existing records at the National Board of Health and Welfare.

A major problem within this area is the lack of data sources (e.g. those input by the Social Services on behalf of people with dementia and within primary care). Furthermore, the existing data sources are not used in a correct manner. This means that it has still not been possible to continuously monitor eight of the quality indicators, whether at the national, regional or local level. It is therefore urgent that Health and Medical Care and Social Services develop individual-based data that enable the follow-up and evaluation of quality in medical care and the longer term care of people with dementia.

29.1.6 Involvement of the Alzheimer association (and/or people with dementia)

The Alzheimer Society of Sweden and Dementia Association were both part of the reference group which was consulted when the guidelines were being drafted. There were no people with dementia involved. The Alzheimer Society of Sweden recommended regional forums on the matter to ensure that the people with dementia were heard.

The National Guidelines reflect some of the themes addressed by The Alzheimer Society of Sweden during presentations which are held about 30 times a year for patients, next of kin and health personnel all over Sweden. Dementia Association, which had requested that guidelines be developed, closely follows the work of the National Board of Health and Welfare with regard to its work on these guidelines.

29.1.7 Alzheimer association's overall assessment of the National Dementia Strategy

The Alzheimer Society of Sweden thinks that the National Dementia Strategy for Sweden provides adequate guidelines on how dementia care should be provided. They reinforce the individual's right to diagnosis and treatment, facilitating dementia care both for patients and at the organisational level.

29.2 Diagnosis, treatment and research

29.2.1 Issues relating to diagnosis

29.2.1.1 *Which healthcare professionals are responsible for diagnosing dementia*

It is primarily the GP who examines and diagnoses a person with possible symptoms of dementia. Sometimes GPs prefer to refer patients with suspected dementia to a specialist for diagnosis. Young people are always examined in a memory clinic.

In Sweden, there is a dementia nurse in every community whom older people can consult if they have concerns about their memory. These nurses are fully trained to administer the MMSE and clock-test. If they detect a problem, they make a report which the person can then take to his/her doctor.

Well-functioning care centres have a GP with a good knowledge of dementia care who examines all patients with cognitive decline. Home visits are also possible. Many care centres do not have a GP with sufficient knowledge and patients experience an unsatisfactory examination. Many patients are not investigated for dementia. It is the aim of the National Swedish Board of Health and Welfare to have all patients satisfactorily examined.

29.2.1.2 *Type and degree of training of GPs in dementia*

Dementia is included in the training that GPs receive at university. However, the degree of training in dementia differs considerably from one university to the next.

In Autumn 2012, a new Masters in dementia care is starting. This is a web-based two-year Masters programme in dementia care for physicians. It has been developed through collaboration between the Karolinska Institutet and the Swedish Foundation Silviahemmet.

Over the last five years, some memory clinics have tried to educate GPs about dementia. Doctors from the memory clinic come out and visit GPs regularly.

The National Board of Health and Welfare also considers that Health and Medical Care and Social Services should offer staff the possibility of long-term training, combined with practical training, instruction and feedback.

29.2.1.3 *Required tests to diagnose dementia*

There is no simple assessment method that can ascertain whether a person has a dementia-type illness. The information below is based on the National Board of Health

and Welfare recommendation. In the first place, Health and Medical Care should carry out a basic investigation of dementia that is based on:

- structural amnesia, interviews with those close to the person, assessment of the patient's physical and psychological condition, assessment of cognition through cognitive tests (MMSE together with the clock drawing test)
- structured assessment of function and activity capacity
- taking of samples to exclude other conditions that may cause cognitive impairment
- structural brain imaging with computer tomography that can contribute to identifying cognitive impairment and exclude other conditions in the brain that may cause cognitive impairment.

A basic investigation is not always sufficient to ascertain whether a person has a dementia-type illness. The Health and Medical Services advises carrying out an extended dementia examination that includes one or several of the following elements:

- neuropsychological tests
- structural brain imaging with magnetic camera
- lumbar puncture for analysis of biomarkers
- functional brain imaging with SPECT.

29.2.2 Issues relating to medical treatment

29.2.2.1 *The availability of medicines in general*

The National Board of Health and Welfare recommended that Health and Medical Care offer treatment with cholinesterase inhibitors (donepezil, galantamine and rivastigmine) to combat cognitive impairment symptoms in people with mild to moderate Alzheimer's disease.

Health and Medical Care should offer treatment with cholinesterase inhibitors (donepezil, galantamine and rivastigmine) to combat cognitive impairment symptoms in people with mild to moderate Alzheimer's disease.

Health and Medical Care should also offer treatment with memantine for cognitive impairment symptoms in people with moderate to severe Alzheimer's disease. Health and Medical Care should also follow up the treatment when the dose is adjusted and subsequently, at regular intervals of at least once a year. This should also include a consideration of the possible need to discontinue treatment.

The National Board of Health and Welfare considers that the effect of the recommendations on treatment with cholinesterase inhibitors and memantine entails an increase of medication costs by a maximum of SEK 170 million. The total cost to society as a whole for the treatment with medicine, however, is expected to be unchanged or to decline.

In Sweden, medicines on a special list are covered up to a certain degree depending on the overall expenditure on medicines of a patient during a twelve-month period.

If the expenditure does not exceed SEK 900 (approx. EUR 99), the patient covers 100% of the drug costs for a period of 12 months from the first purchase.

For expenditure between SEK901 and SEK1,700 (approx. EUR 186), the patient covers 50% of the costs.

For expenditure between SEK1,701 and SEK3,300 (approx. EUR 362), the patient covers 25% of the costs.

For expenditure between SEK3,301 and SEK4,300 (approx. EUR 471), the patient covers 10% of the costs.

Costs above SEK4,300 are subsidized totally.²³

29.2.2.2 The availability of Alzheimer treatments

All AD drugs are available in Sweden and are part of the reimbursement system.

In Sweden, although many people, including GPs, feel that medical drugs are expensive, some AD drugs only cost EUR 180 per year in total.

29.2.2.3 Conditions surrounding the prescription and reimbursement of AD drugs

No specific examinations are required for medicines to be reimbursed and the system does not provide upper or lower MMSE limits for treatment with different AD drugs. Prescriptions can be made by specialists, as well as general practitioners. There are no restrictions as to the access of people living alone or in nursing homes to available treatments.

Prescription and reimbursement	Donepezil	Rivastigmine	Galantamine	Memantine
Available	Yes	Yes	Yes	Yes
Reimbursed	Yes	Yes	Yes	Yes
Initial reimbursed if prescribed by	Specialist doctor	Specialist doctor	Specialist doctor	Specialist doctor
Continuing treatment reimbursed if prescribed by	Specialist doctor	Specialist doctor	Specialist doctor	Specialist doctor
Required examinations	None	None	None	None
MMSE limits	None	None	None	None

23 European Commission (2011): MISSOC – Mutual information system on social protection: Social protection in the Member States of the European Union, of the European Economic Area and in Switzerland: Comparative tables

29.2.3 Issues relating to research

Research is carried out mainly in universities and faculties. There is also an institute for brain research (Swedish Brain Power). Swedish Brain Power is a national consortium of researchers in the field of neurodegenerative diseases. The aim of Swedish Brain Power is to foster a link between clinical and basic research in nursing, particularly in relation to dementia and older people.

The National Knowledge Centre for Dementia compiles and disseminates information about scientific research, both in the clinical field and in basic science subjects. At the same time, the Centre runs a variety of courses for doctors, nurses, carers and other people with an interest in dementia.

Knowledge centres for dementia have been set up in several counties in Sweden. The Centre will contribute towards the development and dissemination of knowledge in dementia care.

Such development must be in accordance with the national guidelines for the care of dementia from 2010 (The National Social Welfare Board). The Centre runs a variety of courses for doctors and nurses.

Sweden is involved in the EU Joint Programme – Neurodegenerative Disease Research (JPND) and is an Associate partner in the Joint Action “Alzheimer Cooperative Valuation in Europe (ALCOVE)”.

29.3 References

National Social Welfare Board, *Guidelines and recommendations on dementia care*, Stockholm 2010, <http://www.socialstyrelsen.se/>

29.4 Acknowledgements

Kristina Westerlund, The Alzheimer Society of Sweden

30 Switzerland

30.1 Background information about the National Dementia Strategy

30.1.1 Status and historical development of the National Dementia Strategy

On 12 March 2012, the Swiss Council of States (the upper house of the federal Parliament), following the positive decision of the Swiss National Council (the lower house of the federal Parliament), approved a series of proposals which effectively call upon the federal government and the cantons to prepare a national dementia strategy. The next step will be to establish priorities and assign action items to regional authorities and associations.

30.1.2 Involvement of the Swiss Alzheimer Association (and/or people with dementia)

The Swiss Alzheimer Association is an active supporter for a national dementia strategy and has proposed that the following be included:

- promotion of professional training (for GPs and other health professionals) to improve timely diagnosis, early intervention and advice for people with dementia and their carers;
- support for family caregivers, and available, affordable and adequate services all over Switzerland;
- campaigns to raise awareness within society.

30.2 Diagnosis, treatment and research

30.2.1 Issues relating to diagnosis

30.2.1.1 Which healthcare professionals are responsible for diagnosing dementia

GPs are permitted to diagnose dementia and/or Alzheimer's disease but in situations where they are uncertain, it is recommended that they refer patients to specialists (such as neurologists or geriatricians) or memory clinics which also make diagnoses.

In Switzerland, there is a system known as Tarmed which stands for "tarif médical". Every medical act has a value in points which is calculated based on the time needed, the difficulty of the task and the infrastructure needed. The points are converted into a monetary value which is fixed by each Canton.

The special act of "cognitive analysis and advice" allows for 60 minutes. This can only be charged by specialists, not GPs. The latter can only charge for advice and other acts.

GPs cannot therefore charge for longer consultations based on the fact that a person has dementia or suspected dementia.

There are no incentives for GPs to improve or increase timely diagnosis at federal level. However, some Cantons offer continuing education in dementia for GPs.

30.2.1.2 *Type and degree of training of GPs in dementia*

The amount of training in dementia that GPs receive in the course of their professional training to become a GP differs from one university to the next. Dementia is included in courses on psychiatry, geriatrics and internal medicine. GPs are obliged to do 80 hours of continuing education per year but not specifically in dementia.

30.2.1.3 *Required tests to diagnose dementia*

There are as yet no official guidelines or recommendations which must be used in order to diagnose dementia and/or Alzheimer's disease. A consensus on the diagnosis and treatment of people with dementia has been approved by most dementia experts in Switzerland. This is the "Consensus 2012 on the Diagnosis and Treatment of Patients with Dementia in Switzerland". It describes the state of the art regarding diagnosis and can be downloaded in French and German from the website of the Swiss Alzheimer Association at:

<http://server25.hostpoint.ch/~alzch1/alz.ch/index.php/examen-et-diagnostic.html>

<http://server25.hostpoint.ch/~alzch1/alz.ch/index.php/abklaerung-und-diagnose.html>

30.2.2 *Issues relating to medical treatment*

30.2.2.1 *The availability of medicines in general*

The Federal Office for Social Insurance draws up a positive list of pharmaceuticals for which the compulsory health insurance system will pay (the specialty list). Maximum prices are also set for these products.

30.2.2.2 *The availability of Alzheimer treatments*

All four AD drugs are available. There are no restrictions for people with dementia living alone or in nursing homes.

30.2.2.3 *Conditions surrounding the prescription and reimbursement of AD drugs*

AD drugs are part of the reimbursement system. Treatment decisions can be made by any doctor whether it is for treatment initiation or treatment continuation. The Swiss system requires the doctor to carry out an MMSE at the time of diagnosis, as well as a first follow-up examination after three months which can then be followed by examinations every six months. Treatment with acetylcholinesterase inhibitors should be discontinued if the MMSE score falls below 10 and with memantine for MMSE scores under 3. Combined treatment is not reimbursed.

Prescription and reimbursement	Donepezil	Rivastigmine	Galantamine	Memantine
Available	Yes	Yes	Yes	Yes
Reimbursed	Yes	Yes	Yes	Yes
Initial drug reimbursed if prescribed by	No restrictions	No restrictions	No restrictions	No restrictions
Continuing treatment reimbursed if prescribed by	No restrictions	No restrictions	No restrictions	No restrictions
Required examinations	MMSE	MMSE	MMSE	MMSE
MMSE limits	Above 10	Above 10	Above 10	Above 3 but under 19

30.2.3 Issues relating to research

Switzerland is involved in the EU Joint Programme – Neurodegenerative Disease Research (JPND) but not in the Joint Action “Alzheimer Cooperative Valuation in Europe (ALCOVE)”.

30.3 References

Monsch, A.U. et al. (2012), *Consensus 2012 sur le diagnostic et le traitement des patients atteints de démence en Suisse*, Praxis, 101, 19, 1-12

30.4 Acknowledgements

Marianne Wolfensberger, Swiss Alzheimer Association

31 *Turkey*

31.1 **Background information about the National Dementia Strategy**

31.1.1 **Status and historical development of the National Dementia Strategy**

There is no state-developed or state-confirmed national strategy and there are no plans underway in Turkey to develop a National Dementia Strategy.

In a few cities, some local politicians are thinking along these lines. Some politicians are nevertheless becoming aware of the benefit of social programmes. In Istanbul, two municipalities have small-scale Alzheimer Care Facilities but these are rare examples and do not represent in any way a national strategy.

In 2010, the Turkish Alzheimer Society, Alzheimer Derneği, developed a national strategy (<http://www.alzheimerderneği.org.tr>). The main pillars are: a) to enhance efforts for increasing awareness at all levels of society b) to support development of respite care, day care centres and nursing homes in terms of care, c) better training of primary care physicians, in particular of newly established family physicians in terms of diagnosis and d) to increase co-operation with legislators in order to improve legislation in support of people with Alzheimer's disease and their families.

31.2 **Diagnosis, treatment and research**

31.2.1 **Issues relating to diagnosis**

31.2.1.1 ***Which healthcare professionals are responsible for diagnosing dementia***

GPs are permitted to diagnose dementia and AD but the majority of GPs refer their patients to secondary or tertiary healthcare facilities. Neurologists, psychiatrists and geriatricians are the main healthcare professionals who diagnosis dementia and AD.

GPs do not have fixed consultation times and there are no incentives for GPs to improve or increase timely diagnosis.

31.2.1.2 ***Type and degree of training of GPs in dementia***

The Turkish Alzheimer Association has initiated the organisation of the teaching courses about the diagnosis of Alzheimer's disease, mainly targeting the education of the general practitioners (GPs).

The Turkish Association of Neuropsychologists also holds nationwide courses about how to conduct a neuropsychological evaluation, another important instrument in the early diagnosis.

GPs in Turkey are medical doctors who have completed 6 years of education at a medical faculty. During this education, training in dementia is limited to that provided in the

modules on neurology. GPs are not obliged to undergo continuing education. However, it is envisaged that in the future there will be a credit system for GPs and they will need to ensure that they obtain sufficient credit.

31.2.1.3 Required tests to diagnose dementia

The Turkish Association of Neurology has published guidelines relating to the timely diagnosis of the dementia. However, these guidelines are not obligatory and there are no other guidelines or recommendations which are obligatory.

Although there are no obligatory tests which must be carried out in order to make a diagnosis of dementia and/or AD, nearly all specialists perform at least an MMSE as part of the diagnostic procedure.

31.2.2 Issues relating to medical treatment

31.2.2.1 The availability of medicines in general

There is a list of drugs which are refundable under the social coverage system known as the SGK (<http://www.sgk.gov.tr>).

31.2.2.2 The availability of Alzheimer treatments

The Ministry of Health has approved all four AD drugs.

31.2.2.3 Conditions surrounding the prescription and reimbursement of AD drugs

All four AD drugs are part of the reimbursement system. Patients must have a medical report showing that they have Alzheimer’s disease. These reports can only be given in clinical centres and by specialists, but once there is such a report other physicians can also prescribe. The Turkish system does not require any specific examinations to be carried out, nor does it impose upper or lower MMSE scores for reimbursement. There are no restrictions for the reimbursement of people living alone or in nursing homes.

