European Collaboration on Dementia:

First Interim Report

This project has received financial support from the European Commission.

Neither the European Commission nor any person acting on its behalf is responsible for any use that might be made of the following information.

. Alzheimer Europe . Route de Thionville 145 . L- 2611 Luxembourg .

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1 WP 1 – Coordination

1.1 Introduction

The work package on coordination was aimed at the overall project management and the coordination of activities of the various work packages, as well as the contractual and financial administration of the project, the organization and follow-up of meetings and the reporting to the European Commission.

Furthermore, the work package aimed at developing internal rules for conflict resolution, risk management and financial reporting.

The work package was also dedicated to the identification of third parties for consultation and endorsement of the guidelines and recommendations developed in the framework of the project.

1.2 Progress so far

Financial regulations were developed and presented to the work package leaders and all other participating organisations (See Annex 1).

Alzheimer Europe collected information on **organisations with an interest in dementia** across Europe and in particular on those organisations affiliated to the organisations involved in the steering committee, namely European Alzheimer's Disease Consortium, European Association of Geriatric Psychiatry, Dementia Panel of the European Federation of Neurological Societies, Interdem, International Association of Gerontology – European Region and the North Sea Dementia Research Group (See Annex 2 for list of organisations).

The **steering committee** met in the framework of the Alzheimer Europe conference in Paris (2 July 2006). The various work package leaders provided an update of the progress of their respective work packages at the meeting, with the members of the steering committee providing useful contact information and guidance on the future progress of their work (See Annex 3 for the minutes of the meeting).

Also, the meetings of the different work packages were organised at the same time, in order to allow work package leaders to provide an update of their work, identify areas for collaboration or overlap and to benefit from the experience of the different project partners.

While progress on this work package was satisfactory so far, a number of issues, such as the integration of the addresses of interested organisations in an Internet-based database or the adaptation of the AE Intranet to allow better exchange of information between project partners envisaged in the project application have not yet been finalised.

Similarly, the internal rules on conflict resolution and risk management have not been completed.

These actions of the work package will be completed in 2007.

1.3 Annex 1: Financial regulations

1.3.1 Introduction

These financial regulations provide information to the different project partners on their financial reporting duties to Alzheimer Europe and the European Commission. They should be read in conjunction with the financial provisions contained in the contract from the European Commission, of which each centre received a copy by e-mail.

1.3.2 Payment procedures

1.3.2.1 Bank information

Each centre shall provide full banking details to Alzheimer Europe, which will use this information for the payment of grants to the different centres.

1.3.2.2 Initial payment

After the contract has been signed by all contract partners and the European Commission, a first payment of 30% of the overall grant will be made to Alzheimer Europe. Alzheimer Europe will provide each participating centre with 30% of their respective grant.

1.3.2.3 Second payment

As specified in the financial provisions of the Commission contract, Alzheimer Europe will be paid a further 20% of the total grant after receipt and acceptance by the European Commission of the first interim report and first financial report. These reports should be sent to the Commission no later than 1 March 2007.

To allow Alzheimer Europe to prepare the global financial report, each centre shall provide Alzheimer Europe with a detailed breakdown of all expenditure and will do so no later than 31 January 2007.

Failure to so by the deadline of 31 January 2007 will result in the missing centre not receiving the second payment of its total grant and payment will be deferred until the next reporting period. Similarly, centres having used up less than 70% of their initial grant payment will not be paid their second instalment until the next reporting period.

Centres having complied with these regulations and having used up at least 70% of their initial grant payment will be paid a further 20% of their grant after receipt of the second instalment from the European Commission.

1.3.2.4 Third payment

A further 20% of the total grant will be paid to Alzheimer Europe after receipt and acceptance by the European Commission of the second interim report and second financial report. These reports should be sent to the European Commission no later than 1 March 2008.

To allow Alzheimer Europe to prepare the global financial report, each centre shall provide Alzheimer Europe with a detailed breakdown of all expenditure and will do so no later than 31 January 2008.

Failure to so by the deadline of 31 January 2008 will result in the missing centre not receiving the third payment of its total grant and payment will be deferred until the next reporting period. Similarly, centres having used up less than 70% of their previous grant payments will not be paid their third instalment until the next reporting period.

Centres having complied with these regulations and having used up at least 70% of their previous grant payments will be paid a further 20% of their grant after receipt of the third instalment from the European Commission.

1.3.2.5 Payment of the grant balance

The grant balance will be paid to Alzheimer Europe after acceptance by the Commission of the final report and final financial report.

Alzheimer Europe will transfer these funds to the different project partners immediately after receipt of the final payment by the European Commission.

Payments to be made to project partners will not exceed the amounts for Community contribution included in the Commission Contract.

1.3.2.6 Calculation of final Commission grant

The final grant of the European Commission may not exceed €843,019 for the total of the project, nor can it exceed 59.23% of the total cost of the project. Should the total cost of the project be less than €1,423,190, the final grant of the Commission will be reduced proportionately.

The same rules apply to the different budgets of the project partners in that the grant will be reduced if the total expenditure of a project partner is below the total expenditure budgeted for the centre.

At the same time, should the total expenditure of a centre exceed the total amount of the budgeted expenditure, the grant may not be increased proportionately.

1.3.3 Financial Reporting

Each centre is responsible for the management of its budget and shall provide Alzheimer Europe with yearly financial reports of all costs incurred by the centre for the project. Alzheimer Europe will collect the financial reports of the different partners and present global financial reports to the European Commission for the totality of the project.

1.3.3.1 Deadlines for financial reporting

In line with the requirements of the European Commission, project partners are required to submit their financial reports at least one month before the deadline for submission of the global financial report to the European Commission.

- For the first financial report (covering the period of 1 January 2006 to 31 December 2006), the deadline is 31 January 2007
- For the second financial report (covering the period of 1 January 2007 to 31 December 2007), the deadline is 31 January 2008
- For the first financial report (covering the period of 1 January 2008 to 31 December 2008), the deadline is 28 February 2009.

1.3.3.2 Structure of financial report

Each centre shall include the following information on its financial report which will need to be printed on the headed letter paper of the participating centre and signed by a representative of the centre. A model financial report is enclosed in the annex.

1.3.3.3 Declaration of honour

The financial report shall be preceded by the following mention:

> *The undersigned, NAME AND FUNCTION, acting on behalf of NAME OF CENTRE hereby certifies that the following constitutes a fair and true presentation of the expenditure occurred by NAME OF CENTRE for the carrying out of activities of the project "European Collaboration on Dementia – Agreement Number 2005108" for the year YEAR.*

1.3.3.4 Staff costs

Staff costs should be presented as follows:

> *NAME OF STAFF MEMBER: NUMBER OF DAYS x DAILY RATE = TOTAL*

Supporting evidence: Each centre will be required to send in to Alzheimer Europe the filled in time sheets (See Annex) for the days spent by staff of the centre on the project

For the calculation of costs, you can use the following formulas (either total monthly staff costs including all costs to the employer divided by 20 OR total yearly staff costs including all costs to the employer divided by 220).

1.3.3.5 Travel costs

Travel costs should be presented as follows:

> *1. NAME OF STAFF MEMBER*
>
> *2. REASON FOR TRAVEL (i.e. Working group or steering committee or other project linked meeting)*
>
> *3. ORIGIN OF TRAVEL TO PLACE OF MEETING*
>
> *4. METHOD OF TRAVEL (i.e. PLANE, TRAIN, VAR)*
>
> *5. COST*

Supporting evidence: Each centre will be required to send in to Alzheimer Europe a copy of the ticket or invoice together with the financial report.

1.3.3.6 Subsistence allowances

Subsistence costs should be presented as follows:

> *1. NAME OF STAFF MEMBER*
>
> *2. MEETING (i.e. Working group or steering committee or other project linked meeting)*
>
> *3. PLACE OF MEETING*

4. COST = NUMBER OF DAYS OF MEETING x DAILY RATE = TOTAL

Supporting evidence: No supporting evidence will be required from the different centres. The centres are obliged to use the daily per diems fixed by the European Commission (See in Annex).

Each centre will be required to send in to Alzheimer Europe a copy of the ticket or invoice together with the financial report.

1.3.3.7 Consumables and supplies (ONLY work package leaders)

Work package leaders have a budget of €2,000 for literature searches and for purchases of publications

The work package leaders therefore need to provide a detailed breakdown for the costs incurred under this heading.

Supporting evidence: The work package leaders should include copies of the various invoices with their financial report.

1.3.3.8 Other costs (ONLY University of Oxford)

The University of Oxford has a budget of €3,000 for the translation of existing guidelines. When reporting these costs, it needs to provide a detailed breakdown of these costs.

For each translated document, it will need to specify the language from which the document was translated, the number of words or pages of the document, the cost per word or page and the total cost per translated document.

Supporting evidence: Invoices for the different translations need to be included with the financial reports.

1.3.3.9 Overheads

Each centre can include 7% overheads to the total of its expenditure.

1.3.4 Budget adjustments

When presenting their financial reports, centres should stay as close as possible to the original budget. Nevertheless, it is possible for centres to adjust the estimated budget by making transfers between different lines of expenditure. These adjustments may not exceed 10% (See Article I.3.4. of the Commission contract for full details).

1.3.5 Other reporting

The different workpackage leaders should prepare progress reports on the different working groups and submit them by the same deadline as that for the financial reports.

The following documents should be included with the different reports:

1. For the first interim report: A brief progress report together with the minutes of the different meetings, as well as a bibliography for the collected literature on the subject.
2. For the second interim report: A brief progress report together with the minutes of the different meetings, as well as a comparative report on the findings of the literature search.
3. For the final report: A detailed progress report together with the minutes of the different meetings, as well as the new consensus documents or recommendations.

1.3.6 Annex I: Model Financial Report

The undersigned, NAME AND FUNCTION, acting on behalf of NAME OF CENTRE hereby certifies that the following constitutes a fair and true presentation of the expenditure occurred by NAME OF CENTRE for the carrying out of activities of the project "European Collaboration on Dementia – Agreement Number 2005108" for the year YEAR.

1. Staff costs

Staff member	Number of days worked on project	Daily Rate	Total
		TOTAL:	

2.1. Travel costs

Staff member	Reason for travel and date	From … to …	Method of travel	Cost
			TOTAL:	

2.2. Subsistence costs

Staff member	Reason for travel and date	Meeting Place	Number of Days	Daily per diem	Cost
				TOTAL:	

3. Consumables and supplies (Work package leaders ONLY)

Description of expense	Cost
TOTAL:	

4. Other costs (University of Oxford ONLY)

Name of document	From language to language	Number of pages/words	Cost per page/word	Cost
			TOTAL:	

OVERVIEW

Total eligible costs	**1+2+3+4**
Overheads	**7%**
TOTAL COSTS	**1+2+3+4+7%**
Commission grant	**Percentage of TOTAL COSTS as per contract**
Applicant's contribution	**TOTAL COSTS – Commission grant**
TOTAL INCOME	**Same total costs**

1.3.7 Annex II: Per diem rates of the European Commission

Belgium 201.14

Czech Republic 230.00

Denmark: 239.77

Germany: 171.17

Estonia: 190.00

Greece: 165.67

Spain: 195.46

France: 169.85

Ireland: 220.26

Italy: 174.67

Cyprus: 160.00

Latvia: 250.00

Lithuania: 250.00

Luxembourg: 188.92

Hungary: 215.00

Malta: 175.00

Netherlands: 210.02

Austria: 203.05

Poland: 270.00

Portugal: 193.80

Slovenia: 170.00

Slovak Republic: 175.00

Finland: 233.32

Sweden: 234.18

United Kingdom: 235.92

Bulgaria: 275.00

Romania: 230.00

Turkey: 220.00

Iceland: 245.00

Liechtenstein: 175.00

Norway: 220.00

1.4 Annex 2: Inventory of dementia-related organisations in 31 European countries

1.4.1 European EuroCoDe network organisations

1.4.1.1 Alzheimer Europe

Alzheimer Europe is a non-profit organisation, which aims to improve the care and treatment of Alzheimer patients through intensified collaboration between its member associations.

The majority of people with dementia live at home and are cared for by their relatives and friends. Although many organisations are active in supporting them, carers often work alone, and lack the know-how and inspiration, which could be given by others.

AE thus hopes, through its activities, to answer a growing need in society, and especially among the community of people affected by the existence of the disease. The exchange of experience and knowledge as well as collaboration on new approaches will stimulate and motivate people with dementia. Further to this, it will ensure that information on best practice in the care of Alzheimer sufferers is available throughout Europe and beyond.

Alzheimer Europe activities are geared towards attaining the following objectives:

- To improve the exchange of information between Alzheimer associations;
- To stimulate the development of projects in the domains of information, support and caregiving for people with dementia;
- To establish contacts between Alzheimer associations in view of setting up and coordinating common transnational projects;
- To arrange for the translation of booklets, pamphlets and other material of interest to various organisations in the member states of the European Union;
- To organise an annual international conference offering participants the possibility to inform themselves about new findings in the fields of research on, and treatment of the Alzheimer's disease.

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www.alzheimer-europe.org

1.4.1.2 European Alzheimer's Disease Consortium (EADC)

The EADC is a fully functional network of European centres of excellence working in the field of Alzheimer's Disease. It provides a setting in which to increase the basic scientific understanding of the disease and to develop ways to prevent, slow, or ameliorate the primary and secondary symptoms of Alzheimer's disease. This is done by facilitating large Europe wide research studies. The EADC is funded by the European Commission and as such enjoys the privilege of complete independence and autonomy from the pharmaceutical industry whilst maintaining close working links with it.

The EADC is a network of 45 European centres of excellence working in the field of Alzheimer's Disease.

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reynish.e@chu-toulouse.fr
www.alzheimer-europe.org/eadc

1.4.1.3 European Association of Geriatric Psychiatry (EAGP)

The EAGP was founded in 1971 as an informal association of psychiatrists, neurologists, neuropathologists, psychologists and sociologists from various European Countries who have a special interest in the psychogeriatric field.

Thus, the EAGP was the first international association concerning the special subject of geriatric psychiatry. Today the EAGP has about 250 members from 26 European countries.

The objectives of the EAGP are research promotion, pre- and post graduate education, further development of geriatric psychiatry and the cooperation with national and international bodies engaged in the field.

The EAGP aims to accomplish its objectives through:

- Organisation of congresses on geriatric psychiatry
- Encouragement of collaboration between all professions concerned with mental health in old age
- Publications in the official organ of the association, the „International Journal of Geriatric Psychiatry"
- Organisation of training courses in geriatric psychiatry
- Fostering of scientific projects

European Association of Geriatric Psychiatry
c/o Dr. Brigitte Grass-Kapanke
Rheinische Kliniken
Psychiatrische Kliniken der Heinrich- Heine-Universität
Bergische Landstr. 2
40629 Düsseldorf
GERMANY
www.eagp.com

1.4.1.4 European Federation of Neurological Societies (EFNS)

The EFNS is an organisation that unites and supports neurologists across the whole of Europe.

Currently 40 European national neurological societies are registered members of the EFNS, which represents more than 12,000 European neurologists.

The 10 missions of EFNS are to:

- Broaden the base of clinical neurology in Europe
- Raise public awareness about the importance of the brain and its disorders
- Strengthen the standard, availability and uniformity of neurological services in Europe
- Create and maintain continuing medical education (CME) guidelines and accreditation
- Support and encourage European clinical neuroscience research programmes
- Strengthen the standard, quantity and equality of pre-graduate and post-graduate teaching and training
- Strengthen WFN, EU and WHO relations
- Strengthen the collaboration with related professional and lay organisations
- Organise European Neurology Congresses and Neurological Teaching Courses
- Publish the European Journal of Neurology

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1.4.1.5 European Union Geriatric Medicine Society (EUGMS)

A number of organisations have been supporting a European profile for geriatric medicine and momentum has been building up over the last decade. The European Section of the International Association of Gerontology has been a positive force, and the institution of the Geriatric Medicine Section of the UEMS in 1997 was a defining point. This meant that geriatric medicine was officially recognised in more than eight European countries.

It was felt, however, that there was still a lack of a central focus for continuing professional development and academic matters in the European Union. The first group met to discuss the EUGMS in September 1999 in Paris. After a number of meetings at different European cities, the European Union Geriatric Medicine Society was finally created, and was launched in Paris in August 2001, when its 1st Congress took place.

The missions of EUGMS are:

- To develop geriatric medicine in the member states of the European Union as an independent specialty caring for all older people with age-related disease
- To campaign for the availability of these services to all citizens of the European Union
- To promote education and continuing professional development, and in particular a biennial scientific meeting
- In conjunction with the Section of Geriatric Medicine of the EUMS, to promote geriatric medicine to the European Commission and Parliament
- To promote evidence-based guidelines for the most efficacious prevention and treatment strategies for older people in the European Union

European Union Geriatric Medicine Society (EUGMS)
Marjory Warren House
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Tel: +44 -20- 76 08 13 69
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secretariat@eugms.org
www.eugms.org

1.4.1.6 Early Detection & Timely INTERvention in DEMentia Network (INTERDEM)

INTERDEM is:

- A network that is dedicated to person-centred values and working together with people with dementia and their family carers, by placing them at the centre of research and practice and encouraging their active participation
- A multi – professional network of gerontological research-practitioners who focus on psychosocial (as opposed to neurobiological) approaches to the early recognition and intervention in dementia, throughout Europe
- A network of researchers, practitioners, people with dementia and their carers who have a particular focus on early and timely support, psychosocial intervention and disability prevention in dementia, at the primary / community - specialist care interface.
- Psychosocial researchers, practitioners, people with dementia and families, from the UK, Spain, The Netherlands, Ireland, Italy, Portugal, France, Belgium, Germany, Sweden, Poland and Greece (plus Hong Kong)
- An aim to develop and carry out pan - European psychosocial research and person-centred practice in dementia

Interdem

c/o Dr Esme Moniz-Cook, Coordinator
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E.D.Moniz-Cook@hull.ac.uk
www.alzheimer-europe.org/INTERDEM

1.4.1.7 International Association of Gerontology European Region (IAG-ER)

IAG-ER is the European part of the World Organisation: the International Association of Gerontology (IAG) founded in 1952 in Liège by Prof. Brull.

It has three sections:

- The biological section
- The medical section
- The behavioural and social section.

The aims are to:

- Promote gerontological research in these fields
- Promote training of highly qualified personnel
- Promote the interests of gerontological organisations in all questions pertaining to international matters
- Promote and assist in the arrangements for holding the European Congresses of Gerontology at four year intervals, separate congresses of the sections, and also of the International Congresses of IAG

International Association of Gerontology European Region (IAG-ER)
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Fax:+33 -1- 49 59 45 24
robert.moulias@wanadoo.fr
www.iag-er.org

1.4.1.8 EuroCoDe national network organisations

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Obere Augartenstrasse 26-28
1020 Wien
Tel: +43 -1- 332 51 66
Fax: +43 -1- 334 21 41
alzheimeraustria@via.at
www.alzheimer-selbsthilfe.at

Österreichische Gesellschaft für Geriatrie und Gerontolgie
Sozialmedizinisches Zentrum
Apollogasse 19
1070 Wien
Tel: +43 -1- 521 03 13 07
Fax: +43 -1- 521 03 13 09
franz.boehmer@wienkav.at
www.geriatrie-online.at

Österreichische Gesellschaft für Neurologie (ÖGN)
Garnisongasse 7/22
1090 Wien
Tel.: +43 -1- 512 80 91 19
Fax.: +43 -1- 512 80 91 80
oegn@admicos.com
www.oegn.at

Alzheimerliga der Deutschsprachigen Gemeinschaft VoE - Patienten Rat & Treff

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4700 Eupen
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Fax: +32 –87– 55 76 83
patienten.rat@skynet.be
www.alzheimer.be/alzheimerliga/index.html

Belgische Vereniging voor Gerontologie en Geriatrie
Nieuwpoort Steenweg, 57
8400 Oostende
Tel: +32 -59- 55 34 04
Fax: +32 -59- 51 99 43
jpbaeyens@skynet.be
www.geriatrie.be

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Unité médicale, Bâtiment B 30 - Sart Tilman
4000 Liège 1
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eric.salmon@ulg.ac.be
www.ulg.ac.be/crc/fr/esalmon.html

ExpertiseCentra Dementie Vlaanderen
Sint Bavostraat 29
02610 Wilrijk
Jum.verschraegen@dementie.be
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Ligue Alzheimer
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www.alzheimer.be

Ligue Nationale Alzheimer Liga
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Quality of Life and Dementia
Department of General Practice
Academisch Centrum Huisartsgeneeskunde
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Bulgarian Society of Neurology
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stamenova@mbox.cit.bg

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chrisele@spidernet.com.cy

Pancyprian Alzheimer Association
Stadiou Street 31a
6020 Larnaca
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Fax: +357-24- 62 71 06
alzhcyprus@yahoo.com

Czech Alzheimer Society
Centre of Gerontology, Šimùnkova 1600
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Fax: +420 -2- 86 88 27 88
Martina.Rokosova@gerontocentrum.cz
www.alzheimer.cz

Czech Neurological Society
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www.czech-neuro.cz

Czech Society of Geriatrics and Gerontology

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Danish Geriatric Society
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Dansk Neurologisk Selskab (Danish Neurological Society)
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Department of General Practice and Central Research Unit for General Practice
Institute of Public Health
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Estonian Ludvig Puusepp Society of Neurologists and Neurosurgeons
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1.5 Annex 3: Minutes of the Steering Committee meeting in Paris (2 July 2006)

1.5.1 Present:

Steering committee members:

- Maurice O'Connell — Alzheimer Europe
- Jean-Pierre Bayens — IAG-ER, EUGMS
- Ralf Ihl — EAGP
- Rabih Chattat — Interdem
- Anthea Innes — North Sea Group / Univ. of Sterling
- Helen Regan — Alzheimer Disease International

Work package leaders:

- Lutz Frölich — CIMH Mannheim
- Myrra Vernooij-Dassen — Alzheimer Research Nederlands
- Anders Wimo — Karolinska Institute
- Dianne Gove — Alzheimer Europe
- Emma Reynish — Hôpitaux de Toulouse

Alzheimer Europe:

- Sabine Henry — Ligue Alzheimer
- Heike von Lützau-Hohlbein — Deutsche Alzheimer Gesellschaft.
- Annette Dumas — Alzheimer Europe
- Jean Georges — Alzheimer Europe

Apologies

- Rupert McShane

1.5.2 Welcome

Maurice O'Connell welcomed the participants and invited them to introduce themselves.

1.5.3 Technical, financial and administrative questions

Jean Georges explained that the aim of the meeting was to gather the steering group and other organisations involved in the project to share progress since the meeting in Luxembourg in February 2006.

Jean Georges informed the group that the contract with the Commission was not signed yet, although this should be a matter of days.

The money will be paid out once the contract has been signed. Alzheimer Europe will receive the money and will distribute it the participating centres. Alzheimer Europe will explain how to claim expenses.

The travel costs for this meeting will be reimbursed for the steering committee members and a per diem will be paid (according to Commission guidelines). Work package leaders will need to account for their costs in the financial accounts submitted to Alzheimer Europe.

1.5.4 Progress report WP4 – Social support systems - Dianne Gove

The group will look at how health and services interact through a literature search.

A questionnaire will be given to each working group member (each in charge of 5 countries). Dianne will be in charge of the rest. The questionnaire is 22-pages long (including notes and a cover letter).

A hand-out with the names of the persons responsible per country, questions on the section on anti-dementia-drugs and the topics covered by the questionnaire was distributed to the participants (attached to this report). The document also includes some definitions linked to the questionnaire on social support systems.

The draft survey has been approved and will be tested. The second stage will be a meeting in November 06, 2006 to discuss the problems faced with filling the questionnaire. In January 2007, the questionnaire will be sent to the member organisations.

The Alzheimer Europe 2006 Dementia Yearbook will use some information gathered by this WP. The Yearbook will be used towards policy makers to identify inter alia barriers to access.

A discussion followed. To the questionnaire on anti-dementia drugs, it was suggested to find out how many people take the drug in each country and to include off-label use.

To the question of price, it was suggested to know the price of a daily dose rather than the price per tablet or capsule.

It was also suggested to be more precise in the questionnaire and find out for which disease the drugs have been prescribed.

Bus passes should be included to the questionnaire section 6.5 (work/tax-related support to people with dementia).

Finally, comments were made on the length of the questionnaire.

1.5.5 Progress report WP6 – Psycho-social interventions – Myrra Vernooij-Dassen

The group will gather and analyse guidelines on psycho-social interventions in Europe, investigate the gaps in the availability of guidelines, build on the existing guidelines and interventions used in other European countries and disseminate the results among European countries.

The focus is on general guidelines that will be on the Internet and used in all settings.

The countries involved are the UK, France, Spain, Denmark, and Luxembourg.

The hand-out that was distributed (attached) listed the research questions, and the methodologies used.

Methodology 2: palliative care should be considered in this section. Also, it was recommended the guidelines include the professionals' needs and consider action plans.

The suggestions made were to put in place a model that evaluates the studies, emphasize the cultural differences between the Member States, include care support programmes and support groups for people with dementia.

It was strongly recommended to have regular links with the Work Packages to discuss their respective results and avoid overlap. The importance of meetings like the meeting today was unanimously stressed.

To the question of deadlines, the group was reminded that the official publication of the EuroCoDe is end 2008 and that we should stick to this date. Interim reports will be on the Internet. It was also agreed that centres may already publish parts of their results in scientific journals. Rules for such publications would need to be developed prior to this.

An archive system must be put in place to keep track of all information that has been collected for future references.

1.5.6 Progress report WP 7 – Prevalence – Emma Reynish

The group decided to be more specific in what will be achieved by this WP. They wish to be able to come up with figures that could give a realistic figure of the prevalence and incidence of Alzheimer's disease.

The literature available is small. The next steps are to widen the range of literature search and collate data :

- do as wide a search as possible. The findings should be gathered in a database that is hoped to be hosted on Alzheimer's Europe's website
- carry a meta-analysis of prevalence data following a set of criteria (listed in the hand-out attached).

One of the difficulties encountered is the European diversity (different people are in charge, some populations have been studied, others not).

The question is: are there truly differences in the incidence of dementia in Europe

The participants agreed that the focus should be on Alzheimer's disease. Of interest to AE is also early onset dementia, as Eurodem seemed to have understimated these figures.

There were discussions around MCI (mild cognitive inmpairment). The figures risk to be disappointing because too vague. It was agreed that MCI was a problem and would be skipped.

1.5.7 Progress report WP 8 – Socio-economic costs – Anders Wimo

The conclusions of the meeting in Luxembourg in February 2006 were handed out (attached). Anders Wimo reported that the commitments made by some participants to come up with contributions had not been fulfilled.

Under point 3, it was agreed that it was important to define the concepts. The perspective is on the cost of illness but this perspective needs to be defined.

Under point 4/5, concept about informal care : it is essential to clearly define informal care (i.e. support in activities of daily living, but also supervision activities). This will have an impact on how we estimate the cost of care. It was agreed that the easiest would be to make an estimation in hours rather than in costs. Reliable instruments and methods to validate the results are needed.

Myrra mentioned she had a report on the role of informal care givers and will send it to the WP leader.

The work this group is carrying out should take the opportunity to make a statement that the informal carer is often an elderly person. This redresses the balance when older people are considered as a burden. They in fact play a key role in society.

Point 6 : there is very little data about Eastern European countries and the group will need to focus on this issue.

Point 10: one needs to be prudent when reading the data about access to treatment. The case of Greece was given where a recent study showed that close to 100% of people with dementia are treated but the medicines actually were sold abroad (parallel imports).

It was agreed that there could be an overlap between WP4 and WP8 and that there should be close coordination between the two groups. The reference lists will be shared.

To the question about putting this WP in perspective with NICE, this was not deemed relevant as this WP does not deal with cost-effectiveness.

1.5.8 Report progress on WP 9 – Prevention – Lutz Frölich

A hand-out of the report of the meeting in Luxembourg on February 2006 was distributed along with a document outlining the risk factors in dementia and Alzheimer's disease.

The WP leader reported that studies had been identified. Only treatable factors will be addressed

It is important to define what are the limitations of risk factors (definitions of the risk factors, different levels of prevention). The idea is to focus on risk reduction rather than prevention.

Many pathologies are associated to Alzheimer's disease at 90. The risk factors are deducted from the real world. Some elements increase or decrease the risk factors. This can have an effect on other risks.

Some risk factors are independant but many interfere with one another (case of diabetes, Parkinson's disease and Alzheimer's disease). This reservation has to be included in the report.

The goal of this group is to give the Commission insight leads where research should be carried out (one project rather that smaller projects that do not meet the needs).

The focus must be more on what is treatment and what is prevention.

1.5.9 Round up and closing

Jean Georges stated that at the end of the project, we should have been able to bring different networks together, made policy recommendations at national and European level. The focus will be on where research should be lead, what are the priorities and what is needed.

The next meeting will be in November 06, in Brussels. The meeting is organised before an Alzheimer Europe lunch in the European Parliament on November 07. The agenda of the EP lunch will be Alzheimer's disease centenary specific policy activities (presentation of the first Dementia Yearbook and Paris Declaration).

Jean Georges invited the WP leaders to help Alzheimer Europe in approaching key opinion leaders to endorse the Declartion.

Maurice O'Connell closed the meeting by thanking all participants for their work

2 WP 2 – Dissemination

2.1 Introduction

The aim of the work package is to disseminate the various indicators developed by the project to as wide an audience as possible. This should be done through a public web site as well as the web sites of the project partners. Also, the annual conferences organised by Alzheimer Europe will serve to disseminate the findings of the project.

Also, to increase the collaboration between the different stakeholders involved in the dementia field in Europe, a Yearbook with the contact details of these organisations should be produced. The findings of the various work packages should equally be presented in these Yearbooks.

2.2 Progress so far

2.2.1 Dissemination at meetings and conferences

The Eurocode project was presented in detail to the participants at the Alzheimer Europe Annual General Meeting in Paris (29 June 2006), as well as the Annual Conference of the organisation (29 June to 1 July 2006).

Also, the European Association of Geriatric Psychiatry organised a specific workshop to present the project aims of the Eurocode project during their Annual meeting in Cologne (21-23 September 2006) at which Lutz Frölich, Jean Georges, Andrzej Kiejna, Rupert McShane and Myrra Vernooy-Dassen took part.

A number of working group members also presented the project results at other meetings they attended.

2.2.2 Dementia in Europe Yearbook

The first edition of the Year Book was launched in 2006. In the first edition, Alzheimer Europe presented the list of organisations involved in the Eurocode project (See under Work package 1) and presented the preliminary results of two work packages, namely prevalence estimates for 31 European countries, as well as information on the reimbursement systems for anti-dementia drugs.

Alzheimer Europe was honoured that Commissioner Kyprianou, the President of the European Parliament Committee for Public Health, Karl Heinz-Florenz and the Finnish Minister for Health and Social Services, Ms. Liisa Hyssälä agreed to write a foreword to the first edition of this Yearbook.

2,000 copies of the Yearbook were produced and Alzheimer Europe disseminated them widely, by sending 10 copies to each of the Alzheimer Europe member organisations, 50 copies to the European Commission, as well as one copy to all Members of the European Parliament in the Committees for Public Health, Research, Social Affairs and Women's Rights.

The Yearbook was formally launched at a meeting organised by Alzheimer Europe in the European Parliament on 7 November which was hosted by Ms. Astrid Lulling, MEP from Luxembourg.

2.2.3 Website

General information on the project aims and partners was included on the general website of Alzheimer Europe (www.alzheimer-europe.org).

In order to provide greater visibility to the results of the Eurocode project and the more general campaign of Alzheimer Europe to make dementia into a European public health priority, Alzheimer Europe developed a new website (www.dementia-in-europe.eu) which is dedicated to the public policy impact of Alzheimer's disease and other forms of dementia. The information collected through the Eurocode project on the prevalence of dementia and the reimbursement of anti-dementia drugs has been included on this new website.

3 WP 3 – Evaluation

3.1 Introduction

The project results will be evaluated by the Steering Committee and will be sent for endorsement to the network partners and their member organisations and centres. Also, an external evaluation of the action will be carried out by three external experts who will be independent of the various project partners.

3.2 Progress so far

As the different work packages mostly concentrated on the literature search and the analysis of the state of the art for their respective fields, it was too early to involve the outside evaluators in the project. The evaluators will be formally designated at the meeting of the Eurocode steering committee in Oslo in 2007.

4 WP 4 - Social Support Systems

4.1 Introduction

The overall aim of work package 4 is to determine the level of state support for people with dementia and their carers in each member country of the European Union, and additionally in Iceland, Turkey, Norway and Switzerland. As state support may be lacking in some countries and/or in certain domains, we are also interested in finding out whether alternative arrangements exist e.g. support from NGOs, charitable organisations and religious groups etc. This will be achieved by means of a survey which will be given to each of our member associations. They will be responsible for filling in the survey and/or passing it on to relevant experts (e.g. in the fields of law, social support, taxation and employment etc.) if necessary.

The project started in February 2006 with the kick-off meeting. This meeting was the first opportunity for the members of the working group to get together, define the methodology and agree on each person's respective contribution.

The members of the working group are as follows:

- Dianne Gove, Work package leader (Alzheimer Europe)
- Sirkkaliisa Heimonen, Alzhheimer keskusliitto and Ikainst Institut (Finland)
- Hans-Jürgen Freter, Deutsche Alzheimer Gesellschaft (Germany)
- Eugen Stefanut, Romanian Alzheimer Association (Romania) to 11/2006
- Letitia Dobranici, Romanian Alzheimer Association (Romania) from 11/2006
- Louise McCabe, University of Stirling (United Kingdom)
- Maria do Rosario Zincke dos Reis, APFADA (Portugal)

Two additional participants agreed to attend meetings and to be involved in the project, namely:

Federico Palmermiti	Fondation Alzheimer Mederic (France)
Sabine Henry	Ligue Alzheimer (Belgium)

4.2 Methodology

The methodology for the project was partly influenced by the original project proposal but worked out within the working group on the basis of the experience and ideas of the various members. The main methodology can be summarised as follows:

- Carry out literature review (ongoing process)
- Draft questionnaire
- Pilot questionnaire on the group
- Refine and finalise the questionnaire
- Send out questionnaire with motivating cover letter to member associations
- Send out reminder 1 month later from group member responsible for each country
- Collect responses and discuss within the group

- Request clarification if necessary and ask any additional questions (if decided by group)
- Work on the presentation of the responses i.e. write country reports
- Make recommendations and highlight best practices

4.3 Progress to date

In 2006, there were two working group meetings and one steering committee meeting. This enabled the WP4 to finalise the questionnaire by the end of the year so that it could be sent out, according to plan, in January 2007. Piloting the questionnaire within the group proved particularly useful in highlighting potential problems, clarifying the text and making the questionnaire more straightforward.

The group was conscious of the need to keep the questionnaire as short as possible but at the same time, of the need to cover all possible kinds of support and to have sufficient additional information to be able to put the information gathered into a meaningful context.

As this resulted in a fairly lengthy questionnaire, the group paid particular attention to the wording of the cover letter in order to ensure that it would motivate member associations to take part in the survey. For this reason, it was also decided that members of the working group would each be responsible for 4 or 5 member associations and would contact them personally once the questionnaire had been sent out.

Alzheimer Europe also carried out a survey on the drug reimbursement systems in Europe. The results of this survey were included in the 2006 edition of the Dementia in Europe Yearbook (See Annex 3 for full results).

4.4 Plans for the next phase of the project

In 2007, the working group will concentrate on trying to ensure that accurate information is obtained from as many countries as possible, clarifying any issues that are unclear, obtaining additional information if necessary and deciding how to best present the results. If everything goes according to plan, this will leave 2008 for work on the recommendations and best practices which should then be endorsed and made available to the public.

4.5 Annex 1: Minutes of the working group meeting, Luxembourg, 25-26 February 2006

Present: Dianne GOVE

Eugen STEFANUT

Fédérico PALERMITI

Hans-Jürgen FRETER

Jean GEORGES

Louise McCABE

Maria Do ROSARIO Dos REIS ZINCKE

Sabine HENRY

Sirkkaliisa HEIMONEN

4.5.1 Organisational issues

The meeting started after a plenary session involving all the participants from the various work packages. LMC was unfortunately unable to attend the first part of the WP4 meeting (i.e. on Saturday) due to problems with a flight. HJF suggested reorganising the agenda so as to start with the general issues and then have the short presentations and discussions later. This proposal was accepted.

4.5.2 Literature review

Participants agreed to take an active part in the search for relevant documentation. It became clear that very few had access to relevant databases (with the exception of ES) but that all could try to obtain reports from other organisations dealing with these issues, as well as from governments. It was decided that we should not limit our search to comparative reports but should also include information from single countries. Participants agreed to send summaries of relevant information in English to DG. As we will be covering a large number of countries and cannot guarantee the same degree of involvement from each Alzheimer Association, the information collected will be used in a practical way to complete the various country reports. Documents can be scanned or sent by post to DG.

4.5.3 Responsibility for the survey results

DG asked if each member of the group would be willing to accept responsibility for obtaining responses to the survey from 4 to 5 countries. This would mean that the surveys would be sent to all AE member associations which would then be responsible for providing the information. The role of the WP4 group members would be to make sure that the surveys are returned on time and to follow-up on any issues that seem unclear. We will ask for the surveys to be returned to the relevant group member with a copy to DG. Participants agreed to divide the countries as follows:

Dianne Gove	Belgium Estonia France Latvia

	Lithuania Netherlands Poland Slovakia Turkey
Eugen Stefanut	Bulgaria Czech Republic Hungary Romania Slovenia
Hans-Jürgen Freter	Austria Germany Luxembourg Switzerland
Louise McCabe	Cyprus England and Wales Republic of Ireland Malta Scotland
Maria do Rosario Dos Reis Zincke	Greece Italy Portugal Spain
Sirkkaliisa Heimonen	Denmark Finland Iceland Norway Sweden

4.5.4 WP4 and the AE Yearbook

JG was asked which results from WP4 would be needed for the Alzheimer Europe Yearbook. He explained that only information about the reimbursement of drugs would be included in this year's publication. We will contact our member associations for information but this will not be part of the main survey as we will need the information much sooner.

4.5.5 Scope of the project

After quite some discussion about the scope of the project, it was finally decided that the aim of the survey was to provide a **description/explanation of the situation in each country concerning the extent to which the State supports carers and people with dementia**. The information obtained will eventually be presented in the form of individual country reports, as well as a global report summarising some of the main differences between countries and containing policy recommendations and examples of best practice.

We will not be systematically measuring the actual number of services provided in each country. However, such information may be revealed in response to questions about the limitations of State support e.g. an association might report that the State supports day care if a need has been assessed but that there are only 3 day care centres in the whole country.

FP emphasised the importance of including details of the **mechanisms of social protection** in each country i.e. relevant legislation and the structure of the social support system. It was agreed to include this in the country reports.

It was also agreed that the **relationship between health care and social care** in each country needs to be understood in order to have a clear picture of how the State attempts to meet the social support needs of carers and people with dementia. It was felt that this was particularly

important in view of the fact that in many countries the State has more of an obligation to provide and finance health care as opposed to social care. The point was also made that people with dementia and carers sometimes suffer the consequences of gaps in the system e.g. where neither the health care system nor the social care system has responsibility for a particular form of social support.

4.5.6 How general or detailed should the survey be?

The group decided not to go into too much detail but rather to ask the following kinds of questions for each form of social support:

Does the State provide support for _____ ? (e.g. respite care, home help, transport etc.)

If so, please explain how.

If not, what options are available to people?

As we want to be able to compare the situation between countries, we may decide to ask for specific details for some aspects of social support (and in order to ensure that we do not miss out important information).

It was decided to ask for a description of the services available, details of which services are lacking (according to the Alzheimer Associations) and information about any restrictions governing access to services or allowances.

4.5.7 Procedure for drafting the survey

The group discussed how to go about drawing up the survey. The following procedure was decided upon:

1. DG to draw up survey on the basis of the group discussion
2. Members of the group to comment on the first draft.
3. DG to make any necessary changes.
4. Second draft to be sent to members of the working group.
5. Group members to complete the survey and report on any problems they encountered or necessary changes which became evident.
6. Group to discuss their experience and make proposals for an improved survey (at the next meeting in November 2006).
7. DG to draw up and circulate within the group a third draft of the survey.
8. After comment from the group and amendment of the draft, DG to send out the fourth draft to all Alzheimer Europe's member associations.

4.5.8 Second day of the meeting/plenary session

At the request of a group leader from one of the other work packages, the second day of the meeting again started with the plenary session. After two short presentations, a lengthy discussion took place in an attempt to identify and deal with possible overlap between two work packages. This was followed by short summaries of progress within the other groups.

Following these presentations, DG briefly discussed collaboration with WP8 with Anders Wimo and Dave McDaid. They suggested checking the European Commission's DG Employment and Social Affairs work on social protection (the MISSOC website). They were interested in the WP4 group including a question in the survey about where to obtain information on the exact existence of social care provisions in each country e.g. statistics about the number of places in residential homes and day care centres. They do not need us to actually obtain such details but rather just to find out where or from whom they could obtain this kind of information.

Esme Moniz-Cook mentioned possible overlap between WP4 and WP6 (on psychosocial interventions). DG agreed to keep the group leaders of WP4 and WP6 informed of our progress so that we can ensure that we don't duplicate work and so that we might be able to share certain information.

4.5.9 Reorganisation of the time schedule

Having decided to include an additional stage in the drafting of the survey, it was necessary to adapt the time schedule for completion of tasks. The following deadlines were accepted:

Timeframe	Task
By the end of March 2006	Complete first draft
April 2006	Comments from the working group
May to September 2006	Working group to complete the survey
October 2006	Results to be sent to DG and circulated within the group
November 2006	Meeting to discuss and improve the survey
December 2006	Final amendments to be made
January 2007	Survey to be sent out to Alzheimer associations
February to June 2007	Alzheimer Associations to complete the survey

4.5.10 Content of the survey

The group then discussed the content of the survey, starting with dementia drugs and drug reimbursement systems. It was agreed to limit questions to the four main dementia drugs. Suggested questions included: when were the drugs licensed and when were reimbursement decisions made, who has the right to prescribe such drugs, what are the start and cut-off criteria for prescription, for which diseases have the drugs been approved, what is the price per tablet/capsule, how does the reimbursement system work, are there regional differences concerning access to the drugs and is bi-therapy possible?

Other areas of social support were then considered, such as:

- Home care (e.g. bathing, taking medication, skin care, dealing with incontinence)
- Home help (e.g. housework, laundry, assistance with meals etc.)
- Occupational therapy/ergotherapy
- Home adaptation
- Day care
- Respite care
- Residential care
- Palliative care

- Legislation (relating to State obligations and specific forms of social support)
- Employment issues (time off, flexible hours, incapacity law, pension contributions)
- Government policies (State policy concerning the provision of services)
- Organisation and funding of social support (long-term care insurance, allowances)
- Tax refunds (due to incapacity, for employing home help assistants)
- Benefits (continence pads, free transport, free TV licence)

A discussion followed about certain terms used which might be confusing (e.g. the difference between allowances and benefits or between occupational therapy and ergotherapy) and about different opinions as to how to categorise certain forms of support e.g. for Romania, should personal assistants be classed as a service or as an allowance if the personal assistant is the spouse of the person with dementia and therefore receiving money for the care that they provide?

4.5.11 The conference in Paris

JG asked members of the group if they would like to have a workshop in Paris[1] to discuss some of the issues linked to the survey. All agreed in principle but some stated that it would be necessary to check with their organisations with regard to financing. Nevertheless, they provisionally agreed to deal with the following topics:

Employment provisions	Sirkkaliisa Heimonen
Drug reimbursement	Maria do Rosario Dos Reis Zincke
Long-term care insurance	Hans-Jürgen Freter
Assessment and legislation	Louise McCabe
The system in Romania	Eugen Stefanut

Each person will speak for about 10 minutes and there will be plenty of time to discuss the various issues with the people attending the workshop. Members of the group agreed to send a brief extract of their presentation to JG who will then submit the proposal to the French Alzheimer association.

4.5.12 Close of the meeting

DG thanked members of the working group for their work and the meeting was brought to a close. The next meeting will be held in November 2006.

4.5.13 Annexes

A timetable of the revised work schedule is attached as a separate document. On the next page, you will find contact details for members of the group and references to some of the documents mentioned during the meeting.

[1] the 16th Annual Alzheimer Europe conference – 29 June to 1 July 2006

4.5.13.1 Participants of WP4

Dianne GOVE	Alzheimer Europe	Luxembourg	dianne.gove@alzheimer-europe.org
Eugen STEFANUT	Societatea Alzheimer Romania	Romania	eugen_stefanut@yahoo.com
Hans-Jürgen FRETER	Deutsche Alzheimer Gesellschaft	Germany	hans-juergen.freter@deutsche-alzheimer.de
Louise McCABE	University of Stirling	United Kingdom	l.f.m.mccabe@stir.ac.uk
Maria do Rosario DOS REIS ZINCKE	APFADA	Portugal	zinckedosreis@mail.telepac.pt
Sirkkaliisa HEIMONEN	Alzheimer Keskusliitto	Finland	sirkkaliisa.heimonen@ikainst.fi

4.5.13.2 Additional participants

Federico PALERMITI	Fondation Medéric Alzheimer	France	palermiti@med-alz.org
Jean GEORGES	Alzheimer Europe	Luxembourg	jean.georges@alzheimer-europe.org
Sabine HENRY	Ligue Alzheimer	Belgium	henry.sabine@skynet.be

4.5.13.3 Interesting documentation

1. Eurofamcare national background reports based on services for supporting family carers of elderly people in Europe, Countries covered include: AT, BE, CH, CZ, DE, DK, EL, ES, FR, HU, IRE, IT, LUX, MT, NL, NO, PL, PT, SE, SF, SLV, and UK (2002 to 2005)
2. Procare reports on providing integrated health and social care for older persons, Countries covered include: AT, DE, DK, EL, FR, IT, NL, SF and UK (2003)
3. Brodsky, J., Habib, J. and Mizrahi, I. (2000), A review of long-term care laws in five developed countries, Countries covered include: AT, DE and NL
4. Joël, M-E and Cozette, E. (Eds.) (2002), Prise en charge de la maladie d'Alzheimer en Europe, INSERM. Countries covered include: BE, DE, DK, ES, FR, PT, SE and UK
5. MISSOC comparative tables on social provision e.g. entitlement to services, certain relevant laws, reimbursement systems for medication and health services etc. Countries covered include: All EU member states, Can be accessed at: http://europa.eu.int/comm/employment_social/missoc/missoc4_en.pdf

4.6 Annex 2 - Minutes of the working group meeting - Brussels, 6 November 2006

Present: Dianne GOVE

Letitia DOBRANICI

Fédérico PALERMITI

Hans-Jürgen FRETER

Louise McCABE

Maria Do ROSARIO Dos REIS ZINCKE

Sabine HENRY

Sirkkaliisa HEIMONEN

4.6.1 Organisational issues

The group agreed that each person would give feedback based on their experience of filling out the draft questionnaire. Numerous pointed were raised by various members of the group, often leading to a group discussion. For this reason, the various issues raised will be recorded here in the same order as they appear in the questionnaire.

4.6.2 The overall structure of the questionnaire

It was decided to refer to the two sections of the questionnaire as Part 1 and Part 2 to avoid confusion when referring to the various sub-sections of Part 2. Sabine HENRY suggested rearranging the sections and the items in Part 2 in order to put questions about services and support for people with dementia before those for carers e.g. section 6 before section 5. This proposal was accepted.

4.6.3 Explanations and definitions

There was general agreement that the explanations and definitions currently in the appendix would be far more useful if included in the actual questionnaire at the end of each specific question. It was decided to move the definition of social support to the beginning of part 1 of the questionnaire.

Letitia DOBRANICI felt that it was unclear whether respondents should mention all existing services (irrespective of whether people with dementia can use them) or just those specifically for people with dementia. It was agreed that we would like to know about services and support that are specifically designed for people with dementia as well as more general services/support (e.g. including those for elderly, dependent and/or disabled people) provided that people with dementia can use them. An explanation will be included at the beginning of Part 2.

4.6.4 Part 1 of the questionnaire

4.6.4.1 Legal provisions

Hans-Jürgen FRETER pointed out that although it is interesting to know which laws exist, there is a risk that the information provided might be misleading in the sense that it might paint a rosy picture of legal provisions, which in reality, are not enforced or have little impact on the provision

of support/services. Federico PALERMITI suggested asking respondents to separate laws and acts from decrees in order to separate theory from practice. This proposal was accepted. An example of how to present information on legislation and decrees will be included in the appendix.

4.6.4.2 Additional information requested

A few additional items were proposed for inclusion in Part 1 of the questionnaire such as:

- A reference to possible interaction between the State, the private sector and voluntary associations/NGOs
- Details of government priorities linked to dementia/action plans for dementia
- Whether services are adequate and sufficiently accessible (covering issues such as people living in rural areas, age discrimination and other barriers to access)
- The extent to which available services actually respond to the specific needs of people with dementia
- Whether the State supports Alzheimer associations and if so, how.

It was pointed out that the combination of a reference to the funding of the healthcare and welfare systems in question 2 and to how specific services and support are funded in question 4 could lead to confusion.

4.6.4.3 Quality of care

It was decided not to ask directly about quality of care as this is beyond the scope of our project. However, it was decided to include something about minimum standards of care and the control of services in the question about the legal framework in case there are decrees covering these issues.

4.6.5 Part 2 of the questionnaire

4.6.5.1 The extent and appropriateness of services provided

In the last draft of the questionnaire, we asked about the extent to which services are provided which led to some confusion. Sirkkaliisa HEIMONEN suggested taking out this question and trying to incorporate into Part 1 some reference to the main deficits of services, difficulties accessing services and the extent to which the needs of people with dementia are taken into account by the services provided. This proposal was accepted.

4.6.5.2 Whether services are funded or provided freely by the State

Some members of the group were unclear about how to answer the question about the degree of State funding for individual services (due to the either/or construction). Dianne GOVE proposed a solution which gives respondents the possibility to tick more than one box in order to indicate whether the State funds the service partly, completely or not at all, with the same options for the service user. This proposal was accepted.

4.6.5.3 The cost of care

At the request of members of WP8, a question was included in the last version of the questionnaire about the cost of each service. None of the members of the working group provided this information. The reason for this omission was discussed. Members of the working group had found

it difficult to obtain such information and felt that in any case, prices varied too much from one service provider to another and from region to region. It was also felt that as the questionnaire was already very long and as the cost of care was beyond the scope of this work package, it would be unwise to cover the issue of cost. We could perhaps ask a few precise questions about the cost of certain services on behalf of WP8 once we have received most questionnaires back.

4.6.5.4 Section 1 – Types of care - Palliative care

Louise McCABE pointed out that the definition of palliative care was misleading as it did not make it sufficiently clear that we were interested in palliative care in the last stage of the disease and not throughout the whole course of the disease (which would in theory be possible due to the fact that dementia is a terminal illness). It was agreed to alter the definition.

4.6.5.5 Section 2 – Personal assistance at home

Sirkkaliisa HEIMONEN suggested taking out the question about other kinds of nursing care as the main kinds of nursing care directly linked to dementia had already been covered. This proposal was accepted.

4.6.5.6 Section 4 – Psychosocial support and training

Federico PALERMITI suggested adding a question about the existence of a general information service i.e. to inform people about services and orientate them towards specific dementia counselling services etc.

It was also agreed that there should be a question about holidays for people with dementia as there is already one about holidays for carers.

The questions on support for Alzheimer associations and training for volunteers were rejected as it was felt that whilst important issues, they are not directly about support or services for people with dementia or carers. The question on support for Alzheimer associations will nevertheless be included in Part 1 of the questionnaire.

4.6.5.7 Section 5 – Work/tax related support to carers

It was decided to change the order of this section and section 6 in order to put people with dementia first and to add explanations about flexible working hours and free/subsidised pension contributions. The title was changed.

4.6.5.8 Section 6 – Work/tax related support to people with dementia

The title was also changed.

4.6.5.9 Section 7 – Other

An additional section was added to allow respondents to add any further information.

4.6.6 Responsibility for different countries

As there had been changes within the group, Dianne GOVE went through the responsibility of each member of the group for specific countries and made a small change based on the fact that we do not have a contact person for every country. The countries are now divided as follows:

Dianne Gove	Belgium

	Estonia France Latvia Lithuania Netherlands Poland Slovenia Turkey
Letitia Dobranici	Bulgaria Czech Republic Hungary Romania Slovakia
Hans-Jürgen Freter	Austria Germany Luxembourg Switzerland
Louise McCabe	Cyprus England and Wales Republic of Ireland Malta Scotland
Maria do Rosario Dos Reis Zincke	Greece Italy Portugal Spain
Sirkkaliisa Heimonen	Denmark Finland Iceland Norway Sweden

4.6.7 The cover letter

The group decided to make the following changes to the cover letter in order to increase the chance of member associations taking the time to fill out the rather lengthy questionnaire. The following changes were agreed upon:

- To make the first paragraph sound more friendly and straightforward.
- To add a paragraph about what the survey could bring to member associations in order to motivate them to participate.
- To change the date for completion from 30 June to 30 March 2007.
- To delete the last paragraph and add the request for details of the contact person to the preceding paragraph.

4.6.8 Deadline for return of the questionnaires

Hans-Jürgen FRETER suggested making the deadline for the return of the questionnaires much earlier so as to avoid people putting the questionnaire on the back-burner for too long and then forgetting to do it. Letitia DOBRANICI proposed that members of the working group send out a letter introducing themselves to the associations in the countries that they are covering about one month after the questionnaire has been sent out. It is hoped that this will serve to remind them about the questionnaire and make the request more personal.

4.6.9 Revised work schedule

The following deadlines were set for the dispatch and completion of the questionnaires:

End of November: Completion of next draft

End of December: Comments and approval (from the working group)

Mid January 2007: Dispatch of the questionnaire (by Dianne GOVE)

Mid February 2007: Introduction and reminder from members of the working group

End of March 2007: Deadline for completion of the questionnaire

4.6.10 Close of the meeting

DG thanked members of the working group for their work and the meeting was brought to a close.

4.6.11 Annexes

A timetable of the revised work schedule is attached as a separate document.

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4.7.1 Copies of laws relating to social services/home care (in English)

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2. **Estonia** – Social Welfare Act of 8 February 1995 with subsequent amendments (covers involuntary placement, social services, the welfare of the elderly and the financing of social welfare)
3. **Iceland** – The Local Authorities Social Services Act, 27 March 1991 (covers the obligation to provide home care services for the elderly) has possibly been repealed by the following act (need to find out if this is the case)
4. **Iceland** – Act on the Affairs of the Elderly, No.125, 31 December 1999 (covers the right to access to health and social services and to enjoy a normal domestic life for as long as possible, informing the elderly of services available, the Senior Citizens' Construction Fund and details of services for the elderly)
5. **Latvia** – Law on Social Services and Social Assistance, 1 January 2003 (covers entitlement to social services, home care, long-term residential care, the purpose of social care services, the right to social care based on age and functional disorder, family obligation to provide care)
6. **Lithuania** – Law on the Health System, I-552, 19 July 1994 (covers access to and confidentiality of information, home nursing for the elderly, refusal of health care by guardian and responsibility for the healthcare of elderly parents)

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8. **Sweden** – The Social Services Act (SFS 2001: 453) with amendments up to and including SFS 2004:851 (municipal responsibilities, entitlement to assistance, older persons and carers, home help)

4.8 Annex 4: The availability of anti-dementia drugs in Europe

4.8.1 The availability of anti-dementia drugs in Europe

4.8.1.1 Existing treatments for Alzheimer's disease in Europe

No drug treatments can provide a cure for Alzheimer's disease or the other common forms of dementia. However, drug treatments have been developed that can temporarily slow down the progression of symptoms in some people with Alzheimer's disease. Donepezil, rivastigmine and galantamine all work in a similar way and are known as acetylcholinesterase inhibitors. Memantine[2] works in a different way to the other three.[3]

4.8.1.1.1 Acetylcholinesterase inhibitors

Research has shown that the amount of a chemical called acetylcholine is diminishing in the brains of people with Alzheimer's disease. Acetylcholine is one of the many chemicals that nerve cells use to communicate and is a neurotransmitter that plays a critical role in memory and learning processes.

Donepezil, rivastigmine and galantamine have a common mode of action as all three drugs prevent an enzyme known as acetylcholinesterase from breaking down acetylcholine in the brain. However, rivastigmine inhibits both acteylcholinesterase and butyrylcholinesterase, the two enzymes that break down acetylcholine in the brain. Galantamine also appears to act on the nicotinic neuronal receptors in the brain, making them release more acetylcholine.

Increased concentrations of acetylcholine lead to improved communication between nerve cells involved in memory and learning, which may in turn temporarily improve or stabilise some of the key symptoms of Alzheimer's disease.

It is possible that one of these drugs might suit a particular individual better than another. The specialist may be able to advise whether there is any advantage associated with a particular drug.

At present acetylcholinesterase inhibitors are only used in people with mild to moderate Alzheimer's disease. They are not effective for everyone and may only temporarily improve memory or delay memory loss. Research is being undertaken to find out whether any of these drugs may be effective in the later stages of Alzheimer's disease.[4]

In February 2006, following a positive opinion from the Committee for Medicinal Products for Human Use (CHMP) of the European Medicines Agency, the European Commission granted rivastigmine EU Marketing Authorization for the symptomatic treatment of mild to moderately severe dementia associated with idiopathic Parkinson's disease (PDD).

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[2] Donepezil is marketed in Europe under the name Aricept, rivastigmine as Exelon, galantamine as Reminyl and memantine as Ebixa or Axura.

[3] Alzheimer's Society (UK), *Information sheet on Drug treatments for Alzheimer's disease - Aricept, Exelon, Reminyl and Ebixa* (August 2003)

[4] Alzheimer's Society (UK), *op. cit*.

4.8.1.1.2 Memantine

The action of memantine is different to that of the acetylcholinesterase inhibitors. Memantine blocks another neurotransmitter in the brain known as glutamate. Glutamate is released in excessive amounts when brain cells are damaged by Alzheimer's disease, causing the brain cells to be damaged further. Memantine is thought to protect brain cells by blocking this release of excess glutamate.

Memantine can temporarily slow down the progression of symptoms in people in the middle and later stages of the disease. This is the first time a drug has been available for this group of people. There is also a suggestion that memantine may slow down the disease process itself.[5]

At first memantine was licensed for the treatment of moderately-severe to severe Alzheimer's disease, but following a positive opinion from the Committee for Medicinal Products for Human Use (CHMP) of the European Medicines Agency in October 2005, the European Commission granted memantine an extension of the indication to the treatment of patients with moderate to severe Alzheimer's disease.

4.8.1.2 Inequalities in access to Alzheimer treatments in Europe

In its Strategic Plan (2006-2010), Alzheimer Europe has provided a clear mission statement for its work. Its core objective is defined as 'changing perceptions, policy and practice in order to improve the access by people with dementia and their carers to treatment options and care services'.

Access by European citizens to existing anti-dementia drugs is of course a key concern of Alzheimer associations throughout Europe and in 2005 and 2006, Alzheimer Europe coordinated a response of its national organisations to the appraisal document of the National Institute for Health and Clinical Excellence (NICE) in the United Kingdom on the treatments available for Alzheimer's disease. In its response, the organisations expressed their grave concern about the proposal to limit access of UK citizens to treatments which are available to people with Alzheimer's disease in other European countries.

As a follow-up to this response and as part of its European Commission financed project "European Collaboration on Dementia (EuroCoDe)", Alzheimer Europe carried out an extensive survey of its members to highlight any inequalities within the European Union with regard to the access of people with Alzheimer's disease to existing treatments. In its survey, Alzheimer Europe concentrated on finding out which of the available treatments were reimbursed under national health systems in different European countries, but also aimed at quantifying the delays experienced by different countries in granting such reimbursement, as well as any other access restrictions imposed by national health systems for the reimbursement of these medicines.

4.8.1.3 The reimbursement of Alzheimer treatments in Europe

Reimbursement systems in Europe vary quite considerably, but each European country has a system in place that guarantees that essential medicines are made available to patients at an affordable price which is at least partly underwritten by the national health systems.

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[5] Alzheimer's Society (UK), *op. cit.*

The following table shows whether the four drugs available for the treatment of Alzheimer's disease have been authorised (A) and whether they are part of the reimbursement system (R) of the respective countries. However, the table does not give any indications as to the level of reimbursement provided or the access restrictions imposed by the reimbursement systems.

Country	Donepezil		Rivastigmine		Galantamine		Memantine	
	A	R	A	R	A	R	A	R
Austria	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Belgium	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Bulgaria	Yes	No	Yes	No	Yes	No	No	No
Cyprus	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Czech Republic	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Denmark	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Estonia	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes
Finland	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
France	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Germany	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Greece	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Hungary	Yes	Yes	Yes	Yes	No	No	Yes	Yes
Iceland	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Ireland	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Italy	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No
Latvia	Yes	No	Yes	No	Yes	No	Yes	No
Lithuania	Yes	Yes	No	No	Yes	No	Yes	Yes
Luxembourg	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Malta	Yes	No	Yes	No	Yes	No	Yes	No
Netherlands	No	No	Yes	Yes	Yes	Yes	Yes	Yes
Norway	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No
Poland	Yes	Yes[6]	Yes	Yes	Yes	No	Yes	No
Portugal	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Romania	Yes	Yes	Yes	Yes	No	No	Yes	Yes
Slovak Republic	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Slovenia	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Spain	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Sweden	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Switzerland	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Turkey	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
United Kingdom	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No[7]

As can be seen from the above table, with the exception of Bulgaria, Latvia and Malta, one or more acetylcholinesterase inhibitors are reimbursed in all the European countries, covered by the Alzheimer Europe survey, even if there may be slight variations as to which of the medicines are available and reimbursed. Memantine, as the more recent drug approved for the treatment of Alzheimer's disease, has not yet been made subject to a reimbursement decision in Bulgaria, Italy, Latvia, Malta, Norway and Poland. Similarly, most health trusts in the United Kingdom do not cover memantine under the National Health System.

4.8.1.4 Access and reimbursement restrictions

The question of whether treatments for Alzheimer's disease are reimbursed under the national health systems provides important information on the existing inequalities in access to treatment in Europe. Nevertheless, it does not provide a complete picture since various conditions imposed by

[6] Reimbursement of donepezil is limited to the generic versions of this product.

[7] Although individual health trusts are free to reimburse memantine, the Scottish Medicines Consortium rejected their use through the NHS and the opinion of the National Institute for Health and Clinical Excellence (NICE) was pending when this publication went to print.

the health systems may impose further restrictions on the access of people with Alzheimer's disease to existing treatments.

The proposed changes by the National Institute for Health and Clinical Excellence (NICE) in the United Kingdom would for example limit the reimbursement of anti-dementia drugs to people in the moderate stages of the disease and exclude people with mild Alzheimer's disease.

Similarly, some countries have reserved reimbursement to treatment decisions made by specialist doctors or in specialist centres. Some have gone further by also requiring a continuing treatment decision to be made by a specialist doctor. Also, reimbursement may not be made available to people with Alzheimer's disease living alone or living in nursing homes. Other systems require specific examinations to be carried out prior to a reimbursement decision being made. Finally, there are quite considerable differences between European countries which have defined upper and lower MMSE score limits for the initiation and discontinuation of treatment[8]. It is therefore not surprising that a recent article[9] warned about the "alarming arbitrariness" of these prescription and reimbursement criteria in Europe.

Country	Initial treatment decision	Continuing treatment decision	Special examinations required	Upper and lower MMSE scores (ACHI)[10]	Upper and lower MMSE scores (memantine)[11]
Austria	Specialist doctors	Specialist doctors	MMSE	26-10	14-3
Belgium	Specialist doctors	Specialist doctors	Diagnostic protocol	>10	15-0
Bulgaria	No reimbursement				
Cyprus	No information				
Czech Republic	Specialist doctors	Specialist doctors	MMSE	20-13	16-6
Denmark	No restrictions[12]	No restrictions	Diagnostic protocol	None	None
Estonia	No information				
Finland	No[13] restrictions	No restrictions	None	None	None
France	Specialist doctors	No restrictions	None	26-10	15-0
Germany	No restrictions	No restrictions	None	None	None
Greece	Specialist doctors	No restrictions	None	None	None
Hungary	Specialist	Specialist	Diagnostic	26-10	18-0

[8] The Mini-Mental State Examination (Folstein et al. 1975) is a quick test which gives an overall estimate of a person's intellectual capacity and can therefore be used to give a rough assessment of the progress of dementia over time. It gives a score from 30 (full mental capacity) to 0 (severe impairment).

[9] R.C. Oude Voshaar, A. Burns, M.G.M. Olde Rikkert : Alarming arbitrariness in EU Prescription and reimbursement criteria for anti-dementia drugs, Int J Geriatr Psychiatry ; 2006 ; 21 :29-31

[10] Unless obtained from our member organisations, we included data from R.C. Oude Voshaar et.al., op.cit

[11] Unless obtained from our member organisations, we included data from R.C. Oude Voshaar et.al., op.cit

[12] Although an application for reimbursement can be made by any doctor on behalf of a patient, the diagnosis must have been made by a specialist (neurologist, psychiatrist or geriatrician).

[13] Any doctor can prescribe anti-dementia drugs, but reimbursement can only be done if the diagnosis has been established by a specialist.

	doctors	doctors	protocol		
Iceland	No restrictions[14]	No restrictions	Diagnostic protocol	None	None
Ireland	No restrictions	No restrictions	None	None	None
Italy	Alzheimer Evaluation Unit	Alzheimer Evaluation Unit	Diagnostic protocol	26-10	N/A
Latvia	No information				
Lithuania			MMSE	None	20-0
Luxembourg	No restrictions	No restrictions	Diagnostic protocol	26-10	15-0
Malta	No reimbursement				
Netherlands	Specialist doctors	Specialist doctors	Diagnostic protocol	26-10	14-3
Norway	No restrictions[15]	No restrictions	MMSE	> 12	N/A
Poland	No restrictions	No restrictions	MMSE	26-10	N/A
Portugal	Specialist doctors	Specialist doctors	None	None	None
Romania	Specialist doctors	Specialist doctors	Diagnostic protocol	> 12	> 12
Slovak Republic	Specialist doctors	Specialist doctors	MMSE	24-13	24-13
Slovenia	Specialist doctors	No restrictions	MMSE	26-10[16]	26-10
Spain	Specialist doctors	Specialist doctors	MMSE	None	None
Sweden	No restrictions	No restrictions	None	None	None
Switzerland	No restrictions	No restrictions	MMSE	>10	>3
Turkey	Specialist doctors	No restrictions	None	None	None
United Kingdom	Specialist doctors	No restrictions[17]	MMSE	30-12	N/A

4.8.1.5 Market access delays

A final aspect that Alzheimer Europe covered in its survey on the availability of anti-dementia drugs concerned the dates of the market authorisation, product launches and reimbursement decisions in the different countries. While differences in market authorisations already point to significant delays in some countries for the approval of new medicines, these delays are further exacerbated by the time it takes for pricing decisions to be made and for products to be launched, as well as for new treatments to be included in the reimbursement system.

The following table shows the delays experienced in some countries for the market authorisation, the launch or the reimbursements decisions for three of the Alzheimer medicines.

	Galantamine Market autorisation dates	**Memantine Launch dates**	**Rivastigmine Reimbursement dates**

[14] Although prescriptions can be filled in by any doctor, the diagnosis needs to be confirmed by a specialist.

[15] Norway specifies that treatment decisions should be made by a doctor with an interest in and knowledge of dementia, but does not restrict treatment decisions to specialist doctors.

[16] For patients with MMSE scores higher than 26, more extensive neuropsychological examinations have to be carried out that indicate cognitive decline consistent with Alzheimer's disease.