Prescription and reimbursement	Donepezil	Rivastigmine	Galantamine	Memantine
Available	Yes	Yes	Yes	Yes
Reimbursed	Yes	Yes	Yes	Yes
Initial drug reimbursed if prescribed by	Specialist doctor	Specialist doctor	Specialist doctor	Specialist doctor
Continuing treatment reimbursed if prescribed by	No restrictions	No restrictions	No restrictions	No restrictions
Required examinations	None	None	None	None
MMSE limits	None	None	None	None

31.2.3 Issues relating to research

The Scientific and Technological Research Council of Turkey (<http://www.tubitak.gov.tr>), the Turkish Association of Neurology (<http://www.noroloji.org.tr>) and some other organisations provide initiations and funding. The Turkish Alzheimer Association has started to organise a nationwide scientific congress (annually). There are also satellite meetings for caregivers and GPs. Turkey is involved in EU projects on the harmonization of the biomarkers in AD.

31.3 Acknowledgements

Başar Bilgiç, Neurologist and member of the Executive Committee of the Turkish Alzheimer Association, Istanbul University and the Turkish Alzheimer Association

32 *United Kingdom (England)*

32.1 **Background information about the National Dementia Strategy**

32.1.1 **Status and historical development of the National Dementia Strategy**

The National Dementia Strategy for England is current.

Up until 2007 dementia was not recognised as a priority by government. The Older Person's National Service Framework included a standard on mental health, which referenced dementia.

Alzheimer's Society produced a report in 2007 called Dementia UK which highlighted the costs of dementia and the projections of the number of people who will have dementia in the future. The National Audit Office published a report in the summer of 2007 which concluded that dementia services were not delivering value for money to taxpayers, nor to people with dementia and their families. This report made recommendations on improving early diagnosis and early intervention, improving the management of support and services in the community. This was followed by a report from the Public Accounts Committee in January 2008 into improving services and support for people with dementia concluded that, despite the significant financial and human impact of dementia, the Department of Health was not giving dementia the same priority status as cancer and coronary heart disease.

Due to these key events, there was growing interest from the public, government, policy makers and the NHS in dementia. The Minister for Care Services at the time, Ivan Lewis MP, responded with a commitment to develop a National Dementia Strategy.

32.1.2 **Duration of the National Dementia Strategy**

The Strategy officially started in February 2009 and runs for five years. Following a change in government, The Prime Minister's Challenge on Dementia goes faster and further to deliver the aims of the Strategy by 2015.

32.1.3 **How the National Dementia Strategy is funded**

The Strategy received funding of £150 million during the first two years. This funding was allocated to Primary care Trusts, although the money was not ring-fenced. The All-Party Parliamentary Group on Dementia carried out an inquiry in 2010 into how the money had been spent. The subsequent report *A missed opportunity* found that nearly two-thirds of Primary Care Trusts had not allocated their Strategy funding. A number of Primary Care Trusts said that they were unable to disaggregate their National Dementia Strategy funding from baseline or other funding.

The Strategy's implementation was largely to be funded through efficiency savings, for example reducing unnecessary use of acute hospital beds, and re-directing this to other

areas (such as early intervention services). However, this is dependent on many factors and is very difficult to achieve.

32.1.4 Provisions or procedure for implementing the Strategy

The Strategy states that implementation has to be discussed and decided in partnership with the NHS, local authorities and other key stakeholders. Details should be determined locally and, where necessary, the Department of Health plays an enabling role. This means that there are some national levers, such as the NHS Operating Framework, which sets out the priorities for the NHS for the coming year. The 2012/13 states that commissioners will be expected to place greater demands on providers around quality of dementia care and there is a target on increasing diagnosis of dementia in hospitals. Nevertheless, decisions around improving dementia care and support are made and accounted for locally.

32.1.4.1 General Practitioners (GPs)

It should be the role of GPs to identify individuals who they think show symptoms of dementia. GPs should then refer their patient on to a specialist assessment service for a diagnosis. This is the start of the pathway for a timely diagnosis of dementia and once diagnosed, to receive the care and support people with dementia need.

32.1.4.2 Primary Care Trusts (PCTs)

Primary Care Trusts are responsible for commissioning suitable services. Specialist services need to be commissioned to deliver good-quality early diagnosis and intervention. The Croydon Memory Service Model was tested in a pilot run by the Department of Health in 2007 and was found to be successful in the evaluation.

Following a diagnosis, people with dementia need to access high-quality information and will often seek advice on accessing care and support. The Strategy recommends that PCTs commission a dementia adviser to act as a single point of contact for people once they have received a diagnosis. However, the Strategy also states that there is a need for demonstrator sites and evaluation of service provision prior to country-wide implementation.

32.1.4.3 Home care providers

Successful commissioning is central to improving home care services for people with dementia. Home care can be provided by local authorities or privately. The Strategy recommends the establishment of an evidence base for effective specialist home care services and then commissioners can implement best practice based on the evidence.

32.1.4.4 Hospitals

The responsibility for improving the quality of care for people with dementia in general hospitals lies with hospitals themselves. The Strategy states that hospitals should identify a senior clinician within a general hospital to take the lead for the improvement of dementia in the hospital. Hospitals need to develop an explicit care pathway for the

management and care of people with dementia in hospital, led by the senior clinician. In addition, specialist liaison older people's teams should be commissioned to work in general hospitals.

32.1.4.5 Care providers

Care home providers (local authority or private) are responsible for implementing this objective. The Strategy states that this objective can be delivered through:

- the identification of a senior staff member within the care home to take the lead for quality improvement in the care of dementia in the care home;
- the development of a local strategy for the management and care of people with dementia in the care home, led by that senior staff member;
- only appropriate use of anti-psychotic medication for people with dementia;
- the commissioning of specialist in-reach services from older people's community mental health teams to work in care homes;
- readily available guidance for care home staff on best practice in dementia care.

32.1.5 Procedure for monitoring progress made in achieving the goals set

The National Audit Office took a key role in monitoring progress. A report from the National Audit Office in January 2010 reviewed implementation of the Strategy and found that implementation had been slow to get started. This was followed by a Public Accounts Committee report in March 2010. In light of these, the Department of Health published a revised and focused implementation plan for the Strategy, identifying four priority areas for work in the 2010/11 period:

- good-quality early diagnosis and intervention for all;
- improved quality of care in general hospitals;
- living well with dementia in care homes;
- reduced use of antipsychotic medication.

The review also described the Department of Health's work to identify key outcomes that people with dementia expect by the end of the term of the Strategy and develop measurable indicators across health and social care.

The NHS Operating Framework is published annually and sets out the priorities, direction and vision for the forthcoming year. The 2010/11 NHS Operating Framework made dementia a priority. The NHS Operating Framework for 2011/12 outlined that NHS organisations were expected to make progress on the National Dementia Strategy, including the four key priority areas outlined in the implementation plan. It also underlined the need for joint working with local authorities in improving dementia services and highlights the crucial importance that the NHS help people with dementia and carers understand the range and quality of local services available to them.

The Department of Health also commissioned an audit of the recommendation in the Strategy to reduce the use of antipsychotic drugs. Data on prescriptions of antipsychotics to people with a diagnosis of dementia were extracted from GP practice records in November and December 2011. Only a small number of practices included in the audit chose to opt out, so the data on prescriptions should provide a robust indication of prescriptions of antipsychotics to people with a diagnosis of dementia. However, there are problems with the audit. For example, it is likely that a significant number of people with dementia without a diagnosis who are prescribed antipsychotics were not included.

Following a change of government, it was recognised that the progress of the Strategy was slow, so the Prime Minister made a commitment to drive improvements in dementia care in the Prime Minister's Challenge on Dementia. Three champion groups have been appointed to consider how to meet the commitments made. These groups will report to Mr Cameron by September with an action plan and then report again on progress in March 2013 (Chidgey, 2012).

32.1.6 Involvement of the Alzheimer association (and/or people with dementia)

32.1.6.1 Development of the Strategy

Staff from Alzheimer's Society, people with dementia and carers took part in the three working groups which developed different parts of the Strategy. Over 50 stakeholder events were held in England as part of the consultation exercise. These were attended by over 4,000 individuals. Approximately 600 responses to the consultation document were received. Alzheimer's Society's response to the written consultation drew on feedback from 50 people with dementia and 300 carers.

32.1.6.2 Implementation and monitoring

Alzheimer's Society holds the Primary Care Trusts, NHS, local authorities and government to account. We do this by:

- carrying out research into how well people are living with dementia and producing reports, such as *Dementia 2012: A National Challenge*;
- analysing data from the Quality and Outcomes Framework and external audits;
- responding to government consultations on policy issues;
- engaging with parliamentarians in the All-Party Parliamentary Group on Dementia;
- supporting the All-Party Parliamentary Group on Dementia in inquiries, such as *A Mis-spent Opportunity*;
- raising awareness of dementia with GPs and the public through our campaigns, such as 'Worried About Your Memory?';
- highlighting issues in the media.

32.1.7 Alzheimer association's overall assessment of the National Dementia Strategy

Alzheimer's Society believes that the National Dementia Strategy is fundamental to improving the lives of people with dementia. The organisation was heavily involved in the development and supports the recommendations made. Alzheimer's Society worked with the Prime Minister and Department of Health to produce the Prime Minister's Challenge on Dementia. This was in recognition that more had to be done to achieve the aims of the Strategy.

Nevertheless, Alzheimer's Society has continuing concerns over the funding of the Strategy and its implementation.

32.2 Diagnosis, treatment and research

32.2.1 Issues relating to diagnosis

32.2.1.1 *Timely diagnosis in the National Dementia Strategy*

The Strategy recommends good-quality early diagnosis and intervention for all. This recommendation states that all people suspected of having dementia should have access to a pathway of care that delivers: a rapid and competent specialist assessment, an accurate diagnosis sensitively communicated to the person with dementia and their carers.

The Strategy explains that this can be delivered through the commissioning of good-quality services, available locally, for early diagnosis and intervention in dementia, which have the capacity to assess all new cases occurring in that area.

The Prime Minister's Challenge on Dementia aims to build on the Strategy and highlights the Government's commitment to driving improvements in health and care for people with dementia. The Government has committed to working with GPs to identify how best to improve early diagnosis of dementia through improvements in awareness, education and training. It has also committed to provide funding for continual dementia awareness campaigns up to 2015.

The National Institute for Health and Clinical Excellence (NICE) oversees the Quality and Outcomes Framework (QOF), which does not form part of the Strategy. This is a voluntary incentive for General Practitioners, which rewards them for how well they care for patients. The Dementia indicators aim to incentivise GPs to keep a register of all their patients with dementia, have a record of each individuals' care plan and a record of regular reviews for each patient.

32.2.1.2 Which healthcare professionals are responsible for diagnosing dementia

GPs can carry out initial examinations and then refer to a specialist secondary service. They cannot give a diagnosis themselves. The diagnosis is made by a specialist consultant such as:

- a neurologist
- a specialist in medicine for older people (geriatrician)
- a general adult psychiatrist
- an old age psychiatrist.

GPs tend to offer patients appointments of 10 minutes for routine consultations (Oxtoby, 2010). If patients need longer, it may be possible to book a double appointment. In addition, it is sometimes possible to book a telephone consultation. Such consultations comprise 10-20% of all GPs' contacts with their patient and according to the Royal College of General Physicians (2012), this figure is rising.

The National Institute for Health and Clinical Excellence (NICE) oversees the Quality and Outcomes Framework (QOF), which does not form part of the Strategy. This is a voluntary incentive for GPs, which rewards them for how well they care for patients. The Dementia indicators aim to incentivise GPs to keep a register of all their patients with dementia, have a record of each individuals' care plan and a record of regular reviews for each patient.

32.2.1.3 Type and degree of training of GPs in dementia

The GP curriculum, which is set by the Royal College of General Practitioners, includes two references to dementia, one under care of older people and one under mental health. How this curriculum is then interpreted is up to individual deaneries. There are 14 deaneries in England and 1 for each of Wales, Scotland and Northern Ireland. As such, the training GPs receive in dementia varies depending on where a GP is trained. All GPs will have a basic understanding of the condition, the appropriate assessment tools and how the condition progresses. They will also have an awareness of the treatments available for Alzheimer's disease, and of licensed anti psychotics. Other than this, there is no requirement for further training.

Continuing education is an obligation for GPs, as they must accrue a certain number of Continuing Professional Development (CPD) points in order to pass their yearly review. GPs will usually carry out online learning modules (such as those provided by BMJ Learning), but there is no set curriculum for what they have to study. Study is self-directed, and as such GPs will not necessarily undertake any further training in dementia care.

32.2.1.4 Required tests to diagnose dementia

The official guidelines for assessment of dementia can be found on the NICE website (please see under "references". In summary, the recommendations are:

- take a history
- do a cognitive and mental state examination
- conduct a physical examination and other appropriate investigations (e.g. blood and urine tests)
- review medication to identify and minimise the use of drugs which may affect cognitive functioning.

The MMSE is the most commonly used cognitive test, but others are also used, such as the six-item Cognitive Impairment Test (6-CIT), the General Practitioner Assessment of Cognition (GPCOG) and the 7-Minute Screen.

The NICE guidelines further recommend that a diagnosis of the subtype of dementia should be made by healthcare professionals with expertise in differential diagnosis using international standardised criteria. The NINCDS/ADRDA (National Institute of Neurological and Communicative Diseases and Stroke/Alzheimer's Disease and Related Disorders Association) is preferred for Alzheimer's disease or alternatively the DSM-IV (Diagnostic and Statistical Manual of Mental Disorders, fourth edition) or the ICD-10 (International Classification of Diseases, 10th revision). They also recommend structural imaging to exclude other cerebral pathologies and to help establish the subtype diagnosis (mainly magnetic resonance imaging (MRI) but also computed tomography (CT) scanning. For full details, please refer to their website.

32.2.2 Issues relating to medical treatment

32.2.2.1 *Issues related to medical treatment in the National Dementia Strategy*

Antipsychotic medication

The Strategy addresses the issue of inappropriate prescriptions of antipsychotic medication, particularly in care homes.

The Prime Minister's Challenge on Dementia aims to build on the Strategy. The Challenge recommends that the NHS and social care work together with wider partners to reduce inappropriate prescribing of antipsychotic drugs to people with dementia with a view to achieving overall a two-thirds reduction in the use of antipsychotic medication by 2015.

Alzheimer's Society is part of a call to action on reducing antipsychotic drugs, which is being pushed throughout the NHS. This call to action focuses on ensuring reviews take place and as part of this the Society has produced guides for healthcare professionals and families to inform them about antipsychotics and how regularly they should be reviewed.

National Institute for Health and Clinical Excellence

Although not part of the Strategy, the National Institute for Health and Clinical Excellence (NICE) reviews drug treatments and decides if they offer value for money for the NHS. In 2011, NICE issued guidance that people with Alzheimer's disease should have

increased access to available drugs. NICE also issues guidance on the commissioning of memory services.

Acute care

Commissioning for Quality and Innovation (CQUIN) are payments designed to drive up the quality of care in hospitals. Hospitals can earn payments if they meet certain CQUIN goals. The first CQUIN payment for dementia has only just been introduced. The CQUIN has three aims:

- to identify people with dementia: members of staff will ask members of the family or friends of a person admitted to hospital if the patient has suffered any problems with their memory in the last 12 months;
- to assess people with dementia: if there is evidence to suggest a problem with their memory, that person will be given a dementia risk assessment;
- to refer on for advice: a referral would be made for further support either to a liaison team, a memory clinic or a GP.

The Prime Minister's Challenge on Dementia states that from April 2013, the CQUIN payment will be extended to the quality of care delivered to people with dementia.

32.2.2.2 The availability of Alzheimer treatments

There are currently four drugs for Alzheimer's disease licensed in the UK (Donepezil, Rivastigmine, Galantamine and Memantine), and one drug licensed for the treatment of severe aggression/agitation in people with Alzheimer's disease. One of these drugs, rivastigmine is also licensed for the treatment of Parkinson's disease dementia. There are no licensed drug treatments for other forms of dementia.