[17] The NICE guidance in existence (September 2006) allows general practitioners to continue treatment under shared care protocols.

First country	Sweden (03/2000)	Germany, Denmark, Iceland (08/2002)	Switzerland (03/1997)
Within 6 months	Austria, Belgium, Denmark, Finland, Iceland, Ireland, Norway, Switzerland, United Kingdom	Austria, Greece, Ireland, Netherlands, Norway, Sweden, United Kingdom	
Within 6 – 12 months	France, Germany, Greece, Italy, Luxembourg, Poland, Portugal, Spain	Finland, France, Hungary, Slovenia, Spain	
Within 1 to 2 years	Czech Republic, Lithuania, Slovak Republic, Slovenia	Belgium, Czech Republic, Poland, Portugal, Romania, Slovak Republic, Switzerland, Turkey	France, Germany, United Kingdom
Within 2 to 3 years		Croatia, Italy, Serbia-Montenegro	Spain, Netherlands
Within 3 to 4 years	Latvia, Malta, Netherlands	Cyprus	Ireland
Over 4 years	Cyprus		Austria, Belgium, Hungary

Although it was impossible to find data for all the countries covered in our survey, the findings point to significant delays in some countries as to the access of people with Alzheimer's disease to treatment options available to patients in other countries. With the decision to centralise market authorisations for drugs for the treatment of neurodegenerative diseases, such as Alzheimer's disease, at the level of the European Medicines Agency, the delays between the Member States of the European Union will disappear.

Nevertheless, due to the pricing discussions in some countries or internal company decisions, the launch dates of products will continue to vary and some people with Alzheimer's disease will have earlier access to new treatments than others.

Similarly, true access to anti-dementia drugs is only obtained by patients, once these drugs are part of the reimbursement system, as otherwise treatment with these drugs may be limited only to those people who can afford to pay for them themselves. As can be seen from the above table, although rivastigmine was authorised through the centralised procedure with European wide marketing authorisation on 12 May 1998, there were significant differences as to the dates when individual countries included this treatment in their reimbursement systems.

For Alzheimer Europe, these differences are unacceptable as the organisation campaigns for people with Alzheimer's disease throughout Europe to have equal access to a high standard of care services and treatment options.

4.8.1.6 Treatment rates

The Alzheimer Europe survey shows important differences between European countries as to the numbers of people with Alzheimer's disease having access to existing treatments. Other recent publications similarly aimed at identifying differences as to the numbers of people with Alzheimer's disease being treated.

A survey conducted by Pfizer amongst 200 carers from 6 different European countries (France, Germany, Italy, Poland, Spain and United Kingdom) showed that a majority of physicians recommended treatment at the time of diagnosis. Nevertheless, there were marked differences between countries, with UK carers reporting that treatment was recommended at the time of

diagnosis in only 51% of cases, whereas carers in Poland or Spain reported that this was the case in 86% of cases.

As to the treatment recommended, carers reported mainly prescription medicines (98%), either specific Alzheimer's treatments (86%) or medication to treat mood and behaviour (61%). Other therapies, such as counselling (29%), day care (26%), cognitive therapy (21%) or support groups (15%) were less often recommended by doctors.[18]

Similarly, a recent study by Waldemar[19] et. al. calculated the rates of people with Alzheimer's disease who receive treatment by combining the Alzheimer Europe prevalence rates with data obtained from International Marketing Services about the sales of donepezil, galantamine, rivastigmine and memantine.

Country	Percentage of carers reporting treatment at diagnosis[20]	Percentage of patients treated[21]
Austria		32
Belgium		30
Bulgaria		6
Czech Republic		9
Denmark		28
France	83	50
Germany	78	26
Greece		97
Hungary		3
Ireland		46
Italy	85	18
Netherlands		8
Poland	86	16
Portugal		33
Slovak Republic		10
Spain	86	40
Sweden		47
Switzerland		28
United Kingdom	51	18

4.8.1.7 Conclusions

The Alzheimer Europe survey and other studies in this field confirm that people with Alzheimer's disease do not have equal access to existing dementia treatments in Europe. Rather, access is subject to a great many restrictions and there are huge variations in access between European countries.

4.8.1.8 Acknowledgements

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- ABELA Stephen, Malta Dementia Society, Malta

[18] D. Wilkinson et. al. Inequalities in dementia care across Europe : An Agenda for Change, *Int J Clin Pract,* March 2005, **59** (Suppl. 146), 17-24

[19] G. Waldemar, K.T.T. Phung, A. Burns, J. Georges, F. Ronholt Hansen, S. Iliffe, C. Marking. M. Olde Rikkert, J. Selmes, G. Stoppe, N. Sartorius, Access to diagnostic evaluation and treatment for dementia in Europe, in press Int J Geriatr Psychiatry

[20] D. Wilkinson, op.cit.

[21] G. Waldemar, op.cit.

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4.8.2 Availability of anti-dementia drugs in Austria

4.8.2.1 The availability of medicines in general

Austria keeps a list of pharmaceutical products for which expenses are covered by the health care system. Nevertheless, patients and carers need to cover part of the costs of medicines. This charge is currently set at € 4.60 per item prescribed. For infectious diseases and in cases of need, medicines may be free of charge.[22]

[22] European Commission (2006): 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

4.8.2.2 The availability of Alzheimer treatments

All four anti-dementia drugs are available to patients in Austria and are included on the list of pharmaceutical products that are covered by the health care system.

Prescription is limited to specialist doctors and this applies to both treatment initiation, as well as to continuing treatment decisions. 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 health care system, nevertheless the Austrian Alzheimer Association pointed out that the treatment of people in nursing homes was limited by the medicines budgets of the nursing homes in question.

The Austrian Alzheimer Association also pointed out that bi-therapy with an acetylcholinesterase inhibitor and memantine was specifically excluded from reimbursement in Austria and that patients would have to pay for one of the drugs in that case.

	Donepezil	Rivastigmine	Galantamine	Memantine
Reimbursement	Yes	Yes	Yes	Yes
Initial treatment decision	Specialist doctors	Specialist doctors	Specialist doctors	Specialist doctors
Continuing treatment decision	Specialist doctors	Specialist doctors	Specialist doctors	Specialist doctors
Required examinations	MMSE	MMSE	MMSE	MMSE
MMSE limits	26-10	26-10	26-10	14-3
People living alone	No restrictions	No restrictions	No restrictions	No restrictions
People in nursing homes	Nursing home budgets	Nursing home budgets	Nursing home budgets	Nursing home budgets

4.8.3 Availability of anti-dementia drugs in Belgium

4.8.3.1 The availability of medicines in general

In Belgium, the reimbursement system has classified drugs 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 € 10.20.
- For medicines in category C (less useful drugs), the patient is required to pay 50% up to a ceiling of € 17.00. This percentage may go up to 60% or 80% for drugs certain medicines in this group which fall under category CS (ease drugs) or Cx (for example: contraceptives).

For medicines for which an identical generic product exists, the refund by the reimbursement system is reduced by 30%.[23]

4.8.3.2 The availability of Alzheimer treatments

All four anti-dementia drugs are available to patients in Belgium and are part of the reimbursement system.

[23] European Commission (2006): 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

Belgium has a very strict treatment protocol for drugs to be reimbursed. Amongst others, it limits the prescription of anti-dementia drugs to specialist doctors, both for treatment initiation and for treatment continuation. An MMSE score of between 24-12 is required for the reimbursement of acetylcholinesterase inhibitors and a score of between 15 and 3 for the reimbursement of memantine.

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 Alzheimer, 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.

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

	Donepezil	Rivastigmine	Galantamine	Memantine
Reimbursement	Yes	Yes	Yes	Yes
Initial treatment decision	Specialist doctors	Specialist doctors	Specialist doctors	Specialist doctors
Continuing treatment decision	Specialist doctors	Specialist doctors	Specialist doctors	Specialist doctors
Required examinations	Diagnostic protocol	Diagnostic protocol	Diagnostic protocol	Diagnostic protocol
MMSE limits	24-12	24-12	24-12	15-3
People living alone	No restrictions	No restrictions	No restrictions	No restrictions
People in nursing homes	No restrictions	No restrictions	No restrictions	No restrictions

4.8.4 Availability of anti-dementia drugs in Bulgaria

4.8.4.1 The availability of medicines in general

Alzheimer Europe was unable to obtain detailed information on the general reimbursement system of medicines in Bulgaria.

4.8.4.2 The availability of Alzheimer treatments

According to Alzheimer Bulgaria, except for memantine, all anti-dementia treatments are available in Bulgaria, but none of them are part of the reimbursement system in that country and patients and carers need to cover these costs themselves.

	Donepezil	Rivastigmine	Galantamine	Memantine
Reimbursement	No	No	No	No
Initial treatment decision	N/A	N/A	N/A	N/A
Continuing treatment decision	N/A	N/A	N/A	N/A
Required examinations	N/A	N/A	N/A	N/A
MMSE limits	N/A	N/A	N/A	N/A
People living alone	N/A	N/A	N/A	N/A
People in nursing homes	N/A	N/A	N/A	N/A

4.8.5 Availability of anti-dementia drugs in Cyprus

4.8.5.1 The availability of medicines in general

In Cyprus, medicines are provided by hospitals or institutions. Drugs prescribed are included in an approved list. Patients are required to pay 50% of the costs of treatments on the approved list.[24]

[24] European Commission (2006): 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

4.8.5.2 The availability of Alzheimer treatments

All anti-dementia drugs are available in Cyprus and are part of the reimbursement system. Alzheimer Europe was unable to obtain detailed information on reimbursement restrictions in Cyprus.

	Donepezil	Rivastigmine	Galantamine	Memantine
Reimbursement	Yes	Yes	Yes	Yes
Initial treatment decision	No information	No information	No information	No information
Continuing treatment decision	No information	No information	No information	No information
Required examinations	No information	No information	No information	No information
MMSE limits	No information	No information	No information	No information
People living alone	No information	No information	No information	No information
People in nursing homes	No information	No information	No information	No information

4.8.6 Availability of anti-dementia drugs in the Czech Republic

4.8.6.1 The availability of medicines in general

In the Czech Republic, medicinal products are classified into three categories and reimbursement may vary 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. [25]

4.8.6.2 The availability of Alzheimer treatments

All four anti-dementia drugs are available in the Czech Republic and are part of the reimbursement system.

The Czech Republic limits reimbursement of these 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 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 reimbursement restrictions for people living alone or in nursing homes.

	Donepezil	Rivastigmine	Galantamine	Memantine
Reimbursement	Yes	Yes	Yes	Yes
Initial treatment decision	Specialist doctors	Specialist doctors	Specialist doctors	Specialist doctors
Continuing treatment decision	Specialist doctors	Specialist doctors	Specialist doctors	Specialist doctors
Required examinations	MMSE	MMSE	MMSE	MMSE
MMSE limits	20-13	20-13	20-13	16-6
People living alone	No restrictions	No restrictions	No restrictions	No restrictions
People in nursing homes	No restrictions	No restrictions	No restrictions	No restrictions

4.8.7 Availability of anti-dementia drugs in Denmark

4.8.7.1 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 medication of a patient during a year.

- If the total expenditure on medicines in a year does not exceed DKK 480 (approx. € 63), the patient covers 100% of the drug costs.

[25] European Commission (2006): 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 total medicines expenditure between DKK 480 and DKK 1,165 (approx. € 156), the patient covers 50% of the costs.
- For total medicines expenditure between DKK 1,165 and DKK 2.730 (approx. € 366), the patient covers 25% of the costs.
- For total medicines expenditure above DKK 2,730, 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 3,520 (approx. €472).

Finally, in special cases the health service can contribute to medicines not on the list or contribute fully to medicines for dying persons. [26]

4.8.7.2 The availability of Alzheimer treatments

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

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 are excluded.

The system does not provide upper or lower MMSE limits for the treatment with different anti-dementia 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 Alzheimer treatments.

	Donepezil	Rivastigmine	Galantamine	Memantine
Reimbursement	Yes	Yes	Yes	Yes
Initial treatment decision	No restrictions	No restrictions	No restrictions	No restrictions
Continuing treatment decision	No restrictions	No restrictions	No restrictions	No restrictions
Required examinations	Diagnostic protocol	Diagnostic protocol	Diagnostic protocol	Diagnostic protocol
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

4.8.8 Availability of anti-dementia drugs in Estonia

4.8.8.1 The availability of medicines in general

In Estonia, patients normally pay EEK 50 (approx. € 3.20) as well as a further 50% of the cost of medicines exceeding that basic amount.

[26] European Commission (2006): 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 listed chronic conditions, patients pay EEK 20 (approx. € 1.28) for medicines, whereas the health insurance fund covers either the totality of the remaining costs (for diseases, such as HIV, cancers, tuberculosis and others) or 75% of the remaining costs (for diseases, such as asthma or nephritis amongst others).

Finally, the health insurance fund also covers 90% of extra costs for children up to 10 years of age, persons on an invalidity pension and for people over the age of 63.[27]

4.8.8.2 The availability of Alzheimer treatments

All four anti-dementia drugs are authorised for use in Estonia and with the exception of Exelon, they are part of the reimbursement system and reimbursed at 50%. Alzheimer Europe was unable to obtain detailed information on the specific conditions for reimbursement in Estonia and existing access restrictions.

4.8.9 Availability of anti-dementia drugs in Finland

4.8.9.1 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% or 100% of the cost of medicines over the value of € 3 per product which the patient will need to cover out of his/her own funds.

Should the total pharmaceutical expenses of an individual exceed € 616.72 in a year, these costs are fully covered without participation by the patient.[28]

4.8.9.2 The availability of Alzheimer treatments

All anti-dementia drugs are available in Finland and are part of the reimbursement system. 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 will carry out a thorough examination which often includes a CT or MRI scan. There are no upper or lower MMSE limits for the treatment with different anti-dementia drugs. Any doctor can prescribe Alzheimer treatments, but to be reimbursed, the prescription must be accompanied by a statement of 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 will cover the cost of these medicines.

	Donepezil	Rivastigmine	Galantamine	Memantine
Reimbursement	Yes	Yes	Yes	Yes
Initial treatment decision	No restrictions	No restrictions	No restrictions	No restrictions
Continuing treatment decision	No restrictions	No restrictions	No restrictions	No restrictions
Required examinations	None	None	None	None
MMSE limits	None	None	None	None

[27] European Commission (2006): 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

[28] European Commission (2006): 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

People living alone	No restrictions	No restrictions	No restrictions	No restrictions
People in nursing homes	No restrictions	No restrictions	No restrictions	No restrictions

4.8.10 Availability of anti-dementia drugs in France

4.8.10.1 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. Reimbursement can thus vary between 30% and 70% with medicines for certain diseases being reimbursed 100%.[29]

4.8.10.2 The availability of Alzheimer treatments

All anti-dementia drugs are available in France and are fully reimbursed at 100% through the reimbursement system. 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 done by a specialist (a neurologist, psychiatrist or geriatrician), whereas continuing treatment prescriptions can be filled in by general practitioners as well. There are no restrictions as to the access of people living alone or in nursing homes to available Alzheimer treatments.

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 had access to these treatments.

	Donepezil	Rivastigmine	Galantamine	Memantine
Reimbursement	Yes	Yes	Yes	Yes
Initial treatment decision	Specialist doctors	Specialist doctors	Specialist doctors	Specialist doctors
Continuing treatment decision	No restrictions	No restrictions	No restrictions	No restrictions
Required examinations	None	None	None	None
MMSE limits	26-10	26-10	26-10	15-0
People living alone	No restrictions	No restrictions	No restrictions	No restrictions
People in nursing homes	No restrictions	No restrictions	No restrictions	No restrictions

4.8.11 Availability of anti-dementia drugs in Germany

4.8.11.1 The availability of medicines in general

In Germany, patients generally pay 10% of the cost of medicines with a minimum contribution of € 5 per product and a maximum contribution fixed at € 10. 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.[30]

[29] European Commission (2006): 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

[30] European Commission (2006): 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

4.8.11.2 The availability of Alzheimer treatments

All anti-dementia drugs are available in Germany and are part of the reimbursement system. 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 anti-dementia drugs. There are no restrictions as to the access of people living alone or in nursing homes to available Alzheimer treatments. Also, the German system does not limit treatment initiation or continuation decisions to specialist doctors.

The German Alzheimer Association underlined that due to the introduction of medicines budgets for individual doctors, some doctors were less inclined to prescribe Alzheimer treatments.

	Donepezil	Rivastigmine	Galantamine	Memantine
Reimbursement	Yes	Yes	Yes	Yes
Initial treatment decision	No restrictions	No restrictions	No restrictions	No restrictions
Continuing treatment decision	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

4.8.12 Availability of anti-dementia drugs in Greece

4.8.12.1 The availability of medicines in general

The Greek system provides for different levels of participation in patients to the cost of medicines. As a general rule, patients should pay 25% of medicines prescribed by a doctor. Nevertheless, for certain diseases such as Parkinson's disease or Crohn's disease, this contribution by patients is lowered to 10%. Similarly, the contribution is reduced to 10% for retired persons receiving the minimum pension.

Finally, for certain chronic conditions such as cancer or diabetes, medicines are fully covered. The same is true for medicines during pregnancy or for medicines necessary for employment accidents.[31]

4.8.12.2 The availability of Alzheimer treatments

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

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. Also, Greece does not require any specific diagnostic examinations to be carried out, nor does the system provide upper or lower treatment limits.

Finally, the Greek system reimburses medicines for people living alone or in nursing homes.

	Donepezil	Rivastigmine	Galantamine	Memantine
Reimbursement	Yes	Yes	Yes	Yes
Initial treatment decision	Neurologists or psychiatrists	Neurologists or psychiatrists	Neurologists or psychiatrists	Neurologists or psychiatrists
Continuing treatment decision	No restrictions	No restrictions	No restrictions	No restrictions

[31] European Commission (2006): 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

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

4.8.13 Availability of anti-dementia drugs in Hungary

4.8.13.1 The availability of medicines in general

In Hungary, in-patient medicines are free of charge for patients. Out-patient medicines on the official list are covered basically by the Health Insurance Fund by 50 to 100%. This percentage depends on a decision made by a professional body which makes their decisions on the type of drug.

Elderly people with a low income and disabled people can receive a special card which entitles them to free medication. Finally, victims of employment injuries and occupational diseases also receive medicines free of charge.[32]

4.8.13.2 The availability of Alzheimer treatments

Except for galantamine, anti-dementia drugs are available in Hungary and 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 governing 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 has been 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 set up (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.

	Donepezil	Rivastigmine	Galantamine	Memantine
Reimbursement	Yes	Yes	No	Yes
Initial treatment decision	Specialist doctors	Specialist doctors	N/A	Specialist doctors
Continuing treatment decision	Specialist doctors	Specialist doctors	N/A	Specialist doctors
Required examinations	Diagnostic protocol	Diagnostic protocol	N/A	Diagnostic protocol
MMSE limits	26-10	26-10	N/A	18-0
People living alone	Caution against use	Caution against use	N/A	Caution against use
People in nursing homes	No restrictions	No restrictions	N/A	No restrictions

4.8.14 Availability of anti-dementia drugs in Iceland

4.8.14.1 The availability of medicines in general

In Iceland, medicines are divided into 4 main categories depending on their type and category. Payments by patients for medicines can vary from 0 to 100% of their overall cost, again depending

[32] European Commission (2006): 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

on the category of the medicine. Patients only pay this co-payment to the pharmacy with the rest of the costs being paid to pharmacies by the health insurance.

- Category 1: Essential medicines used for the treatment of life threatening and chronic conditions such as diabetes, cancer and psychotic disorders are reimbursed 100%.
- Category 2: Medicines of great therapeutic value for well defined and chronic diseases such as hypertension, asthma, psoriasis and depression are partly reimbursed
- Category 3: Medicines of lesser therapeutic value such as medicines for arthritis or hormone replacement therapy in menopause are also partly reimbursed
- Category 4: Medicines for which the indication is too broad or not well defined as well as medicines for minor conditions (tranquilisers, analgesics, antibiotics and lipid regulating drugs) are not generally reimbursed.

Medicines in categories 1, 2 and 3 are on the positive list, but products not on the positive list may be reimbursed in individual cases, when certain criteria are fulfilled[33].

4.8.14.2 The availability of Alzheimer treatments

All four anti-dementia drugs are available in Iceland. They are included in category 4 and are thus not part of the positive list. Nevertheless, reimbursement is possible under the following criteria.

People that have been diagnosed by a specialist can receive a special drug card which allows them to have their medicines reimbursed. For treatment with acetylcholinesterase inhibitors, the specialist needs to diagnose a patient with either Alzheimer's disease or Lewy Body dementia according to the ICD 10 criteria. For treatment with memantine, patients need to score at least five points on the GDS (Global Deterioration Scale).

Although diagnosis needs to be done by a specialist, it is possible for general practitioners to prescribe treatment with either class of drugs. A follow-up of the patient needs to be done every year and the drug card will not be renewed if a patient has deteriorated by more than two points on their MMSE scores and if carers do not believe the medicines had any results.

The Icelandic reimbursement system does not have any specific restrictions for the reimbursement of Alzheimer treatments for people living alone or in nursing homes.

	Donepezil	Rivastigmine	Galantamine	Memantine
Reimbursement	Yes	Yes	Yes	Yes
Initial treatment decision	No restrictions	No restrictions	No restrictions	No restrictions
Continuing treatment decision	No restrictions	No restrictions	No restrictions	No restrictions
Required examinations	Diagnostic protocol	Diagnostic protocol	Diagnostic protocol	Diagnostic protocol
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

4.8.15 Availability of anti-dementia drugs in Ireland

4.8.15.1 The availability of medicines in general

Approved medicines prescribed by GPs are free of charge for persons with full eligibility. Similarly, no charge is required from people under the age of 16 who are suffering from a mental handicap or

[33] European Commission (2006): 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 mental illness as well as persons suffering from specified long-term illnesses for the treatment of the illness in question.

Finally, under the drugs payment scheme, no individual or family is required to pay more then € 85 per month for approved prescribed medicines.[34]

4.8.15.2 The availability of Alzheimer treatments

All anti-dementia drugs are available in Ireland and are part of the general system described above. 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 anti-dementia 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 by any doctor and are not limited to specialists, be it for treatment initiation or continuation decisions.

	Donepezil	Rivastigmine	Galantamine	Memantine
Reimbursement	Yes	Yes	Yes	Yes
Initial treatment decision	No restrictions	No restrictions	No restrictions	No restrictions
Continuing treatment decision	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

4.8.16 Availability of anti-dementia drugs in Italy

4.8.16.1 The availability of medicines in general

Medicines in Italy are included in one of the three following groups:

- Group A is for medicines termed "essential" for the treatment of more serious diseases and conditions and are free of charge for people insured except for the fixed amount for the prescription.
- Group C is for other medicines and for over-the-counter medicines. For these medicines, the cost is borne in totality by the insured person,
- Group H is for medicines free of charge but limited to use in hospitals or out of hospitals according to the laws of the Italian regions.[35]

4.8.16.2 The availability of Alzheimer treatments

All anti-dementia drugs are available in Italy and with the exception of memantine are reimbursable under strict conditions. The Italian government launched the Cronos project in 2000 to assess the impact of a multi-level therapeutic approach which included a two year free-of-charge treatment with acetylcholinesterase inhibitors.

Reimbursement is limited to persons participating in this project and requires a diagnostic assessment in one of the 503 Alzheimer Evaluation Units set up for this project. The first six months of the treatment are provided free of charge by the pharmaceutical companies manufacturing the medicines. The project provides specialists with a diagnostic protocol they need

[34] European Commission (2006): 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

[35] European Commission (2006): 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 follow. Treatment with acetylcholinesterase inhibitors is open for people with an MMSE score between 26 and 10 and memantine for people with MMSE scores below 14.

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

	Donepezil	Rivastigmine	Galantamine	Memantine
Reimbursement	Yes	Yes	Yes	No[36]
Initial treatment decision	Alzheimer Evaluation Units	Alzheimer Evaluation Units	Alzheimer Evaluation Units	N/A
Continuing treatment decision	Alzheimer Evaluation Units	Alzheimer Evaluation Units	Alzheimer Evaluation Units	N/A
Required examinations	Diagnostic protocol	Diagnostic protocol	Diagnostic protocol	N/A
MMSE limits	26-10	26-10	26-10	N/A
People living alone	No restrictions	No restrictions	No restrictions	N/A
People in nursing homes	No restrictions	No restrictions	No restrictions	N/A

4.8.17 Availability of anti-dementia drugs in Latvia

4.8.17.1 The availability of medicines in general

Medicines in Latvia are included in one of four categories which determine the reimbursement rates:

- Medicines without which it is not possible to maintain life functions are reimbursed at 100%.
- Medicines without which there would be difficulties in ensuring a patient's life functions are reimbursed at 90%.
- Medicines without which the current health status could not be maintained are reimbursed at 75%.
- Medicines which are necessary to improve a patient's health condition are reimbursed at 50%.[37]

4.8.17.2 The availability of Alzheimer treatments

All four anti-dementia drugs are marketed in Latvia, but none of them are part of the reimbursement system.

4.8.18 Availability of anti-dementia drugs in Lithuania

4.8.18.1 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 protection.

Finally, 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.[38]

[36] Certain Italian regions may have different reimbursement rules. In Trentino for example, memantine can be reimbursed.

[37] European Commission (2006): 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

[38] European Commission (2006): 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

4.8.18.2 The availability of Alzheimer treatments

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. The same information for memantine was not available. There are no restrictions in Lithuania for the reimbursement of these treatments for people living alone or in nursing homes.

Alzheimer Europe has no information on whether there are special requirements in Lithuania as to which doctors can prescribe Alzheimer treatments.

	Donepezil	Rivastigmine	Galantamine	Memantine
Reimbursement	Yes	No	No	Yes
Initial treatment decision	No information	N/A	N/A	No information
Continuing treatment decision	No information	N/A	N/A	No information
Required examinations	MMSE	N/A	N/A	No information
MMSE limits	20-0	N/A	N/A	No information
People living alone	No restrictions	N/A	N/A	No restrictions
People in nursing homes	No restrictions	N/A	N/A	No restrictions

4.8.19 Availability of anti-dementia drugs in Luxembourg

4.8.19.1 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% of their cost,
- Preferential reimbursement is 100%,
- Reduced reimbursement is 40% and
- Certain medicines are not reimbursed.[39]

4.8.19.2 The availability of Alzheimer treatments

In Luxembourg, all anti-dementia drugs are available and are part of the normal reimbursement system (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 to see 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 acetylcholintesterase 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.

	Donepezil	Rivastigmine	Galantamine	Memantine
Reimbursement	Yes	Yes	Yes	Yes
Initial treatment decision	No restrictions	No restrictions	No restrictions	No restrictions
Continuing treatment decision	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	15-0

[39] European Commission (2006): 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

People living alone	No restrictions	No restrictions	No restrictions	No restrictions
People in nursing homes	No restrictions	No restrictions	No restrictions	No restrictions

4.8.20 Availability of anti-dementia drugs in Malta

4.8.20.1 The availability of medicines in general

According to information from the website of the Health Division (Ministry of Health)[40], the government supplies medicines free of charge to all in-patients in government hospitals. Medicines are supplied for free from government pharmacies and district clinics to entitled persons. 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 to free medicines for that condition irrespective of financial position. These include many chronic diseases such as malignanty, cancers, chronic cardiovascular and respiratory disease, endocrine diseases, schizophrenia and others. Certain conditions such as stroke, dementia and depression are not included. The list was last updated in 1999.

Other persons entitled to free drugs (who are issued a Grey Card that has the same function as the pink card) are members of religious orders, inmates of charitable institutions, certain grades of employees in the Health Division, certain grades of employees in the police and armed forces, prisoners, and persons injured on government duty.

4.8.20.2 The availability of Alzheimer treatments

All four anti-dementia drugs are available to patients in Malta. Alzheimer's disease is not on the list of covered diseases (schedule V) and anti-dementia drugs thus need to be funded through out-of-pocket payments. Prescriptions can be effected both by specialists and family doctors.

	Donepezil	Rivastigmine	Galantamine	Memantine
Reimbursement	No	No	No	No
Initial treatment decision	N/A	N/A	N/A	N/A
Continuing treatment decision	N/A	N/A	N/A	N/A
Required examinations	None	None	None	None
MMSE limits	N/A	N/A	N/A	N/A
People living alone	N/A	N/A	N/A	N/A
People in nursing homes	N/A	N/A	N/A	N/A

4.8.21 Availability of anti-dementia drugs in the Netherlands

4.8.21.1 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 as a huge change in the system. Hospital and GP care, drugs and other short term care is 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.

[40] Health Division: Free medicinals. Accessed 1st September 2006 from www.sahha.gov.mt

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. [41]

4.8.21.2 The availability of Alzheimer treatments

With the exception of donepezil, anti-dementia drugs are available in the Netherlands and are part of the reimbursement system. Since these drugs are on annex 2 of the positive list, certain criteria need to be fulfilled prior to reimbursement. Only specialist doctors can initiate and continue treatment and the reimbursement system provides a clear diagnosis and treatment protocol.

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, the Dutch Alzheimer's organisation 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.

	Donepezil	Rivastigmine	Galantamine	Memantine
Reimbursement	No	Yes	Yes	Yes
Initial treatment decision	N/A	Specialist doctors	Specialist doctors	Specialist doctors
Continuing treatment decision	N/A	Specialist doctors	Specialist doctors	Specialist doctors
Required examinations	N/A	Diagnostic protocol	Diagnostic protocol	Diagnostic protocol
MMSE limits	N/A	26-10	26-10	14-3
People living alone	N/A	No restrictions	No restrictions	No restrictions
People in nursing homes	N/A	No restrictions	No restrictions	No restrictions

4.8.22 Availability of anti-dementia drugs in Norway

4.8.22.1 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. € 200).

For drugs on the important medicines list, patients are required to pay 36% of the cost. This only applies to the cost of drugs up to a ceiling of NOK 500 (approx. € 63) for a three months period. Costs over that ceiling are fully covered by the reimbursement system and no costs are incurred by

[41] Martikainen J, Rajaniemi S. Drug reimbursement systems in EU MemberStates, Iceland and Norway. Helsinki: The Social Insurance Institution, Finland, Social security and health reports 54, 2002. 130 pp. ISBN 951-669-612-0.

the patient. Similarly, pensioners in receipt of a minimum pension do not need to pay cost-sharing charges for important medicines.[42]

4.8.22.2 The availability of Alzheimer treatments

All four anti-dementia drugs are available to patients in Norway, but 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.

Norway does not limit the prescription of anti-dementia 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.

	Donepezil	Rivastigmine	Galantamine	Memantine
Reimbursement	Yes	Yes	Yes	No
Initial treatment decision	No restrictions	No restrictions	No restrictions	N/A
Continuing treatment decision	No restrictions	No restrictions	No restrictions	N/A
Required examinations	MMSE	MMSE	MMSE	N/A
MMSE limits	> 12	> 12	> 12	N/A
People living alone	No restrictions	No restrictions	No restrictions	N/A
People in nursing homes	No restrictions	No restrictions	No restrictions	N/A

4.8.23 Availability of anti-dementia drugs in Poland

4.8.23.1 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 up to a maximum of 0.5% of lowest salary,
- For special additional medicines, patients pay 30% or 50% of the cost,
- For all other medicines, patients pay the totality of the cost.

Hospital medicines are free of charge.[43]

4.8.23.2 The availability of Alzheimer treatments

In Poland, all anti-dementia 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 reimbursements is limited to those generic versions.

Treatment with acetylcholintesterase inhibitors is for people with MMSE scores between 26 and 10 and memantine for MMSE scores below 14.

[42] European Commission (2006): 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

[43] European Commission (2006): 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

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.

	Donepezil	Rivastigmine	Galantamine	Memantine
Reimbursement	Yes	Yes	No	No
Initial treatment decision	No restrictions	No restrictions	N/A	N/A
Continuing treatment decision	No restrictions	No restrictions	N/A	N/A
Required examinations	MMSE	MMSE	N/A	N/A
MMSE limits	26-10	26-10	N/A	N/A
People living alone	No restrictions	No restrictions	N/A	N/A
People in nursing homes	No restrictions	No restrictions	N/A	N/A

4.8.24 Availability of anti-dementia drugs in Portugal

4.8.24.1 The availability of medicines in general

The Portuguese system provides five different levels of participation of patients in the cost of medicines. Depending on the situations[44], the state contributes, 100% (only in very special situations defined by a Health Minister decree, when the drugs are indispensable to sustain life), 95% (level A) 70% (level B), 40% (level C) or 20% (level D) of the cost of medicines, and patients or carers are only required to pay the remaining costs. The degree of contributions is fixed in several official lists drawn up by the health services.

The contributions by the state can be increased by 10% for generic medicines and by 5%, in the level A (95%) and in the levels B, C and D by 15%, for pensioners whose annual total income is less than 14 times the minimum wage.[45]

4.8.24.2 The availability of Alzheimer treatments

All four anti-dementia drugs are available to patients in Portugal and are part of the reimbursement system. They are classified as level C drugs and the State covers 40% of their costs.

Portugal limits both initial and continuing treatment decisions to neurologists and psychiatrists. It does not require any specific diagnostic examinations to be carried out, nor does the system provide upper or lower treatment limits.

Finally, the Portuguese system reimburses medicines for people living alone or in nursing homes.

	Donepezil	Rivastigmine	Galantamine	Memantine
Reimbursement	Yes	Yes	Yes	Yes
Initial treatment decision	Specialist doctors	Specialist doctors	Specialist doctors	Specialist doctors
Continuing treatment decision	Specialist doctors	Specialist doctors	Specialist doctors	Specialist doctors
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

[44] Infarmed (National Pharmacy and Medicines Institute) has no general criteria to decide the level of reimbursement of any drug. There are diseases whose drugs (specific or not) are all totally reimbursed. Usually they follow a cost/benefit evaluation. A drug can be excluded from the reimbursement system based on its excessive cost. Infarmed has a large discretionary power in this matter.