32.2.2.3 Conditions surrounding the prescription and reimbursement of AD drugs

In the first instance, these drugs can only be prescribed by a consultant. A GP will need to refer the person to a hospital for a specialist assessment. A consultant will carry out a series of tests to assess whether the person is suitable for treatment and will write the first prescription, if appropriate. Subsequent prescriptions may be written by the GP or the consultant.

The National Institute of Health and Clinical Excellence (NICE) is the Government body responsible for assessing the cost and clinical effectiveness of drug treatments and producing guidance on which treatments should be funded by the NHS.

Guidance published in January 2011 sets out that anticholinesterase treatments should be available to people in the mild to moderate stages of Alzheimer's disease and that Ebixa (Memantine) should be available for people in the severe stages and for people who are unable to tolerate anticholinesterase treatments. There are no restrictions on the prescription or reimbursement of AD drugs for people living alone or in nursing homes.

Prescription and reimbursement	Donepezil	Rivastigmine	Galantamine	Memantine
Available	Yes (also for Parkinson's disease in dementia)	Yes	Yes	Yes
Reimbursed	Yes	Yes	Yes	Yes
Initial drug reimbursed if prescribed by	Consultant	Consultant	Consultant	Consultant
Continuing treatment reimbursed if prescribed by	GP or consultant	GP or consultant	GP or consultant	GP or consultant
Required examinations	NICE diagnostic criteria	NICE diagnostic criteria	NICE diagnostic criteria	NICE diagnostic criteria
MMSE limits	10 - 26	10 – 26	10 – 26	10 - 20

32.2.3 Issues related to research in the National Dementia Strategy

The Strategy recommends that there needs to be a clear picture of current research evidence available and where there are gaps in research. It recognises that evidence needs to be available on the existing research base on dementia in the UK and the gaps need to be filled.

The Prime Minister’s Challenge on Dementia aims to build on the Strategy. The Challenge commits to:

- more than double funding for dementia research to over £66 million by 2015. The level of funding for dementia research in 2009/10 was £26.6 million;
- major investment in brain scanning;
- £13 million for social sciences research on dementia;
- £36m funding over five years for a new National Institute of Health Research (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;
- participation in high-quality research. Offering people the opportunity to participate in research will be one of the conditions for accreditation of memory services.

32.3 References

Alzheimer’s Society (2012), the Mini Mental State Examination (MMSE): http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=121

BMJ Learning: <http://learning.bmj.com/learning/home.html>

Chidgey, A. (2012), The Prime Minister's dementia challenge, *Dementia in Europe: the Alzheimer Europe Magazine*, 11, p.34, Alzheimer Europe

NICE clinical guidelines (CG42: Dementia: Supporting people with dementia and their carers in health and social care: <http://publications.nice.org.uk/dementia-cg42/guidance#diagnosis-and-assessment-of-dementia>

Oxtoby, K. (2010), *Consultation times*, BMJ Careers, article consulted online on 25 October 2012 at: <http://careers.bmj.com/careers/advice/view-article.html?id=20001044>

Royal College of General Practitioners (2012), Information reported in connection with an advertised course: <http://www.rcgp.org.uk/courses-and-events/south-england/south-west-thames-faculty/enhance-your-telephone-consultations-and-triage.aspx>

32.4 Acknowledgements

Laura Cook, Policy Officer, Alzheimer's Society

33 *United Kingdom (Northern Ireland)*

33.1 **Background information about the National Dementia Strategy**

33.1.1 **Status and historical development of the Northern Ireland Dementia Strategy**

Following a consultation in 2010, the Department of Health, Social Services and Public Safety (DHSSPS) published a regional strategy for improving dementia services and support in Northern Ireland in November 2011. The strategy focused on improving understanding and early diagnosis, on the need for support and training for staff and on supporting independence of those affected by dementia.

33.1.2 **Duration of the Northern Ireland Dementia Strategy**

The Strategy's Action Plan extends to 2015 - the limit of the current Assembly term.

33.1.3 **How the Northern Ireland Dementia Strategy is funded**

There are no details about funding for the implementation of the Strategy. It is acknowledged that significant resources are needed to take the actions forward. Reference is made to opportunities to release and redirect resources and the fact that there is already substantial investment in appropriate care and support which will be continued. An example of redirecting resources and opportunities to "invest to save" is an estimated 10% reduction in care home places releasing approximately £10m of public expenditure. Health Minister Edwin Poots who presented the Strategy to the Assembly in 2011 declared that no additional funds would be allocated to its implementation. However, in September 2012 he announced his intention to allocate £1 million to the project.

33.1.4 **Provisions or procedure for implementing the Strategy**

The Strategy contains an action plan in which each proposed action is described and the organisation responsible for its implementation identified. This is accompanied by a target date for completion. Most of the completion dates are either 2012 or 2013. Several simply state "ongoing". The new Mental Capacity legislation, which is in development, is scheduled to be enacted during the lifetime of the current Assembly, so it will happen before Spring 2015.

33.1.5 **Procedure for monitoring progress made in achieving the goals set**

A few monitoring tasks are included in the action plan including 'ongoing' monitoring by the Department of Health, Social Services and Public Safety (DHSSPS) of implementation of Advocacy Services Guidance, which was published in January 2012.

The Health and Social Care Board and Public Health Agency will jointly lead the Dementia Strategy Implementation Group which will oversee progress and report to the Minister for Health at six month intervals. Otherwise no formal monitoring arrangements are contained in the Strategy.

33.1.6 Involvement of the Alzheimer Society (and/or people with dementia)

Alzheimer's Society participated on the DHSSPS Strategy Steering group and on its Project Group.

Alzheimer's Society in Northern Ireland secured funding from the DHSSPS to undertake a research project which would support people with dementia to participate in the development of the Dementia Strategy. The Society worked in association with the Mental Health Foundation and designed and realised the Listening Well project.

The project set out to secure the views of people with dementia around key themes which had been identified by the Bamford Review of Mental Health and Learning Disability. These views were sought and documented in order to influence development of the Dementia Strategy for Northern Ireland. The project was realised in two strands involving 1:1 interviews of people with dementia in their own homes, right across Northern Ireland and a single workshop event in the form of focus groups which included people with dementia and carers.

The report was launched by Alzheimer's Society in Belfast in November 2009. It is entitled 'Listening Well; people with dementia informing the development of health and social care policy.' Listening Well findings are incorporated throughout Improving Dementia Services in Northern Ireland: A Regional Strategy.

33.1.7 Alzheimer Society overall assessment of the Northern Ireland Dementia Strategy

Alzheimer's Society welcomed the development of the strategy and the DHSSPS commitment to involvement of people with dementia in the process, through the Listening Well project. The Society sees the Strategy as a huge opportunity to improve the quality of life of people with dementia but also to raise awareness of dementia in the population generally, informing people about reducing their risk of developing the condition, recognising symptoms to encourage early diagnosis and intervention and provision of appropriate community support. However, lack of additional funding for implementation of such a significant strategy is a cause for concern.

33.2 Diagnosis, treatment and research

33.2.1 Issues relating to diagnosis

33.2.1.1 *Timely diagnosis in the Northern Ireland Dementia Strategy*

Awareness raising, support at the time of diagnosis and tackling stigma

The strategy contains the following observations and objectives in relation to the early diagnosis of dementia. First, it is necessary to raise awareness of the symptoms of dementia and to address stigma. People must know where to access help. Information and advice services are needed particularly in the voluntary and community sectors.

GPs and primary care teams should be able to recognise the possibility of dementia and there should be locally agreed pathways and protocols for referral to specialist services for diagnosis.

In concrete terms, the Public Health Agency will draw up and lead on a plan to address stigma, raise public awareness about what can be done to reduce the risk of or delay dementia and raise public awareness of the signs and symptoms of dementia and about the benefits of seeking help early. Trusts will also ensure that people who are diagnosed with dementia have access to advice and support at the time of diagnosis. This is to be provided by the Memory Services which should also be able to signpost to other sources of information and support.

Recognising that the stigma must be tackled at various levels and in different contexts, measure will be taken to challenge stigma relating to dementia and encourage better understanding among those providing services to the public. These measures will be developed by the HDSSPS, HSC Board, Public Health Agency and HSC Trusts in partnership with other public bodies and with local community and voluntary sector bodies.

Training, appropriate referral and specialist support

Recent research suggests that many GPs do not feel that they have sufficient training to diagnose and manage dementia (DHSSPS, 2005). Some are nevertheless diagnosing dementia alone without referring patients for specialist assessment despite the recommendation from the 1995 policy review that GPs should refer patients suspecting of having dementia for specialist assessment. Two recommendations have therefore been made. The first is to supplement an information pack for GPs provided and distributed by the Dementia Services Development Centre's Northern Ireland Officer with information on local services available. The second is for the HSC Board in collaboration with the Public Health Agency and HSC Trusts to draw up criteria and clear protocols for referral from GPs to Memory Services. The HSC board, in collaboration with LCGs, Public Health Agency and Trusts will agree on a minimum range of services to be offered by memory services. This would be the same set of services for community as for hospital-based Memory Services.

The number of referrals is likely to increase, especially as the number of older people increases. The capacity of the specialist services to manage that increase will be taken into account. The Strategy also acknowledges that there is likely to be a small number of cases which are complex and make diagnosis difficult. Examples include cases of dementia in younger people or atypical cases. For this reason, it is envisaged to set up a regional tertiary service led by one Trust with agreed referral criteria from local memory services.

33.2.1.2 Which healthcare professionals are responsible for diagnosing dementia

GP may diagnose dementia but as mentioned above, according to the 1995 recommendation, they should forward patients to a specialist for assessment.

The Strategy identified significant variation across Health and Social Care Trusts regarding memory services and specialists taking the lead in providing them, as outlined above. The Health and Social Care Board and Public Health Agency will work with Health and Social Care Trusts to draw up criteria and clear protocols for referral from GPs to memory services by March 2013.

GPs usually spend 10 minutes per consultation but this can be extended according to need. For example, if a patient with dementia and his/her carer require more time, it can be allocated, but it is not always easy to gauge appropriate time in advance.

The National Institute for Health and Clinical Excellence (NICE) oversees the Quality of Outcomes Framework (QoF) as in England. This is a voluntary incentive for GPs, which rewards them according to how well they care for patients. GPs keep a register of all their patients with dementia, have a record of each individuals' care plan and a record of reviews.

33.2.1.3 *Type and degree of training of GPs in dementia*

The GP curriculum is set by the Royal College of General Practitioners as in England. All GPs have a basic understanding of the condition, the appropriate assessment tools and how the condition progresses, as well as awareness of treatments available for Alzheimer's disease and licensed anti-psychotics.

GPs are expected to continue their professional development. There is no set curriculum and study is self-selected according to individual interest or perceived training need, as in England.

33.2.1.4 *Required tests to diagnose dementia*

The National Institute of Health and Clinical Excellence (NICE) produces official guidelines as in England. Commonly used tests include the 6-item Cognitive Impairment Test (6-CIT) and the MMSE as in England.

33.2.2 *Issues relating to medical treatment*

33.2.2.1 *Medical treatment in the Northern Ireland Dementia Strategy*

The Strategy emphasises the need to promote the use of appropriate medication and to avoid the inappropriate use of antipsychotic drugs for the management of behavioural and psychological symptoms of dementia. The Northern Ireland strategy relies on NICE guidance in respect of antipsychotics. The action point with regard to medication is:

"The HSC Board and PHA will ensure that medication for the management of dementia is prescribed appropriately, that medication review is an integral part of the care management process and that a range of therapeutic interventions are available to people with dementia and their carers appropriate to their assessed needs."

The Strategy also refers to NICE guidance in identifying a range of therapeutic interventions which should be available to people with dementia, including psychological therapies and states that the Health and Social Care Board and Public Health Agency will conduct an audit of interventions available for people with dementia care across all settings, including nursing and residential care.

33.2.2.2 *The availability of Alzheimer treatments*

NICE reviews drug treatments for Alzheimer’s disease and determines the clinical and cost-effectiveness of drugs for use in the National Health Service (NHS), as in England. There are four drugs for Alzheimer’s disease currently licensed in the United Kingdom and one for the treatment of severe aggression/agitation in people with Alzheimer’s disease. There are no licensed drug treatments for other forms of dementia.

33.2.2.3 *Conditions surrounding the prescription and reimbursement of AD drugs*

NICE guidance published in January 2011 states that anti cholinesterase treatments should be available to people in the mild to moderate stages of Alzheimer’s disease and that Ebixa (Memantine) should be available for people in the severe stages and for people who are unable to tolerate anti cholinesterase treatments. The situation is broadly the same as in England although the NICE link with Northern Ireland was only established in 2006. There are no restrictions concerning the prescription and reimbursement of AD drugs for people living alone or in care homes.

Prescription and reimbursement	Donepezil	Rivastigmine	Galantamine	Memantine
Available	Yes	Yes	Yes	Yes
Reimbursed	Yes	Yes	Yes	Yes
Initial drug reimbursed if prescribed by	Consultant	Consultant	Consultant	Consultant
Continuing treatment reimbursed if prescribed by	GP or consultant	GP or consultant	GP or consultant	GP or consultant
Required examinations	NICE diagnostic criteria	NICE diagnostic criteria	NICE diagnostic criteria	NICE diagnostic criteria
MMSE limits	10 - 26	10 – 26	10 – 26	10 - 20

33.2.3 *Issues relating to research*

Section 13 of the Northern Ireland Dementia Strategy is entitled “promoting research”. It starts with the statement that research on dementia is needed in three main areas, namely cause, cure and care. Emphasis is placed on understanding “the biological basis of dementia, possible ways of preventing neurodegeneration, the psychological and social supports that are most effective and ensuring that potential interventions are trialled and made available to patients as quickly as possible.” The importance of developing a coordinated approach to research, and pooling talents and resources is also recognised.

One of the main aims of the Northern Ireland Dementia Strategy is for the Health & Social Care R & D to support researchers in the preparation of high quality applications for research on dementia for National Institutes of Health peer review via the US-Ireland R & D partnership as well as for major funding via UK Research Councils, the EU framework programme and major charities. This approach is based on the fact that Northern Ireland has a very small academic basis and limited resources for health-related research. The HSC R & D also intends to continue supporting the NICRN (Dementia) which carries out multidisciplinary, policy and practice relevant social scientific research with a particular emphasis on the rights of people with dementia and their unpaid carers.

Finally, the HSC R & D aims to support initiatives to build inter-disciplinary and/or inter-professional research in health and/or social care for people with dementia, especially those having a strong element of patient or public involvement.

33.3 References

Department of Health, Social Services and Public Safety (2011), Improving dementia services in Northern Ireland: a regional strategy, Accessed online on 10 July 2012 at: <http://www.dhsspsni.gov.uk/improving-dementia-services-in-northern-ireland-a-regional-strategy-november-2011.pdf>

Listening Well: People with dementia informing development of health and social care policy (Northern Ireland): http://www.alzheimers.org.uk/site/scripts/download_info.php?fileID=819

Edwin Poots MLA, Minister for Health. Elizabeth Byrne McCullough, Alzheimer's Society Policy & Public Affairs, Northern Ireland (2012), Focus on Dementia Strategies: Northern Ireland, Dementia in Europe: the Alzheimer Europe Magazine, p.37

Interview with Edwin Poots: <http://www.alzheimer-europe.org/Policy-in-Practice2/National-Dementia-Plans/United-Kingdom-Northern-Ireland#fragment-2>

Interview with Elizabeth Byrne McCullough: <http://www.alzheimer-europe.org/Policy-in-Practice2/National-Dementia-Plans/United-Kingdom-Northern-Ireland#fragment-3>

33.4 Acknowledgements

Laura Cook, Policy Officer, Alzheimer's Society

Elizabeth Byrne McCullough, Policy & Public Affairs Officer, Alzheimer's Society in Northern Ireland

34 *United Kingdom (Scotland)*

34.1 **Background information about the National Dementia Strategy**

34.1.1 **Status and historical development of the National Dementia Strategy**

The Scottish government made a commitment in May 2009 to prepare and publish a National Dementia Strategy for Scotland. Initial work was influenced by and focused on five “workstreams” described as:

- Treatment and improving the response to behaviours that carers and staff find challenging;
- Assessment, diagnosis and the patient pathway – improving the journey of people with dementia and their carers;
- Improving general service response to dementia;
- Rights, dignity and personalisation;
- Health improvement, public attitudes and stigma.