[45] European Commission (2006): 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

4.8.25 Availability of anti-dementia drugs in Romania

4.8.25.1 The availability of medicines in general

A positive list of medicines to be reimbursed is compiled annually by the Ministry of Health and the National Health Insurance. This list determines which prescription drugs are covered by health insurance funds. The list is based on recommendations from the College of Physicians and the College of Pharmacists.

The reimbursement list applies to inpatients and outpatients. In fact, there are two lists: one containing substances that are 100% reimbursable for people suffering from one or more of a list of diseases (cancer, tuberculosis, diabetes, etc.); the other containing other substances on which the reference price system is applied and of which 70% of the reference price is reimbursed.[46]

4.8.25.2 The availability of Alzheimer treatments

With the exception of galantamine, all other anti-dementia 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.

Treatment initiation and treatment continuation are restricted to specialists only (neurologists, psychiatrists or old age psychiatrists). 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 (neuropsychological tests, CT or MRI scans and laboratory tests). For Alzheimer medicines to be reimbursed, these tests need to be carried out and included in a medical report.

Until recently, the system did not prescribe any upper or lower treatment limits, 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 12.

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

	Donepezil	Rivastigmine	Galantamine	Memantine
Reimbursement	Yes	Yes	No	Yes
Initial treatment decision	Specialist doctors	Specialist doctors	N/A	Specialist doctors
Continuing treatment decision	Specialist doctors	Specialist doctors	N/A	Specialist doctors
Required examinations	Diagnostic protocol	Diagnostic protocol	N/A	Diagnostic protocol
MMSE limits	Over 12	Over 12	N/A	Over 12
People living alone	No restrictions	No restrictions	N/A	No restrictions
People in nursing homes	No restrictions	No restrictions	N/A	No restrictions

[46] WHO, Pharmaceuticals in Romania, accessed September 2006: Http://www.who.dk/pharmaceuticals/Topics/Overview/20020414_8

4.8.26 Availability of anti-dementia drugs in Slovakia

4.8.26.1 The availability of medicines in general

In Slovakia, medicines are included in a list specifying whether patients being prescribed these medicines are fully or partially refunded for their costs. The Slovak system does not differentiate between different groups of people based on age or income.[47]

4.8.26.2 The availability of Alzheimer treatments

All four anti-dementia drugs are available in Slovakia and 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. Patients with MMSE scores between 24 and 13 can receive one of the four anti-dementia drugs. Unlike most other European countries, memantine is thus available for people with mild to moderate Alzheimer's disease and not for severe Alzheimer's disease.

There are no restrictions for people living alone or in nursing homes.

	Donepezil	Rivastigmine	Galantamine	Memantine
Reimbursement	Yes	Yes	Yes	Yes
Initial treatment decision	Specialist doctors	Specialist doctors	Specialist doctors	Specialist doctors
Continuing treatment decision	Specialist doctors	Specialist doctors	Specialist doctors	Specialist doctors
Required examinations	MMSE	MMSE	MMSE	MMSE
MMSE limits	24-13	24-13	24-13	24-13
People living alone	No restrictions	No restrictions	No restrictions	No restrictions
People in nursing homes	No restrictions	No restrictions	No restrictions	No restrictions

4.8.27 Availability of anti-dementia drugs in Slovenia

4.8.27.1 The availability in medicines in general

The Slovenian system has three lists of medicines, a positive, an interim and a negative list.

Medicines on the positive list are reimbursed at a level of 75%, those on the interim list at a level of 25% and medicines on the negative list need to be paid for entirely by patients themselves.

Drugs used during hospital treatment and drugs for children, mental disorders and some other diseases are free of charge.

According to the Slovenian Alzheimer's society, the vast majority of people (more than 90 %) pay an additional voluntary insurance (€20,7 monthly) which covers several medical costs. Amongst other things, this voluntary insurance guarantees 100 % reimbursement for medicines on the positive and interim lists.

4.8.27.2 The availability of Alzheimer treatments

All four anti-dementia drugs are available to patients in Slovenia and all four are on the interim list and available for reimbursement.

In Slovenia, the initial prescription of anti-dementia drugs can only be done by a specialist doctor (psychiatrist or neurologist), whereas there are no restrictions for continuing treatment decisions.

[47] European Commission (2006): 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 diagnosis of Alzheimer's disease and an MMSE score between 10 and 26 are requirements for the reimbursement of any of the anti-dementia drugs. Nevertheless, the Slovenian Alzheimer association also explains that for patients with an MMSE over 26, reimbursement is possible if further more extensive neuropsychological tests show cognitive decline of a patient consistent with Alzheimer's disease. The Slovenian system reimburses medicines for people living alone or in nursing homes.

Unlike most other European countries, memantine is available for people with mild to moderate Alzheimer's disease, but not for severe Alzheimer's disease.

	Donepezil	Rivastigmine	Galantamine	Memantine
Reimbursement	Yes	Yes	Yes	Yes
Initial treatment decision	Specialists	Specialists	Specialists	Specialists
Continuing treatment decision	No restrictions	No restrictions	No restrictions	No restrictions
Required examinations	MMSE	MMSE	MMSE	MMSE
MMSE limits	10-26	10-26	10-26	10-26
People living alone	No restrictions	No restrictions	No restrictions	No restrictions
People in nursing homes	No restrictions	No restrictions	No restrictions	No restrictions

4.8.28 Availability of anti-dementia drugs in SPain

4.8.28.1 The availability of medicines in general

Medicines are free of charge for hospital treatment, persons over 65 years of age with insufficient means of victims, as well as for victims of employment injuries and occupational diseases.

Otherwise, patients need to contribute 40 % of the price of medicines or 10% for certain special medicines with a maximum limit of € 2.64.[48]

4.8.28.2 The availability of Alzheimer treatments

All four anti-dementia drugs are available in Spain and 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.

	Donepezil	Rivastigmine	Galantamine	Memantine
Reimbursement	Yes	Yes	Yes	Yes
Initial treatment decision	Specialist doctors	Specialist doctors	Specialist doctors	Specialist doctors
Continuing treatment decision	Specialist doctors	Specialist doctors	Specialist doctors	Specialist doctors
Required examinations	MMSE	MMSE	MMSE	MMSE
MMSE limits	Below 23	Below 23	Below 23	Below 17
People living alone	No restrictions	No restrictions	No restrictions	No restrictions
People in nursing homes	No restrictions	No restrictions	No restrictions	No restrictions

[48] European Commission (2006): 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

4.8.29 Availability of anti-dementia drugs in Sweden

4.8.29.1 The availability of medicines in general

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

- If the expenditure does not exceed SEK 900 (approx. € 63), the patient covers 100% of the drug costs.
- For expenditure between SEK 901 and SEK 1,700 (approx. € 181), the patient covers 50% of the costs.
- For expenditure between SEK 1,701 and SEK 3,300 (approx. € 351), the patient covers 25% of the costs.
- For expenditure between SEK 3,301 and SEK 4,300 (approx. € 458), the patient covers 10% of the costs.
- Costs above SEK 4,300 are totally covered by the healthcare system.[49]

4.8.29.2 The availability of Alzheimer treatments

All four anti-dementia drugs are available in Spain and 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. Alzheimer Europe was unable to obtain information on the MMSE limits for the reimbursement of the four medicines in question.

There are no restrictions for people living alone or in nursing homes.

	Donepezil	Rivastigmine	Galantamine	Memantine
Reimbursement	Yes	Yes	Yes	Yes
Initial treatment decision	Specialist doctors	Specialist doctors	Specialist doctors	Specialist doctors
Continuing treatment decision	Specialist doctors	Specialist doctors	Specialist doctors	Specialist doctors
Required examinations	MMSE	MMSE	MMSE	MMSE
MMSE limits				
People living alone	No restrictions	No restrictions	No restrictions	No restrictions
People in nursing homes	No restrictions	No restrictions	No restrictions	No restrictions

4.8.30 Availability of anti-dementia drugs in Switzerland

4.8.30.1 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. [50]

4.8.30.2 The availability of Alzheimer treatments

All four anti-dementia drugs are available in Switzerland and 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

[49] European Commission (2006): 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

[50] WHO, Pharmaceuticals in Switzerland, accessed September 2006: Http://www.who.dk/pharmaceuticals/Topics/Overview/20020414_8

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.

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

	Donepezil	Rivastigmine	Galantamine	Memantine
Reimbursement	Yes	Yes	Yes	Yes
Initial treatment decision	No restrictions	No restrictions	No restrictions	No restrictions
Continuing treatment decision	No restrictions	No restrictions	No restrictions	No restrictions
Required examinations	MMSE	MMSE	MMSE	MMSE
MMSE limits	>10	>10	>10	>3
People living alone	No restrictions	No restrictions	No restrictions	No restrictions
People in nursing homes	No restrictions	No restrictions	No restrictions	No restrictions

4.8.31 Availability of anti-dementia drugs in Turkey

4.8.31.1 The availability of medicines in general

The majority (about 75 percent) of drug purchases throughout the country are reimbursable through public sector agencies such as the Pension Fund, and the Social Insurance Agency. [51]

4.8.31.2 The availability of Alzheimer treatments

All four anti-dementia drugs are available in Turkey and 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.

Finally, there are no restrictions for the reimbursement of people living alone or in nursing homes.

	Donepezil	Rivastigmine	Galantamine	Memantine
Reimbursement	Yes	Yes	Yes	Yes
Initial treatment decision	Specialist doctors	Specialist doctors	Specialist doctors	Specialist doctors
Continuing treatment decision	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

4.8.32 Availability of anti-dementia drugs in the United Kingdom

4.8.32.1 The availability of medicines in general

Free prescriptions are generally available to children under the age of 16 (25 in Wales), people aged 16 to 19 but still in full education (England and Scotland only), people over the age of 60, pregnant women and women who have given birth in the last 12 months as well as people and their partners receiving income support.

Nevertheless, since primary care trusts have budgetary control over health care expenditure in their area, this entitles them to make decisions on which medicines will be available to patients free of charge in their area. It is therefore not always possible to provide general information as to which medicines are free of charge to patients throughout the United Kingdom. For some

[51] WHO, Pharmaceuticals in Turkey, accessed September 2006: Http://www.who.dk/pharmaceuticals/Topics/Overview/20020414_8

treatments, the National Institute for Health and Clinical Excellence may provide guidance documents which are widely followed by primary care trusts throughout the United Kingdom.

Under the devolved government arrangements for Scotland, NHS Quality Improvement Scotland does not reassess the evidence used in NICE guidance documents, but only seeks to identify contextual differences between England/Wales and Scotland. Hence NICE recommendations if approved for England and Wales are often also implemented in Scotland.

4.8.32.2 The availability of Alzheimer treatments

All anti-dementia drugs are available in the United Kingdom and individual health care trusts may make them available to patients free of charge.

In its guidance of January 2001, the National Institute for Health and Clinical Excellence (NICE) made recommendations for the use of donepezil, rivastigmine and galantamine and recommended that they be made available under the National Health System under certain conditions:

- A diagnosis of Alzheimer's disease should be done in specialist centres and NICE provides a list of examinations that should be carried out,
- Treatment initiation should be recommended by specialist doctors only and treatment continuation decisions should only be done by general practitioners under shared care protocols,
- NICE does not recommend the use of acetylcholinesterase inhibitors for people with an MMSE score inferior to 12.

As for memantine, the Scottish Medicines Consortium rejected the wider use of memantine through the NHS in Scotland. The NICE recommendations were published before memantine became available in the United Kingdom and the recommendations do therefore not cover this product.

The review of these guidelines was still in process as this publication went to press.[52]

United Kingdom[53]	Donepezil	Rivastigmine	Galantamine	Memantine
NICE reimbursement recommendation	Yes	Yes	Yes	No
Initial treatment decision	Specialist doctors	Specialist doctors	Specialist doctors	N/A
Continuing treatment decision	Specialists or GPs under shared care protocols	Specialists or GPs under shared care protocols	Specialists or GPs under shared care protocols	N/A
Required examinations	Diagnostic protocol	Diagnostic protocol	Diagnostic protocol	N/A
MMSE limits	Over 12	Over 12	Over 12	N/A
People living alone	No restrictions	No restrictions	No restrictions	N/A
People in nursing homes	No restrictions	No restrictions	No restrictions	No restrictions

[52] Please refer to the position of Alzheimer Europe on the availability of anti-dementia drugs in this publication for further information on this review process.

[53] The information contained in this table is based on the guidance document of the National Institute for Health and Clinical Excellence. Individual primary care trusts may have different rules in place to the ones in this table.

5 WP5 - Diagnosis and treatment

5.1 Progress report

5.1.1 Background:

Clinical practice guidelines are being used in many countries throughout the world to improve quality of patient care. There is a need for a common, valid and transparent approach to develop good clinical practice guidelines. The project aims to identify diagnostic instruments and guidelines for treatments for dementia used in countries within the EU in order to develop truly European and multi-disciplinary guidelines. Existing guidelines will be compared with the comparative reports on treatment and diagnosis and used to develop possible consensus guidelines.

5.1.2 Objectives:

In year one our objectives were twofold: firstly, to set the parameters: our audience, what exactly we are covering, how we collect data and how we analyse them. Secondly, to develop search strategies for PubMed and EMBASE and to develop a bibliographic databases of guidelines.

5.1.3 Research methodology:

Important issues were discussed at our WP meetings held over the past year:

1. ***Who is our audience?***

For diagnosis as well as treatment we agreed to focus on clinicians.

2. ***What diseases are included under 'dementia'?***

We debated this on several occasions and agreed we should cover Alzheimer's disease (include Down's Syndrome), Vascular dementia, Dementia in Parkinson's disease, Dementia with Lewy Bodies, Mild Cognitive Impairment, Frontotemporal Dementia and (after discussion with main group) treatment of alcohol related dementia. We will look at all severities. We agreed that the WP looking at 'Prevention' would deal with prevention of alcohol related dementia, and we that would deal with treatment of mild cognitive impairment. Reversible dementias are also excluded.

3. ***What treatments are included in our WP?***

Treatment should be anything that gets into the bloodstream. Our remit does not include wider management such as Driving, finances, capacity etc. However we will also consider nutritional treatments for people with dementia (including tube feeding).

4. ***How far back should we look for guidelines and what geographical areas should we cover?***

We decided that only literature from after 2000 should be included and that we should look at all existing guidelines (the whole world)

5. ***Criteria for including and excluding guidelines?***

The first part of the project is to collate a database of existing guidelines. The data to be collected about each guideline, and recorded in database is to be based on the AGREE schedule for assessment of guidelines. An AGREE score is to be recorded for each guideline (AGREE stands for

"Appraisal of Guidelines Research and Evaluation". It originates from an international collaboration of researchers and policy makers who work together to improve the quality and effectiveness of clinical practice guidelines by establishing a shared framework for their development, reporting and assessment (see: http://www.agreecollaboration.org/intro/).

Guidelines to be included

1. Nationality
    a. European
    b. Non-European (English language only)
2. Organization
    a. Government
    b. Professional
    c. Voluntary sector
    d. Commercial? Guidelines which are for insurance purposes only are not to be included
3. Currency – since 2000 or last guidelines (European countries only).
    a. Current
    b. Superceded – ignore these
    c. In development – do not ignore these if there is something concrete to review. But keep distinct in the database.

6. *Method for development of database*

i. Search strategies should be developed for PubMed and EMBASE
ii. Contact persons in each European country will be asked to provide information about their national guidelines on diagnosis and treatment of dementia
iii. a Quorum checklist and flow chart (see: http://www.consort-statement.org/QUOROM.pdf) will be provided so that readers can examine the destination of included and excluded guidelines.

5.1.4 Results:

We have set the parameters within which the research for this work package will be carried out. We have developed preliminary[54] search strategies for PubMed and EMBASE, ran the searches and created a bibliographic databases of guidelines which will form the basis for next year's research: to use the AGREE structure for assessing these guidelines, to report on their strengths and weaknesses, recommend the strong ones, and draw up a composite guideline based on the strongest aspects of each and to define the structure of the consensus guideline we will develop.

5.2 Appendix 1: Minutes of the meeting held in Luxemburg on 25-26 February 2005

Present: Mario Fioravanti, Brigitte Grass-Kapanke, Dymphna Hermans, Rupert McShane

Absent: Peter Tariska and Philip Scheltens

Rupert welcomed everybody and introductions were made.

The first milestone in WP2 is month 2 when discussion regarding the **research methodology** should be finalized. Obviously, as contracts have not been signed yet, no progress has been made with this at all. We decided it would be important to try to make a start with this during our stay in

[54] As the first part of the grant was not paid until the end of October 2006 we were unfortunately not able to appoint the research officer to work on developing these strategies during the year as has been planned. We hope to appoint this officer in the next two weeks.

Luxemburg. Other issues Rupert thought we should discuss at this stage were structure of communications and conflict resolution.

Conflict resolution could be done using the DELPHI model but as this is in fact part of the Alzheimer Europe's WP (D3 – Internal rules for conflict resolution, risk management and financial administration and reporting) which should be delivered in month 6, it was decided to leave that for now and see what has happened on that at the meeting in Paris at the beginning of July (only WP leaders will be expected to attend that meeting).

Rupert: to ensure that this gets discussed at the Paris meeting

Communications: it was decided that it will be valuable to have regular teleconferences with all members of WP5. Skype provides free telecommunications via computers and we agreed it would be ideal if all members could set up Skype on their computers.

Dymphna: to inform all WP members on where to find Skype, how to download it and set it up; also to send out reminders regarding teleconferences

Dymphna and Mario: to test Skype between them by end of March 2006

The first test round will take place on Wednesday 5 April at 12.00h UK time/13.00h Europe time; the call will be organized by Dymphna from Oxford.

The first WP5 teleconference will take place on Wednesday 24 May at 12.00h UK time/13.00h Europe time; the call will be organized by Dymphna from Oxford.

A call for agenda items will be sent out by Dymphna in early May; the agenda and associated papers will be send out a week before the teleconference.

Research methodology: we discussed a number of issues.

Who is our audience?

For diagnosis as well as treatment it was thought that we should focus on clinicians.

What diseases are included under 'dementia'

We should cover AD, VD, PDD, DLB, MCI, FTD and (after discussion with main group) alcohol related dementia. However, we agreed that the WP looking at 'Prevention' would deal with alcohol, and we would deal with treatment of 'MCI'.

What treatments are included in our WP?

Treatment should be anything that gets into the bloodstream.

How far back should we look for guidelines and what geographical areas should we cover

We decided that only literature from the last 5 years should be included and that we should look at all existing guidelines (the whole world)

It was decided that it would be highly desirable to have a **draft/template consensus guideline** ready for both diagnosis and treatment for discussion at the Paris meeting in early July. Even if this has to undergo subsequent changes it will be very useful to have a framework to work to.

Rupert: to develop draft consensus guideline and circulate to WP5 members for discussion at the 24 May teleconference

We looked at a few guidelines in detail to get some idea of the kinds of information we would want to extract and put in our guidelines database.

- Looking at the Scottish BPSD guidelines for example we noted that it will be useful to record the date of the guideline, the date of the next update, level of evidence and grade of recommendation.
- Other fields that were flagged up looking at several other guidelines:
    - Contact details
    - Channel for comments and criticisms
    - People involved/panel selection
    - Development process of guidelines
    - Type of intervention
    - Remit of guideline/mission statement
    - What treatments
    - Do treatment guidelines decide on other issues like consent
    - Does it have a recommendation section
    - Method of generating guidelines (e.g. systematic review)
    - Does it have a summary table
    - Who initiated guideline
    - Statement of method of creating consensus
    - Practice recommendation of a diagnosis (distinction between dementia and sub etiologies?
    - Sensitivity &specificity section?
    - Accuracy and laboratory testing
    - Screening/types of investigations you do
    - Diagnosis communication – how is it done
    - Anything on driving?
    - Anything on financial matters?
    - Capacity for treatment decisions (advanced directives)
    - Structure of services (team work)
    - Evidence base (type of searches and information sources
    - Quorum approach?
    - Evidence tables?

No decision was taken as to how to develop this further for the moment.

The next face to face meeting of WP5 (and all other work packages) will be in Brussels on 14-15-16 November (dates to be confirmed by Jean George)

5.3 Appendix 2: Minutes of EUROCODE WP5 meeting in Brussels 06.11.06

Present: Rupert McShane, Brigitte Grass-Kapanke, Peter Tariska, and Sigurd Sparr

Apologies: Dymphna Hermans, Philip Scheltens, Mario Fioravanti

The main work was to

- define what guidelines should be included and excluded
- define the data items to be collected in the database of guidelines
- define the structure of the document/guideline we are to produce
- identify possible barriers to successful delivery

As well as general discussion, we each considered a separate guideline as a way of helping us to identify issues we would need to address. The texts we looked at were:

- Italian guideline
- SIGN guideline on BPSD
- ANA Practice parameter on vascular
- Canadian guideline on stroke

The next WP5 meeting is 26th February in Brussels

We agreed this would be preceded by an email in mid January (12th), reporting progress on

- List of guideline
- Preliminary database fields
- Recruitment of research worker

and a teleconference shortly after that (date to be arranged).

A draft report on the database is required for presentation at the Steering Group (WP leaders only) in Lisbon on 8th May.

5.3.1 Summary of conclusions

5.3.1.1 Database of guidelines

The first part of the project is to collate a database of existing guidelines. The data to be collected about each guideline, and recorded in database is to be based on the AGREE schedule for assessment of guidelines. An AGREE score is to be recorded for each guideline.

5.3.1.2 Guidelines to be included

1. Nationality
    - European
    - Non-European (English language only)
    - International = English language
2. Organization
    - Government
    - Professional
    - Voluntary sector
    - Commercial? Guidelines which are for insurance purposes only are not to be included
3. Currency – since 1995 or last one (European countries only).
    - Current
    - Superceded – ignore these
    - In development – do not ignore these if there is something concrete to review. But keep distinct in the database.
4. List of diagnoses covered
    - AD (include Downs),
    - VD,
    - PDD,DLB
    - Dementia NOS
    - MCI
    - Reversible dementias exclusion
5. Treatments to be covered
    - Anything which gets into the blood stream
    - Our remit does not include wider management such as Driving, finances, capacity etc

6. Populations
    - MCI
    - Mild
    - Moderate
    - Severe
7. Method for development of database
    - Systematic review of literature
        i. Search strategy reported
        ii. What sort of literature: Published literature or beyond
        iii. QUORUM data will be reported
    - Evidence rated according to quality using AGREE

5.3.1.3 Diagnosis-specific issues to be recorded in database

Considers definition of dementia

Considers definition of MCI

Educational bias issue

Distinguishes screening and diagnosis separately

Differentiation from normal and differential diagnosis

Data on specificities, sensitivities and accuracy are reported

Guidance on delivery of diagnosis included

Incremental benefit

History, Examination, Investigations

This is as far as we got. It is recognized that this is a very partial list of the issues relating to diagnosis that we would expect to be covered in the ideal guideline.

Overall objective specifically described:

Clinical questions covered specifically described

Health benefits, side-effects and risks have been considered in formulating the recommendations

Explicit link between recommendations and supporting evidence

5.3.1.4 Treatment-specific issues

Side effects and treatment effects

Effects on major domains as per Cochrane reviews

- Global,
- Cognition,
- ADL,
- Behaviour,
- QOL,
- Pharmacoeconomics

5.3.2 Summary/composite meta-guideline

We acknowledged that it would be counterproductive, impossible and outside our remit to replicate the literature reviews that have already been done in developing existing guidelines. Our aim is to construct a database of existing guidelines, report on their strengths and weaknesses, recommend

the strong ones, and draw up a composite guideline based on the strongest aspects of each. The risk of plagiarism and copyright issues needs to be addressed by AE.

The AGREE structure for assessing guidelines is to be the frame for assessing others, and defining the structure of our own.

5.3.2.1 Proposed structure of the meta-guideline we will produce:

1. EUROCODE Meta-data
    a. Provenance
        i. EUROCODE
            1. AE
            2. Panel selection : Not formal representative, but designed to include wide variety of interested parties, including associations, professions, nationalities
    b. Process
        i. Statement of method of developing consensus on AGREE score, and description in database
            - 2 per paper: worker+group member.
            - Consensus discussion between the two
            - Disagreements come to the group. Consensus
            - EUROCODE
            - ?external experts for opinion especially where lack of consensus within 5 ?process for selection of these.
        ii. Channel for comments and criticisms
            1. ?AE web site
        iii. Revision - mechanism

    c. Definition
        i. Audience
            1. Comprehensible to lay audience
                a. lay summary
                b. Ask AE about mechanism and timing of lay review of guideline
            2. Clinicians
                a. Psychiatrists, Geriatricians, Neurologists, Psychologists, Specialists nurses
                b. GPs
                    i. Screening – details of accuracy
                    ii. When to refer
        ii. Population
2. The database
3. Which guidelines do we recommend?
    - Diagnosis
        - Research
        - Clinical
        - Epidemiology / Screening
    - Treatment
    - Weblinks?
3. The précis of recommendations we draw from our recommended guidelines
    a. Clinical Question Statement
        i. Diagnostic criteria reliable?
        ii. Accurate for differential diagnosis
            1. Neuropsych differentiation
            2. Commentary: Special tests for special circumstances
                a. Language/culture-free tests
                b. Downs
        iii. Do lab tests improve accuracy
            1. Structural
            2. Quantitative structural
            3. Functional
            4. CSF

5. Genetic biomarkers

iv. Comorbidities to be evaluated at initial assessment eg
1. Depression
2. B12, folate, syphilis

4. Treatment
a. Dementia NOS
b. MCI
c. AD
d. VD
e. PDD/DLB

5.4 Appendix 3: Search strategies for PUBMED and EMBASE

5.4.1 PUBMED

(((consensus NEAR AND (statement* OR conference* OR panel* OR report*)) OR (consensus[Title/Abstract] AND NEAR AND (expert*[Title/Abstract] OR team[Title/Abstract])) OR (guideline[pt]) OR ("health planning guidelines"[mh]) OR ("consensus development conference"[pt]) OR ("consensus development conferences"[mh]) OR (guidelines[mh]) OR ("practice guidelines"[mh]) OR (consensus[ti] AND statement[ti])) AND (("dementia"[MeSH Terms] OR dementia[Text Word]) OR ("alzheimer disease"[All Fields] OR "alzheimer disease"[MeSH Terms] OR alzheimer[Text Word]))) AND "last 5 year"[dp]

5.4.2 EMBASE

1	exp "diagnosis, measurement and analysis"/ or exp therapy/ or exp "general and miscellaneous procedures and techniques"/ or exp practice guideline/
2	(dementia or alzheimer$).mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer name]
3	1 and 2
4	*practice guideline/
5	2 and 4
6	from 5 keep 1-74

5.5 Appendix 4: Reference List - PUBMED and EMBASE search for diagnosis and treatment guidelines since 2000 - January 2007

9. AAN. Guidelines abstracted from the American Academy of Neurology's Dementia Guidelines for Early Detection, Diagnosis, and Management of Dementia. J Am Geriatr Soc. 2003: 51, 6: 869-73.
10. AGS Clinical Practice Committee (2003) **=AAN 2003**. Guidelines Abstracted from the American Academy of Neurology's Dementia Guidelines for Early Detection, Diagnosis and Management of Dementia. J Am Geriatr Soc. 2003: 51, 6: 869-73.
11. Alexopoulos GS, Streim J, Carpenter D, Docherty JP. Using antipsychotic agents in older patients. J Clin Psychiatry. 2004: 65 Suppl 2, 5-99; discussion 100-102; quiz 103-4.
12. American Psychological AssociationPresidential Task Force on the Assessment of Age-Consistent Memory Decline and Dementia **=APA 1998**. Guidelines for the evaluation of dementia and age-related cognitive decline. Washington, DC: American Psychological Association. 1998.
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6 WP 6 – Psycho-social interventions

6.1 Introduction

While pharmacological treatments undergo strict double-blind placebo-controlled studies, the same is very often not the case for the various non-pharmacological or psychosocial interventions used with people with dementia and their carers. Therefore, the aim of this project is to identify the available controlled studies on psychosocial interventions and consensus recommendations in order to develop European guidelines for the use of psychosocial interventions in dementia care. The building blocks of the guidelines are: a) a review of reviews on the effects of psychosocial interventions and b) an inventory on recommendations for psychosocial interventions included in dementia guidelines across Europe.

Based on these results a consensus guideline on the use of psychosocial interventions in dementia will be developed. The development and evaluation of a set of quality indicators for psychosocial interventions in dementia will be the final aim of the project.

6.2 Workgroup members

Workgroup members are involved in the Interdem (Early detection and timely intervention in dementia) network. A multi–professional network of gerontological research-practitioners who focus on psychosocial approaches to the early recognition and intervention in dementia, throughout Europe. Workgroup members are:

Dr Myrra Vernooij-Dassen	Medical Sociologist, Director Alzheimer Centre Radboud University Medical Centre Nijmegen, The Netherlands (work package leader)
Professor Esme Moniz-Cook	Clinical Psychologist, Director IPCRA, University of Hull, UK
Professor Robert Woods	Clinical Psychologist, Director, DSDC, University of Wales, Bangor, UK
Dr Manuel Angel Franco	Psychiatrist Director, INTRAS, Fundacion INTRAS, Spain
Inge Cantegreil-Kallen	Psychologist, Department of Geriatrics, Broca Hospital, Paris, France
Naja Skovgaard	Alzheimer Europe, Denmark
Sandrine Lavallé	Communication officer, Alzheimer Europe, Luxembourg

6.3 Development of guideline (progress)

At the first meeting the discussion focussed on research questions related to the development of guidelines and quality indicators on psychosocial interventions.

The following specific questions were formulated and methods proposed:

1. Will the guidelines be general?
   - Expert discussion.
2. What will be the structure (chapters) of the guidelines?

- Research on instructions on how to construct guidelines (AGREE etc.)
- Inventory of structure of national guidelines

3. Who is going to use the guidelines?
   - Expert decision.
4. Who are going to be the recipients of the guidelines and in which setting will the guidelines be used?
   - Expert decision
5. What interventions will be recommended?
   - Review of reviews.
6. What will be the outcomes?
   - Review of reviews
7. Are we going to prepare quality indicators?
   - Yes, iterative consensus procedure

It was agreed that the guideline should be general rather than giving specific recommendations. The guideline should be applicable to the range of psychosocial problems and interventions. This general level is new and there is no format which can be followed. There is a need for such a general guideline since systematic reviews indicated that no intervention is superior.

Rather than building a guideline for a specific category of professionals, this guideline is meant for use by all stakeholders. It should be potentially helpful for a specific patient. It can be used by professional and non-professional carers.

A general guideline considering this as a starting point should indicate:

a) patients´ and carers´ needs
b) potential interventions
c) suggestions on how to identify needs for care and to make action plans acceptable for all those involved

Perspectives of those involved should be pulled together. The needs to be considered relate to the domains of physical, psychological, social and spiritual aspects.

6.4 Building blocks of guidelines

6.4.1 Review of reviews

To gather available evidence on the effect and effectiveness of psychosocial interventions a literature search was done to identify reviews on the subject.

6.4.1.1 Search strategy

We searched for reviews in Pubmed and the Cochrane library using the following terms:

Dementia (MESH) AND psychosocial OR non-pharmacological OR intervention; limits: review.

Reviews found by using this strategy were used as a source for new references of reviews on the subject. The articles found were presented at the workgroup members and they agreed to only select systematic reviews and reviews that were available in the Cochrane library and not written before 1999. Also, they were asked to add any missing reviews they knew of meeting the selection criteria.

6.4.1.2 Results

The above described search strategy resulted in the selection of 17 reviews (appendix 1). Because some workgroup members are currently involved in writing a Cochrane review that would meet the search criteria, preliminary results will be considered in the development of the guideline. Also,

there seemed to be a lack of reviews focussing specifically on the use of psychosocial interventions in institutional care. Therefore, a review of the literature on this subject especially aiming at the communication between patients and nursing staff is currently been carried out. Preliminary results of this review will also be used in the development of the guideline.

6.4.2 Inventory guidelines on psychosocial interventions across Europe

6.4.2.1 Search for guidelines

To start the inventory the Interdem network was used to gather information on available guidelines on psychosocial interventions in dementia across Europe. Contacts in the following countries were sent an email with a request to gather guidelines on the subject: UK, Spain, the Netherlands, Belgium, France, Germany, Ireland, Italy, Portugal, Switzerland, Greece, Poland, Sweden, Austria, Denmark, Finland.

From contacts of Greece, Poland, and Austria no information was received. The information received from the other contacts was put together in a table (appendix 2) and is discussed hereafter.

6.4.2.2 Results

6.4.2.2.1 Countries with no documents/ guidelines available

In **Finland** there are guidelines on diagnosis and pharmacotherapy of Alzheimer's disease that were published in May 2006 but no documents on psychosocial approaches are available.

In **Sweden** two expert groups are working on the development of guidelines which should be published in Spring 2007. In **Belgium** also no national guidelines are available but documents/guidelines on the subject from Germany and The Netherlands are used in dementia care.

In **Denmark** the Ministry of Social Affairs published a literature review of the documented effects of caring-methods for people with dementia. The conclusion was that the various psychosocial interventions do appear to have a positive effect on people with dementia and on the different problems that often occur along with the disease. But there is no solid documentation on the effect of the methods.

6.4.2.2.2 Countries with papers/reports on psychosocial interventions available

In **France** two consensus papers exist; one was published in 2003 by ANAES which underlined that only reality orientation had some robust evidence of effectiveness and that in general the evidence level of the psychosocial interventions is very low. Another national report concerning psychosocial interventions was published in 2005 (OPEPS) for the Ministry of Health. Conclusions were similar to the ANAES report.

In **Switzerland** a consensus paper on diagnostics and therapy of Alzheimer was published (2003) by the "Forum Alzheimer Suisse". The only important information on psychosocial interventions was the recommendation to first use non-pharmacological interventions in the "treatment" of behavioural symptoms and only in a second time, if no success, to try pharmacological strategies.

In **Ireland** an "Action plan for dementia" (1999) exists, developed by the National Council on Ageing and Older People. The plan is a reflection of the views of health care professionals and

policymakers working in the area of dementia and should serve as a model of best practice for the provision and planning of services to meet the individual needs of people with dementia and their carers. Some attention is given to psychosocial interventions but no specific recommendations about their use are done.

6.4.2.2.3 Guidelines on psychosocial interventions available

In **Italy** different types of guidelines/documents on dementia are available: guidelines governing relationships between the Italian Alzheimer's Societies and pharmaceutical companies, general guidelines coordinated by medical doctors, and guidelines for treatment of Alzheimer's disease (2005). The last one is an evidence-based review article by a committee of experts from the Italian Association of Psychogeriatrics in which several psychosocial interventions are discussed.

In **Germany** the most important and recent (May 2006) guidelines on psychosocial interventions are developed by the Kuratorium Deutsche Altershilfe + das Institut für Pflegewissenschaft der Universität Witten/Herdecke for the German Ministry of Health. These guidelines only focus on institutional care. The German society for psychiatry, psychotherapy, and neurology developed guidelines for treatment of dementia and besides pharmacological treatment also propose different psychosocial interventions for different stages of dementia. Other German guidelines/documents on dementia treatment which give attention to psychosocial approaches focus on day care facilities, use of restraints, and general practitioners.

In **The Netherlands** guidelines on dementia treatment and/or care are available for medical doctors, and nursing staff. The guidelines for geriatricians focus mainly on diagnosis and pharmacological treatment and only list psychosocial interventions in the appendix. The guideline developed for general practitioners gives more attention to the psychosocial environment of dementia patients but recommendations are carefully described. For nursing staff there is a handbook on the use of Snoezelen in institutional care developed by the Netherlands institute for health services research. This institute also developed guidelines for accompanying apathic or depressed dementia patients, which is entirely focused on a psychosocial approach by nursing staff.

In the **UK** the two most important national clinical guidelines on dementia are developed by SIGN (2006) (for Scotland) and for England & Wales, the guidelines produced jointly by NICE & SCIE (2006), covering both health and social care. Both guidelines contain chapters on psychosocial interventions and give recommendations based on systematic literature searches. Several other guidelines/documents which mention the importance of the psychosocial environment and/or use of psychosocial interventions besides pharmacological treatment are available for general practitioners, social care workers, and local government.

In **Spain** also several guidelines are available. The guidelines of the Spanish Society of Familiar and Communitary Medicine (1999), the Spanish Multidisciplinary Group for the Coordinated Attention of a Patient with Dementia (2002), and the Working Group for Alzheimer's Disease and Other Dementias of Late Life (2001) give recommendations on use of psychosocial interventions in dementia care and treatment. Other guidelines/documents mention some psychosocial aspects of dementia treatment and/or care but do not give recommendations on use of specific psychosocial interventions.

6.5 Summary preliminary results

The first results of the review of reviews indicate that interventions directed at both the person with dementia and the informal carer are the most effective ones. Especially when these interventions are multi-component, address personal needs for care and help to reframe dysfunctional perceptions into more effective ones.

The inventory on dementia guidelines across Europe revealed that attention for the use of psychosocial interventions in dementia is growing in several European countries. However, only in 5 countries recommendations for psychosocial interventions have been found in dementia guidelines. This collection of effective psychosocial interventions has to find its way to routine daily practice. The next step will be to compose European guidelines based on the building blocks. The final aim will be the development of easy to use quality indicators that might stimulate the use of available effective interventions.

6.6 Annex 1 - References and conclusions/recommendations of the 17 selected reviews

1. Brodaty H, Green A, Koschera A. Meta-Analysis of Psychosocial Interventions for Caregivers of People with Dementia. JAGS 51:657–664, 2003

Programs that involve the patients and their families and are more intensive and modified to CGs' needs may be more successful. CG interventions can have effects on delaying nursing home admission, which for many is desirable. Unsuccessful interventions are short educational programs (beyond enhancement of knowledge); support groups alone, single interviews, and brief interventions or courses that were not supplemented with long-term contact do not work.

2. Chung JCC, Lai CKY. Snoezelen for dementia (Review). Cochrane Database Syst Rev. 2002;(4):CD003152

Owing to the limited data obtained from the two included RCTs, it is not feasible to draw a conclusion in this review about the efficacy of Snoezelen. Although the pooled results of the two studies did not demonstrate a signifcant result in favour of snoezelen, they independently demonstrated signifcant results in favour of snoezelen. Regarding the short-term effects, Kragt 1997's subjects presented significantly fewer behavioural problems (e.g. apathy, restlessness) during the snoezelen sessions than the control sessions. Baker 2001's subjects were more responsive to their surrounding environments immediately after the sessions.

From the practice perspective, snoezelen programmes demonstrate positive immediate outcomes in reducing maladaptive behaviours and promoting positive behaviours, suggesting that it should be considered as part of the general dementia care programme.

3. Clare L, Woods RT, Moniz Cook ED, Orrell M, Spector A. Cognitive rehabilitation and cognitive training for early-stage Alzheimer's disease and vascular dementia (Review). Cochrane Database Syst Rev. 2003;(4):CD003260.

The present findings do not provide strong support for the use of cognitive training interventions for people with early-stage AD or vascular dementia, although these findings must be viewed with caution due to the limited number of RCTs available and to the methodological limitations identified, and further well-designed trials would help to provide more definitive evidence.

Due to a complete absence of RCTs evaluating an individualised cognitive rehabilitation approach, it is not possible at present to draw conclusions about the efficacy of individualised cognitive rehabilitation interventions for people with early-stage dementia, and further research is required in this area.

4. Cooke DD, McNally MCN, Mulligan KT, Harrison MJG, Newman SP. Psychosocial interventions for caregivers of people with dementia: a systematic review. Aging & Mental Health 2001; 5(2): 120–*135*

The studies reviewed here do show that it is possible to produce consistent improvements in caregivers' knowledge of the carerecipients' illness, but knowledge appears unrelated to psychological and social outcomes. The findings of the review suggest that the inclusion of social components in interventions or a combination of social and cognitive components appears to be relatively effective in improving psychological well-being.

5. Forbes D, Morgan DG, Bangma J, Peacock S, Adamson J. Light Therapy for Managing Sleep, Behaviour, and Mood Disturbances in Dementia (Review) Cochrane Database of Systematic Reviews 2004, Issue 2. Art. No.: CD003946.

There is insufficient evidence of the efficacy of light therapy in managing sleep, behaviour, cognition or mood disturbances associated with dementia. Available studies are of poor quality.

6. Heyn P, Abreu BC, Ottenbacher KJ. The Effects of Exercise Training on Elderly Persons With Cognitive Impairment and Dementia: A Meta-Analysis. Arch Phys Med Rehabil 2004 Vol 85

Exercise training increases fitness, physical function, cognitive function, and positive behavior in people with dementia and related cognitive impairments. Exercise was associated with statistically significant positive treatment effects in older patients with dementia and cognitive impairments. The meta-analysis results suggest a medium to large treatment effect for health-related physical fitness components, and an overall medium treatment effect for combined physical, cognitive, functional, and behavioral outcomes. The results provide preliminary evidence for the effectiveness of exercise treatments for persons with dementia and related cognitive impairments.

7. Lee H, Cameron M. Respite care for people with dementia and their carers. Cochrane Database Syst Rev. 2004;(2):CD004396

Results from three randomized controlled trials provided no evidence of any benefit of respite care for people with dementia or for their caregivers for any outcome including rates of institutionalization and caregiver burden. However, a host of methodological problems in available trials were identified. Further methodo-logically sound research is needed before any firm conclusions can be drawn. No meaningful conclusions for practice can be drawn with the available evidence.

8. Livingston G, Johnston K, Katona C, Lyketsos CG. Systematic review of psychological approaches to the management of neuropsychiatric symptoms of dementia. Am J Psychiatry. 2005 Nov;162(11):1996-2021.

Behavioral management techniques centered on individual patients' behavior are generally successful for reduction of neuropsychiatric symptoms, and the effects of these interventions last for months, despite qualitative disparity. Psychoeducation intended to change caregivers' behavior is effective, especially if it is provided in individual rather than group settings, and improvements in neuropsychiatric symptoms associated with these interventions are sustained for months. We therefore recommend these types of interventions. Music therapy and Snoezelen, and possibly some types of sensory stimulation, are useful treatments for neuropsychiatric symptoms during the session but have no longer-term effects. The cost or complexity of Snoezelen for such small benefit may be a barrier to its use. Specific types of staff education lead to reductions in behavioral symptoms and use of restraints and to improved affective states. Staff education is, however, heterogeneous, although instruction for staff in communication skills and enhancement of staff members' knowledge about dementia may improve many outcomes related to neuropsychiatric symptoms. Teaching staff to use dementia-specific psychological therapies for which there is limited evidence of efficacy may not improve these outcomes.

Little evidence is available on the effectiveness of reminiscence therapy, but more positive evidence exists for cognitive stimulation therapy. Training for caregivers in behavioral management techniques had inconsistent outcomes but merits further study. The evidence for therapeutic activities is very mixed, and the study findings for these interventions are contradictory and inconclusive. Specialized dementia units were not consistently beneficial, but changing the environment visually and unlocking doors successfully reduced wandering in institutions. These promising interventions merit more study.

There is no convincing evidence that simulated presence interventions or reduced stimulation units are efficacious for neuropsychiatric symptoms. Reality orientation therapy, validation therapy, "admiral" nurses, and Montessori activities had no effect on neuropsychiatric symptoms.

9. Neal M, BartonWright P. Validation therapy for dementia. Cochrane Database of Systematic Reviews 2003, Issue 3. Art.No.: CD001394.

There is insufficient evidence from randomized trials to allow any conclusion about the efficacy of validation therapy for people with dementia or cognitive impairment.

10. Pusey H, Richards D. A systematic review of the effectiveness of psychosocial interventions for carers of people with dementia. Aging & Mental Health 2001; 5(2): 107–119

The overall methodological quality of the studies was poor, particularly with regard to sample size, and methods of random allocation. Individualized interventions that utilized problem solving and behaviour management demonstrated the best evidence of effectiveness. This approach is also closest to the effective model of psychosocial interventions currently in use with other severe and enduring illnesses.

11. Price JD, Hermans DG, Grimley Evans J. Subjective barriers to prevent wandering of cognitively impaired people. Cochrane Database Syst Rev. 2000;(4):CD001932

There is no evidence so far that subjective barriers reduce wandering, and the possibility of harm (particularly psychological distress) cannot be excluded. If used, then subjective barriers should form part of a diverse approach to problem wandering, which may include the identification and definition of the problem in the individual, preventative activities such as exercise classes or occupational therapies, and improved communication between carer and wanderer.

12. Sörensen S, Pinquart M, Duberstein P. How Effective Are Interventions With Caregivers? An Updated Meta-Analysis. The Gerontologist. 2002; 42(3): 356–372

Interventions are, on average, successful in alleviating burden and depression, increasing general subjective well-being, and increasing caregiving ability/knowledge. The majority of these effects persist after an average of 7 months postintervention. Providing psychoeducational interventions, psychotherapy, and a combination of several of these interventions, as is done in multicomponent approaches, is most effective for improving caregiver well-being in the short term.

13. Teri L, McKenzie G, LaFazia D. Psychosocial Treatment of Depression in Older Adults with Dementia.Clin Psychol Sci Prac 12: 303–316, 2005

Using multiple techniques, including behavioral skill training, communication, social engagement, and sensory and environmental stimulation in a variety of settings, including long-term care and private homes, 7 of the 11 treatments demonstrated clear improvements in depression. In 6 studies, these improvements were maintained beyond the active treatment period. Commonalities across these programs included assessment strategies, individualization of strategies, providing treatment in a one-on-one format, using multiple treatment components in a coordinated programmatic approach, and focusing on teaching caregivers to deliver treatments to the persons with dementia. Much of what caregivers were taught involved problem-solving disease difficulties and facilitating increased pleasant social interaction.

14. Thorgrimsen L, Spector A, Wiles A, Orrell M. Aroma therapy for dementia. Cochrane Database Syst Rev. 2003;(3):CD003150

Aroma therapy showed benefit on measures of agitation and neuropsychiatric symptoms for people with dementia in the only trial that contributed data to this review, but there were several

methodological difficulties with this study. More well designed large-scale RCTs are needed before conclusions can be drawn on the effectiveness of aroma therapy. Additionally, several issues need to be addressed, such as whether different aroma therapy interventions are comparable and the possibility that outcomes may vary for different types of dementia.

15. Verkaik R, van Weert JCM, Francke AL. The effects of psychosocial methods on depressed, aggressive and apathetic behaviors of people with dementia: a systematic review. Int J Geriatr Psychiatry 2005; 20: 301–314.

There is some evidence that Multi Sensory Stimulation/Snoezelen in a Multi Sensory Room reduces apathy in people in the latter phases of dementia. There is scientific evidence, although limited, that Behavior Therapy–Pleasant Events and Behavior Therapy–Problem Solving reduce depression in people with probable Alzheimer's disease who are living at home with their primary caregiver.

There is also limited evidence that Psychomotor Therapy Groups reduce aggression in a specific group of nursing home residents diagnosed with probable Alzheimer's disease. The evidence comes from a maximum of two high quality RCTs that arrive at the same positive results.

Although the evidence for the effectiveness of some psychosocial methods is stronger than for others, overall the evidence remains quite modest and further research needs to be carried out.

16. Vink AC, Birks JS, Bruinsma MS, Scholten RJS. Music therapy for people with dementia (Review). *Cochrane Database Syst Rev.2004;(3):CD003477*

The methodological quality and the reporting of the included studies were too poor to draw any useful conclusions. Despite five studies claiming a favourable effect of music therapy in reducing problems in the behavioural, social, emotional, and cognitive domains we cannot endorse these claims owing to the poor quality of the studies.

17. Woods B, Spector A, Jones C, Orrell M, Davies S. Reminiscence therapy for dementia (Review). Cochrane Database Syst Rev. 2005 Apr 18;(2):CD001120

The evidence-base for the effectiveness of reminiscence therapy continues to rest largely on descriptive and observational studies, with the few RCTs available being small, of relatively low quality and with some variation in outcome, perhaps related to the diverse forms of RT used. It is too early to provide any indication of the effectiveness of reminiscence therapy in comparison with other psychosocial interventions, such as validation therapy or music therapy.However, given its popularity with staff and participants, there is no reason not to continue with its further development and evaluation. The need for training, support and supervision for staff carrying out this work is emphasised in much of the RT literature.

6.7 Annex 2: Overview of Guidelines

Country	Title	Users	Developers	Policy driven/evidence-based
France	Maladie d'Alzheimer et ANAES: Une publication de l'ANAES: Etudes d'évaluation technologique	Professionals in dementia care	ANAES: guideline group at the Ministry of Health	Policy driven - consensus
	RAPPORT sur la maladie d'Alzheimer et les maladies apparantées (OPEPS)	Health care policy makers	Medical experts	Policy driven - consensus
Switzerland	Diagnostik und Therapie der Alzheimer Krankheit: Ein Konsensus für die Schweiz	Medical specialists and general practitioners	Alzheimer Forum Schweiz: docters, med. Specialists	Evidence based - consensus
Italy	Guidelines for the treatment of Alzheimer's disease from the Italian association of psychogeriatrics	Clinical specialist (neurologists, geriatricians, psychiatrists)	Experts from the Italian Association of Psychogeriatrics	Evidence-based
Germany	Rahmenempfehlungen zum Umgang mit herausforderndem Verhalten bei Menschen mit Demenz	Formal caregivers in institutional care	Kuratorium Deutsche Altershilfe + das Institut für Pflegewissenschaft der Universität Witten/Herdecke	Policy-driven - Experts
	Zur Betreuung Demenzkranker in Tagespflegeeinrichtungen	Professionals in dementia care	Deutschen Expertengruppe Dementenbetreuung (formal caregivers daycare)	Expert opinion-consensus
	Handlungsempfehlung zu Fixierung und freiheitsbeschränkenden Maßnahmen Demenzkranker	Professionals in dementia care	Deutschen Expertengruppe Dementenbetreuung (professionals dementia care)	Expert opinion-consensus
	Behandlungsleitlinie Demenz	Psychiatrist, psychotherapists, neurologists	German society for psychiatry, psychotherapy, and neurology	Evidence-based and expert consensus
	BDA Manuale-Demenz	General practitioners	German society for general practitioners	Clear and rapid information sheet for use in practice based on experts opinions/experiences.
Netherlands	Diagnostiek en medicamenteuze behandeling van dementie (CBO)	Geriatricians, professionals	geriatricians, professionals	Evidence-based
	Dementie (gezondheidsraad)	Minister of public health	Health council of the Netherlands	Policy driven
	NHG-standaard dementie	General practitioners	General practitioners, professionals	Evidence-based
	Richtlijnen voor verzorgenden (depressie en apathie)	Formal caregivers	Netherlands institute for health services research (NIVEL)	Evidence-based

UK	Management of patients with dementia: A national clinical guideline	Health care professionals	Scottish Intercollegiate Guidelines Network (SIGN)	Evidence-based
	Dementia: Supporting People with Dementia and their Carers	Practitioners and service commissioners	Multidisciplinary team of health and social care professionals, a person with dementia, carers, and guideline methodologists (NICE)	Evidence-based
	Guidelines for the management of agitation in dementia	Clinicians	Specialist old age psychiatrists, geriatricians, psychologists, general practitioners, and social scientists involved in the care of people with dementia in the UK and Ireland	Evidence-based
	Guidelines for the primary care management of dementia	General practitioners	North of England evidence based guidelines development project	Evidence-based
	Knowledge set for dementia	Social care workers	Skills for Care (employment interests, service users and carers and union and professional associations in social care)	National Vocational Qualifications (NVQs) based on National Occupational Standards that are statements from care employers about the best ways for care workers to do the different parts of their work
	Care Homes for Older People, National Minimal Standards	Care homes	Department of Health	Policy driven
	Modern standards and service models for older people	(local) government, people working with older people	National service framework for older people: Department of Health	Policy driven
	Everybody's business. Integrated mental health services for older adults: a service development guide	Health and social care practitioners, guide for developing/improving mental health services	Department of Health	Policy driven
Spain			Neurology Study Group on Behavior and Dementia	
			Spanish Multidisciplinary Group for the Coordinated Attention of a Patient with Dementia	
			Public Sanitary System of Andalucía	
			Working Group for Alzheimer's Disease and Other Dementias of Late Life	

			Spanish Society of Psychiatry	
			Spanish Society of Familiar and Communitary Medicine	
			Guide of quality criteria in social and sociosanitary centres: for elderly people in nursing homes	

6.8 Annex 3: Notes from working group meeting in Luxembourg (25-26 February, 2006)

Participants: Naja Skovgaard, Manuel Franco, Moniga, Esme Moniz-Cook, Sandrine Lavalle, Myrra Vernooij-Dassen. WP 6 members not present: Bob Woods, Anne-Sophie Rigaud

6.8.1 Research questions

The discussion focussed on research questions related to the development of guidelines and quality indicators on psycho-social interventions. The following questions were formulated:

- What is a psycho-social intervention?
- Will the guidelines be general or will guidelines be made for specific intervention?
- What will be the structure of the guidelines?
- Who is going to use the guidelines?
- Who are going to be the recipients of the guidelines and in which settings will the guidelines be used?
- Which interventions will be recommended?
- What will be the recommended outcomes?
- Are we going to prepare quality indicators?
- What will be the dissemination plan?

6.8.2 Methodology

The proposed methodology to address these research questions is:

1. What is a psycho-social intervention?
    a. A literature research will be done on definitions used to describe psycho-social intervention
    b. Expert discussion on description of psycho-social interventions
2. Will the guidelines be general? Expert discussion.
3. What will be the structure (chapters) of the guidelines?
    a. Research on instructions on how to construct guidelines (AGREE etc.)
    b. Inventory of structure of national guidelines
4. Who is going to use the guidelines? Expert decision.
5. Who are going to be the recipients of the guidelines and in which setting will the guidelines be used? Expert decision
6. What interventions will be recommended? Review of reviews.
7. What will be the outcomes? Review of reviews
8. Are we going to prepare quality indicators? Yes, methodology to be decided
9. What will be the dissemination plan? Yes, methodology to be decided

6.8.3 Preliminary results

- Decision: focus on general guidelines applicable to range of psycho-social interventions.
- Users of guidelines will be health care and social care workers.
- The recipients of the guidelines will be persons with dementia and their informal carers. Guidelines will be used in all settings.

6.8.4 Time schedule and division of tasks:

- A literature research on definitions used to describe psycho-social intervention: Researcher WP 6, July 2006
- Selection and study of existing guidelines. Deadline May 1 2006:
    - Naja Skovgaard: Finland, Sweden Denmark.
    - Esme Moniz-Cook: UK
    - Manuel Franco: Spain and Portugal
    - Sandrine Lavalle: France, Belgium. Network Alzheimer Europe
    - Myrra Vernooij-Dassen: The Netherlands, France

6.9 Annex 4: Notes from working group meeting in Hull (24-25 March 2006)

Participants: Manuel Franco, Esme Moniz-Cook, Bob Woods, Myrra Vernooij-Dassen

Aim of meeting: to clarify *how* to define general guidelines

It was agreed in Luxembourg that the guidelines should be general rather than giving specific recommendations. The guideline should be applicable to the range of psycho-social problems and interventions. This general level is new and there is no format which can be followed. There is a need for such a general guideline since systematic reviews indicated that no intervention is superior. Reviews suggest that psychosocial interventions should be directed at patients´ and carers´ specific problems and needs for care.

A general guideline considering this as a point of departure should indicate a) patients´ and carers´ needs; b) potential interventions; c) suggestions on how to identify needs for care and to make action plans acceptable for all those involved. Perspectives of those involved should be pulled together.

The needs to be considered relate to the domains of physical, psychological, social and spiritual aspects.

The interventions presented in the national guidelines can be judged using the indication for the level of evidence as used in Sign (see www. sign.ac.uk : guideline 86 on management of dementia patients and sign 50 on forming guideline recommendations, chapter 6 checklist).

Rather than building a guideline for a specific category of professionals, this guideline

is meant for use by all stakeholders. It should be potentially helpful for a specific patient. It can be used by professional and non-professional carers. It can empower people via the website.

The European perspective is gather and analyse guidelines in European countries and to find gaps in the availability of interventions per country.

6.10 Annex 5 : Notes from working group meeting in Paris (29 June 2006)

Participants

Bob Woods, Inge Cantegreil, Esme Moniz-Cook, Emmelyne Vasse, Rabih Chattat

Emmelyne Vasse is the researcher on this project.

6.10.1 Tasks

6.10.1.1 Guidelines

The guidelines should be gathered by the participants as agreed at the Luxembourg meeting.

The interest is the section on psychosocial interventions. This section should be translated into English, except for the German and the French guidelines.

In order to proceed the request, workpackage members are first asked to send the titles of the guidelines to Myrra Vernooij within one month and to send the translated parts before september 1.

- Selection and study of existing guidelines.
  - Naja Skovgaard: Finland, Sweden Denmark.
  - Esme Moniz-Cook: UK
  - Manuel Franco: Spain and Portugal
  - Sandrine Lavalle: France, Belgium. Network Alzheimer Europe
  - Myrra Vernooij-Dassen: The Netherlands
  - Inge Cantegreil, France and Germany

6.10.1.2 Literature reviews

Emmelyne started the literature study with a review on psychosocial interventions related to communication. The first results have been presented at the Alzheimer Europe conference. Reviews on reviews on carer and combined patient carer interventions will follow, as well as interventions aimed at staff.

Emmelyne will do a literature review on definitions of psychosocial interventions. **Esme** will send the relevant papers to Emmelyne or Myrra. (APA definition and related articles)

6.10.1.3 Theoretical models

- Reviews of theoretical models used in intervention studies. **Emmelyne**
- Selection and very short description of theoretical models used by Interdem members, to start with the Eurocode group**. All workpackage members. Submitting to Myrra before september 1.**

Suggestion made in steering group meeting to add a special chapter on methodology. The steering group also underlines the importance of cultural differences among countries,. This confirms our ambitions.

6.10.2 Cultural background

Interdem members will be asked to respond on the cultural barriers and facilitators of the interventions selected for use.

6.10.3 Methodology

The limitations of the methodology used and a critical appraisal of current methodology (randomised controlled trial) will be presented in a special chapter as well as suggestions on how to adapt the methodology for use in dementia care studies.

6.10.4 Next meeting in november

- Preparation of a list of potential articles and responsibilities
- Discusssion on results of review of reviews
- Preliminary results on guideline study

6.11 Notes of the working group meeting in Brussels (6 November 2006)

Participants present: Manuel Franco, Bob Woods, Esme Moniz-Cook, Myrra Vernooij-Dassen, Inge Cantegreil, Sandrine Lavallé, Pascale Dorenlot, Emmelyne Vasse

6.11.1 Guidelines across Europe, inventory results

All Interdem contacts across Europe were sent a request for searching guidelines on dementia in their country. Answers and/or guidelines were received from Finland, Denmark, UK, Netherlands, Germany, Belgium, France, Switzerland, Spain, Portugal, and Italy.

Pascale Dorenlot will do a last search for guidelines in Sweden, Italy, and Switzerland to complete the inventory.

The collected guidelines will be presented in a table that indicates if guidelines are policy driven or evidence-based and recommendations on psychosocial interventions will be compared with recommendations of systematic reviews.

Also, attention should be given to differences between European countries in the reimbursement of costs for implementing guidelines.

6.11.2 Theoretical models

A chapter of the final document will be dedicated to theoretical models for psychosocial interventions. Participants were asked to describe their "favourite" theoretical model in psychosocial research.

Bob Woods: Kitwood, rehabilitation concept

Esme Moniz-Cook: Stress coping adaptation models → caregivers

Pascale Dorenlot: Not every intervention has a theory behind it. Practice based evidence also important

Manuel Franco: Multicomponent/multidisciplinair approach. Individualized interventions.

Inge Cantegreil: Stress coping model → Psychotherapy after disclosure of diagnosis

Sandrine Lavallé: Importance of matching theory/model with environment of patient.

Myrra Vernooij: Family crisis/support model, Personal disease management → needs patient

6.11.3 Milestones/Quality indicators

Besides European guidelines on psychosocial interventions it would be good to also add quality indicators based on the recommendations done in the guidelines. Manuel explained his work already done on the subject. It was agreed that the guidelines as well as the indicators should be general rather than recommending specific interventions. It was suggested to use the AGREE instrument for the appraisal of the final guidelines/quality indicators.

The process of developing the quality indicators will be explained in more detail at the next meeting.

6.11.4 Review of reviews

It was agreed to only use systematic reviews for the review of reviews. A document with systematic reviews found in Pubmed and Cochrane Library was handed out. No reviews were added/missed.

The next step will be to compare recommendations done in these reviews and compare these with recommendations done in the guidelines across Europe.

Bob suggested using the same strategy as Margaret Gatz did in her review.

6.11.5 Outcomes

Besides the outcomes that will be recommended by the Interdem outcomes workgroup, it is also important to focus on social and environmental outcomes.

7 WP 7 – Prevalence rates

7.1 Background:

In the year 2000 EURODEM (EU funded) based in Erasmus Medical Centre, Rotterdam, published an excellent collaborative study of 11 population based cohorts from 8 countries looking at the prevalence of dementia in Europe. This article is highly relevant today but is based on cohorts commenced in the 1980's, does not include data from Eastern Europe and was published in a specialist scientific journal. This current project will compile a database of all European (including new member states) epidemiological studies in this field up to the present date. These studies will form the basis of a descriptive review of prevalence rates of dementia in Europe in the early 21st century and the establishment of consensual prevalence rates.

7.2 Objectives:

This project will, by means of an extensive literature search using Cochrane review methodologies, compile a database of all European epidemiological studies in this field up to the present date. These studies will be classified by research methodologies, diseases studies, age ranges used, date of the study, geographical location etc. This database will be freely accessible through the AE website and will be an invaluable tool for further collaborative epidemiological research.

These studies will form the basis of a descriptive review of prevalence rates of dementia in Europe in the early 21st century and prior to publication will be circulated for consultation to the membership at large of the network. The received feedback will be integrated into the final document. The first draft of this will be aimed at the scientific community. It will be submitted for peer review then publication in a scientific journal. This review will form the backbone of a second document aimed entirely as a means of disseminating the information to the non scientific community.

7.3 Members WP 7

E Reynish	Toulouse	Reynish.e@chu-toulouse.fr emmareynish@ednet.co.uk;
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LF represented by Barbara Caracciolo	Stockholm	Barbara.Caracciolo@ki.se
M Prince	London	m.prince@iop.kcl.ac.uk
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Andrzej Kiejna	Wroclaw	akiejna@psych.am.wroc.pl
G Salvini (Alz Association)	Italy	gsalvini@alzheimer.it;

7.4 Research methodology:

Important issues were discussed at our WP meetings held over the past year:

The search strategy was agreed as follows

- Scientific databases then bibliography of papers identified.
- Conference proceedings
- PhD Theses

- Family associations
- Partner associations
- Funding organisations

The searching of the available literature will be divided as follows:-

(Due to late arrival of the funding work on data collection by a number of partners has been delayed).-

- CHU Toulouse- UK,France,Spain, Greece, Holland, Belgium
- Karolinska Institute- Scandinavia Italy
- Technischen Universität Munich- Germany Austria Switzerland
- Medical University of Wrocław – Poland, Hungary, Czech Republic Slovakia, Baltic States (See attached Annex II Review of Epidemiology of Dementia in eastern Europe)

7.4.1 Data Collection and Databases

(See attached Annex I Data Collection)

Collection of Data will be performed in 3 specific domains:-

1. Database of European Epidemiological studies on dementia (All) (On AE website)
    i. Description of study and results
    ii. Searchable by key words
2. Database of Studies eligible for meta-analysis
    a. Inclusion Criteria:-
    b. Community based study
    c. Min sample size 300
    d. Study Date after 1990
    e. Age over 65 yrs
    f. Standardise diagnostic criteria (Dementia, AD, VaD) (certainty of diagnosis still to be decided—?probable and possible)
    g. Available raw prevalence data
    h. Participation rate over 50%
3. Early onset dementia,

During the EUROCODE Steering Committee meeting in Paris the participants agreed that the focus should be on Alzheimer's disease. Of interest to AE is also early onset dementia, as Eurodem seemed to have underestimated these figures. There were also discussions around MCI (mild cognitive impairment). The figures risk being disappointing because too vague. It was agreed that MCI was a problem and would be skipped.

7.4.2 Quality Measure of Epidemiological Studies included in the meta-analysis

It was suggested by M Prince that the group should propose a means of assessing the quality of all the epidemiological studies collected. The means of producing such a measure and its feasibility are still being discussed. M Prince envisages using Delphi concencus methods to overcome this problem for the final review document. This possibility will be discussed at length in the next workpackage meeting.

7.5 Results:

We have set the parameters within which the research for this work package will be carried out. We have developed preliminary search strategies, created a database for data collection and are assessing the feasibility of this structure to meet the objectives set out.

7.6 Bibliography

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29. Complete ascertainment of dementia in the Swedish Twin Registry: the HARMONY study Margaret Gatz Laura Fratiglioni, Boo Johansson, Stig Berg James A. Mortimer,Chandra A. Reynolds Amy Fiske, Nancy L. Pedersen, Neurobiology of Aging 26 (2005) 439–447
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31. Blood pressure and dementia in persons 75+ years old: 3-year follow-up results from the Kungsholmen Project Zhenchao Guo, Chengxuan Qiu, Matti Viitanen, Johan Fastbom, Bengt Winblad and Laura Fratiglioni∗ Journal of Alzheimer’s Disease 3 (2001) 585–591

7.7 Annex 1: Data collection

- Database of European Epidemiological studies on dementia (All)
- Database of Studies eligible for meta-analysis
- List of all studies looking at early onset dementia for consensus statement.

7.7.1 Database of European Epidemiological studies on dementia (All)

- *Description of study and results*
- *Searchable by key words*

Data to be collected: (Black Text on data Collection form)

- Title of Study:
- Authors / Responsible for study:
- Institution / Location:
- Where published: e.g. Journal, Abstract, Conference, PhD thesis: etc
- Abstract:
- Comments:

7.7.2 Database of Studies eligible for meta-analysis

Inclusion Criteria:-

- *Community based study*
- *Min underlying population size 300*
- *Study Date after 1990*
- *Age over 65 yrs*
- *Standardised diagnostic criteria (Dementia, AD, VaD)*
- *Available raw prevalence data*
- *Participation rate over 50%*

Data to be collected: (All data collection form)

7.7.3 Preliminary Data Collection Form

Source/Reference	
Title of study	
Authors / Responsible for study	
Where published: e.g. Journal, Abstract, Conference, PhD thesis: etc	
Institution / Location /Geographical region	
Abstract	
Comments	
Dates of Study	Year to year
North/ South / East/ West Europe*	N S E W
Latitude / longitude of principal Town	
Size of underlying population studied	
% of population sampled	
Age range of population studied	
Incident case definition	
Dementia	
Alzheimers Disease	
Probable / Possible	

Vascular Dementia	
Other details.....	
Diagnostic criteria used	
Prevalance case number	M: F Total
Year of measurement of prevelance cases	
Incident case number (1)	M: F Total
Over period of time (1) (year to year)	
Incident case number (2)	M: F Total
Over period of time (2) (year to year)	
Incident case number (3)	M: F Total
Over period of time (3) (year to year)	

7.7.4 UN Classifaction-Division of Europe

Europe

Eastern Europe	Northern Europe	Southern Europe	Western Europe
Belarus	Denmark	Albania	Austria
Bulgaria	Estonia	Bosnia and Herzegovina	Belgium
Czech republic	Finland	Croatia	France
Hungary	Iceland	Greece	Germany
Poland	Ireland	Italy	Luxembourg
Republic of Moldavia	Latvia	Malta	The Netherlands
Romania	Lithuania	Portugal	Switzerland
Russian federation	Norway	Slovenia	
Slovakia	SWEDEN	Spain	
Ukraine	UK	TFYR Macedonia	
		Yugoslavia	

7.7.5 Early onset dementia

1. circulate papers
2. All group to read.
3. Preparation of consensus statement (? other experts to be involved?)