Each workstream resulted in a report which included detailed recommendations and contributed towards the development of the Strategy. These reports can be consulted at:

<http://www.scotland.gov.uk/Topics/Health/health/mental-health/servicespolicy/Dementia>

This work was followed by a process of consultation and dialogue. First, the Dementia Dialogue took place in autumn 2009. Next, a series of engagement events were run by Alzheimer Scotland, in partnership with the Scottish Government, between March and May 2010. This provided a possibility to test the emerging recommendations from the various workstreams. These can also be consulted on the above-mentioned website.

The Strategy was then prepared by the Scottish Government in collaboration with the Dementia Strategy Management Group which consisted of the Chairs of the various workstreams and other key stakeholders in the field of dementia, including Alzheimer Scotland.

The published strategy identified the following five key challenges:

1. Fear of dementia means people delay in getting a diagnosis.
2. Poor post-diagnosis support.
3. General healthcare services do not always respond well to those with dementia.
4. People with dementia and their carers are not always treated with dignity and respect.
5. Families and carers do not always get the help they need to protect their own well-being and care well.

The strategy also identified two priority areas for improvement.

- Providing excellent post-diagnostic support and information, and
- Improving response to dementia in general hospital settings, including alternatives to admission and better discharge planning.

34.1.2 Duration of the National Dementia Strategy

The National Dementia Strategy runs from 2010 to 2013. The strategy is currently under review.

34.1.3 Provisions or procedure for implementing the Strategy

Work to deliver the Dementia Strategy is overseen by the Dementia Strategy Implementation and Monitoring Group. Its remit is to:

1. Ensure delivery of the eight Actions to support the change programme, including being responsible for considering next steps in relation to particular actions, such as the work on knowledge and skills.
2. Monitor the impact of public sector funding pressures on the capacity of partners to deliver on those commitments within the dementia strategy that have a potential resource implication.
3. Establish a monitoring framework which is valid both nationally and locally to track change and improvement over time in respect of dementia services. The framework will build on the benchmarking work set out above and where possible will be based on existing data sources or data which is provided through the benchmarking work. It takes into account issues such as:
 - the number of people with a diagnosis;
 - the number of people receiving post-diagnostic information and support;
 - reductions in unnecessary admissions to general hospitals and reduced period of admission for those for whom it is appropriate;
 - reductions in the use of psychoactive medication;
 - compliance with relevant legal provisions relating to Adults with Incapacity;
 - increases in social and community activities, including physical activity;
 - improvements in the experience of people with dementia and their carers;
 - prepare Annual Reports on the progress of the Strategy;
 - commission a revision of the Dementia Strategy, which takes account of progress and learning, to be in place from June 2013.

34.1.4 Procedure for monitoring progress made in achieving the goals set

Work and progress on the National Dementia Strategy is monitored by the Dementia Strategy Implementation and Monitoring Group which is comprised on key partners in the strategy, including people with dementia and their carers and Alzheimer Scotland. Annual reports were published for 2011 and 2012. These are available at:

<http://www.scotland.gov.uk/Topics/Health/Services/Mental-Health/Dementia>

A revision of the National Dementia Strategy has been commissioned which will take into account progress and learning. An updated strategy is planned for publication during 2013. Alzheimer Scotland is currently working in partnership with the Scottish Government to hold a series of six dialogue events across Scotland between October 2012 and January 2013. The Scottish Government has also arranged a national dialogue event on 12 December 2012. These dialogue events provide an opportunity for key stakeholders, including people with dementia, their partners, families and carers as well as health, social care and other professionals, to discuss the progress of the current strategy and help identify the key priorities which will inform the direction of the next strategy.

34.1.5 Involvement of the Alzheimer association (and/or people with dementia)

Alzheimer Scotland published an election manifesto in 2009 calling for a national dementia strategy for Scotland. The manifesto was informed by the views of people with dementia gathered during a series of consultation road shows across Scotland. The manifesto sought the commitment of all parties to make dementia a national priority. The current Scottish Government made dementia a national priority shortly after the election.

Alzheimer Scotland have been fully engaged, as an equal partner, in the development, implementation and monitoring of Scotland's National Dementia Strategy, as are people with dementia and carers. As well as the evidence gathered by Alzheimer Scotland from its members and those who use services, people with dementia are also represented by the Scottish Dementia Working Group (the "SDWG" is a campaigning and awareness-raising group, formed in 2002, whose members all have dementia) who have been involved in the development of the Strategy. The SDWG aims to ensure that the needs of all groups of people with dementia are met (e.g. including minority groups such as British Sign Language users, people from diverse ethnic groups and younger people with dementia).

The Scottish Government values the individual experiences of people with dementia and those who care for them. Alzheimer Scotland therefore systematically gathers such information which is used to inform the monitoring and implementation of the strategy.

34.1.6 Alzheimer association's overall assessment of the National Dementia Strategy

As highlighted by the one- and two-year reports significant progress has been made in delivering the key aims of the National Dementia Strategy.

These include:

- A guarantee of a minimum of one year's post diagnostic support, from a named link worker, for every person diagnosed with dementia. The guarantee is based on the five-pillar model developed by Alzheimer Scotland.
- New common standards of care for dementia were published in June 2011. The standards are underpinned by the Charter of Rights for People with Dementia and their Carers and underline a common understanding of what constitutes a good quality of care and support – through all stages of the illness and in all care settings. The standards are available at: <http://www.scotland.gov.uk/Publications/2011/05/31085414/0>.
- Alzheimer Scotland also published a guide to the dementia standards for people with dementia and their families and carers to inform them of the standards of care, support and treatment they should expect at any stage of the illness and in every setting. The guide is available at: <http://dementiascotland.org/dementia-strategy/2011/standards-of-care-for-dementia-in-scotland-a-guide-for-people-with-dementia-and-their-carers/>.
- A National Dementia Standards in Hospitals Implementation and Monitoring group has been established, chaired by the Chief Nursing Officer, to coordinate activity in this area of care. A key part of this group's current work is to scrutinise all the evidence in relation to dementia care in hospitals, including the findings of the inspections, to provide information at a national level on progress with the implementation of the dementia standards in hospitals, identify areas where improvement is needed and highlight any best practice.
- The roll out of inspection programme into the care of older people in acute general hospitals by Healthcare Improvement Scotland. All acute hospitals in Scotland's 14 territorial National Health Service Boards are subject to inspection against a number of priority areas, which includes a key set of the Dementia Standards aimed at hospital care to inform this process.
- Promoting Excellence: A knowledge and skills framework was launched in June 2011 and The National Health Service Education for Scotland (NES) and the Scottish Social Services Council (SSSC) have taken forward a range of activities to implement a two-year strategic dementia workforce development plan to support delivery of the change programme and actions outlined in Scotland's National Dementia Strategy. Promoting Excellence is available at: <http://www.scotland.gov.uk/Publications/2011/05/31085332/0>.

This ongoing programme has delivered the production and dissemination of:

- Informed about Dementia: improving practice DVD, a resource targeted at the entire health and social services workforce to support them to achieve the baseline knowledge and skills set out in Promoting Excellence.
- Dementia Skilled-Improving Practice, a comprehensive learning resource with accompanying guidance for managers and educators.

- In March 2012 the first cohort of 100 acute general hospital dementia champions graduated from their programme and continue to be supported in their role as change agents via learning networks. A further 200 champions will be trained between 2012 and 2013, including social services staff. The Champions have been trained to better understand, recognise and respond to the particular needs of people with dementia in acute hospital and associated care settings and will lead front line improvements in dementia care; sustain change in their area; and cascade information and education about dementia to other staff.
- The Scottish Government has agreed to match Alzheimer Scotland funding for an Alzheimer Scotland Specialist Nurse (ASDN) in each of Scotland 14 NHS Health Boards. There are very good early signs that the ASDNs in post are already making a positive impact in ensuring that their respective NHS Boards are responding to the implementation of the Dementia Standards and Promoting Excellence. The establishment in each NHS Scotland Board of an ASDN is closely aligned to the Dementia Champions initiative, each working with the other to ensure an infrastructure to drive forward improvement in the sector.
- The Scottish Government have continued to support an Allied Health Professional (AHP) programme of work for the implementation of the Strategy through our 3 AHP consultants who all have a national remit. More recently the Scottish Government has extended this support with the appointment of the very first AHP consultant to be based in Alzheimer Scotland. All the AHP programme work is embedded in the wider dementia strategy implementation work including the Dementia Champion programme. The three AHP Dementia Consultants each have a national remit as well as being hosted within a health board. These national remits include:
 - Acute care and the role of the Allied Health Professional – NHS Greater Glasgow and Clyde;
 - Early Intervention and the role of supported self management. – NHS Lothian;
 - Activity Participation and the Environment – NHS Lanarkshire.
- The Dementia Demonstrator sites are three health and social care partnerships which are working with the support of a range of national programmes to demonstrate that whole system redesign can deliver better care for more people with the same or less resource. The national programmes have all committed to work together to support the three sites and, in doing so, look for opportunities to better integrate their work nationally on an ongoing basis. The three partnerships are Midlothian CHP, North Lanarkshire CHP and Perth & Kinross CHP and the work includes an economic analysis of the impact of the changes made.

34.2 Diagnosis, treatment and research

34.2.1 Issues relating to diagnosis

34.2.1.1 *Timely diagnosis in the National Dementia Strategy*

Timely diagnosis is mentioned in the executive overview of the Strategy where it is stated that the Scottish Government and its partners are committed to delivering world-class dementia services by continuing to increase the number of people with dementia who have a diagnosis to enable them to have better access to information and support and by improving staff skills and knowledge in both health and social care settings.

Earlier this year, The Alzheimer Society recently published Mapping the Dementia Gap: Progress on improving diagnosis of dementia 2010-2011, detailing relative performance across the United Kingdom. This report shows that rates of diagnosis are improving in Scotland.

Amongst the five key challenges, fear of dementia is mentioned as a reason for people not seeking diagnosis. Stigma is mentioned and the reluctance of some general practitioners (GPs) to diagnose. Solutions are described in the form of informing people of the benefits of diagnosis and improving the quality and availability of post-diagnostic support.

The Scottish Government has made a commitment to guarantee a minimum of one year post diagnostic support for every person diagnosed with dementia provided by a named link worker. The guarantee is based on the five pillars model of Post Diagnostic Support developed by Alzheimer Scotland. The five pillars are:

- help to understand the illness and manage symptoms;
- support to stay connected to the community;
- peer support;
- help with future decision-making;
- developing a personalised care plan for their future care.

The Scottish Government has therefore said that it will introduce a HEAT²⁴ target beginning in 2013 with activity starting in 2012 which will have three components: that all people newly diagnosed would receive a guarantee on post-diagnostic support; that this would constitute a year's worth of post-diagnostic support, including as a key output the building of an all-encompassing person-centred support plan based on the five pillars; and this support would be provided by a named person/link worker.

Four test sites have been set up in Scotland to identify what is required at the local level to deliver the commitment, in terms of service and workforce reconfiguration, and what costs might be identified to deliver it.

²⁴ A HEAT target is a Ministerial measure set by the Government in relation to Health Improvement, Efficiency, Access to services and Treatment.

34.2.1.2 Which healthcare professionals are responsible for diagnosing dementia

GP may assess or refer to specialist consultant or memory clinic.

Individual GP practices will operate different consultation times. It may be possible to extent consultation times but again, this would depend on the individual practice.

34.2.1.3 Type and degree of training of GPs in dementia

It is not known how much or what kind of training GPs receive in dementia in their professional training to become a GP. This is an area that is receiving increased attention as a result of diagnosis targets. This is likely to have the impact of increasing GP awareness. In reality GPs will see very few new cases of dementia, so may not have the skills and knowledge to respond appropriately.

34.2.1.4 Required tests to diagnose dementia

Guidelines are provided by the Scottish Intercollegiate Guidelines Network (86) 2006 on diagnostic tools to use in diagnosis of AD, vascular dementia, Lewy body and fronto-temporal dementia. This guideline is not intended to be construed or to serve as a standard of care but it is advised that significant departures from the national guideline or any local guidelines derived from it should be fully documented.

34.2.2 Issues relating to medical treatment**34.2.2.1 Medical treatment in the National Dementia Strategy**

Sections 64 to 67 of the National Dementia Strategy address the issue of the hospital treatment of people with dementia. Section 64 emphasised that a person with dementia should only be admitted to hospital when the appropriate treatment cannot be provided at home. The reason given is that unfamiliar surroundings and people and the experience of being in hospital may cause stress and anxiety, for anyone but especially for people with dementia whose ability to reason and remember is likely to be impaired. In section 65, the need to make the environment and practices dementia friendly is emphasised, whereas section 66 describes the need to ensure that the cognitive impairment of people with dementia is accurately assessed, especially when they are admitted to emergency services. When admitted to a general hospital, it is stated that information about the person's diagnosis and needs should be communicated to staff and built into the care planning process. Finally, section 66 emphasises the need for hospital staff to carry out an assessment if a person with no known diagnosis of dementia is suspected of having dementia.

34.2.2.2 The availability of medicines in general

Scotland operates a system of free prescriptions.

34.2.2.3 The availability of Alzheimer treatments

All four AD drugs are available in Scotland,

34.2.2.4 Conditions surrounding the prescription and reimbursement of AD drugs

AD drugs will normally be prescribed by a specialist doctor (for example, a psychiatrist) but sometimes by a GP with substantial experience in the diagnosis and treatment of dementia. If a person needs to see a specialist, the GP will arrange this. Normally, the cheapest drug will be selected but the doctor may choose a more expensive drug if there are good clinical reasons for doing so. There are no restrictions on the prescription and reimbursement of AD drugs for people with dementia living alone or in nursing homes.

Prescription	Donepezil	Rivastigmine	Galantamine	Memantine
	Free	Free (and for dementia related to Parkinson's)	Free	Free
Initial treatment decision	Usually a specialist but may be a GP	Usually a specialist but may be a GP	Usually a specialist but may be a GP	Usually a specialist but may be a GP
Continuing treatment decision	No restrictions	No restrictions	No restrictions	No restrictions
Required examinations	Scottish Intercollegiate Guidelines Network (86) 2006	Scottish Intercollegiate Guidelines Network (86) 2006	Scottish Intercollegiate Guidelines Network (86) 2006	Scottish Intercollegiate Guidelines Network (86) 2006

34.2.3 Issues relating to research in the National Dementia Strategy

The National Dementia Strategy contains a section on “continued action to support dementia research” in which the involvement of people with dementia and carers is encouraged. In August 2008, the Scottish Government established the Dementia clinical Research Network for Scotland. Together with Alzheimer Scotland, this network will facilitate the involvement of people with dementia and their carers in research as well as the possibility for people with dementia to participate in early studies of potential treatment. Contact details are provided in the Strategy which people can use to indicate their interest in taking part in research on dementia.

The last year has seen dementia research in Scotland grow significantly. Support from the Chief Scientist Office for the Scottish Dementia Clinical Research Network (SDCRN) has been renewed for a further three years. In September 2011 Alzheimer Scotland launched a new Dementia Research Centre in partnership with the University of Edinburgh. The centre is funded by Alzheimer Scotland in partnership with the University of Edinburgh representing a major investment in dementia research in Scotland. The Centre is setting up a brain tissue bank which will be an important dementia research resource for many years to come.