7.7.5.1 List of all Studies looking at early onset dementia

Ned Tijdschr Geneeskd. 2005 Dec 17;149(51):2862-7.
[Cognitive disorders appearing before the age of 65 in patients of the Alzheimer Centre of the VU Medical Centre: diagnoses and clinical characteristics]
[Pijnenburg YA, Zeeman-Rebel A, van der Flier WM, Romkes RM, Gillissen F, Jonker C, Scheltens P.
VU Medisch Centrum, Postbus 7057, 1007 MB Amsterdam. y.pijnenburg@vumc.nl
OBJECTIVE: To obtain a profile of the causes and clinical characteristics of cognitive disorders in patients referred to a memory clinic before the age of 65 years. DESIGN: Retrospective case-note study. METHOD: Data were collected from 127 subjects with objective cognitive disorders who visited the Alzheimer Centre of the VU Medical Centre in Amsterdam, the Netherlands, in the period from 1 January 2001 to 31 December 2003 with an onset of complaints before the age of 65. Besides the diagnoses, we investigated the clinical presentations, the occurrence of cardiovascular risk factors, the family history, and the presence of noncognitive neurological signs. RESULTS: The most common causes of cognitive decline under the age of 65 were Alzheimer's disease (46%) and frontotemporal dementia (23%). Vascular dementia was seen in 5% and dementia with Lewy bodies in 2%; 9% had mild cognitive impairment but no dementia. Hypertension and a positive family history for dementia were each present in 40% of the patients. Non-cognitive neurological abnormalities were found only in cases of non-Alzheimer dementia. During the period under investigation, the number of patients with objective cognitive disorders increased more than did the number without a cognitive disorder. CONCLUSION: Within the population of a memory clinic, Alzheimer's disease was the most frequent cause of cognitive decline under the age of 65, followed by frontotemporal dementia. The distribution differed from causes of dementia at an older age, where vascular dementia had the second place.

Dement Geriatr Cogn Disord. 2006;21(2):59-64. Epub 2005 Nov 4

Early-onset dementia: frequency and causes compared to late-onset dementia

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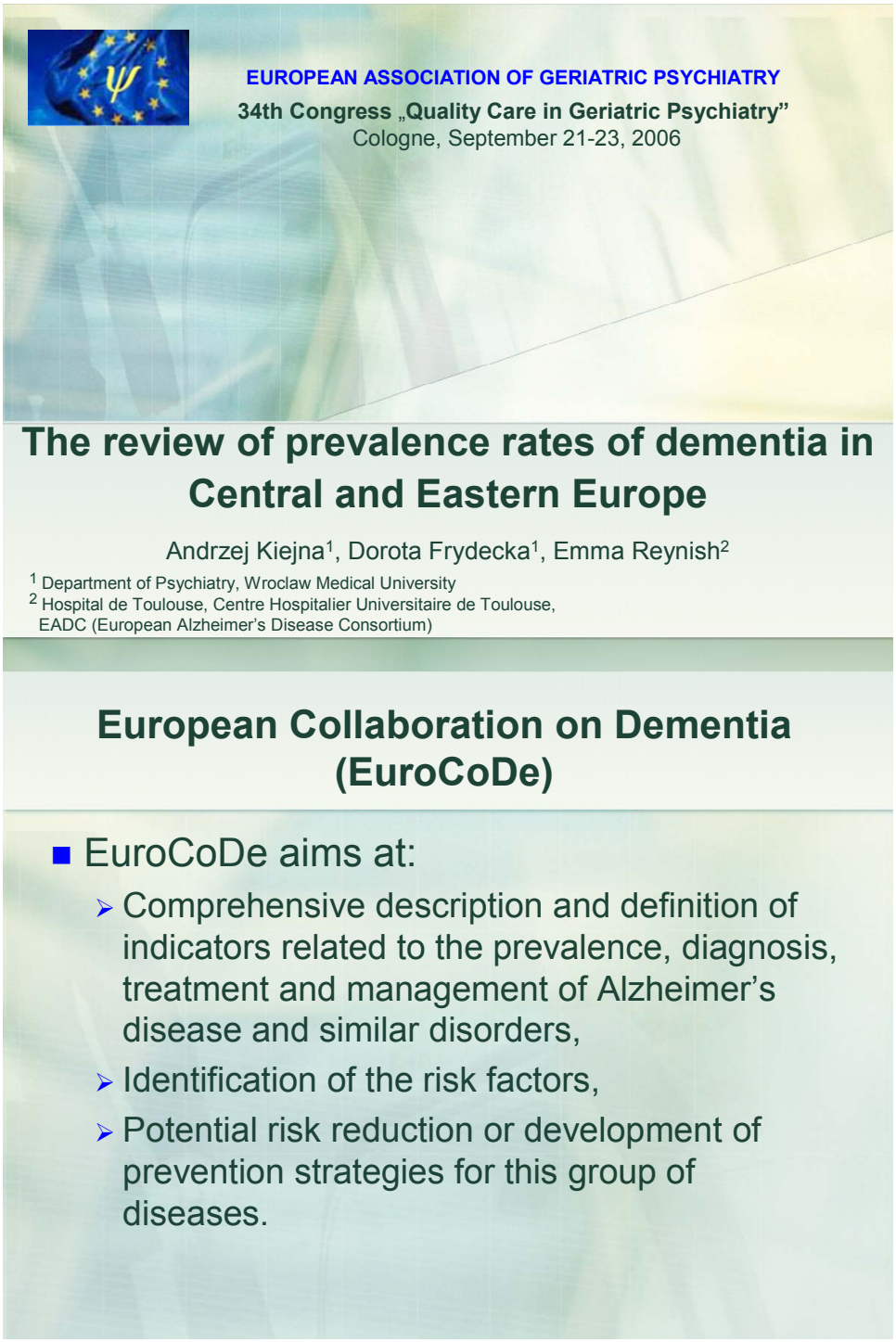
BACKGROUND: Research on the epidemiology of dementia has focused on the elderly. Few investigations have studied differences in etiologic frequencies between early-onset dementia (EOD), with onset at an age of less than 65 years old, and the more common late-onset disorder. OBJECTIVES: To determine relative frequencies and characteristics of EOD versus late-onset dementia (LOD; age of onset > or =65 years) diagnosed in a large memory disorders program over a 4-year period. METHODS: We reviewed medical records, including an extensive neurobehavioral and neurological evaluation, of all patients seen at a large Veteran's Affairs Medical Center Memory Disorders clinic between 2001 and 2004 and assessed demographic variables, final diagnoses, presence of dementia, and differential diagnosis of dementing illnesses. RESULTS: Among 1,683 patients presenting for evaluation of an acquired decline in memory or cognition, 948 (56%) met established clinical criteria for a dementing illness. About 30% (n = 278) of these had an age of onset of <65 years, compared to 670 with LOD. Patients were predominantly male (98%). Compared to the late-onset group, the EOD patients were less severely impaired on presentation, but they did not differ in gender distribution or educational background. The EOD group had significantly more dementia attributed to traumatic brain injury, alcohol, human immunodeficiency virus (HIV), and frontotemporal lobar degeneration compared to the LOD patients. In contrast, the LOD group had significantly more Alzheimer's disease compared to the EOD group. CONCLUSIONS: This study, conducted at a Veterans Affairs Hospital, is the largest series to date on EOD, and found a previously unexpectedly large number of patients below the age of 65 with cognitive deficits and impaired functioning consequent to head trauma, alcohol abuse, and HIV. These findings highlight the differential distribution and importance of preventable causes of dementia in the young.

7.8 Annex 2:



EUROPEAN ASSOCIATION OF GERIATRIC PSYCHIATRY

34th Congress „Quality Care in Geriatric Psychiatry"

Cologne, September 21-23, 2006

The review of prevalence rates of dementia in Central and Eastern Europe

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European Collaboration on Dementia (EuroCoDe)

- EuroCoDe aims at:
  - Comprehensive description and definition of indicators related to the prevalence, diagnosis, treatment and management of Alzheimer's disease and similar disorders,
  - Identification of the risk factors,
  - Potential risk reduction or development of prevention strategies for this group of diseases.

The aims of this project were:

- To gather existing epidemiological studies in the field of dementia from Central and Eastern Europe (Poland, Hungary,Czech Republic, Lithuania, Estonia, Slovenia, Croatia, Bosnia and Hercegovina, Serbia, Macedonia, Albania, Bulgaria, Romania)
- To analyze the respective merits and shortcomings of the individual studies

Which dementias were concerned?

- Particular attention was given to providing information about various forms of dementia:
  - Alzheimer's disease (AD),
  - Vascular dementia (VaD),
  - Lewy-body dementia (LBD),
  - Fronto-temporal dementia,
  - Other rarer forms of dementia
- As well as about different stages of the disease
  - Mild,
  - Moderate,
  - Severe.

The following information sources were searched through:

- Scientific databases,
- Conference proceedings,
- PhD theses,
- Family associations,
- Partner associations,
- Funding organizations.

Set of criteria for the search:

- Community based studies,
- Conducted after 1990,
- Minimum sample size of 300,
- In age over 65 years,
- Preferably diagnosed using standardized criteria,
- With participation rate over 50%,
- With available raw prevalence data.

Where the search was done?

- The search was mainly conducted through Internet and by exchanging e-mails with dementia researchers from the European countries.
- National associations were contacted for the relevant information:
  - Alzheimer Disease Societies Croatia,
  - Ceska Alzheimerovska Spolecnost,
  - Societea Romanna Alzheimer,
  - Alzheimer Society of Serbia and Montenegro,
  - Slovak Alzheimer's Society,
  - Hungarian Alzheimer Society.
- WHO Mental Health Atlas was also used.

1

Main observations:

- Literature in the area of epidemiology of dementia that was available through the search proved to be highly unsatisfactory.
- For most of the countries the figures on prevalence come from National Centers of Mental Health or Central Statistical Offices and, therefore, are not precise.

2

Main observations:

- Some studies were found that presented the numbers on incidence of dementia in specific settings:
  - Homes for elderly,
  - Cerebrovascular outpatient units,
  - Neurological units,
  - Psychogeriatric and psychiatric units.
- These studies did not meet the criteria of epidemiological researches!

Deatailed results - Poland -

- Four population-based epidemiological studies in rural and urban populations were found.
  1. Gabryelewicz, T. The prevalence of dementia in the population of the Warsaw district of Mokotow from 65 to 84 years of age.
  2. Rossa, G. The prevalence of Alzheimer's type dementia and vascular dementia in the district of Swiebodzin.
  3. Wender, M; Mularczyk, J, Modestowicz, R. Epidemiology of Alzheimer's disease in the selected region of Wielkopolska
  4. Pająk A, Szczudlik A. Cognitive impairment and cardiovascular disease risk factors.

1. Study by Gabryelewicz - Warsaw

- Random sample of 1,000 persons
- Largest city in Poland - Warsaw,
- Aged 65-84 years,
- Two-phase population based study:
  - Screening phase (MMSE)
  - Cambridge Mental Disorders of the Elderly Examination

Psychiatr Pol. 1999; 33(3):353-66

1. Study by Gabryelewicz – Warsaw - Dementia Prevalence -

- All dementias – 5,7 %,
- Dementia of Alzheimer's type (DAT) – 2,3 %
- Vascular Dementia (VaD) – 2,7 %
- Age-specific prevalences of dementia:
  - 65-69 years – 1,9%,
  - 70-74 years – 5,8%,
  - 75-79 years – 8,6%,
  - 80-84 years – 16,5%

Psychiatr Pol. 1999; 33(3):353-66

2. Study by Rossa - Świebodzin

- Sample of 7417 persons,
- Aged above 45 years,
- 4999 persons aged 45-64, and 2418 persons >64,
- Small town of Swiebodzin and its surroundings,
- Clinical diagnosis was established by detailed anamnesis, neurological, general and psychological examinations (which included MMSE, MSQ, SPMSQ).

Psychiatr Pol. 1997; 31(1):121-34

2. Study by Rossa – Świebodzin - Dementia Prevalence -

	♂	♀	Total population
DAT	0,23 %	1,17 %	1,4 %
VaD	0,51 %	1,01 %	1,52 %
Mixed	0,08 %	0,12 %	0,2 %
Other	0,16 %	0,28 %	0,44 %
Total	0,98 %	2,59 %	3,57 %

The ♀ : ♂ ratio with respect to type of dementia in age groups:

	45-64 ♀ : ♂	> 64 ♀ : ♂	Total population ♀ : ♂
DAT	5,33 : 1	4,37 : 1	4,52 : 1
VaD	1,21 : 1	3,33 : 1	2,4 : 1
Mixed	0,66 : 1	2,33 : 1	1,5 : 1
Other	1,5 : 1	2,25 : 1	1,75 : 1
Total	1,68 : 1	3,56 : 1	2,8 : 1

Psychiatr Pol. 1997; 31(1):121-34

3. Study by Wender et al. – Steszew

- Epidemiological survey of Alzheimer's disease,
- Small town and commune of Steszew (nearby Poznan),
- Sample of n=13 023 subjects,
- Clinical diagnosis established by detailed anamnesis, neurological, general and psychological examinations.

Przegl Epidemiol. 1990; 44(3):215-21

3. Study by Wender et al. – Steszew - Alzheimer's Disease prevalence -

- Overall – 1,1%,
- In the age group >65 years – 1%.
- Severe AD in the age group >65 years – 2,6%.
- The detected overall incidence rate of AD in the year 1988 was:
  - In the age group 45-65 – 2%,
  - In the age group >65 – 2,6%.

Przegl Epidemiol. 1990; 44(3):215-21

4.Study by Pająk et al.

- Sample size of 1318 persons >64 years,
- Cardiovascular disease risk factors were measured,
- In period of 1983-1984,
- Two-phase study
  - History of cardiovascular disease, blood pressure, MMSE,
  - Detailed neuropsychological and neurological examination, MRI, determination of apoE isoforms and cholesterol levels.
- About 50% had cognitive impairment (MMSE<25),
- 10% had severe cognitive impairment (MMSE<21) with changes in the brain white matter confirmed by MRI.

Przegl.Lek. 1998; 55(12):676-82

Other studies - Poland -

- **Górna R, Rymaszewska J, Kiejna A, Chładzińska-Kiejna S. Dementia in population of patients in Primary Care.**
  - sample size of 131 patients above 65 years old from out-patient primary care clinics in the district of Oleśnica (nearby Wroclaw),
  - diagnostic instruments: Mini Mental State Examination (MMSE), Clock Drawing Test (CDT), Hachinski Scale.

Adv Clin Exp Med 2004,13,3, 457-462

Study by Górna et al. - Results -

- Features characteristic for dementia were noticed in 73 patients (55,7%), 38 patients (29%) had cognitive impairment without dementia.

	♀	♂	total	65-74 years	>74 years
Cognitive impairment	27,5%	32,5%	29%	31,8%	14,3%
Dementia	56%	55%	55,7%	51,8%	76,2%

- Different severity levels of dementia by gender:

	♀	♂	total
Mild dementia	68,6%	90,9%	75,3%
Moderate dementia	29,4%	9,1%	23,3%
Severe dementia	2%	0	1,4%

- Results of Hachinski scale by gender:

	♀	♂	total
Primary dementia	66,7%	81,8%	71,2%
Mixed dementia	15,7%	9,1%	13,7%
Vascular dementia	17,6%	9,1%	15,1%

Prevalence of dementia in a rural population - Poland -

- Epidemiological survey of dementia in a rural area near Gdansk,
- Random sample of 1000 subjects drawn from the total population of n=2527,
- Two-phase study:
  - Screening survey using MMSE,
  - Diagnostic examination using ICD-10 criteria.

	♂	♀	total
DAT	1,1 %	4,0 %	5,1 %
VaD	1,9 %	3,5 %	5,4 %
Dementia	3,0 %	8,8 %	6,7 %

Detailed results - Lithuania -

- Data from National Mental Health Center of Lithuania contain only information from regional mental health centers, so the cases registered by neurologists are not included in the main database.

	Total number of dementia cases in 2002	Incidence of new cases of dementia in 2002
DAT	495	124
VaD	2,161	456
Other	12,167	954
Sum	14,823	1534

- Using the figures from Rotterdam Study:
  - Estimated prevalence ≈31 000 persons,
  - Yearly incidence >6 000 in Lithuanian population.

Detailed results - Serbia -

- 2002 census in Belgrade:
  - 15,7% of people >65 years (14% ♂ and 17,2% ♀) has dementia,
  - Almost 6% increase in comparison to the 1991 census,
- Pilot estimation of dementia prevalence on 1000 randomly chosen medical records in one of the 16 public health centers in Belgrade county (151 768 citizens) provided the following numbers:

Life years	65-69	70-74	75-79	80-84	>84
Dementia	1%	2%	5,1%	23%	65,7%

	Total	♂	♀
Dementia	6,7 %	2,8%	3,9%

Detailed results
- Hungary -

- According to Hungarian Central Statistical Office (1998) dementia was one of the most common reasons for psychiatric hospitalization (13%).
- Estimated prevalence of Alzheimer's disease in Hungary (by Palotas):

Life years	60-65	66-70	71-75	76-80	81-85
AD	1,38%	4,15%	8,78%	15,32	21,68%

Hungary
- Cerebrovascular Diseases -

- 1999 study of vascular cognitive impairment in Hungarian cerebrovascular outpatients:
  - Out of 247 consecutive patients, 176 had cerebrovascular disorder diagnosed either by CT or by the clinical signs.
  - Of these, 5% fulfilled the criteria of dementia.
- 2002 study on cerebrovascular outpatients using MMSE and the Barthel Index:
  - From the total of 176 cases, 9 of the patients fulfilled the criteria for dementia (5,1%).

Detailed results
- Czech Republic -

- Khachaturyan's method of diagnosing AD in 2 197 autopsies of people aged 65-99 years using the principle of "epidemiologic" autopsy (Thomayer University Hospital, 1988-1992) showed:
  - AD rate in men – 0,7%/100 000/year,
  - AD rate in women – 1,4%/100 000/year.
- Demographically standardized death rate in AD is:
  - in men 285,25/100 000,
  - in women 604,24/100 000.
- The prevalence of AD in the whole group was 7,46%.

Koukolík F. Epidemiologic autopsy in Alzheimer's disease. Cas Lek Cesk 1996 Jun 12; 135(12) :378-81

Detailed results
- Czech Republic -

- Autopsies of 132 men and 212 woman aged 60-99 years (Thomayer's University Hospital, 1995-1996) using the principle of "epidemiologic" autopsy showed:
  - The crude rate of Binswanger's disease – 7,9%.
  - It's ½ of the crude rate of Alzheimer's disease found in the same cohort.

Koukolík F, Neubertová E. Epidemiologic autopsy of Binswanger's disease. Cas Lek Cesk 1997 Mar 19; 136(6) :181-5.

Study by Saks et al. - Estonia -

- Questionnaire sent to 200 general practitioners (GP),
- GPs were asked each to collect data, use medical records, and interview five randomly selected patients,
- Sample size ≈1 000 people aged ≥65 years (which comprised ≈0,5% of 206 915 of total older urban and rural population),
- Cognitive status determined by MMSE,
- The prevalence of cognitive disorders:

	65-84	≥85	total elderly population
Cognitive disorders	20,7%	51,3%	23,1%

Saks et al. Health Status of the Older Population in Estonia. Public Health 42(6):663-668,2001

Study by Kruja et al. - Albania -

- Random sample of 1 000 persons >60 years taken from municipal register of Tirana City,
- Two-phase study:
  - Screening phase (MMSE) and neurological examination,
  - Diagnosis according to clinical and radiological criteria of dementia (ICD-10),
- Prevalence data:

	Overall	♂	♀
Dementia	7,75 %	4,83%	11,45%

Kruja et al. Epidemiology of dementia in Tirana - Albania. Poster from 6th EFNS Congress, Vienna, 2002

Extrapolation of Incidence Rate for Dementia based on USA statistics

- Incidence Rate for Dementia:
  - Approx. 1/738 or
  - 0,14% or
  - 368 320 people in USA.
- This calculation is automated and does not take into account any genetic, cultural, environmental, social, racial or other differences across the various countries.
- As such, it may be highly inaccurate and only give a general indication as to the actual prevalence or incidence of dementia in USA.

Extrapolation of Incidence Rate for Dementia based on USA statistics

Country	Extrapolated Incidence	Population Estimated Used
Czech Republic	1 687	10 246 178
Hungary	13 585	10 032 375
Poland	52 304	38 626 349
Albania	4 800	3 544 808
Bosnia & Herzegovina	551	407 608
Croatia	6 089	4 496 869
Macedonia	2 762	2 040 085
Serbia & Montenegro	14 659	10 825 900
Bulgaria	10 180	7 517 973
Estonia	1 816	1 341 664
Latvia	3 123	2 306 306
Lithuania	4 885	3 607 899
Romania	30 272	22 355 551
Slovakia	7 344	5 423 567
Slovenia	2 723	2 011 473

1

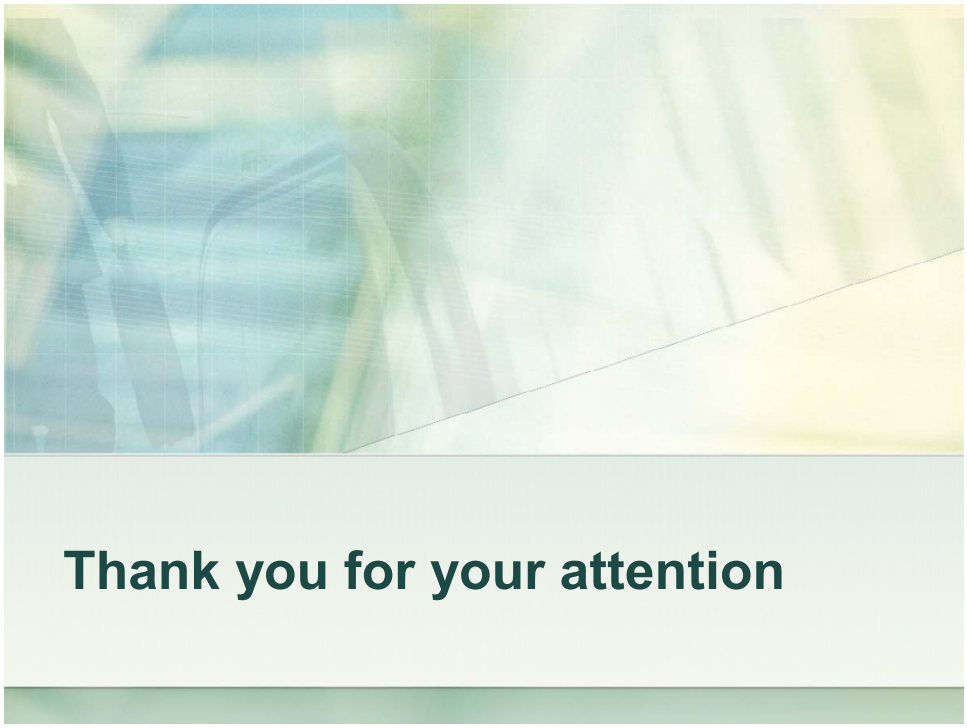
Conclusions

- Literature search performed to identify the data on epidemiology in Central and Eastern Europe shows high diversity in applied methodology and selected populations (rural, urban) on which studies were conducted.
- It is extremely difficult to summarize the results and to draw clear conclusions on prevalence of dementia in this region.

2

Conclusions

- There is a great need for population-based epidemiological studies in order to get precise information on prevalence of dementia in Central and Eastern Europe.
- There is not only need but also strong will to intitiate such studies in the future (according to assurances given us by researchers from various countries).


Thank you for your attention

7.9 Annex 3: The prevalence of dementia in Europe

7.9.1 Introduction

The term "dementia" refers to a range of symptoms commonly found in people with brain diseases which result in the damage and loss of brain cells. Losing brain cells is a natural process but with dementia this occurs at a much faster rate and involves a gradual and slow deterioration of a person's ability to function, affecting memory, attention, concentration, language and thinking. There are numerous forms of dementia. The most common form is Alzheimer's disease, sometimes referred to as dementia of the Alzheimer's type (DAT). Other common forms include dementia with Lewy bodies, vascular or multi-infarct dementia and Pick's disease, to name but a few. It is also possible to have a combination of different kinds of dementia.

The likelihood of developing dementia increases with age even though it does not only affect older people and old age alone does not cause dementia.

The number of people with dementia in a given population is known as the prevalence of dementia. This can be calculated by applying prevalence rates to population statistics for specific age groups. A number of studies have been carried out in order to determine prevalence rates, generally for 5 year age groups and sometimes for men and women separately. The rates do not usually differentiate between different forms of dementia or different stages of the disease. This is a drawback to existing studies as such information would be of great importance to policy makers responsible for organising the provision of services.

In the framework of the EuroCoDe project, the project partners of Alzheimer Europe are currently carrying out a meta-analysis of existing prevalence studies in the whole of Europe, including the new Member States, in order to devise new consensual prevalence rates for dementia. A database will also be compiled of all European epidemiological studies in this field to-date. They will be classified by research methodology, disease type, age range, date and geographical location etc. This work, which will be carried out in collaboration with a group of European experts, is expected to be finished by the end of 2008.

7.9.2 Examples of major prevalence studies

Meanwhile, in order to provide information on the number of people with dementia in Europe, we have used prevalence rates from two existing studies.

The first is from the European Community Concerted Action on the Epidemiology and Prevention of Dementia group (EURODEM for short)[55]. In the course of their work, members of the above-mentioned group pooled data on the prevalence of moderate to severe dementia in several European countries and came up with a set of prevalence rates for men and women in 9 different age groups (30-59, 60-64, 65-69, 70-74, 75-79, 80-84, 85-89, 90-94 and 95-99). The study included people with dementia who were living at home as well as those in institutions, nursing homes and residential care.

[55] For more details about this study, please refer to the article: Hofman, A. et al. (1991), The prevalence of dementia in Europe: a collaborative study of 1980-1990 findings, *International Journal of Epidemiology*, Volume 20, No.3, pages 736-748.

Table 1: EURODEM prevalence rates

Age group	Male	Female
30-59	0.16%	0.09%
60-64	1.58%	0.47%
65-69	2.17%	1.10%
70-74	4.61%	3.86%
75-79	5.04%	6.67%
80-84	12.12%	13.50%
85-89	18.45%	22.76%
90-94	32.1%	32.25%
95-99	31.58%	36.00%

A second, more recent study was carried out by Ferri et al. (2005)[56] on behalf of Alzheimer's Disease International (ADI). For this study, 12 international experts conducted a systematic review of published studies on dementia and agreed on prevalence estimates for every World Health Organisation (WHO) world region, for men and women combined, in five year age groups from 60 to 84 years and for people over 85. A DELPHI consensus method was used. This is a technique which makes it possible to derive quantitative estimates through the qualitative assessment of evidence. Where information is scarce, experts can make inferences using data from comparable contexts and express opinions free from peer-group pressure. For our calculations, we used the prevalence rates for Western Europe (Region A) and Eastern Europe (Regions B and C)[57].

Table 2: Ferri et al. prevalence rates

Age group	Region A	Region B/C
60-64	0.9%	0.9%
65-69	1.5%	1.3%
70-74	3.6%	3.2%
75-79	6%	5.8%
80-84	12.2%	12.2/11.8%
85+	24.8%	24.7/24.5%

7.9.3 The population of people with dementia in Europe

The following table shows the number of people with dementia living in Europe using the EURODEM and Ferri et al. prevalence rates on the basis of population statistics obtained from Eurostat (the official statistics office of the European Community).[58]

Calculations based on the two different sources of prevalence rates provide different estimates of the number of people with dementia in Europe. This is not only because the prevalence rates differ slightly for each age group but also because Ferri et al. did not include prevalence rates for the 30-59 age group, whereas EURODEM did.

Also, as mentioned above, Ferri et al. developed their prevalence rates through a DELPHI approach i.e. based on a consensus statement by experts in the field of dementia and not directly from epidemiological studies.

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[56] For more details about this study, please refer to the article: Ferri, C.L. , Prince, M. et al. (2005), Global prevalence of dementia: a Delphi consensus study, *The Lancet*, Vol. 366, December 17/24/31, 2005

[57] The EURO B category included countries with a low adult mortality rate and the EURO C category, those with a high adult mortality rate.

[58] Unless otherwise indicated, the latest Eurostat figures used are from 2005.

Table 3: The number of people with dementia in Europe

Country	Age group[59]	Number of people with dementia (EURODEM)	As % of total population	Number of people with dementia (Ferri et al.)	As % of total population
Austria	30-94	104,428	1.27	94,441	1.15
Belgium	30-99	140,639	1.35	127,174	1.22
Cyprus	30-99	6,725	0.9	6,054	0.81
Czech Republic	30-99	105,553	1.03	93,973	0.92
Denmark	30-99	68,430	1.26	62,318	1.15
Estonia (2004)	30-99	15,065	1.12	12,955	0.96
Finland	30-99	65,362	1.25	59,360	1.13
France	30-99	847,808	1.36	760,715	1.22
Germany	30-94	1,118,429	1.36	1,010,245	1.22
Greece	30-99	135,566	1.22	123,700	1.12
Hungary	30-89	100,567	1	88,070	0.87
Ireland	30-94	35,381	0.86	31,940	0.78
Italy	30-99	905,713	1.55	820,462	1.4
Latvia	30-99	25,969	1.13	22,509	0.98
Lithuania	30-99	35,298	1.03	30,169	0.88
Luxembourg	30-94	4,857	1.07	4,370	0.96
Malta	30-89	3,427	0.85	3,148	0.78
Netherlands	30-99	183,485	1.13	165,585	1.02
Poland	30-99	350,511	0.92	300,447	0.79
Portugal	30-94	129,916	1.23	119,308	1.13
Slovenia	30-99	21,788	1.09	19,302	0.97
Slovakia	30-99	44,813	0.83	38,232	0.71
Spain	30-99	583,208	1.36	533,388	1.24
Sweden	30-99	138,641	1.54	128,220	1.42
UK (2004)	30-89	660,573	1.11	621,717	1.04
EU25 TOTAL		**5,832,152**	**1.27**	**5,277,802**	**1.14**
Bulgaria	30-99	87,797	1.13	76,556	0.99
Iceland	30-99	2,845	0.97	2,584	0.88
Norway	30-99	61,077	1.33	56,227	1.22
Romania	30-99	200,893	0.93	172,130	0.79
Switzerland	30-94	97,068	1.31	88,900	1.2
Turkey	30-74	129,715	0.18	78,546	0.11
other countries TOTAL		**579,385**		**474,943**	

[59] For an accurate estimate of the numbers of people with dementia in a given country, detailed population statistics with breakdowns in 5 year age groups are necessary. For countries, for which the statistics do not provide this information up to the 95-99 age group, this will result in significant underestimations of the numbers of people with dementia. This is the case in this table for Austria, Germany, Hungary, Ireland, Luxembourg, Malta, Portugal, Switzerland, Turkey and the United Kingdom.

GRAND TOTAL		**6,411,547**		**5,752,745**	

From the above table, it can be calculated that the estimated number of people with dementia living in the European Union is between **5.3 and 5.8** million people. This means that between **1.14% and 1.27%** of citizens in the European Union are living with a form of dementia.

With the ageing of European societies, these numbers have increased substantially over the past 45 years, both in absolute figures, but equally as a percentage of the overall population. This is likely to increase dramatically in the next 35 years. According to estimations by Ferri et al. (2005), the number of people with dementia over the age of 60 in the EURO A region will increase from 4.9 million in 2001 to 9.9 million in 2040. The increase will be from 1 to 2.8 million and from 1.8 to 3.2 million for the EURO B and C regions respectively.

7.9.4 A word of caution

Estimations of the prevalence of dementia in Europe, as well as in separate countries, are extremely useful but should also be treated with some caution for the following reasons.

They are based on the availability of population statistics which may differ from one country to the next and even from one organisation providing statistics to the next. In some countries, statistics are available for every age group. In others, statistics for some age groups (particularly the oldest) are missing for some or all of the years used in the calculations.

Although there are fewer people in the older age groups, the percentage having dementia is higher. Consequently, this can distort the results, giving the impression that there are fewer people with dementia than there really are. Also, if statistics for a particular age group are available for some years and not for others (within the same country), this could give the false impression of a sudden increase in the number of people with dementia.

Another problem is that if prevalence rates were calculated on the basis of analyses of diagnosed cases, a large number of people with dementia would be excluded from the figures. Furthermore, this would differ from one country to the next depending on the rate of diagnosis in each country. Many people in the early stages of dementia have not yet been diagnosed and some people with dementia will unfortunately never receive a diagnosis.

7.9.5 National reports and charts

More detailed calculations of the number of people with dementia in each country, based on the two sets of prevalence rates from EURODEM and Ferri et al. and the population statistics from EUROSTAT, can be found in the chapters containing information on individual countries.

Calculations can also be made using other prevalence rates and/or population statistics from other sources such as national governments. For this reason and also due to possible limitations linked to making estimates, our calculations are only intended to provide a rough estimate of the number of people with dementia in Europe. The actual number of people with dementia in Europe is likely to be somewhat higher.

7.9.6 Prevalence of Dementia in Austria

Alzheimer Europe estimates the number of people with dementia in Austria in 2005 as being between 94,441 (Ferri et al.) and 104,428 (Eurodem). This represents 1.15% (Ferri et al.) to 1.27%

(Eurodem) of the total population of 8,206,524, which is almost identical to the EU average (i.e. 1.14% to 1.27%).

The Alzheimer Europe figures underestimate the number of people with dementia in Austria, as it was impossible to obtain sufficiently detailed population statistics of the number of people in Austria over the age of 94.

Table 1: The number of people with dementia in Austria in 2005

		Eurodem		**Ferri et al.**
	Men with dementia	Women with dementia	Total number of people with dementia	Total number of people with dementia
30-59	2,852	1,601	4,453	
60-64	3,720	1,198	4,918	4,414
65-69	3,777	2,172	5,948	5,572
70-74	6,344	6,754	13,099	11,254
75-79	5,485	11,432	16,918	16,814
80-84	7,966	20,631	28,597	26,663
85-89	3,798	12,717	16,515	
90-94	3,276	10,704	13,981	29,725
Total	37,218	67,210	**104,428**	**94,441**

7.9.7 Prevalence of Dementia in Belgium

Alzheimer Europe estimates the number of people with dementia in Belgium in 2005 as being between 127,174 (Ferri et al.) and 140,639 (Eurodem). This represents 1.22% (Ferri et al.) to 1.35% (Eurodem) of the total population of 10,445,852. The number of people with dementia in Belgium, as a percentage of the total population, is slightly higher than the EU average of 1.14% to 1.27% (Ferri et al. and Eurodem, respectively).

Table 1: The number of people with dementia in Belgium in 2005

		Eurodem		**Ferri et al.**
	Men with dementia	Women with dementia	Total number of people with dementia	Total number of people with dementia
30-59	3,579	1,983	5,562	
60-64	3,814	1,188	5,002	4,447
65-69	5,055	2,872	7,926	7,410
70-74	9,709	10,080	19,789	16,983
75-79	7,945	15,239	23,184	23,166
80-84	12,276	24,406	36,682	34,413
85-89	5,497	16,100	21,597	
90-94	3,870	13,107	16,977	
95-99	559	3,360	3,919	40,754
Total	52,304	88,335	**140,639**	**127,174**

7.9.8 Prevalence of Dementia in Bulgaria

Alzheimer Europe estimates the number of people with dementia in Bulgaria in 2005 as being between 76,556 (Ferri et al.) and 87,797 (Eurodem). This represents 0.99% (Ferri et al.) to 1.13% (Eurodem) of the total population of 7,761,049. The number of people with dementia in Bulgaria as a percentage of the total population is lower than the EU average of 1.14% to 1.27% (Ferri et al. and Eurodem, respectively).

Table 1: The number of people with dementia in Bulgaria in 2005

		Eurodem		**Ferri et al.**
	Men with dementia	Women with dementia	Total number of people with dementia	Total number of people with dementia
30-59	2,,589	1,490	4,079	
60-64	3,175	1,114	4,289	3,941
65-69	3,866	2,468	6,334	5,233
70-74	7,725	8,699	16,424	12,574
75-79	5,963	11,644	17,607	16,987
80-84	7,994	14,873	22,867	21,488
85-89	3,138	6,775	9,914	16,333
90-94	1,863	3,631	5,494	
95-99	231	559	790	
Total	36,544	51,253	**87,797**	**76,556**

7.9.9 Prevalence of Dementia in Cyprus

Alzheimer Europe estimates the number of people with dementia in Cyprus in 2005 as being between 6,054 (Ferri et al.) and 6,725 (Eurodem). This represents 0.81% (Ferri et al.) to 0.9% (Eurodem) of the total population of 749,175. The number of people with dementia in Cyprus as a percentage of the total population is much lower than the EU average of 1.14% to 1.27% (Ferri et al. and Eurodem, respectively).

Table 1: The number of people with dementia in Cyprus in 2005

	Eurodem			**Ferri et al.**
	Men with dementia	Women with dementia	Total number of people with dementia	Total number of people with dementia
30-59	239	141	380	
60-64	259	82	342	306
65-69	303	168	471	438
70-74	482	485	967	829
75-79	384	666	1,050	1,056
80-84	575	866	1,442	1,362
85-89	408	746	1,154	2,063
90-94	284	493	777	
95-99	54	89	143	
Total	2,989	3,736	**6,725**	**6,054**

7.9.10 Prevalence of Dementia in the Czech Republic

Alzheimer Europe estimates the number of people with dementia in the Czech Republic in 2005 as being between 93,973 (Ferri et al.) and 105,553 (Eurodem). This represents 0.92% (Ferri et al.) to 1.03% (Eurodem) of the total population of 10,220,577. The number of people with dementia in the Czech Republic as a percentage of the total population is somewhat lower than the EU average of 1.14% to 1.27% (Ferri et al. and Eurodem, respectively).

Table 1: The number of people with dementia in the Czech Republic in 2005

		Eurodem		**Ferri et al.**
	Men with dementia	Women with dementia	Total number of people with dementia	Total number of people with dementia
30-59	3,541	1,986	5,527	
60-64	4,309	1,453	5,762	5,237
65-69	3,992	2,538	6,530	6,220
70-74	7,473	8,870	16,343	14,108
75-79	5,973	13,422	19,394	19,184
80-84	8,319	19,734	28,053	26,208
85-89	3,037	9,488	12,525	23,016
90-94	2,333	7,472	9,805	
95-99	299	1,315	1,615	
Total	39,276	66,277	**105,553**	**93,973**

7.9.11 Prevalence of Dementia in Denmark

Alzheimer Europe estimates the number of people with dementia in Denmark in 2005 as being between 62,318 (Ferri et al.) and 68,430 (Eurodem). This represents 1.15% (Ferri et al.) to 1.26% (Eurodem) of the total population of 5,411,405. The number of people with dementia in Denmark as a percentage of the total population is almost identical to the EU average of 1.14% to 1.27% (Ferri et al. and Eurodem, respectively).

Table 1: The number of people with dementia in Denmark in 2005

		Eurodem		**Ferri et al.**
	Men with dementia	Women with dementia	Total number of people with dementia	Total number of people with dementia
30-59	1,875	1,032	2,907	
60-64	2,504	756	3,260	2,875
65-69	2,527	1,373	3,900	3,619
70-74	4,066	3,998	8,064	6,904
75-79	3,430	6,037	9,467	9,514
80-84	5,486	10,191	15,677	14,732
85-89	3,845	10,135	13,980	24,674
90-94	2,294	6,694	8,988	
95-99	377	1,810	2,187	
Total	26,404	42,026	**68,430**	**62,318**

7.9.12 Prevalence of Dementia in Estonia

Alzheimer Europe estimates the number of people with dementia in Estonia in 2004 as being between 12,955 (Ferri et al.) and 15,065 (Eurodem). This represents 0.96% (Ferri et al.) to 1.12% (Eurodem) of the total population of 1,351,069. The number of people with dementia in Estonia as a percentage of the total population is somewhat lower than the EU average of 1.14% to 1.27% (Ferri et al. and Eurodem, respectively).

Table 1: The number of people with dementia in Estonia in 2004

	EURODEM			**Ferri et al.**
	men	Women	total	men/women
30-59	408	257	665	
60-64	494	203	697	670
65-69	602	478	1,080	926
70-74	1,009	1,512	2,521	1,954
75-79	688	2,171	2,858	2,679
80-84	704	2,514	3,218	2,883
85-89	420	1,789	2,209	3,844
90-94	280	1,225	1,505	
95-99	42	271	312	
Total	4,646	10,419	**15,065**	**12,955**

7.9.13 Prevalence of Dementia in Finland

Alzheimer Europe estimates the number of people with dementia in Finland in 2005 as being between 59,360 (Ferri et al.) and 65,362 (Eurodem). This represents 1.13% (Ferri et al.) to 1.25% (Eurodem) of the total population of 5,236,611. The number of people with dementia in Finland as a percentage of the total population is almost the same as the EU average of 1.14% to 1.27% (Ferri et al. and Eurodem, respectively).

Table 1: The number of people with dementia in Finland in 2005

		Eurodem		**Ferri et al.**
	Men with dementia	Women with dementia	Total number of people with dementia	Total number of people with dementia
30-59	1,807	996	2,803	
60-64	2,098	660	2,757	2,458
65-69	2,470	1,434	3,904	3,663
70-74	4,156	4,485	8,641	7,428
75-79	3,463	7,230	10,692	10,626
80-84	4,592	11,118	15,710	14,670
85-89	2,675	9,455	12,131	20,516
90-94	1,544	5,682	7,226	
95-99	232	1,266	1,498	
Total	23,036	42,325	**65,362**	**59,360**

7.9.14 Prevalence of Dementia in France

Alzheimer Europe estimates the number of people with dementia in France in 2005 as being between 760,715 (Ferri et al.) and 847,808 (Eurodem). This represents 1.22% (Ferri et al.) to 1.36% (Eurodem) of the total population of 62,370,800. The number of people with dementia in

France as a percentage of the total population is slightly higher than the EU average of 1.14% to 1.27% (Ferri et al. and Eurodem, respectively).

Table 1: The number of people with dementia in France in 2005

		Eurodem		**Ferri et al.**
	Men with dementia	Women with dementia	Total number of people with dementia	Total number of people with dementia
30-59	20,476	11,787	32,263	
60-64	21,014	6,535	27,550	24,485
65-69	26,641	15,319	41,960	39,305
70-74	51,778	54,884	106,663	91,622
75-79	44,313	85,460	129,773	129,629
80-84	74,479	144,573	219,052	205,622
85-89	33,708	91,455	125,162	270,053
90-94	32,716	98,044	130,760	
95-99	5,895	28,730	34,625	
Total	311,020	536,788	**847,808**	**760,715**

7.9.15 Prevalence of Dementia in Germany

Alzheimer Europe estimates the number of people with dementia in Germany in 2005 as being between 1,010,245 (Ferri et al.) and 1,118,429 (Eurodem). This represents 1.22% (Ferri et al.) to 1.36% (Eurodem) of the total population of 82,500,849. The number of people with dementia in Germany as a percentage of the total population is somewhat higher than the EU average of 1.14% to 1.27% (Ferri et al. and Eurodem, respectively).

The Alzheimer Europe figures underestimate the numbers of people with dementia in Germany, as it was impossible to obtain detailed enough population statistics of the numbers of people in Germany over the age of 94.

Table 1: The number of people with dementia in Germany in 2005

		Eurodem		**Ferri et al.**
	Men with dementia	Women with dementia	Total number of people with dementia	Total number of people with dementia
30-59	28,900	15,772	44,673	
60-64	40,359	12,424	52,783	46,780
65-69	53,702	29,884	83,585	77,871
70-74	75,059	76,570	151,629	130,027
75-79	59,645	121,644	181,289	180,431
80-84	77,746	203,067	280,813	261,771
85-89	37,470	133,498	170,968	313,365
90-94	32,946	119,742	152,688	
Total	405,828	712,600	**1,118,429**	**1,010,245**

7.9.16 Prevalence of Dementia in Greece

Alzheimer Europe estimates the number of people with dementia in Greece in 2005 as being between 123,700 (Ferri et al.) and 135,566 (Eurodem). This represents 1.12% (Ferri et al.) to 1.22% (Eurodem) of the total population of 11,082,751. The number of people with dementia in Greece as a percentage of the total population is slightly below the EU average of 1.14% to 1.27% (Ferri et al. and Eurodem, respectively).

Table 1: The number of people with dementia in Greece in 2005

		Eurodem		**Ferri et al.**
	Men with dementia	Women with dementia	Total number of people with dementia	Total number of people with dementia
30-59	3,760	2,111	5,870	
60-64	4,168	1,396	5,564	5,048
65-69	6,045	3,644	9,689	9,148
70-74	12,191	12,408	24,599	21,093
75-79	9,669	16,210	25,879	26,093
80-84	12,266	18,823	31,089	29,357
85-89	7,143	11,447	18,591	32,961
90-94	4,806	6,734	11,540	
95-99	1,074	1,671	2,745	
Total	61,121	74,445	**135,566**	**123,700**

7.9.17 Prevalence of Dementia inHungary

Alzheimer Europe estimates the number of people with dementia in Hungary in 2005 as being between 88,070 (Ferri et al.) and 100,567 (Eurodem). This represents 0.87% (Ferri et al.) to 1% (Eurodem) of the total population of 10,097,549. The number of people with dementia in Hungary as a percentage of the total population is considerably lower than the EU average of 1.14% to 1.27% (Ferri et al. and Eurodem, respectively).

The Alzheimer Europe figures underestimate the numbers of people with dementia in Hungary, as it was impossible to obtain detailed enough population statistics of the numbers of people in Hungary over the age of 89.

Table 1: The number of people with dementia in Hungary in 2005

		Eurodem		**Ferri et al.**
	Men with dementia	Women with dementia	Total number of people with dementia	Total number of people with dementia
30-59	3,277	1,935	5,211	
60-64	3,985	1,515	5,500	5,171
65-69	4,151	3,107	7,257	6,158
70-74	7,610	10,153	17,762	13,699
75-79	5,940	14,678	20,619	19,600
80-84	8,554	20,789	29,343	26,499
85-89	3,705	11,169	14,875	16,944

Total	37,221	63,346	**100,567**	**88,070**

7.9.18 Prevalence of Dementia in Iceland

Alzheimer Europe estimates the number of people with dementia in Iceland in 2005 as being between 2,584 (Ferri et al.) and 2,845 (Eurodem). This represents 0.88% (Ferri et al.) to 0.97% (Eurodem) of the total population of 293,577. The number of people with dementia in Iceland as a percentage of the total population is considerably lower than the EU average of 1.14% to 1.27% (Ferri et al. and Eurodem, respectively).

Table 1: The number of people with dementia in Iceland in 2005

		Eurodem		**Ferri et al.**
	Men with dementia	Women with dementia	Total number of people with dementia	Total number of people with dementia
30-59	96	52	148	
60-64	91	28	118	105
65-69	99	52	151	139
70-74	197	182	379	324
75-79	167	267	434	439
80-84	261	401	663	626
85-89	182	373	555	953
90-94	100	214	315	
95-99	19	64	83	
Total	1,212	1,633	**2,845**	**2,584**

7.9.19 Prevalence of Dementia in Ireland

Alzheimer Europe estimates the number of people with dementia in Ireland in 2005 as being between 31,940 (Ferri et al.) and 35,381 (Eurodem). This represents 0.78% (Ferri et al.) to 0.86% (Eurodem) of the total population of 4,109,173. The number of people with dementia in Ireland as a percentage of the total population is much lower than the EU average of 1.14% to 1.27% (Ferri et al. and Eurodem, respectively).

The Alzheimer Europe figures underestimate the numbers of people with dementia in Ireland, as it was impossible to obtain detailed enough population statistics of the numbers of people in Ireland over the age of 94.

Table 1: The number of people with dementia in Ireland in 2005

		Eurodem		**Ferri et al.**
	Men with dementia	Women with dementia	Total number of people with dementia	Total number of people with dementia
30-59	1,321	738	2,059	
60-64	1,357	399	1,756	1,537
65-69	1,493	789	2,282	2,108
70-74	2,544	2,368	4,912	4,195
75-79	1,947	3,483	5,430	5,451

80-84	2,893	5,320	8,214	7,720
85-89	1,952	4,838	6,790	10,928
90-94	1,087	2,851	3,938	
Total	14,593	20,787	**35,381**	**31,940**

7.9.20 Prevalence of Dementia in Italy

Alzheimer Europe estimates the number of people with dementia in Italy in 2005 as being between 820,462 (Ferri et al.) and 905,713 (Eurodem). This represents 1.4% (Ferri et al.) to 1.55% (Eurodem) of the total population of 58,462,375. The number of people with dementia in Italy as a percentage of the total population is somewhat higher than the EU average of 1.14% to 1.27% (Ferri et al. and Eurodem, respectively).

Table 1: The number of people with dementia in Italy in 2005

		Eurodem		**Ferri et al.**
	Men with dementia	Women with dementia	Total number of people with dementia	Total number of people with dementia
30-59	20,357	11,510	31,867	
60-64	24,847	8,026	32,873	29,523
65-69	32,946	19,004	51,949	48,687
70-74	58,722	61,544	120,266	103,255
75-79	48,714	93,418	142,131	142,026
80-84	75,771	150,812	226,583	212,561
85-89	38,285	103,985	142,270	284,410
90-94	34,264	94,267	128,531	
95-99	5,553	23,690	29,243	
Total	339,458	566,255	**905,713**	**820,462**

7.9.21 Prevalence of Dementia in Latvia

Alzheimer Europe estimates the number of people with dementia in Latvia in 2005 as being between 22,509 (Ferri et al.) and 25,969 (Eurodem). This represents 0.98% (Ferri et al.) to 1.13% (Eurodem) of the total population of 2,306,434. The number of people with dementia in Latvia as a percentage of the total population is considerably lower than the EU average of 1.14% to 1.27% (Ferri et al. and Eurodem, respectively).

Table 1: The number of people with dementia in Latvia in 2005

		Eurodem		**Ferri et al.**
	Men with dementia	Women with dementia	Total number of people with dementia	Total number of people with dementia
30-59	713	440	1,154	
60-64	857	358	1,215	1,173
65-69	1,079	864	1,943	1,668
70-74	1,637	2,529	4,166	3,233
75-79	1,206	3,845	5,051	4,731
80-84	1,211	4,712	5,923	5,478

85-89	633	2,833	3,466	6,226
90-94	492	2,011	2,503	
95-99	99	449	547	
Total	7,927	18,041	**25,969**	**22,509**

7.9.22 Prevalence of Dementia in Lithuania

Alzheimer Europe estimates the number of people with dementia in Lithuania in 2005 as being between 30,169 (Ferri et al.) and 35,298 (Eurodem). This represents 0.88% (Ferri et al.) to 1.03% (Eurodem) of the total population of 3,425,324. The number of people with dementia in Lithuania as a percentage of the total population is well below the EU average of 1.14% to 1.27% (Ferri et al. and Eurodem, respectively).

Table 1: The number of people with dementia in Lithuania in 2005

		Eurodem		**Ferri et al.**
	Men with dementia	Women with dementia	Total number of people with dementia	Total number of people with dementia
30-59	1,065	658	1,723	
60-64	1,159	476	1,635	1,572
65-69	1,416	1,112	2,528	2,162
70-74	2,413	3,538	5,951	4,608
75-79	1,752	5,084	6,836	6,437
80-84	2,009	6,227	8,236	7,399
85-89	946	3,529	4,475	7,991
90-94	674	2,403	3,076	
95-99	280	557	837	
Total	11,714	23,584	**35,298**	**30,169**

7.9.23 Prevalence of Dementia in Luxembourg

Alzheimer Europe estimates the number of people with dementia in Luxembourg in 2005 as being between 4,370 (Ferri et al.) and 4,857 (Eurodem). This represents 0.96 % (Ferri et al.) to 1.07% (Eurodem) of the total population of 455,000. The number of people with dementia in Luxembourg as a percentage of the total population is somewhat lower than the EU average of 1.14% to 1.27% (Ferri et al. and Eurodem, respectively).

The Alzheimer Europe figures underestimate the numbers of people with dementia in Luxembourg, as it was impossible to obtain detailed enough population statistics of the numbers of people in Luxembourg over the age of 94.

Table 1: The number of people with dementia in Luxembourg in 2005

		Eurodem		**Ferri et al.**
	Men with dementia	Women with dementia	Total number of people with dementia	Total number of people with dementia
30-59	164	90	254	
60-64	163	50	213	188

65-69	194	110	304	284
70-74	358	366	724	621
75-79	290	558	848	847
80-84	334	825	1160	1082
85-89	187	621	807	1,348
90-94	113	434	547	
Total	1,803	3,054	**4,857**	**4,370**

7.9.24 Prevalence of Dementia in Malta

Alzheimer Europe estimates the number of people with dementia in Malta in 2005 as being between 3,148 (Ferri et al.) and 3.427 (Eurodem). This represents 0.78% (Ferri et al.) to 0.85% (Eurodem) of the total population of 402,668. The number of people with dementia in Malta as a percentage of the total population is much lower than the EU average of 1.14% to 1.27% (Ferri et al. and Eurodem, respectively).

It should be noted that due to the lack of availability of statistics from EUROSTAT for 2005 for the 90+ age group, these calculations probably underestimate the number of people with dementia in Malta. Statistics from the Maltese government indicate that there were 1,492 people aged between 90 and 100 in 2004. Using EURODEM prevalence rates, this would represent 319 people with dementia, which would bring the total number of people with dementia in 2005 to at least 3,746.

Table 1: The number of people with dementia in Malta in 2005

		Eurodem		**Ferri et al.**
	Men with dementia	Women with dementia	Total number of people with dementia	Total number of people with dementia
30-59	136	76	212	
60-64	147	47	194	174
65-69	176	104	281	264
70-74	276	315	590	509
75-79	214	406	620	620
80-84	329	582	911	857
85-89	196	423	619	724
Total	1474	1,953	**3,427**	**3,148**

7.9.25 Prevalence of Dementia in the Netherlands

Alzheimer Europe estimates the number of people with dementia in the Netherlands in 2005 as being between 165,585 (Ferri et al.) and 183,485 (Eurodem). This represents 1.02% (Ferri et al.) to 1.13% (Eurodem) of the total population of 16,305,526. The number of people with dementia in the Netherlands as a percentage of the total population is a little lower than the EU average of 1.14% to 1.27% (Ferri et al. and Eurodem, respectively).

We would like to point out that the Dutch Alzheimer Association has cautioned against the use of these prevalence rates (in particular the data from Ferri et al.), as the organization feels that these rates underestimate the size of the problem in the Netherlands as identified by the National Health Council, which published data on the prevalence of dementia in the Netherlands and estimated that there were 193,912 people with dementia in the Netherlands in 2005.

Nevertheless, in order to provide comparative data between the different countries, Alzheimer Europe includes here the calculations based on the Eurodem and Ferri prevalence rates.

Table 1: The number of people with dementia in the Netherlands in 2005

		Eurodem		**Ferri et al.**
	Men with dementia	Women with dementia	Total number of people with dementia	Total number of people with dementia
30-59	5,857	3,224	9,081	
60-64	6,531	1,930	8,462	7,417
65-69	7,132	3,837	10,969	10,163
70-74	12,156	12,132	24,288	20,808
75-79	9,572	17,988	27,560	27,576
80-84	14,434	29,225	43,659	40,940
85-89	8,530	25,975	34,505	58,682
90-94	4,637	15,750	20,387	
95-99	702	3,873	4,574	
Total	69,551	113,934	**183,485**	**165,585**

7.9.26 Prevalence of Dementia in Norway

Alzheimer Europe estimates the number of people with dementia in Norway in 2005 as being between 56,227 (Ferri et al.) and 61,077 (Eurodem). This represents 1.22% (Ferri et al.) to 1.33% (Eurodem) of the total population of 4,606,363. The number of people with dementia in Norway as a percentage of the total population is slightly higher than the EU average of 1.14% to 1.27% (Ferri et al. and Eurodem, respectively).

The Norwegian Alzheimer Association uses prevalence rates developed by Ott[60] et al which would result in greater numbers of people with dementia in Norway (i.e. 66,758).

Table 1: The number of people with dementia in Norway in 2005

		Eurodem		**Ferri et al.**
	Men with dementia	Women with dementia	Total number of people with dementia	Total number of people with dementia
30-59	1,580	860	2,439	
60-64	1,765	526	2,291	2,013
65-69	1,779	979	2,758	2,565
70-74	3,248	3,184	6,432	5,506
75-79	3,047	5,347	8,394	8,437
80-84	5,442	10,038	15,480	14,549
85-89	3,737	9,996	13,733	23,157
90-94	2,001	5,808	7,809	
95-99	320	1,421	1,741	

[60] Ott, A., Breteler,M.M., van Harskamp, F., Stijnen, T. & Hofman, A. 1998, "Incidence and risk of dementia. The Rotterdam Study", *Am.J.Epidemiol.,* vol. 147, no. 6, pp. 574-580

Total	22,919	38,158	**61,077**	**56,227**

7.9.27 Prevalence of Dementia in Poland

Alzheimer Europe estimates the number of people with dementia in Poland in 2005 as being between 300,447 (Ferri et al.) and 350,511 (Eurodem). This represents 0.79% (Ferri et al.) to 0.92% (Eurodem) of the total population of 38,173,835. The number of people with dementia in Poland as a percentage of the total population is considerably lower than the EU average of 1.14% to 1.27% (Ferri et al. and Eurodem, respectively).

Table 1: The number of people with dementia in Poland in 2005

		Eurodem		**Ferri et al.**
	Men with dementia	Women with dementia	Total number of people with dementia	Total number of people with dementia
30-59	12,583	7,248	19,831	
60-64	10,785	3,896	14,681	13,604
65-69	14,496	9,831	24,326	20,302
70-74	26,116	32,651	58,766	45,196
75-79	19,232	46,452	65,683	62,524
80-84	23,670	59,260	82,930	77,380
85-89	10,711	34,807	45,518	81,441
90-94	7,719	24,493	32,212	
95-99	1,314	5,249	6,563	
Total	126,625	223,886	**350,511**	**300,447**

7.9.28 Prevalence of Dementia in Portugal

Alzheimer Europe estimates the number of people with dementia in Portugal in 2005 as being between 119,308 (Ferri et al.) and 129,916 (Eurodem). This represents 1.13% (Ferri et al.) to 1.23% (Eurodem) of the total population of 10,529,255. The number of people with dementia in Portugal as a percentage of the total population is slightly below the EU average of 1.14% to 1.27% (Ferri et al. and Eurodem, respectively).

The Alzheimer Europe figures underestimate the number of people with dementia in Portugal, as it was impossible to obtain sufficiently detailed population statistics for the number of people in Portugal over the age of 94.

Table 1: The number of people with dementia in Portugal in 2005

		Eurodem		**Ferri et al.**
	Men with dementia	Women with dementia	Total number of people with dementia	Total number of people with dementia
30-59	3,448	2,016	5,464	
60-64	3,997	1,366	5,363	4,892
65-69	5,296	3,211	8,507	8,040
70-74	9,728	10,484	20,212	17,375
75-79	7,600	14,681	22,281	22,254

80-84	11,275	20,598	31,873	29,964
85-89	6,583	16,009	22,592	36,784
90-94	4,086	9,537	13,624	
Total	52,013	77,903	**129,916**	**119,308**

7.9.29 Prevalence of Dementia in Romania

Alzheimer Europe estimates the number of people with dementia in Romania in 2005 as being between 172,130 (Ferri et al.) and 200,893 (Eurodem). This represents 0.79% (Ferri et al.) to 0.93% (Eurodem) of the total population of 21,658,528. The number of people with dementia in Romania as a percentage of the total population is much lower than the EU average of 1.14% to 1.27% (Ferri et al. and Eurodem, respectively).

Table 1: The number of people with dementia in Romania in 2005

		Eurodem		**Ferri et al.**
	Men with dementia	Women with dementia	Total number of people with dementia	Total number of people with dementia
30-59	7,045	4,043	11,088	
60-64	7,259	2,564	9,823	9,045
65-69	10,321	6,748	17,069	14,158
70-74	17,687	20,344	38,030	29,142
75-79	13,279	26,326	39,605	38,174
80-84	16,015	31,677	47,692	44,747
85-89	6,006	14,849	20,856	36,863
90-94	4,727	9,518	14,246	
95-99	788	1,696	2,484	
Total	83,127	117,766	**200,893**	**172,130**

7.9.30 Prevalence of Dementia in Slovakia

Alzheimer Europe estimates the number of people with dementia in Slovakia in 2005 as being between 38,232 (Ferri et al.) and 44,813 (Eurodem). This represents 0.71% (Ferri et al.) to 0.83% (Eurodem) of the total population of 5,384,822. The number of people with dementia in Slovakia as a percentage of the total population is much lower than the EU average of 1.14% to 1.27% (Ferri et al. and Eurodem, respectively).

Table 1: The number of people with dementia in Slovakia in 2005

		Eurodem		**Ferri et al.**
	Men with dementia	Women with dementia	Total number of people with dementia	Total number of people with dementia
30-59	1,793	1,028	2,821	
60-64	1,657	619	2,276	2,129
65-69	1,731	1,236	2,967	2,498
70-74	3,099	4,074	7,173	5,529
75-79	2,380	5,763	8,143	7,751
80-84	3,427	8,100	11,527	10,769

85-89	1,357	3,856	5,213	9,557
90-94	1,085	2,862	3,947	
95-99	177	568	745	
Total	16,707	28,106	**44,813**	**38,232**

7.9.31 Prevalence of Dementia in Slovenia

Alzheimer Europe estimates the number of people with dementia in Slovenia in 2005 as being between 19,302 (Ferri et al.) and 21,788 (Eurodem). This represents 0.97% (Ferri et al.) to 1.09% (Eurodem) of the total population of 1,997,590. The number of people with dementia in Slovenia as a percentage of the total population is slightly lower than the EU average of 1.14% to 1.27% (Ferri et al. and Eurodem, respectively).

Table 1: The number of people with dementia in Slovenia in 2005

		Eurodem		**Ferri et al.**
	Men with dementia	Women with dementia	Total number of people with dementia	Total number of people with dementia
30-59	716	388	1,104	
60-64	799	259	1,058	951
65-69	942	572	1,514	1,431
70-74	1,604	1,976	3,581	3,096
75-79	1,115	2,834	3,949	3,877
80-84	1,317	3,911	5,228	4,860
85-89	558	2,101	2,659	5,087
90-94	503	1,751	2,254	
95-99	73	369	443	
Total	7,626	14,162	**21,788**	**19,302**

7.9.32 Prevalence of Dementia in Spain

Alzheimer Europe estimates the number of people with dementia in Spain in 2005 as being between 533,388 (Ferri et al.) and 583,208 (Eurodem). This represents 1.24% (Ferri et al.) to 1.36% (Eurodem) of the total population of 43,038,035. The number of people with dementia in Spain as a percentage of the total population is somewhat higher than the EU average of 1.14% to 1.27% (Ferri et al. and Eurodem, respectively).

However, on the basis of a door to door survey carried out by Jesús de Pedro in 2003, Fundación Alzheimer España estimate the population of people over 65 to be 6,900,000 and the prevalence rate to be 12%. This would mean that 850,000 people over the age of 65 had dementia, of which they estimate that between 380,000 and 390,000 would have Alzheimer's disease.

Table 1: The number of people with dementia in Spain in 2005

		Eurodem		**Ferri et al.**
	Men with dementia	Women with dementia	Total number of people with dementia	Total number of people with dementia
30-59	14,907	8,300	23,207	
60-64	15,691	5,014	20,705	18,539

65-69	19,283	11,148	30,430	28,530
70-74	40,119	41,066	81,185	69,629
75-79	32,819	59,789	92,608	92,853
80-84	48,543	87,735	136,278	128,150
85-89	31,200	80,563	111,763	195,687
90-94	19,253	50,114	69,367	
95-99	3,980	13,685	17,665	
Total	225,795	357,413	**583,208**	**533,388**

7.9.33 Prevalence of Dementia in Sweden

Alzheimer Europe estimates the number of people with dementia in Sweden in 2005 as being between 128,220 (Ferri et al.) and 138,641 (Eurodem). This represents 1.42% (Ferri et al.) to 1.54% (Eurodem) of the total population of 9,011,392. The number of people with dementia in Sweden as a percentage of the total population is considerably higher than the EU average of 1.14% to 1.27% (Ferri et al. and Eurodem, respectively).

Table 1: The number of people with dementia in Sweden in 2005

		Eurodem		**Ferri et al.**
	Men with dementia	Women with dementia	Total number of people with dementia	Total number of people with dementia
30-59	2,997	1,637	4,634	
60-64	4,278	1,258	5,536	4,846
65-69	4,325	2,309	6,635	6,139
70-74	7,416	7,231	14,647	12,535
75-79	6,875	11,882	18,757	18,873
80-84	12,776	21,636	34,412	32,413
85-89	9,095	21,512	30,607	53,413
90-94	5,260	13,722	18,982	
95-99	829	3,601	4,431	
Total	53,851	84,790	**138,641**	**128,220**

7.9.34 Prevalence of Dementia in Switzerland

Alzheimer Europe estimates the number of people with dementia in Switzerland in 2005 as being between 88,900 (Ferri et al.) and 97,068 (Eurodem). This represents 1.20% (Ferri et al.) to 1.31% (Eurodem) of the total population of 7,415,102. The number of people with dementia in Switzerland as a percentage of the total population is slightly higher than the EU average of 1.14% to 1.27% (Ferri et al. and Eurodem, respectively).

The Alzheimer Europe figures underestimate the numbers of people with dementia in Switzerland, as it was impossible to obtain detailed enough population statistics of the numbers of people in Switzerland over the age of 94.

Table 1: The number of people with dementia in Switzerland in 2005

		Eurodem		**Ferri et al.**
	Men with dementia	Women with dementia	Total number of people with dementia	Total number of people with dementia

30-59	2639	1477	4116	
60-64	3151	973	4124	3658
65-69	3302	1886	5189	4855
70-74	5865	6112	11977	10281
75-79	4868	9363	14231	14218
80-84	7995	15329	23325	21901
85-89	5535	14230	19765	
90-94	3777	10565	14342	
Total	37132	59936	**97068**	**88900**

7.9.35 Prevalence of Dementia in Turkey

Alzheimer Europe estimates the number of people with dementia in Turkey in 2005 as being between 78,546 (Ferri et al.) and 129,715 (Eurodem). This represents 0.11% (Ferri et al.) to 0.18% (Eurodem) of the total population of 71,607,500. The number of people with dementia in Turkey as a percentage of the total population is much lower than the EU average of 1.14% to 1.27% (Ferri et al. and Eurodem, respectively).

The Alzheimer Europe figures significantly underestimate the numbers of people with dementia in Turkey, as it was impossible to obtain sufficiently detailed population statistics of the numbers of people in Turkey over the age of 74.

Table 1: The number of people with dementia in Turkey in 2005

		Eurodem		**Ferri et al.**
	Men with dementia	Women with dementia	Total number of people with dementia	Total number of people with dementia
30-59	20454	11268	31722	
60-64	15042	4763	19805	17690
65-69	17089	9730	26818	21736
70-74	25701	25669	51370	39120
Total	78286	51430	**129715**	**78546**

7.9.36 Prevalence of Dementia in the United Kingdom

Alzheimer Europe estimates the number of people with dementia in the United Kingdom in 2004 as being between 621,717 (Ferri et al.) and 660,573 (Eurodem). This represents 1.04% (Ferri et al.) to 1.11% (Eurodem) of the total population of 59,699,828. The number of people with dementia in the United Kingdom as a percentage of the total population is slightly lower than the EU average of 1.14% to 1.27% (Ferri et al. and Eurodem, respectively).

The Alzheimer Europe figures underestimate the numbers of people with dementia in the United Kingdom, as it was impossible to obtain sufficiently detailed population statistics of the number of people in the United Kingdom over the age of 89.