34.3 References

Alzheimer Scotland Quarterly Newsletters: www.alzscot.org

Scottish Government (2010), *Scotland's National Dementia Strategy*, Edinburgh

Scottish Government (2011), *Promoting Excellence: skills and knowledge framework for dementia care*, Edinburgh

Scottish Government (2011), *Standards of Care for Dementia*, Edinburgh

Scottish Government (2011), *Dementia Strategy one year report*, Edinburgh

Scottish Government (2012), *Dementia Strategy two year report*, Edinburgh

SIGN (2006), *Guideline 86: managing patients with dementia*, Edinburgh

34.4 Acknowledgements

Jim Pearson, Deputy Director of Policy, Alzheimer Scotland

Maureen Thom, Information Manager

35 *United Kingdom (Wales)*

35.1 Background information about the National Dementia Strategy

35.1.1 Status and historical development of the National Dementia Strategy

A public consultation was carried out in order to identify what was needed in order to ensure a quality of life for people with dementia in Wales. Four priority areas were identified as a result of this consultation which were outlined in the “National Dementia Vision for Wales: Dementia Supportive Communities”:

- “1. Improved service provision through better joint working across health, social care, the third sector and other agencies;
2. Improved early diagnosis and timely interventions;
3. Improved access to better information and support for people with the illness and their carers, including a greater awareness of the need for advocacy;
4. Improved training for those delivering care, including research.”

35.1.2 Duration of the National Dementia Strategy

The National Dementia Vision for Wales was launched on 16 February 2011. Unlike other National Dementia Strategies, the National Dementia Vision for Wales does not set a time limit. It describes a series of commitments to be implemented with immediate effect.

35.1.3 How the National Dementia Strategy is funded

In July 2010, the Welsh Assembly Government announced its intention to provide additional funding of £1.5 million per year to support and implement the above-mentioned goals.

35.1.4 Provisions or procedure for implementing the Strategy

The Mental Health Programme Board has been set up by the Minister for Health and Social Services. Its task is to ensure NHS (National Health Service) Wales, local government and the voluntary sector work together effectively and efficiently to ensure that coordinated services are delivered.

35.1.5 Procedure for monitoring progress made in achieving the goals set

The Mental Health Programme Board will regularly report to the Ministers on its progress and the latter will ensure that the improvements are made.

35.1.6 Involvement of the Alzheimer association (and/or people with dementia)

The Alzheimer’s Society worked closely with the Welsh government in developing the action plans and responded to a consultation on a draft strategy. The Society aims to maintain pressure on the Welsh government to ensure that it delivers on the commitments made in this vision and action plans. On the Society’s website, people are invited

to email or write to their Assembly Member (AM) to stress the importance of improving services for people with dementia in Wales.

35.1.7 Alzheimer association's overall assessment of the National Dementia Strategy

The Alzheimer Society has welcomed the vision and action plans.

35.2 Diagnosis, treatment and research

35.2.1 Issues relating to diagnosis

35.2.1.1 *Timely diagnosis in the National Dementia Strategy*

Improved early diagnosis is one of the four priority areas identified for improvement. Some of the measures in the vision are relevant to timely diagnosis ranging from pre-diagnostic to post-diagnostic support. For example, there is a commitment to employ dementia clinical co-ordinators to support people who have been diagnosed with dementia. Another commitment is to develop information packs for newly diagnosed people and to create a dedicated information helpline. The third commitment focuses on awareness raising by ensuring that dementia issues are communicated to health colleagues in other disciplines through networks and bulletins.

35.2.2 Issues relating to medical treatment

35.2.2.1 *Medical treatment in the National Dementia Strategy*

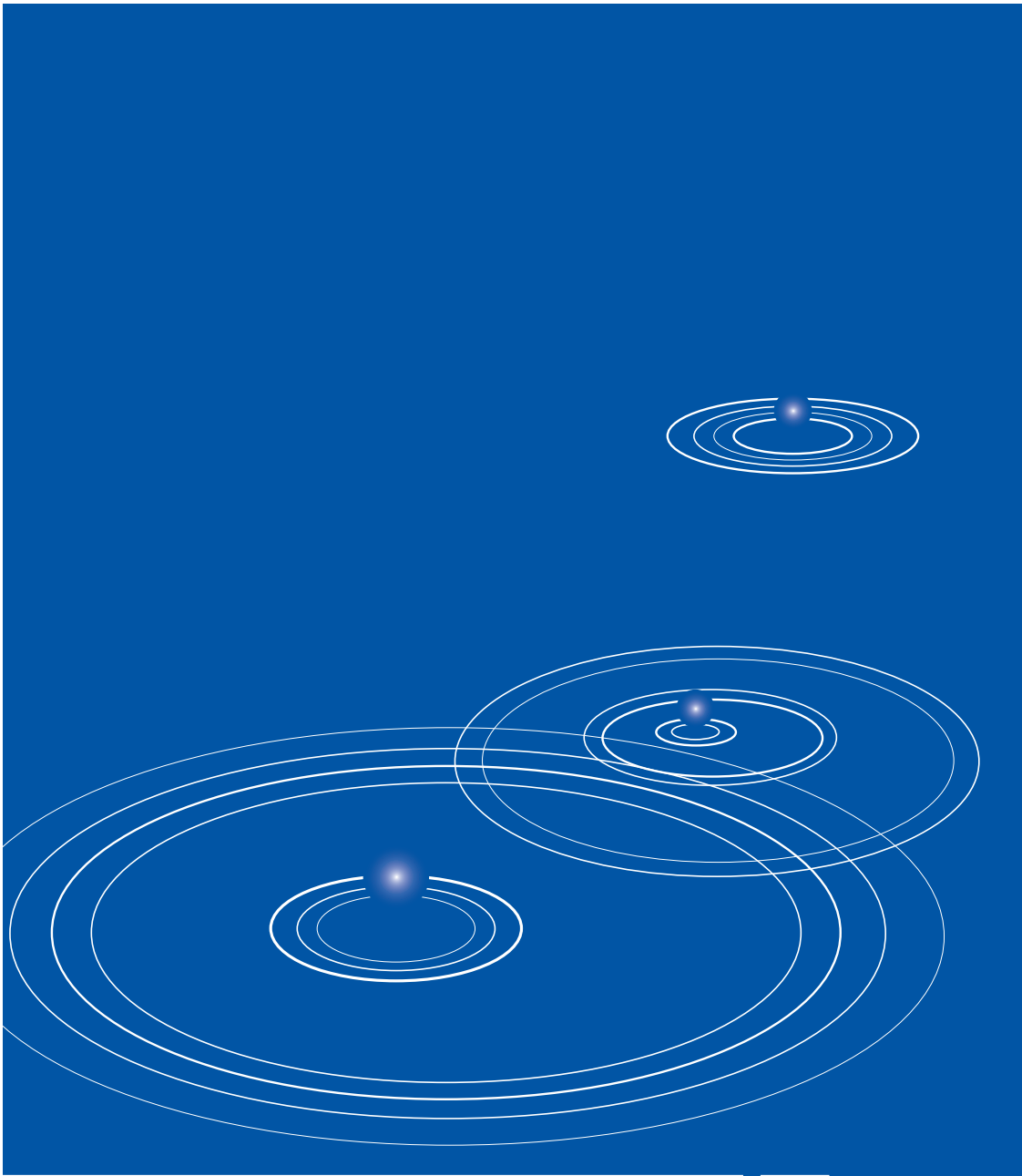
Timely interventions are mentioned in the list of priority areas for improvement. Further information is not provided in the vision document.

35.2.3 Issues relating to research in the National Dementia Strategy

One of the commitments of the vision is to recognise the importance of dementia research and to continue to support research into the cause, care and cure of dementia. This includes offering funding opportunities to researchers who wish to carry out such research.

35.3 References

Welsh Assembly Government (2011), National Dementia Vision for Wales: Dementia Supportive Communities,



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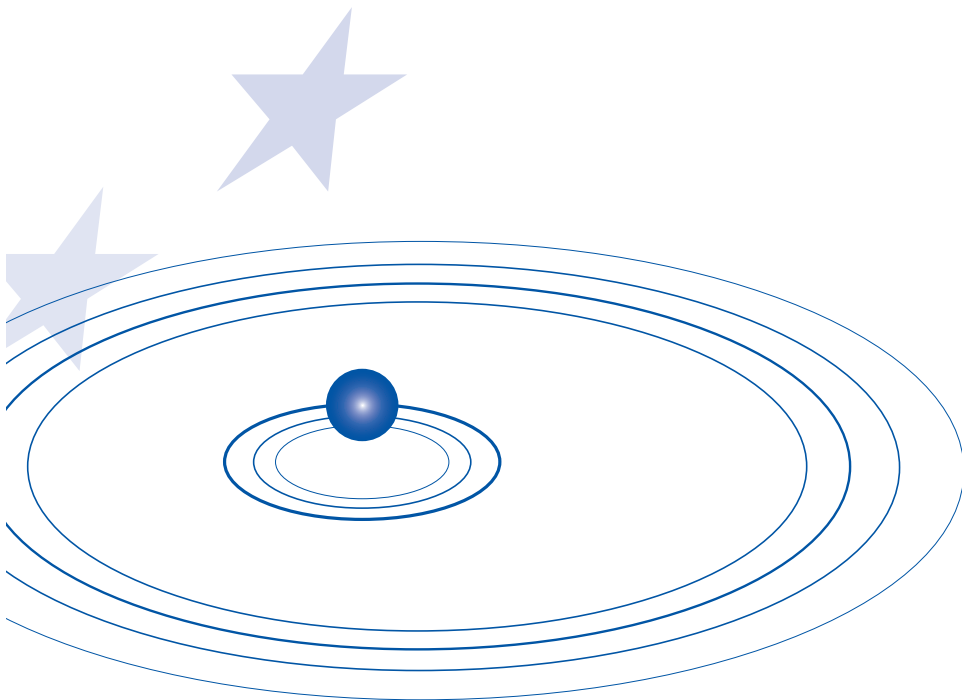






Alzheimer Europe Annual Report 2011

*Adopted at Annual General Meeting in Vienna
(4 October 2012)*



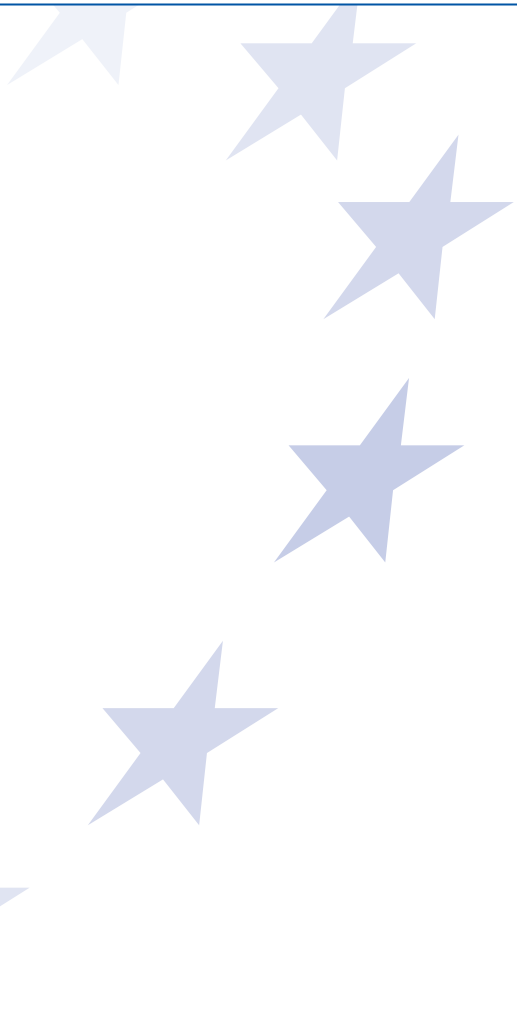
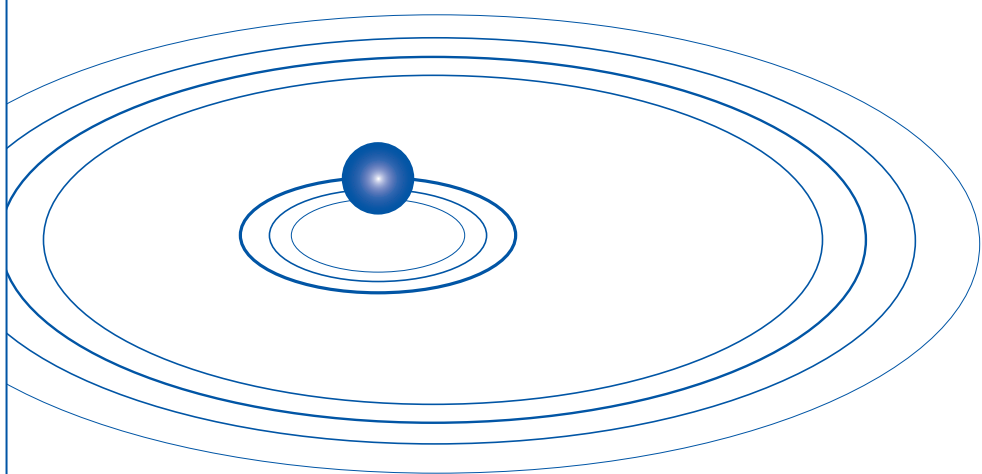


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Annual Report 2011

1.1 Preface



As I look back on my first two years as Chairperson of Alzheimer Europe, I have to admit to being proud about the impressive list of our achievements.

When we adopted a new strategic plan in 2011, we did so after a thorough satisfaction survey amongst our member organisations. It was heartening to see that members overwhelmingly endorsed the activities carried out in previous years and gave their full backing to building on those priorities over the next five-year period.

I am particularly impressed with the clear commitment our members have given to the need to improve the ways in which we involve people with dementia in our activities. The adoption of our policy on including people with dementia in working groups, projects and policy work and the development of a bursary system for people with dementia for our annual conferences constitute important milestones in becoming a more inclusive organisation. The development of a European Working Group of People with Dementia and the decision to invite the Chairperson of this group to attend our Board meetings with full voting rights are particularly exciting new initiatives.

Thanks to our European Dementia Ethics Network, we are now recognised as a leader in Europe when it comes to ethical and legal issues in the dementia field. Last year's publication on the ethical issues of dementia research and our yearbook with the national reports on restrictions of freedom are important additions to our growing list of publications in this area.

I am also confident that we are getting closer to our stated aim of establishing a European Dementia Observatory as we have been able to cover an increasing range of scientific and policy developments in our e-mail newsletter and our magazine.

Our policy focus is similarly paying off dividends and the membership of our European Alzheimer's Alliance continues to increase. At the end of last year, we counted 58 Members of the European Parliament from 21 European countries as active participants. I particularly enjoyed the meetings we organised with public affairs representatives from our member organisations which allowed us to exchange information on campaigning and lobbying activities on a national level, but also to jointly develop strategies on how to ensure dementia becomes a European and national priority.

Our Annual Conferences have become true networking opportunities and over the past few years, we have been able to steadily increase the number of participants with last year's conference in Warsaw, held under the motto "European solidarity without borders" attracting close to 500 participants from 44 countries.

Alzheimer Europe has also become a recognised partner for European funded research projects and collaborations. In 2011, we were involved as full partners in both the PharmaCog and DECIDE projects where we supported the dissemination activities and took part in the discussion of ethical issues. More and more project coordinators acknowledge the importance of involving carers' and patients' organisations and have therefore contacted us when developing applications for funding.

Although the list of achievements is already quite impressive, I want to add another undoubted highlight of our activities last year: the Value of knowing survey which we conducted together with the Harvard School of Public Health and the Alzheimer associations in Germany, France, Poland, Spain and the US thanks to an educational grant provided by Bayer AG. This survey gave us important information on the general public's perceptions and knowledge of Alzheimer's disease, the fear caused by the disease and the willingness and interest of people to find out more about a possible diagnosis or their likelihood of developing the disease in the future. The media interest generated by the survey publication was tremendous and I was delighted to see the results covered and commented by such prestigious publications and news agencies as Reuters, CNN or Spiegel in Germany.

When presenting and discussing this list of successful projects and initiatives with policy makers, I am always struck that they completely overestimate the size of the organisation. The list of achievements is impressive all on its own; the fact that these projects have been carried out by a small team of five permanent staff and two consultants is testimony to their dedication to our common cause. My heartfelt thanks go to our Executive Director, Jean Georges and his team comprised of Alex Teligadas, Annette Dumas, Dianne Gove, Julie Fraser, Grazia Tomasini and Gwladys Guillory.

I also want to thank the other members of the Board who have aptly supported me at our regular meetings to ensure that our activities and finances are in line with the work plan and budget approved by our membership. Their advice and input were essential for an accurate monitoring and evaluation of our programmes.

Finally, none of our activities would have been possible without adequate financial support. The operating grant provided by the European Commission for a second year made it easier to carry out our core activities. Also, as in previous years, the Luxembourg Alzheimer's Association seconded the Executive Director to work on behalf of Alzheimer Europe and provided us with rent free offices. In addition, we were able to count on project funding from a number of foundations and corporate sponsors which we thank in the financial report of this publication.

I hope you will share my enthusiasm for Alzheimer Europe and its achievements when reading the rest of this Annual Report.

Heike von Lützu-Hohlbein
Chairperson

1.2 *Executive Summary*

In 2011, Alzheimer Europe

- Received an operating grant under the EU public health programme to finance its core activities,
- Continued with the development of the European Dementia Ethics Network bringing together European experts in the field of dementia ethics and carried out an in-depth literature review on the ethical aspects of dementia research (informed consent, representation of people unable to consent, placebo research, genetic testing),
- Published a report with its position and recommendations on the ethical issues of dementia research,
- Carried out an inventory of national legislation on restrictions of freedom (involuntary internment, coercive measures, mistreatment and abuse and driving),
- Dedicated its 2011 Dementia in Europe Yearbook to the subject of restrictions of freedom and included descriptive national reports on the legislation in place in 32 European countries,
- Continued to cover scientific and policy developments in the framework of its European Dementia Observatory and included a total of 443 news articles in its monthly e-mail newsletter,
- Expanded its website, which increased the number of visitors by over 32% in comparison to 2010 and brought total visitors to 217,471,
- Implemented the new policy of involving people with dementia by including people with dementia in the working group on the ethical aspects of dementia research, by including people with dementia as keynote speakers at the AE Conference in Warsaw and by creating a bursary system for people with dementia attending the AE Conference,
- Adopted changes to its Statutes to allow the setting up of a European working group of people with dementia whose chairperson will be an “ex officio” member of the Alzheimer Europe Board,
- Organised its 21st Annual Conference in Warsaw under the theme “European Solidarity without borders” which was attended by 472 participants from 44 countries,
- Approved a new strategic plan for the period 2011-2015,
- Welcomed the Jersey Alzheimer’s Association as new full member and Compassion Alzheimer Bulgaria as a new provisional member,
- Developed closer ties with ALCOVE, the Joint Action on Dementia and dedicated a lunch debate in the European Parliament to a presentation of ALCOVE’s aims and objectives,

- Collaborated with the Joint Programming Initiative on Neurodegeneration and participated in the stakeholder consultation for the development of the initiative's Strategic Research Agenda,
- Actively participated in the workshops organised by the European Commission for the establishment of the European Innovation Partnership on Active and Healthy Ageing,
- Collaborated with the European Medicines Agency as an accredited patient organisation,
- Continued as an active member of the European Patients' Forum,
- Developed closer ties with AGE, the European Platform for elderly people,
- Contributed to discussions on regionalisation with Alzheimer's Disease International,
- Networked with other European dementia networks,
- Increased the membership of the European Alzheimer's Alliance to 58 Members of the European Parliament from 21 Member States and all seven political groups,
- Organised three lunch debates in the European Parliament which were hosted by Marina Yannakoudakis, MEP (United Kingdom), Sirpa Pietikäinen, MEP (Finland) and Frieda Brepeols, MEP (Belgium),
- Focused on the development and implementation of national dementia strategies,
- Published three editions of its "Dementia in Europe Magazine" which carried interview from a variety of national and European policy makers,
- Dedicated a special conference supplement of the magazine to the situation of people with dementia in Poland,
- Carried out a survey on the perceptions and attitudes of the general public in 5 countries (France, Germany, Poland, Spain and the US) and their views on the value of a diagnosis in collaboration with the Harvard School of Public Health thanks to an educational grant by Bayer Healthcare,
- Presented the findings of the survey on the "Value of Knowing" at the Alzheimer's Association International Conference in Paris, the Conference of the International Psychogeriatrics Association in The Hague, the Alzheimer Europe Conference in Warsaw and one of the lunch debates organised in the European Parliament,
- Generated great media interest in the key findings of the survey which showed AD as a major concern, high personal experience of Alzheimer's disease and a high willingness to confront the disease by getting a diagnosis,
- Continued its involvement in the PharmaCog and DECIDE projects by disseminating research results to the general public and by dedicating a workshop on these projects at the Alzheimer Europe Conference in Warsaw,

1.3 AE Core Activities

In 2011, Alzheimer Europe received the support of the European Commission. The following core activities of the organisation were funded thanks to an operating grant to Alzheimer Europe in the framework of the Public Health Programme.

1.3.1 European Dementia Ethics Network

The work on dementia ethics started in 2009 and had the aim of collecting and disseminating ethical positions and recommendations, to provide in-depth coverage of specific ethical dilemmas and to develop, where possible, consensual positions and recommendations.

Building on the work carried out in 2010, the focus of the 2011 activities was on developing a report on the ethical issues of dementia research (informed consent, representation of people unable to consent, placebo research, genetic testing).

An in-depth literature review was carried out with the aim of providing an objective analysis of the literature relating to the ethics of dementia research. In order to ensure that lay people were familiar with the issues discussed in the report, for each section, background information was provided for each topic addressed (e.g. what do we mean by ethics, what is research, what do clinical trials involve etc.). This was followed by a balanced argument of various positions regarding the ethical issues linked to that topic and finally, we proposed our position regarding various issues.

At the end of the report, a few useful annexes were included. The first was a sample consent form which could be adapted to the needs of a particular study. Secondly, we included a list of issues to consider when drafting a participant information sheet and finally, we included a list of issues to be considered by researchers and ethical committees when designing or evaluating a research proposal.

Alzheimer Europe organised two meetings of the working group on the ethics of dementia research. These were attended by all the members of the working group as well as two members of the Steering Committee, Iva Holmerová (Czech Republic) and Sabine Jansen (Germany).

The members of the working group were as follows:

- Dr Peter Annas, Senior Research Scientist, PhD. and AstraZeneca's representative in the PharmaCog project (and co-leader of the Ethics work package in the same project).
- Ms Angela Clayton-Turner, volunteer, carer and involved in selecting, monitoring and disseminating research for the Alzheimer's Society and in ethical procedures for brain donations for research. She is also a lay member of her local Research Ethics Committee.

- Dr Thomas Frühwald, Senior physician of the Department of Acute Geriatrics of the Hietzing Hospital in Vienna, Austria. Committee member of the Geriatric Medicine Section of the European Union of Medical Specialists, Board member (Vice President) of the Austrian Society of Geriatrics and Gerontology.
- Ms Dianne Gove, Information Officer at Alzheimer Europe, Luxembourg.
- Dr Fabrice Gzil, Head of Social Studies Department, Fondation Ménétrie Alzheimer in Paris, France. He recently produced ethical guidelines for researchers interested in obtaining funding for social sciences research.
- Associate Professor Iva Holmerová, Charles University, Centre of Gerontology in Prague, Czech Republic.
- Ms Sabine Jansen, Executive Director of the Deutsche Alzheimer Gesellschaft e.V. (the German Alzheimer Society).
- Mr James McKillop (MBE) and Mrs Maureen McKillop. James has taken part in several research studies and has been a member of several working groups within Alzheimer Europe (including the last ethics project). He is a founding member of the Scottish Dementia Working Group. James has dementia and Maureen is his wife and carer.
- Dr Carlo Petrini, Head of the Bioethics Unit of the National Institute of Health in Rome, Italy.
- Dr Rasa Ruseckienė, Consultant in adult and old age psychiatry, therapist, work experience in UK psychiatric hospitals, involved in project to promote psychiatric services in Lithuania.
- Prof. Sandro Sorbi, Professor of Neurology, Department of Neurological Science and Psychiatry at the University of Florence, Italy. He is responsible for coordinating the new EFNS guidelines on dementia with a section on the ethics of research.

The members of the Steering Committee, which was formed in 2010, were also involved in the development of the report and the recommendations. They were sent copies of the various drafts of the report of the ethics of dementia research for comment. Some, in addition, attended one of the meetings of the working group, provided constructive feedback to the text and proposed additional relevant literature to consider. In 2011, the Steering Committee was comprised of the following experts:

- Christian Berringer (German Ministry of Health)
- François Blanchard (France)
- Alain Franco (France)
- Jean Georges (Alzheimer Europe)
- Cees Hertogh (Netherlands)
- Iva Holmerová (Czech Republic)
- Sabine Jansen (Germany)

- Kati Juva (Finland)
- Malou Kapgen (Luxembourg)
- Mary Marshall (United Kingdom)
- Celso Pontes (Portugal)
- Cornelia Reitberger (German Ministry of Health)
- Sigurd Sparr (Norway).

1.3.2 Legal Rights Project

In 1998, Alzheimer Europe had dedicated a project to an inventory of legislation affecting people with dementia. The successful Lawnet project resulted in the development of national reports for the 15 Member States of the European Union.

In 2009, Alzheimer Europe decided to embark on a three-year project to update the national reports to include all legislative reforms which had been undertaken since the earlier Lawnet project and to develop national reports for those countries that had joined the European Union, as well as other countries covered by the organisation (Iceland, Norway, Switzerland and Turkey).

In 2009 and 2010, Alzheimer Europe therefore completely reviewed, updated and, where necessary, drafted new reports on two major themes. The first was biomedical issues, including consent to treatment, the right to information, advance directives and end-of-life questions. The second, in 2010, was about issues related to proxy decision making (e.g. guardianship measures and continuing powers of attorney) and various forms of legal capacity (e.g. relating to marriage, making a will or a contract, voting, civil liability and criminal responsibility).

In 2011, Alzheimer Europe focused on restrictions of freedom and was able to count on the active contributions of several legal experts from its member organisations, as well as a number of independent lawyers and legal experts. This year, we also received assistance from a legal advisor to an MEP. In addition, Alzheimer Europe received the support of Fondation Médéric Alzheimer for the development of the 32 national reports which were published in the 2011 edition of the organisation's Dementia in Europe Yearbook.

Thanks to the support of national Alzheimer associations and legal experts, it was possible to produce national reports for all the countries of the European Union as well as for Croatia, Iceland, Norway, Switzerland and Turkey. For the United Kingdom, separate reports were produced for England and Scotland due to the differences in legal systems.

The reports covered four main themes:

- Involuntary internment
- Coercive measures
- Mistreatment and abuse
- Driving

The national reports were included in the 2011 version of the Dementia in Europe Year-book.

1.3.3 European Dementia Observatory

In the past years, Alzheimer Europe has greatly improved the information it provides to its members and external stakeholders on key developments. As a long-term objective, Alzheimer Europe would like to set up a European Dementia Observatory where all relevant developments in the dementia field would be monitored and reported on.

In 2011, the monthly e-mail newsletters contained information on the latest activities of Alzheimer Europe and those of the European Alzheimer’s Alliance and its member organisations, as well as information on interesting policy initiatives both on a national and European level. Alzheimer Europe also covered research developments in its monthly newsletter.

In 2011, Alzheimer Europe published 11 editions of its newsletter with one newsletter spanning the holiday period in “August-September” where there was limited news.

A total of 443 articles were featured in 2011 in Alzheimer Europe’s monthly e-mail newsletters and these articles can be broken down as follows:

Subject	Number of articles (2011)	Number of articles (2010)
Activities and projects of Alzheimer Europe	45	28
European policy developments in the field of dementia	75	54
National policy developments	29	27
Activities and projects of AE member organisations	82	93
Scientific developments	145	202
Dementia in Society	37	35
New resources and publications	27	35

The information was also included on the Alzheimer Europe website which continued to receive a significant number of visitors throughout the year. Compared to 2010, the website attracted 32.4% more visitors as the number of unique visitors increased from 164,242 in 2010 to 217,471 in 2011.

Month	Visitors (2011)	Visitors (2010)
January	14,953	12,003
February	16,987	12,723
March	18,215	15,419
April	15,494	13,071
May	16,107	12,645
June	17,359	12,757
July	20,426	12,114
August	15,057	12,623
September	19,921	15,996
October	22,796	16,364
November	22,653	16,068
December	17,503	12,459
Total:	217,471	164,242

1.3.4 Involving people with dementia

The involvement of people with dementia in the policy making process of the organisation was identified as a priority in the new strategic plan of Alzheimer Europe.

In 2010, AE adopted recommendations for the organisation to involve people with dementia which formalised the organisation’s policy of involving people with dementia in working groups and conferences and AE’s bursary system for people with dementia to attend AE Conferences.

This was put into practice in 2011 and James McKillop and his wife Maureen were asked to participate in the working group meetings on the ethical aspects of dementia research.

The bursary system at the AE Conference in Warsaw allowed a total of 14 people with dementia and their carers (from Poland, Czech Republic, Greece, Belgium, Germany and from England and Scotland) to attend the conference. During the duration of the conference, Alzheimer Europe kept a meeting room available for the participating people with dementia for informal meetings in a relaxed atmosphere and for “getting away” from the busy conference venue. In addition, a plenary session on the “Value of diagnosis” was

organised at the Conference and three people with dementia took part in a round table discussion on the importance of disclosing a diagnosis of dementia.

At the Annual General Meeting of Alzheimer Europe, the organisation's members approved changes to the statutes to set up a European Working Group of People with Dementia with the chairperson of this group being an "ex-officio" member of the AE Board.

1.3.5 21st Alzheimer Europe Conference in Warsaw

In 2011, Alzheimer Europe organised its 21st Annual Conference in collaboration with the Polish Alzheimer's Association. The theme of the conference was "European Solidarity without borders" and focused on how societies can show greater solidarity with people with dementia and their carers and how Alzheimer organisations in all European countries have campaigned for greater inclusion and participation of people with dementia.

The conference received the Patronage of the European Parliament and of the President of the Republic of Poland, Mr Bronisław Komorowski.

A total of 472 participants from 44 countries attended the conference, making it one of our best attended events in the past ten years. Keynote speakers came from a variety of backgrounds and included:

- Sube Banerjee (United Kingdom)
- Maria Barcicowska (Poland)
- Jean Georges (Alzheimer Europe)
- Geoff Huggins (United Kingdom)
- Alexander Kurz (Germany)
- Archie Latta (United Kingdom)
- Florence Lustman (France)
- Antoni Montserrat Moliner (European Commission)
- Maurice O'Connell (Ireland)
- Tadeusz Parnowski (Poland)
- Helga Rohra (Germany)
- Marek Romecki (Poland)
- Andrzej Szczudlik (Poland)
- Myrra Vernooij-Dassen (Netherlands).

The number of presentations amounted to 117 and the parallel sessions were dedicated to a wide range of subjects:

- Awareness campaigns and lobbying
- Behavioural and psychological symptoms in dementia
- Care evaluation
- Dementia diagnosis and assessment
- Dementia strategies
- Effective communication
- End-of-life care in dementia
- Family carers
- Legal issues
- People with dementia
- Policy initiatives
- Preventing isolation and loneliness
- Psychosocial interventions
- Residential and community care
- Sexuality and relationships
- Supporting people with dementia and their carers.

In addition, several workshops were organised in Polish.

Alzheimer Europe asked participants to evaluate different aspects of the conference and a total of 63 feedback forms were returned. The different plenary sessions were all judged highly with between 81 and 93% of delegates rating the four plenary sessions as "good" or "very good" and only between 0 and 3% rating the plenary sessions as "poor". Similarly, 85% of delegates felt that the choice of topics for parallel sessions had been "good" or "very good". Asked whether delegates would recommend an Alzheimer Europe Conference to friends and colleagues, 98% replied positively.

The Annual General Meeting of Alzheimer Europe also took place in the framework of the 21st Alzheimer Europe Conference in Warsaw. At the meeting, the members of the organisation approved the annual and financial reports, adopted the new strategic plan (2011-2015) of the organisation and the organisation's 2012 Work Plan and Budget.

1.3.6 Organisational issues

1.3.6.1 Strategic Plan

The new strategic plan of Alzheimer Europe had been developed in 2010 after a survey of the members' views on past activities and future priorities. The plan was presented at the 2010 Annual Meeting and welcomed by members. In order to allow additional feedback from members, it was decided to delay the official adoption until 2011.

For the period 2011-2015, the organisation identified the following key strategic priorities:

1. Making dementia a European priority
2. Supporting policy with facts
3. Basing our actions on ethical principles and
4. Building a stronger organisation.

This new strategic plan was adopted unanimously by the members attending the Annual General Meeting in 2011.

1.3.6.2 Membership development

With the exception of Hungary, Latvia and Lithuania, Alzheimer Europe currently counts members in all of the Member States of European Union.

In 2011, Alzheimer Europe welcomed the Jersey Alzheimer's Association as a new full member of the organisation and Compassion Alzheimer Bulgaria as a new provisional member and also continued the provisional membership of Alzheimer Bulgaria, Alzheimer's Disease Societies (Croatia), the Estonian Alzheimer's Association and Alzheimer Uniti (Italy).

1.3.6.3 Collaboration with EU Initiatives

In 2011, Alzheimer Europe developed closer ties with the ALCOVE project, the European Joint Action on Dementia and organised two face-to-face meetings with the coordinators for the ALCOVE launch in Luxembourg and during the Alzheimer Europe Conference in Warsaw. In addition, Alzheimer Europe organised a lunch debate in Brussels where Armelle Desplanques-Leperre presented the objectives of the Joint Action to Members of the European Parliament and representatives of Alzheimer Europe's member organisations.

Alzheimer Europe also actively participated in the stakeholder consultations organised by the Joint Programming on Neurodegeneration to ensure that the views of people with dementia and their carers were reflected in the development of the Joint Programming's Strategic Research Agenda.

The development of the European Innovation Partnership on Active and Healthy Ageing constituted a key achievement for the European Commission involving a number of Directorates General in the process. Alzheimer Europe actively participated in a number of meetings either representing the specific interests of people with dementia or the wider patient community as a representative of the European Patients' Forum. In particular, Alzheimer Europe contributed to workshops on "assisted living and social inclusion", on "prevention, early diagnosis and screening" and on "care and cure".

Alzheimer Europe continued its collaboration with the European Medicines Agency in 2011. AE staff participated in the plenary meeting for all patient organisations accredited at the European Medicines Agency and the training session on the review of product information.

1.3.6.4 Strategic Partnerships

In 2011, Alzheimer Europe continued as an active member of the European Patients' Forum and participated in the EFPIA think tank meetings which bring together patient representatives and the pharmaceutical industry to discuss issues of common concern.

Alzheimer Europe also developed closer ties with AGE, as well as the Ageing, Mental health and Carers Intergroups in the European Parliament.

Alzheimer Europe contributed to the ongoing discussions within Alzheimer's Disease International (ADI) on regionalisation with a view of developing closer contacts with ADI. The Chair and Executive Director of AE attended the ADI Conference in Toronto to present the organisation's views.

Finally, Alzheimer Europe continued its networking with organisations active in the dementia field and organised meetings with representatives of the European Alzheimer's Disease Consortium, the European Union Geriatric Medicine Society, the Interdem network and the International Association of Gerontology and Geriatrics.

1.4 European Public Affairs Activities

1.4.1 European Alzheimer's Alliance

Alzheimer Europe continued its close contacts with Members of the European Parliament. The number of MEPs who joined the European Alzheimer's Alliance grew from 50 to 58 by the end of 2011, representing 21 Member States of the European Union and all of the seven political groups in the European Parliament.

In 2011, Alzheimer Europe organised three successful lunch debates in the European Parliament which were well attended by MEPs:

- On 15 March, Marina Yannakoudakis, MEP (United Kingdom) hosted a lunch debate entitled "European activities on long-term care: What implications for people with dementia and their carers" at which Arnaud Senn and Wojciech Dziworski from the European Commission presented various initiatives of the Directorates General for Employment, Social Affairs and Equal Opportunities and for Health and Consumers in the field of long-term care.
- On 28 June, Sirpa Pietikäinen, MEP (Finland) hosted a lunch debate at which Armelle Leperre-Desplanques, coordinator of the ALzheimer COoperative Valuation in Europe (ALCOVE) project presented the aims of the Joint Action which brings together representatives of health ministries from 19 European countries.
- The lunch debate on 6 December hosted by Frieda Brepoels, MEP (Belgium) was dedicated to a presentation of the findings of Alzheimer Europe's survey on the "Value of knowing".

A number of Alliance members also supported Alzheimer Europe's work by contributing to the organisation's Dementia in Europe magazine. This was the case of MEPs Elena Oana Antonescu (Romania), Milan Cabrnach (Czech Republic), Nessa Childers (Ireland), Françoise Grossetête (France), Elzbieta Katarzyna Lukacijewska (Poland), Marisa Matias (Portugal), Antonyia Parvanova (Bulgaria) and Patrizia Toia (Italy).

1.4.2 Policy Watch and "Dementia in Europe Magazine"

A clear focus of Alzheimer Europe's work in 2011 was on European and national policy developments in the field of Alzheimer's disease and other related dementias.

Alzheimer Europe closely followed implementation of existing dementia strategies or Alzheimer plans in countries such as France, the Netherlands, Norway and the United Kingdom (England and Scotland). In 2011, a new strategy was launched in Denmark and the development of dementia strategies was started and/or continued in countries such as Cyprus, the Czech Republic, Finland, Ireland, Luxembourg and Malta.

In 2011, Alzheimer Europe increased the publication rate of its magazine and published three editions of the "Dementia in Europe Magazine". These magazines included a variety of articles on policy developments, as well as interviews with European and national policy makers including EU Commissioners for Employment, Social Affairs and Inclusion László Andor and Research and Innovation Máire Geoghegan-Quinn. Alzheimer Europe also included detailed information on its various projects and meetings, such as the European Parliament lunch debates and Annual Conference of the organisation. In addition, the magazine featured a section on "Living with dementia" where people with dementia and carers provided insightful accounts of their own experiences of dementia.

The magazine launched at the 21st Alzheimer Europe Conference included a special supplement dedicated to Poland highlighting a number of interviews with Polish policy makers and their views on the situation of people with dementia in Poland.

1.5 *Other activities and projects*

1.5.1 **Value of knowing**

In collaboration with the Harvard School of Public Health and with the support of Bayer healthcare, Alzheimer Europe developed a survey to investigate the differences in public perception and awareness of Alzheimer's disease and to identify the views of the general public on the value of a diagnosis of Alzheimer's disease. In addition, Alzheimer Europe worked closely together with the Alzheimer association in France, Germany, Poland, Spain and the US where the survey was carried out.

The field work was carried out in February 2011. In total, 2,678 members of the public aged 18 years and older were interviewed by telephone. The detailed results were published in 2011 and presented at the Alzheimer's Association International Conference (AAIC) in Paris. The poster and results were selected as a "hot topic" by the conference organisers and the publication of results generated a lot of media interest in all countries, with mentions of the study in such prestigious media outlets as Reuters, CNN, MSNBC or Spiegel.

Most respondents stated that they would see a doctor if they or a family member were exhibiting symptoms such as confusion and memory loss to clarify whether these symptoms were due to Alzheimer's disease. AD ranked as a major concern in many of the five countries surveyed, second only to cancer (except in Poland). Those aged 60 and over had the highest fear of AD. The majority of the public surveyed had personal experience with AD and about one in three respondents had a family member with AD.

After the successful launch of the results, AE and its member organisations collaborated on the publication of a brochure with all the key survey results. This brochure was published in English, French, German, Polish and Spanish and widely disseminated in collaboration with Alzheimer Europe's member organisations.

The results were also presented at a special symposium organised in the framework of the Conference of the International Psychogeriatrics Association in The Hague, Netherlands. At the Alzheimer Europe Conference in Warsaw, a plenary session was dedicated to a presentation and discussion of the results.

1.5.2 **PharmaCog**

Alzheimer Europe continued its involvement in the PharmaCog project. PharmaCog, short for "Prediction of cognitive properties of new drug candidates for neurodegenerative diseases in early clinical development" is a project which started its work on 1 January 2010 thanks to significant funding from the Innovative Medicines Initiative.

Alzheimer Europe represents the interests of people with dementia and their carers in this consortium and helps with the dissemination of the research results to a lay audience. In 2011, the organisation updated the section of its Internet site dedicated to the PharmaCog project, provided progress reports of the project in its newsletter and magazine and organised a symposium with project leaders in the framework of the Annual Conference in Warsaw.

1.5.3 Decide

In 2011, Alzheimer Europe also continued its collaboration with the DECIDE project which is funded through the Seventh Framework Programme of the European Union (FP7). The aim of DECIDE (Diagnostic Enhancement of Confidence by an International Distributed Environment) is to design, implement, and validate a GRID-based e-Infrastructure.

Alzheimer Europe helped with the dissemination of research results to the patient and carer community. The interim review of the project was organised in the framework of the AE Conference in Warsaw. In addition, a workshop was dedicated to a presentation of the project results to the conference audience.

1.6 *Annex: Meetings attended by AE representatives*

Date	Meeting	Location
13 January	EuroParl Interview with Marisa Matias, MEP	Brussels, Belgium
26 January	European Parliament Meeting hosted by Nessa Childers, MEP, Eleana Oana Antonescu, MEP and Marisa Matias, MEP	Brussels, Belgium
27 January	Meeting with European Patients' Forum and Age Intergroup	Brussels, Belgium
1 February	Meeting with Polish Alzheimer's Association	Warsaw, Poland
2 February	Breakfast meeting of Antoniya Parvanova, MEP on active and healthy ageing	Brussels, Belgium
2 February	Meeting with Sanofi	Brussels, Belgium
3-4 February	International Pharmaco-economic Conference on Alzheimer's disease (IPECAD)	London, United Kingdom
10 February	EFPIA think tank	Brussels, Belgium
18 February	Meeting with Novartis	Basel, Switzerland
18-19 February	Conference of Romanian Alzheimer's Society	Bucharest, Romania
3-4 March	Steering Committee of PharmaCog project	Paris, France
9 March	IMI Symposium at AD/PD Conference	Barcelona, Spain
10 March	Meeting with Hungarian Permanent Representation	Brussels, Belgium
13-14 March	AE Board meeting	Brussels, Belgium
14-15 March	Workshop with AE member organisations	Brussels, Belgium
15 March	European Parliament lunch-debate dedicated to European activities on long term care	Brussels, Belgium
22 March	Meeting of Philippe Juvin, MEP on clinical trials	Brussels, Belgium
22 March	Family Platform	Brussels, Belgium
26-29 March	Alzheimer's Disease International (ADI) Conference	Toronto, Canada
29 March	Working group of "Value of Knowing" project	Toronto, Canada
1 April	GSK Health Advisory Board	London, United Kingdom

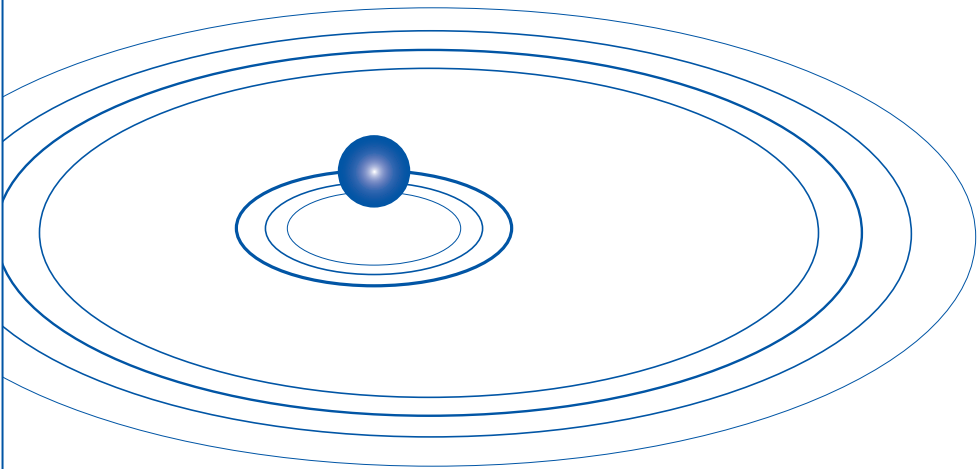
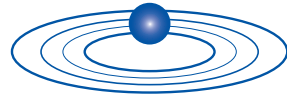
Date	Meeting	Location
1 April	Meeting with Alzheimer's Society	London, United Kingdom
7 April	EFPIA think tank	Brussels, Belgium
12-13 April	General Assembly of European Patients' Forum	Brussels, Belgium
13 April	Meeting with Université de Nancy	Luxembourg, Luxembourg
14-15 April	Fundamental Rights Platform	Vienna, Austria
14-17 April	Meeting with International Association of Gerontology and Geriatrics	Bologna, Italy
3 May	Mental Health Interest Group "Stigma and Depression"	Brussels, Belgium
5 May	Meeting with Parliament Magazine	Brussels, Belgium
6 May	Meeting with France Alzheimer	Paris, France
9-10 May	Meeting with Polish Alzheimer's Association	Warsaw, Poland
11 May	Workshop on "Framing and reframing dementia" of European Foundation Initiative on Dementia	Stirling, United Kingdom
17-19 May	Sounding Board of Interlinks project	Noordwijkerhout, Netherlands
18-20 May	Conference of European Association of Palliative Care (EAPC)	Lisbon, Portugal
20 May	Meeting with Vilija Blinkeviciute, MEP	Brussels, Belgium
20 May	Meeting with WeDo project	Brussels, Belgium
23 May	Meeting of Marisa Matias, MEP on future of EU research	Brussels, Belgium
23 May	Meeting with Alzheimer Portugal	Brussels, Belgium
25 May	Meeting with ALCOVE	Luxembourg, Luxembourg
26 May	Stakeholder meeting of Joint Programming Initiative on Neurodegeneration	Brussels, Belgium
27 May	Meeting with Polish EU Representation	Brussels, Belgium
2-3 June	Working Group meeting on ethics of dementia research	Luxembourg, Luxembourg
6 June	Meeting with Janssen	Brussels, Belgium
7 June	Meeting with Sanofi	Brussels, Belgium

Date	Meeting	Location
14 June	Carers Interest Group	Brussels, Belgium
15 June	European Commission Workshop on European Innovation Partnership on Active and Healthy Ageing "Assisted living and social inclusion"	Brussels, Belgium
17 June	Seminar of Nessa Childers, MEP on "Shared priorities – The dementia agenda in Europe and Ireland"	Dublin, Ireland
17 June	Meeting with European Union Geriatric Medicine Society	Dublin, Ireland
20 June	Stakeholder meeting of Joint Programming Initiative on Neurodegeneration	Rome, Italy
20 June	Meeting with Françoise Grossetête, MEP	Brussels, Belgium
20-21 June	European Commission Workshop on European Innovation Partnership on Active and Healthy Ageing "Prevention, early diagnosis and screening"	Brussels, Belgium
21 June	Meeting with Sanofi	Brussels, Belgium
23 June	European Commission Workshop on European Innovation Partnership on Active and Healthy Ageing "Care and cure"	Brussels, Belgium
26-27 June	AE Board meeting	Brussels, Belgium
27-28 June	Workshop with AE member organisations	Brussels, Belgium
28 June	European Parliament lunch-debate dedicated to ALCOVE project	Brussels, Belgium
28 June	Meeting with Eurodiaconia	Brussels, Belgium
28 June	Meeting with Lundbeck and Pfizer	Brussels, Belgium
16-21 July	Alzheimer's Association International Conference (AAIC)	Paris, France
27-29 July	Observatory Summer School on Ageing and Health Systems	San Servola, Italy
23 August	Meeting with Merck on health literacy	Brussels, Belgium
23-24 August	Working Group meeting on ethics of dementia research	Brussels, Belgium
5-9 September	International Psychogeriatrics Association (IPA) Conference	The Hague, Netherlands
6 September	Parliament Magazine Reception	Brussels, Belgium

Date	Meeting	Location
8 September	Value of Knowing symposium at IPA Conference	The Hague, Netherlands
8 September	Meeting with Alzheimer Angehörige Austria	Vienna, Austria
12-13 September	Meeting with Polish Alzheimer's Association	Warsaw, Poland
13 September	DECIDE project meeting	Rome, Italy
14 September	Meeting with representatives of DG SANCO	Luxembourg, Luxembourg
19 September	Meeting with France Alzheimer on World Alzheimer's Day event	Paris, France
21 September	EPF/EFPIA/PGEU lunch seminar on "Adherence to treatment"	Brussels, Belgium
21 September	Parliament Magazine event "Facing the future"	Brussels, Belgium
22 September	EFPIA think tank meeting	Brussels, Belgium
26-28 September	Ambient Assisted Living (AAL) Forum 2011	Lecce, Italy
6 October	AE Board meeting	Warsaw, Poland
6 October	Annual General Meeting	Warsaw, Poland
6-8 October	21st AE Conference "European solidarity without borders"	Warsaw, Poland
11 October	Alzheimer's Society lunch debate in European Parliament	Brussels, Belgium
13 October	5th Networking Event of Luxembourg BioHealth Community	Esch/Alzette, Luxembourg
17-18 October	IMI PharmaCog Review	London, United Kingdom
20 October	Meeting with Heinz K. Becker, MEP	Brussels, Belgium
24-25 October	European Commission Workshop on European Innovation Partnership on Active and Healthy Ageing	Brussels, Belgium
26-27 October	DECIDE project meeting	Rome, Italy
1-3 November	CARDI Conference on "Global Ageing meets dementia"	Dublin, Ireland
9 November	Meeting with Executive Agency for Public Health	Brussels, Belgium
9 November	Meeting with Ole Christensen, MEP	Brussels, Belgium

Date	Meeting	Location
15 November	Health-EU Portal Editorial Board	Luxembourg, Luxembourg
17-18 November	Meeting with Alzheimer Angehörige Austria	Vienna, Austria
21 November	Meeting with Association Luxembourg Alzheimer	Luxembourg, Luxembourg
21-22 November	CARICT policy and expert workshop	Brussels, Belgium
22 November	EPDA Lunch debate: “Chronic conditions in an ageing population – a spotlight on Parkinson’s disease”	Brussels, Belgium
24 November	Meeting with SCA Global Hygiene	Luxembourg, Luxembourg
28 November	European Commission Conference “Ageing in Dignity: Designing effective strategies for tackling elder abuse”	Brussels, Belgium
29 November	Training day for patients representatives at European Medicines Agency	London, United Kingdom
30 November	EMA Working Party with Patients’ and consumers’ organisations	London, United Kingdom
1 December	Workshop on “The benefits of a simplified and coherent clinical trials framework in Europe”	Brussels, Belgium
5 December	AE Board meeting	Brussels, Belgium
6 December	European Parliament lunch-debate “Public perceptions of Alzheimer’s disease and the value of diagnosis” and launch of Dementia in Europe Yearbook	Brussels, Belgium
6 December	Meeting with office of Elzbieta Lukacijewska, MEP	Brussels, Belgium
6 December	Corporate Round Table	Brussels, Belgium
12 December	Seminar on “Quality improvement in dementia care”	Nijmegen, Netherlands
12 December	Meeting with France Alzheimer in framework of Meeting “Alzheimer’s disease: the future alongside patients and their carers”	Chilly Mazarin, France
21 December	Meeting with Marc Tarabella, MEP	Brussels, Belgium





Financial Report

2.1 Report of the Réviseur d'entreprises agréé



To the Board of Directors
ALZHEIMER EUROPE A.S.B.L.

R.C.S. Luxembourg F2773

145, Route de Thionville
L-2611 LUXEMBOURG

REPORT OF THE RÉVISEUR D'ENTREPRISES AGREE

Following our appointment by the Board of Directors dated October 6th, 2011, we have audited the accompanying financial statements of **ALZHEIMER EUROPE A.S.B.L.**, which comprise the balance sheet as at December 31st, 2011 and the profit and loss account for the year then ended.

Responsibility of the Board of directors for the financial statements

The Board of Directors is responsible for the preparation and fair presentation of these financial statements in accordance with generally accepted accounting principles; and for such internal control as the Board of Directors determines is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

Responsibility of the réviseur d'entreprises agréé

Our responsibility is to express an opinion on these financial statements based on our audit. We conducted our audit in accordance with International Standards on Auditing as adopted for Luxembourg by the Commission de Surveillance du Secteur Financier. Those standards require that we comply with ethical requirements and plan and perform the audit to obtain reasonable assurance about whether the financial statements are free from material misstatement.

An audit involves performing procedures to obtain audit evidence about the amounts and disclosures in the financial statements. The procedures selected depend on the réviseur d'entreprises agréé's judgement, including the assessment of the risks of material misstatement of the financial statements, whether due to fraud or error. In making those risk assessments, the réviseur d'entreprises agréé considers internal control relevant to the entity's preparation and fair presentation of the financial statements in order to design audit procedures that are appropriate in the circumstances, but not for the purpose of expressing an opinion on the effectiveness of the entity's internal control. An audit also includes evaluating the appropriateness of accounting policies used and the reasonableness of accounting estimates made by the Board of Directors, as well as evaluating the overall presentation of the financial statements.

MAZARS LUXEMBOURG - RÉVISEURS D'ENTREPRISES
SOCIÉTÉ ANONYME - RCS LUXEMBOURG B 159962 - TVA INTRACOMMUNAUTAIRE : LU24665334
10A, RUE HENRI M. SCHNADT, L-2530 LUXEMBOURG
TEL: +352 27 114-1 - FAX: +352 27 114 20 - www.mazars.com





We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our audit opinion.

Opinion

In our opinion, the financial statements give a true and fair view of the financial position of **ALZHEIMER EUROPE A.S.B.L.** as of December 31st, 2011 and of the results of its operations for the year then ended in accordance with generally accepted accounting principles.

Luxembourg, February 29th, 2012

For MAZARS LUXEMBOURG, Cabinet de révision agréé
10A, rue Henri M. Schnadt
L-2530 Luxembourg

A handwritten signature in black ink, appearing to read 'Philippe Corbard', written over a horizontal line.

Philippe CORBARD

Appendix:

- Financial statements as at December 31st, 2011

2.2 Balance sheet as of December 31, 2011

ALZHEIMER EUROPE Association sans but lucratif R.C.S. Luxembourg F2773		
<u>Balance sheet as of December 31, 2011</u>		
	<u>2011</u> <u>EUR</u>	<u>2010</u> <u>EUR</u>
ASSETS		
Current assets		
Debtor EU Commission	69 704	100 000
Other debtors	4 599	26 843
Cash at bank and on deposit	519 119	527 841
	<u>593 422</u>	<u>654 684</u>
Prepayments	22 819	4 826
	<u> </u>	<u> </u>
Total Assets	<u>616 241</u>	<u>659 510</u>
LIABILITIES		
Capital and reserves		
Results brought forward	169 200	162 675
Result of the year	4 726	6 525
	<u>173 926</u>	<u>169 200</u>
Creditors		
Payments received on account	143 438	86 433
Trade creditors	67 268	55 743
Other liabilities	41 273	45 582
	<u>251 979</u>	<u>187 758</u>
Deferred income	190 336	302 552
	<u> </u>	<u> </u>
Total Liabilities	<u>616 241</u>	<u>659 510</u>

2.3 Profit and loss account Year ended December 31, 2011

ALZHEIMER EUROPE Association sans but lucratif R.C.S. Luxembourg F2773 Profit and loss account <u>year ended December 31, 2011</u>		
	<u>2011</u> <u>EUR</u>	<u>2010</u> <u>EUR</u>
Other operating income		
Corporate sponsorship	388 533	559 540
Deferred income	302 552	22 919
Sponsorship received on account	-190 336	-302 552
EU Subsidy	226 698	250 000
Co-financing in kind	144 287	138 680
Membership fees and contributions	66 087	53 150
Donations	767	263
Publication sales and royalties	1 303	12 240
Project participation and other subsidies	19 000	59 320
Other operating income	10 041	23 973
AE Conference registration fees	79 644	65 700
Unpayable debts	-	4
External charges		
External experts	-424 747	-340 578
Publication and information material	-114 968	-91 626
Travel expenses	-57 041	-47 598
Communication costs	-21 281	-20 688
Accommodation expenses	-114 185	-127 997
Office rent and associated costs	-24 481	-25 011
Office stationary and related costs	-2 761	-2 366
Leasing	-32 517	-13 069
Membership fees	-1 120	-1 120
Other costs	-2 608	-2 282
Irrecoverable EU subsidy	-13 621	-
Staff costs		
Wages and salaries	-204 992	-182 859
Social security costs	-24 606	-22 544
Interest receivable and similar income	1 840	3 081
Interest payable and similar charges	-6 762	-2 055
	<u>4 726</u>	<u>6 525</u>

2.4 Breakdown of income

2.4.1 Introduction

In 2011, Alzheimer Europe had an audited income of EUR 1,240,751.74 of which EUR 715,693.85 (57.68%) were for the organisation's core activities (including the organisation's Dementia Ethics Network and Annual Conference), EUR 207,012.08 (16.681%) were for the organisation's public affairs activities and EUR 318,045.81 (25.63%) for the organisation's "Value of diagnosis" project.

2.4.2 Funding of core activities (EUR 715,693.85)

In 2011, the core funding of Alzheimer Europe was composed as follows:

- EUR 226,697.71 (31.68%) from public funding,
- EUR 196,874.09 (27.51%) from member organisations,
- EUR 110,406.35 (15.43%) from reserves brought forward from the financial year 2010,
- EUR 81,714.30 (11.42%) from individuals,
- EUR 60,500 (8.45%) from corporate sources,
- EUR 28,600 (4.00%) from foundations and other non-profit organisations,
- EUR 9,061.13 (1.27%) from other sources and
- EUR 1,840.27 (0.26%) from bank interest and similar.

2.4.2.1 Public funding

In 2011, the breakdown of public funding totalling EUR 226,697.71 can be broken down as follows:

- Alzheimer Europe received EUR 189,703.52 as an operating grant from the European Commission, EUR 19,940.63 for its participation in the PharmaCog project and EUR 17,053.56 for its participation in the DECIDE project.

2.4.2.2 Funding from member organisations

In 2010, the EUR 196,874.09 funding from member organisations can be broken down as follows:

- EUR 87,587.49 from the Luxembourg member organisation through the secondment of the AE Executive Director,
- EUR 53,850 in membership fees,
- EUR 12,000 from the Luxembourg member organisation by providing the offices of Alzheimer Europe free of rent,

- EUR 12,236.60 from member organisations covering the travel expenses of AE Board members to attend Board meetings,
- EUR 31,200 in co-financing from Board members and representatives of member organisations in time donated to the organisation (at EUR 300 per day).

2.4.2.3 Deferred income

In 2011, Alzheimer Europe was able to contribute EUR 110,406.35 of deferred income to its core activities which came from income received on account in 2010.

2.4.2.4 Individuals

In 2011, AE received EUR 81,714.30 from individuals which can be broken down as follows:

- EUR 79,643.99 in conference registrations,
- EUR 1,303.38 in publication sales and
- EUR 766.93 in donations.

2.4.2.5 Corporate support

In 2011, Alzheimer Europe received EUR 60,500 from corporate sources as core-funding which can be broken down as follows:

- EUR 15,000 from Bayer, EUR 10,000 from Janssen, Lilly and Pfizer, EUR 7,500 from Sanofi-Aventis and EUR 5,000 from SCA Global Hygiene as support to the Alzheimer Europe Conference in Warsaw,
- EUR 3,000 from Mazars which carried out the audit of the organisation's accounts free of charge.

2.4.2.6 Foundations and organisations

The EUR 28,600 which Alzheimer Europe received in 2011 from foundations and other non-profit organisations can be broken down as follows:

- EUR 5,000 from Fondation Médéric Alzheimer and Fondation Roi Baudouin to support the Alzheimer Europe Conference in Warsaw,
- EUR 9,000 from Fondation Médéric Alzheimer to support the legal rights activities of Alzheimer Europe,
- EUR 9,600 in donated time by experts involved in the ethical work of Alzheimer Europe (at EUR 300 per day).

2.4.2.7 Bank interest and similar

In 2011, Alzheimer Europe had an income of EUR 1,804.27 from bank interest and similar income.

2.4.2.8 Other income

In 2011, EUR 9,061.13 came from other sources not mentioned above.

2.4.3 Funding of public affairs activities (EUR 207,012.08)

In 2011, Alzheimer Europe received EUR 207,012.08 for its public affairs activities, of which

- EUR 206,032.60 (99.53%) came from corporate sponsors and
- EUR 979.48 (0.47%) from other income.

2.4.3.1 Corporate support

The corporate support received by Alzheimer Europe for its public affairs activities in 2011 (EUR 206,032.90) can be broken down as follows:

- Pfizer, Janssen and Lilly each contributed EUR 40,000 as a gold sponsor,
- GlaxoSmithKline contributed EUR 35,000 in support,
- Lundbeck and Sanofi contributed EUR 20,000 each as silver sponsors and
- SCA Global Hygiene contributed EUR 10,000 as a bronze sponsor.

In addition, AE received EUR 108.80 in travel support from Pfizer and EUR 923.80 as travel support and honoraria from GlaxoSmithKline.

2.4.3.2 Other income

In 2011, EUR 979.48 came from sources not included above.

2.4.4 Funding of Value of Knowing-project (EUR 318,045.81)

In 2011, the funding of the Value of Knowing project was composed as follows:

- EUR 125,000 (39.30%) from corporate funding,
- EUR 192,145.81 (60.41%) from reserves brought forward from the financial year 2010 and
- EUR 900 (0.28%) from member organisations.

2.4.4.1 Corporate support

In 2011, AE received an educational grant of EUR 125,000 from Bayer Healthcare for its Value of Knowing project.

2.4.4.2 Deferred income

In 2011, Alzheimer Europe contributed EUR 192,145.81 to the Value of Knowing project from income received on account in 2010.

2.4.4.3 Foundations and organisations

EUR 900 of the income of the Value of Knowing project consisted in time donated by Board members to the project (at EUR 300 per day).

2.4.5 Overall funding

The following table lists all sources of income received in 2011.

In line with the policy of the European Medicines Agency on transparency requirements for accredited patients' organisations, this is presented in total amounts as well as in terms of percentages of the overall income of the organisation.

Funding source	Funding received (2011)	As % of AE income (2011)
Bayer	140,000.00	11.28%
Pfizer	50,108.80	4.04%
Janssen	50,000.00	4.03%
Lilly	50,000.00	4.03%
GlaxoSmithKline	35,923.80	2.90%
Sanofi	27,500.00	2.22%
Lundbeck	20,000.00	1.61%
<i>Sub-total: Pharmaceutical funding</i>	<i>373,532.60</i>	<i>30.11%</i>
SCA Global Hygiene	15,000.00	1.21%
Mazars	3,000.00	0.24%
<i>Sub-total: Other corporate sources</i>	<i>18,000.00</i>	<i>1.45%</i>
Total: Corporate funding	391,532.60	31.56%
Deferred income	302,552.16	24.38%
Total: Deferred income	302,552.16	24.38%
European Commission	226,697.71	18.27%
Total: Public funding	226,697.71	18.27%
Association Luxembourg Alzheimer	99,587.49	8.03%
Other member organisations	98,186.60	7.91%
Total: Member organisations	197,774.09	15.94%
Individuals (Conference fees, donations, registration fees)	81,714.30	6.59%
Total: Individuals	81,714.30	6.59%
Fondation Médéric Alzheimer	14,000.00	1.13%
Fondation Roi Baudouin	5,000.00	0.40%
Other organisations	9,600.00	0.77%
Total: Foundations and organisations	28,600	2.31%
Bank interest and similar	1,840.27	0.15%
Total: Bank interest and similar	1,840.27	0.15%
Other income	9,061.13	0.81%
Total: Other income	9,061.13	0.81%
Total Income	1,240,751.74	100.00%

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