Alzheimer Scotland for example estimates the number of people with dementia in Scotland as 62,000 in 2004, based on national 2004 population projections, which would yield a higher UK figure of 756,500 in 2004. This figure was calculated on the basis of prevalence rates provided by

Harvey[61] and Hofman[62], and population statistics provided by the Government Actuary Department. The latest estimate of the Alzheimer's Society for the UK is 750,000, similar to the Scottish estimate.

Table 1: The number of people with dementia in the United Kingdom in 2004

		Eurodem		**Ferri et al.**
	Men with dementia	Women with dementia	Total number of people with dementia	Total number of people with dementia
30-59	19752	11332	31084	
60-64	22958	7155	30113	26779
65-69	27900	15246	43147	40076
70-74	49535	48850	98385	84242
75-79	41481	73924	115405	115880
80-84	67465	124673	192137	180577
85-89	40812	109490	150302	174162
Total	269903	390670	**660573**	**621717**

[61] Harvey R (1998) *Young onset dementia: epidemiology, clinical symptoms, family burden, support and outcome* London Dementia Research Group, Imperial College School of Medicine

[62] Hofman A, Rocca WA, Brayne C, Breteler MMB et al (1991), *The* prevalence of dementia in Europe: a collaborative study of 1980-1990 findings, *International Journal of Epidemiology* 20(3) 736-48 (EURODEM)

8 WP 8 – Socio-economic impact

Anders Wimo, WP8 leader.

8.1 Introduction

In order to describe and analyse the socio economic impact of AD, the WP 8 of EuroCoDe has 2 basic aims:

- To make an inventory and comparative report of existing studies.
- To present a consensus document on the socio-economic impact of dementia in Europe.

To fulfill these aims, the WP8 consists of several experts from different parts of the EU:

- Associate professor Anders Wimo, Karolinska Institutet (Sweden)
- Research Fellow David McDaid, London School of Economics (UK)
- Professor László Gulácsi , Corvinus University (Hungary)
- Dr Linus Jönsson, European Health Economics (UK)
- Professor Hannu Valtonen, University of Kuopio (Finland)
- Dr Alan Jaques, Alzheimer Europe
- Dr Paul Kenigsberg, Fondation Médéric Alzheimer (France)

To describe the cost of illness of a disease or group is diseases with a chronic progressive long lasting course, some basic points need to be discussed:

- The health economical context (welfare theory)
- Costing taxonomy
- Perspective
- The top-down vs the bottom up approach
- Gross costs (total costs) vs net costs (incremental costs)
- Prevalence or incidence based approach
- The contribution of informal care
- Different care systems in Europé (financing and organisation of care)

For this project, we have also identified some areas of particular importance:

- Care systems for dementia in EU: Long term care resources, day care, home services
- Informal care in EU
- Dementia care in Eastern Europe
- Diagnostic costs
- Drug treatment

A number of particular features of the dementias as illnesses make any estimation of socio-economic cost more complicated than for many other illnesses. These aspects will also have some policy implications:

The boundary between dementia and the normal psychological changes of old age is vague, and there may be conditions which are intermediate in type but do not always lead on to dementia (e.g. Mild cognitive impairment).

1. Dementia is a syndrome with a few common and very many rare causes. The commonest types are Alzheimer's type, vascular dementia and dementia with Lewy bodies. The clinical features of these illnesses differ somewhat, but there is considerable overlap and differential diagnosis is difficult. Indeed there are probably many mixed cases and the nosology of dementia remains controversial.
2. People with mild memory problems have traditionally been reluctant to seek help and there has been a parallel reluctance by doctors to make an early diagnosis. This situation has changed somewhat since the advent of drug treatments used in the early stages of dementia, but it is still common in many parts of Europe for dementia not to be diagnosed till the illness has been established for some years, or even never to be definitively diagnosed.
3. The quality of both syndrome and illness diagnosis is very variable, ranging from 'end of the bed' general practitioner diagnosis to specialist diagnosis in multi-disciplinary memory clinics.
4. Although dementia is generally a disorder of older people (median age in the early 80s), there are a significant number of early onset cases still of working age. The socio-economic costs of early-onset dementia are quite different from those of late onset dementia.
5. The course of dementia is usually long and very variable. Survival times have generally been increasing, presumably due to improvements in general care standards, but are likely to vary considerably from area to area. Survival of 10 to 15 years is now not unusual, but median times have been difficult to estimate.
6. Although institutional care is a common endpoint in severe dementia, the stage at which individuals enter continuing care varies very considerably, depending most crucially on the availability of informal and formal support in the community, but also on clinical features and availability of institutional care.
7. Informal carers, mainly family members, play a central role in the community care of people with dementia. The cost of family care is notoriously difficult to estimate.
8. Treatment and care is provided to people with dementia and their carers from a bewildering variety of providers. Medical care may be largely from primary health care, or there may be specialist input from neurologists, geriatricians, or from general or old age psychiatrists. A wide range of health professionals, including community based nurses, clinical psychologists, occupational therapists and many others, may also be involved from time to time during the course of the illness. Community supports and practical help may be given by these health services or by various public social services, by private (for profit) organisations or by voluntary (not for profit) organisations such as Alzheimer associations. Institutional care

may be provided by any from these care sectors. No particular profession or provider group has overall or even specific responsibility for the care of people with dementia

9. The balance of care provision between community and institutional care and within the community and within each of these stages of care varies greatly from area to area and country to country.

8.2 The working group of WP 8

The team members in WP8 have different profiles in the project.

Hannu Valtonen is focusing on care systems and will put the work in WP8 in a basic theoretical health economical framework.

He will classify European countries health care and social care systems in terms as "Nordic welfare system", "Family based systems", "Market oriented systems" or something similar and then put the cost of illness figures from different European countries in a care system framework.

Anders Wimo, Linus Jönsson and Anders Gustavsson (assistant to Dr Jönsson) are working in the following areas:

- Present a definition of socioeconomic impact as defined in application and also definition(s) of cost of illness.
- Present estimates of cost of illness of dementia in Europe, based on costing models.
- Present available results regarding differences in costs of different types of dementia, such as AD, VaD, PDD.
- Present costs of dementia diagnostics from two levels: basic diagnostics and extended diagnostics at the specialist level.

David McDaid is focusing on informal care.

- The literature search will focus both on quantitative data of the amount of informal care as well as describe costing methods of informal care.
- Discuss "new" components of informal care such as immigrants from eg Eastern Europe, Philippines, North Africa and real "black market" carers vs traditional carers such as spouses, children.

Lazslo Gulasci and his assistant Kristian Karpati are working on the care patterns of dementia in Eastern Europe. Since empirical data from this part of Europe is limited, they are focusing on a project aiming at collecting such data.

Alan Jaques will use Alzheimer Europe´s network to describe care organisation for dementia in the different European countries. He will also describe the consequences for early onset of dementia for the families: lost income, costs of care etc.

Paul Kenigsberg is making search in French databases regarding the socio-economic impact of dementia. He is also organising translations of papers in French, but also German and Italian. Other tasks is to describe French system with taxation relief if private staff is employed to do social care (not nursing), to make database search regarding differences in dementia care due to rural/urban living but also due to different socioeconomic status of patients and caregivers, to discuss the

influence of disability and economic allowance from society due to that and to present a simple figure for theory of change (based on hypothesis, identification of problems etc).

8.3 Findings - Result of the literature search and methodological overviews

8.3.1 Provision and utilisation of health services - the economic questions

Hannu Valtonen

8.3.1.1 Need, supply, demand and utilisation

For each individual, the utilisation of health services seems to be quite unproblematic - we go to doctor when we feel ourselves ill. If the illness turns out be of more severe kind, the doctor sends us to hospital, and finally, when the illness has been cured, we get out of the hospital. However, even as individuals, we may think e.g. that 'is this really so severe that I have to go to see a doctor? Is this worth a visit?' When we look at the whole health care system, then the determination of the utilisation is not simple, and it is not based only on the need of health care. In economics, we study the determination through the concepts need, demand and supply of health services, that together determinate the amount of services used in a given country during any given year.

By demand of health services we mean the amount of services people are willing to use with given prices. The 'prices' here refer not only to the user charges, but all the trouble and effort needed (travelling, time etc.) to obtain the services. The supply of services is defined respectively, it is the amount of services the suppliers (doctors, health care institutions) would be willing to produce in given circumstances. The determination of the supply of health services varies from country to another, depending on the national policies concerning the organisation of health services (production; private, public etc; and financing, taxes, insurance, public and private) and the economic potential of the country (the availability of both manpower and monetary resources).

The actual quantity of services is determined by both demand and supply, and both of these forces may have an independent effect on the utilisation of services. For example, if in some region, some new health care institutions are built, this new capacity may increase the used amount of services even if the needs of the population were unchanged.

Short definitions for these concepts are:

- **need of health services -** morbidity, health status, ability to benefit from health services
- **demand of health services** - the amount of health services people are willing to use determined by the health needs and other demand affecting factors
- **supply of health services** - the amount of health services the providing organisations would be willing to supply for the people, the amount and organisation of the service supply depends on national policies and the economic potential of the country
- **use of health services** - the amount of health services people are actually consuming, determined by demand and supply.

The demand for health services is influenced by other factors than need for the services. These factors are such as gender, incomes, socio-economic status and education (with given needs, the

utilisation of services is higher in higher income as well as higher socio-economic and educational groups, or various cultural factors, with given needs and incomes, the utilisation of services varies across population groups with different cultural background). There may be many different 'other factors' so that an exhaustive listing of them is not possible.

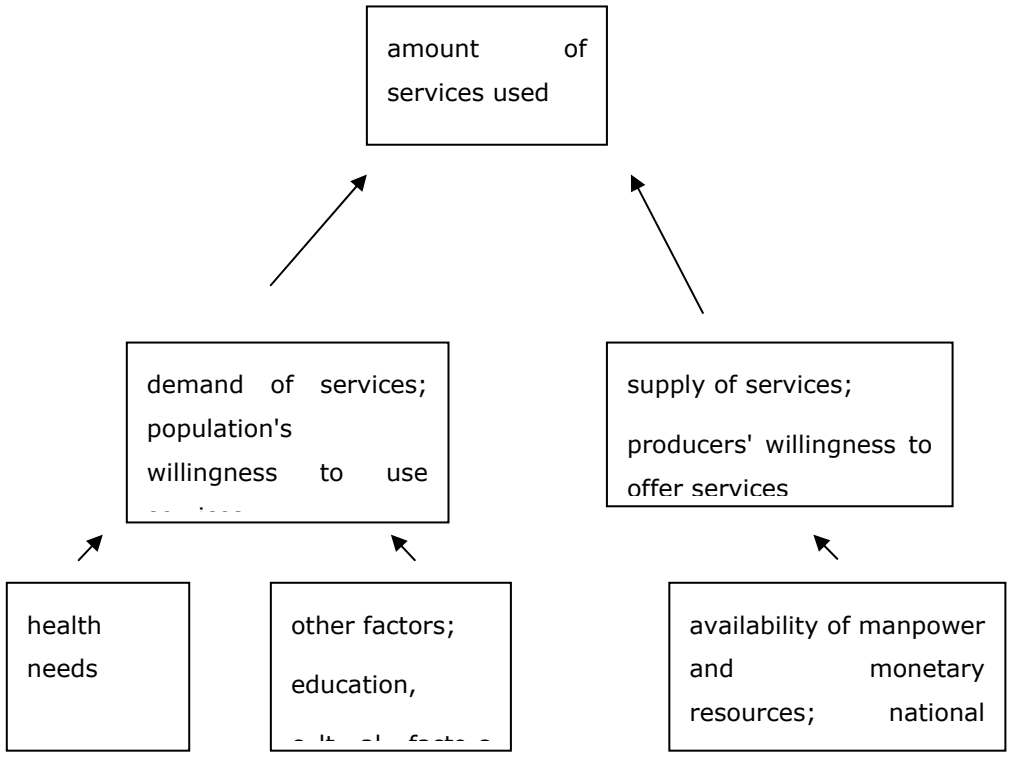

Figure 1. The determination of the utilisation of health services

The socio-economic impact of any disease is linked with the determination of the health service utilisation: When a person is ill, he or she (and in fact the whole society) looses some welfare because of the illness (morbidity, mortality). These welfare losses can be diminished by appropriate treatments, but the treatments require some resources that could have been used in some other activity to improve the welfare of the population (i.e. health care resources have opportunity costs). The size and the nature of both welfare losses and resource burden - the impact of an illness - are determined in the complex interaction of need, demand, and supply. For policy purposes, both the size of these effects at some point of time (static picture of the phenomenon) and the mechanisms determining them (dynamics of the phenomenon) are important.

The socio-economic impact of dementia and Alzheimer's disease can be defined as comprising of these two components:

1) the welfare losses due to the disease, and

2) the resources devoted in diminishing and preventing these welfare losses.

The components are measured in different units because welfare losses (anxiety, pain, suffering, death, for individuals and their families) cannot and should not be measured in monetary terms,

whereas the value of resources used in health and social care are to a large extent easily measurable in monetary terms. If indirect costs (production losses) are to be included in the costs, they should be kept separate from real resource costs.

All welfare losses due to dementia cannot be compensated, removed or prevented, but the progress of the illness might be changed, and the coping of the individuals and their families can be improved. The aim of the impact estimation should thus be

1) to estimate the scale of the problem (welfare losses, preventable welfare losses)
2) to estimate much and in what structures resources (formal and informal) are allocated to dementia care, and after 1) and 2) are known
3) to evaluate how the amounts and organisation of the resources could be reorganised in order to use the resources in diminishing the welfare losses as much as possible and reasonably compared to other welfare needs of the population.

8.3.1.2 Need and demand of health services

Term 'need' means in different contexts different things. In health economics, we use this term in both objective and subjective sense (see e.g. Mooney 2003, 50-59). We may talk about subjectively felt 'perceived need' when individuals feel that now they have to go doctor. A person is said to have need for health services, when a doctor after making a diagnosis states that the person in question has a disease that can be treated with some health services. I.e. the person can benefit from health services. The term 'objective' refers always to some outsider (doctor, nurse, health care professional etc.) making the evaluation of the need from outside. A person may have subjective need for health services, when according to his own evaluation (e.g. perceived health in surveys) of his health is weak, and he could benefit from the health services. The objective and subjective definitions of need are different perspectives to health. They are not competing views of the need for services, and we cannot say that other of them is wrong.

Need can be measured both at individual level and at population level. At individual level e.g. perceived health is a valid subjective measure of health status. Objective measures that are often used, are e.g. the presence of long-term illnesses or a professional evaluation of a person's health status. At population level, e.g. morbidity figures express the health status of a population (like Estonians) to another population (Finns).

For our purposes it is important to remember that 'need' can also be defined as 'capacity to benefit', because this definition leads us to think how well the health and social services are organised - is all the 'capacity to benefit' met?

Need for health services leads to demand of health services. This means that when a person or her doctor feels that she needs health services, she is also willing to use them. People are willing to consume health services, because they feel that they need them, they are sick or the doctor is telling them that they should have some treatments or examinations.

But, there are also other things that may have an effect on demand (people's willingness to use health services). One of them is quite obviously the incomes - if people have to pay all the costs of the health services they are using, the people with low incomes can use smaller amounts of services than richer people, even if their need for services is the same. We may reasonably assume that if

the prices people are paying from their own pockets increase, the demand for health services decreases. If the prices of any good increase people can afford them less. In many health care systems the patients have to pay some out of pocket payments for the services they use. If these payments are high, they may prevent the poorer parts of the population from using health services. Thus, in addition of the need for care also the ability to pay (disposable incomes) has an effect on the demand, the amount of health services the population is willing to use.

Other factors that have similar effect than money prices are time costs - if a person has to travel long time to get to a doctor, the time may affect the behaviour in the same way as money prices.

Further, it is known from different studies that there are also some other factors that affect on demand in addition of need and incomes, and time costs. It seems that in all countries, people with higher education also are willing to use more health services than people with lower education. There are also other things that may affect on demand, such as sex, age, educational level, all sorts of cultural differences etc. Men and women, or people at different ages may behave very differently when thinking about going to see a doctor even if their need were the same.

8.3.1.3 Supply of health services

In the figure, we have the determination of the utilisation of health services. The demand alone can not determinate the amount of services used during a given year, i.e. the people may be willing to consume more services than what actually will be consumed. In the determination of the utilisation we need also the concepts of supply: somebody must supply the services, there must be a capacity to provide health services. The institutions and persons providing the services are willing to produce some amount of services depending on the capacity, availability of hospital beds, personnel etc. If the population is willing to use more services than what is available, the willingness to use does not change into utilisation.

We can empirically measure the supply by various health care capacity measures, numbers of different groups of personnel, available beds, numbers of primary care doctors etc.

8.3.1.4 Utilisation of health services

This is why the utilisation of services is a result of two different societal forces: demand and supply. In health care, the supply has a relatively larger impact on service utilisation than in many other service or commodity markets. This is due to the agency relationship: The supplier of health services (doctor, health care professional) knows usually more about the illnesses, treatments and their potential effectiveness than the patient does, and consequently the supplier has to act as an agent for the patient, representing her. Because of this information asymmetry, relatively much power is located in the supply side. Sometimes it can be said that these services are 'supply-led' services indicating that supply organisation determines the utilisation of the services.

In studying the amount and nature of the services used, in the case of dementia, informal care is important. It is not as easily measurable and registered in various statistics as the formal care.

> "The annual cost of providing informal care to elderly community-dwelling veterans with dementia was estimated to be $18,385 per patient in 1998. The larger components of this cost are caregiving time ($6,295 - 34 %, hv) and caregiver's lost earnings ($10,709 - 58 %, hv). All aspects of costs increase with disease severity and problem behavior. Most of this cost increase derives from the increased caregiving time required for the provision of physical

care." (Moore, M.J. - Zhu, C.W. - Clipp, E.C., Informal costs of dementia care: estimates from the National Longitudinal Caregiver Study. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences* 56:S219-S228 (2001)).

8.3.1.5 Examples of the determination of the utilisation of care:

Overall, the most important background factor was whether the demented person and the caregiver lived together or not. --- Regarding informal support in ADLs, the most important patient related factors were severity of dementia and behavioural disturbances, while important caregiver related factors were low age, a paid remuneration to the caregiver for part of the time and an expressed wish to care. A high coping ability was associated with a greater support in IADL while behavioural disturbances and patient age were associated with supervision. The total informal care time was associated with patient age, the amount of formal care and behaviour. (Wimo, a. et al., Time spent on informal and formal care giving for persons with dementia in Sweden, Health Policy 61 (2002) 255–268).

Barriers to use of formal services: Stigma of dementia, lack of privacy, beliefs and attitudes, lack of awareness, acceptability and accessibility of services, service delivery challenges (Morgan, D.G. Rural families caring for a relative with dementia: barriers to use of formal services, Social Science & Medicine 55 (2002) 1129–1142)

Predisposing (i.e., satisfaction with service use, caregiver/care recipient relationship, demographic characteristics of the caregivers), enabling (knowledge of and barriers to service use, availability of health insurance, location, transportation, assistance from other informal helpers), and need variables explained 40.9% of the variance in service use, 29.8% of the variance in health service use, and 38.1% of the variance in the use of human services. Enabling variables explained more variance in the use of health and human services than did need or predisposing variables. In contrast to the health services utilization literature that points to the importance of need variables, the results of this study lend support to findings in the caregiving literature that indicate that enabling variables are at least as important as need variables in predicting the use of community services by family caregivers of persons with dementia (emphasis - HV). (Toseland, R.W., Predictors of health and human services use by persons with dementia and their family caregivers, Social Science & Medicine 55 (2002) 1255–1266)

8.3.1.6 The dynamics of dementia care utilisation and the socio-economic impact

To be able to correctly estimate the socio-economic impact of dementia and Alzheimer's disease, we should estimate both the welfare losses and the amounts and the value of resources devoted to dementia care.

Welfare loss measures:

- prevalence and incidence
- severity distribution of the illness
- potential of (ideally organised) health and social services to diminish the welfare losses; or the capacity to benefit

Resource use and structure (organisation of provision and financing):

- formal services, health services (at each tier), social services
- informal care

In any country, there is some existing formal health and social care system, and an informal care (family, relatives) care system. In any given year the actual costs of dementia care are the costs of this formal (such as salaries) and informal care (in many cases spouse's time, mental and physical effort) system. If the formal care system costs seem to be small, we cannot conclude that the impact of dementia is small, because in that case the care resource burden is allocated to the families and some of it is visible in the welfare losses of the population.

8.3.1.7 References

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8.3.2 Cost of illness of dementia/AD

Linus Jönsson, Anders Wimo, Anders Gustavsson

A literature review was conducted for papers reporting data on costs of care for patients with diagnosed dementia or possible/probable Alzheimer's disease.

Two approaches was used, the first includes only papers reporting original, patient-level data, the second includes top-down cost-of-illness studies or similar.

The advantage with the first approach is that it allows stratification on disease severity and therefore is useful for modeling purposes. Also, when patient-level data is available it is straight forward to incorporate the uncertainty around the cost estimates in a stochastic economic evaluation.

This is considerably more complicated when costs are derived from multiple sources or based on top-down cost of illness estimate where data is only presented on the aggregate levels. On the other hand, top-down studies may reflect the care system in a better way.

For European specific studies, Medline, EMBASE and Current Contents were searched for the following terms (in any field):

(Dementia OR Alzheimer*) AND (Cost OR Economic) AND (Europe* OR Austria OR Belgium OR Cyprus OR Czech Republic OR Denmark OR Estonia OR Finland OR France OR Germany OR Greece OR Hungary OR Ireland OR Italy OR Latvia OR Lithuania OR Luxembourg OR Malta OR Netherlands OR Norway OR Poland OR Portugal OR Slovakia OR Slovenia OR Spain OR Sweden OR Switzerland OR United Kingdom)

where * is the wildcard character. There was no limitation in the year of publication.

525 references were identified in the automatic database search. Titles were then reviewed manually to exclude irrelevant papers. After this review, the abstracts of 53 remaining papers were retrieved and reviewed manually. After abstract review in total twelve references matching the criteria remained and were included in the review:

A general search has also been conducted in Ingenta, Cochrane Library, NHSEED/THA, HEED, PsycINFO, ERIC, Societal services abstracts and Sociological abstracts. The search terms (MESH/Subheadings when appropriate) were dementia/Alzheimer´s disease/Alzheimer disease combined with costs, economics. A total of 4,234 abstracts were identified during the first round (duplicates were not excluded; most were found in the broad Pubmed search on "dementia" and "economics": 1,116 hits). Obviously irrelevant papers could be excluded from titles or abstracts. Studies focusing on cost-effectiveness or similar were also excluded from this round.

Since methodological aspects are of interest, non-European studies and basic methodological references are so far included.

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8.3.3 Reviewing approaches to the costs of informal care in Europe and assessing methodological developments

David McDaid

8.3.3.1 Introduction

This short report is intended to provide an overview of work undertaken as part of the Eurocode project which focuses on assessing the socio-economic impact of informal (unpaid) care provider by family members of those living with dementia. While the key focus of this work is European, the analysis makes much use of data and methods developed in other parts of the world which are pertinent to the European context.

Specifically there are three key components of this work.

1) Undertake a systematic review to develop a literature map to update what is known about the social and economic costs and consequences of informal care for people living with dementia.

2) As part of this review to also identify recent methodological developments in both the measurement and valuation of the socio-economic impact of informal caregiving for people living with dementia.

3) To undertake an ancillary review to identify methodological developments for valuing informal care regardless of the disease condition addressed. For instance to what extent can developments in looking at the impacts on carers of people with strokes or chronic physical illnesses be transferred to the assessment of carers of people with dementia.

The ensuing sections outline some of the work undertaken to date during the first year of the project.

8.3.3.2 Background

It is important to recognise that there are both rewards and difficulties associated with caregiving; yet often, the positive aspects may be overlooked. This desire and willingness of family members to provide care can though mean that policy makers and other stakeholders are tempted treat informal care as a 'free resource'. However, it can entail significant economic costs for individuals and society. Economic analysis is primarily concerned with the opportunity costs of caring; i.e. what would have been done had an individual not been caring.

Caring for someone with dementia can sometimes be, literally, a 24-hour-a-day activity. While the availability of family carers may reduce the need for professional support, carers will incur a loss of time (and hence a cost) which they could have used for work, or to pursue leisure activities.

Individuals may become isolated from their social network of family and friends as the disease progresses and caregiving becomes a full-time occupation [1]. Evidence of high levels of distress and depression among carers of people with dementia can be seen in many studies of service users and in community surveys [2-6]. They may also incur additional out-of-pocket expenses to support a relative financially. There can also be adverse impacts on their physical health, e.g. as a result of the strains of helping an individual to cope with essential activities of daily living.

Inclusion of the full costs of caring can thus be very important in a comprehensive economic analysis and could make a difference when decision makers have to determine whether it is cost-effective to introduce specific services or programmes to support family caregivers or provide other interventions. It also provides an indication of the costs that may fall on statutory services in future if there is a shortage of such carers due to the ageing of the population in most European countries.

However, because of methodological difficulties in estimating informal care costs, and often too narrow a focus solely on the health care system alone, the cost to family carers has often been ignored within economic analyses. In particular, identifying the best alternative use of time is not always easy, particularly if a family carer already has been responsible, to some extent, for an individual - e.g. a spousal carer already undertaking a range of activities that benefit the whole household. This has led to a considerable variation in estimates of the cost of caring with estimates for Alzheimer's Disease and other dementias ranging from 36 to 85 per cent of total costs in one review [7].

Improving our understanding firstly of what is known about its *actual* impacts on caregivers in different settings and contexts across Europe is a key element of our literature review. A second issue is to look at the different ways in which the contributions of informal caregivers can be measured and the valuations attached to such contributions. Again variations in methods used can lead to substantially different estimates in the costs of care emerging. In undertaking this work it is important to recognise that work assessing the economic value of informal caring has not been restricted to dementia alone; estimates can for instance be found for other mental disorders as well as for physical diseases [8-10]. Our literature review also looks at the transferability and relevance of measurement and valuation methods used for carers of people living with other health problems.

8.3.3.3 Literature Review Methodology

8.3.3.3.1 Search protocol

Our literature review protocol has been developed in accordance with guidelines set out by the NHS Centre for Reviews and Dissemination.[11] Given the overlaps between literature on the economics of informal care generally and studies looking at dementia specifically all three elements of our review are being run concurrently.

8.3.3.3.2 Inclusion criteria

All studies must look at the economic impact of informal (i.e) unpaid care usually provided by family members. Help provided by volunteers, often through non governmental organisations is excluded from this review. Cost of illness studies which include the costs of informal care as part of their analysis are included. Given our remit no diseases areas are excluded but special attention is given to Alzheimer's Disease and related dementias.

8.3.3.3.3 Languages

No languages restrictions have been specified – translation of abstracts into English to determine relevance is undertaken as appropriate.

8.3.3.3.4 Time Frame

In terms of the time frame, no specific cut off has been set. While we recognise that this increases the amount of material to process, our view has been that this does not make the task unmanageable because of the limited production of economic information in this area. This being said it is of course a bias that many of the electronic sources of information used go no further back that the mid 1960s.

8.3.3.3.5 Geographical coverage

Our primary focus is on information from the EU, Candidate Countries and Associate Countries, plus Switzerland. There is much literature on informal care from other parts of the world; given our focus partly on methodological innovation we have not imposed any geographical restrictions on our search, although it should be noted that we did not seek to search and low and middle country only sources of information.

8.3.3.3.6 Economic analyses

In addition to 'cost of illness' studies which merely report the costs associated with an illness there are also a number of different approaches to the economic evaluation of interventions to alleviate the impact of poor health. Full details cannot be provided here, but there are some excellent accounts of health economic evaluation methods e.g. [12, 13]. Some of these evaluations will include the costs of informal care in their analysis; however to keep our literature review manageable we have not sought to specifically identify such economic evaluations but we should capture both interventions intended for informal carers e.g. respite care as well as other interventions through the use of informal care key terms and free text words.

8.3.3.3.7 Sources of information

In determining which databases to include in our search, we have in part been informed by a Health Development Agency (in England) /NICE publication on the flexibility and quality of databases that are broadly relevant to health related concerns [14]. This document provides an excellent guide to which databases make use of a suitable controlled vocabulary and general flexibility for searching. We are also mindful of the general guidance on reviewing in the social science which recommends that a broad range of bibliographic databases be searched [15].

Databases searched include most of the key medical bibliographic databases. These include the US National Library of Medicine's PubMed (Medline) database. This database includes a specific controlled vocabulary MeSH (Medical Subject Headings) for economic evaluation and public health interventions allowing a more precise search strategy to be developed.[16]

Other health related databases searched included Psychinfo (Formerly Psychlit) a database which includes many psychiatric and psychology journals not picked up within Medline. In addition we have searched CINAHL (The Cumulative Index to Nursing & Allied Health database covers nearly all English-language publications, including those of the American Nurses Association and the National

League for Nursing) and AGELINE which contains bibliographical details of literature on ageing and it is compiled by the American Association of Retired Persons (note US spellings). We chose not to search the EMBASE database on time grounds as previous work has shown that very few additional cost related papers are found compared with a search of Medline; in fact papers would be lost if Embase were to substitute for Medline.[17] Given our focus on economic methodologies we are also searching the Econlit database which indexes 800 economics journals.

Clearly it is advantageous if databases provide access to abstracts and use a standardised controlled vocabulary of key terms. With the exception of Econlit, whose interface is rather limited, all of the above databases do use such controlled vocabularies. Caution must be exercised however as the quality of indexing of studies, using controlled vocabulary terms is also important; even in databases such as Medline where specific terms exist to categorise economic evaluations for example, a high degree of papers are incorrectly classified, most likely because of the limited expertise of the librarians cataloguing papers in identifying what constitutes an economic evaluation.[17]

In going beyond databases with controlled vocabulary searching facilities, we had to trade off the potential for finding additional studies against the potential functional limitations of some databases. This might mean that we would spend much time retrieving a high number of irrelevant records, or have insufficient information to make any judgement on a paper.

Additional databases chosen included the International Bibliography of the Social Sciences (IBSS) and some French and Spanish databases - CISMeF (Catalogue and Index of Health Resources in French) [18] , as well as ISOC a database of social science and humanities journals, and IME a biomedical sciences database, both freely available via the Spanish Ministry of Education and Science.

8.3.3.3.8 Electronic search Strategy

Initial searches were conducted to help refine the strategy, trading the overall recall rate (number of search hits) with the precision of the search (number of relevant hits within any one search).

The search strategy used also had to be tailored to the restrictions of the different databases used. Where feasible (as with Medline) we have relied on structured key wording for both informal care and economic analysis. We have made use of strategy previously developed to identify health economic evaluations, that has a good level of precision but minimising recall and thus helps keep search manageable.[17] Thus in Medline we have used the following strategy

1. Home Nursing+ (MesH)
2. Caregivers+ (MeSH)
3. Dementia+ (MeSH)
4. Carer*.ti
5. Caregiv*.ti
6. Informal care.ti
7. 1 OR 2 OR 3 OR 4 OR 5 OR 6
8. Costs and Cost Analysis+ (MeSH)

9. economics.sh
10. 8 OR 9
11. 7 AND 10

All MeSH (Medical Subject Headings) have been exploded so as to pick up MeSH terms further down the classification hierarchy; economics as a subheading has also been used. In addition we have also searched for articles that include either carers or caregivers or informal care in the title. Only those papers with abstracts have been included. One limitation with this analysis is that it will miss papers currently being loaded onto Medline (as these papers will not as yet have MeSH terms) but again many of these should be picked up by our search for keywords in the title of articles. In Econlit we have focused on different terms for unpaid family carers only while in databases such as IBSS we have been restricted to using freetext terms in titles and abstracts only.

8.3.3.3.9 Econlit search strategy

1. Informal care – all fields
2. Caregiv* - all fields
3. Carer* - all fields
4. 1 OR 2 OR 3

Electronic search strategies have been saved where possible using the appropriate software platform so as to allow easy adaptation, updating and repeated testing of search strategies. This allows any key terms omitted to be added at a later stage if appropriate and then scrutinise only the additional references retrieved.

8.3.3.3.10 Handsearch

The gold standard of any literature review remains the handsearch and a number of key journals are being handsearched. (See Box 1) (Many journals have already published on-line issues until mid 2007). The handsearch is the ultimate recognition that many papers may be missed by electronic searches alone because of the vagaries of bibliographic coding systems; moreover some papers do not mention their economic component in their abstracts.

8.3.3.3.11 Snowballing

A 'snowballing' process has been adopted so that references of relevant papers (where available) were checked so as to potentially throw up other relevant papers.

8.3.3.3.12 Websites

Increasingly web sites provide a useful source of additional information. We will also searching a number of key websites which provide access to governmental and NGO reports as well as academic working papers. To complement this a strictly limited Google search with narrowly defined Boolean operators looking at informal care will also be conducted.

Box 1: Journals to handsearch (to be augmented)

Age and Ageing

Alzheimer's Disease and Associated Disorders

British Journal of Psychiatry
Dementia and Geriatric Cognitive Disorders
Health Economics
International Journal of Geriatric Psychiatry
Journal of Health Economics
Scandinavian Journal of Public Health
Social Science and Medicine

8.3.3.4 Reviewing method

Reviewing involves a two stage process; abstracts of papers identified from the electronic search are checked for relevance. If abstracts meet inclusion criteria they are coded and full papers obtained for subsequent detailed analysis. Only full papers (reviews, methods papers and original studies) were included – letters and editorials were excluded..

8.3.3.4.1 Coding and storage of studies found

We have used an approach recommended and developed by the Evidence for Policy and Practice Information Co-ordinating Centre (EPPI-Centre) at the Institute of Education, London. This approach allows detailed analysis of what might be very disparate sources of information, and has also been used to help in the review of information which crosses disciplinary boundaries.[19] For instance we can classify studies by country of authors, disease area for informal care, relationship of informal carers etc.

8.3.3.5 Preliminary Results

Over 3000 papers meeting our inclusion criteria were initially identified, including more than 2,687 (reduced to 2016 after limits applied) in Medline alone. Final inclusion figures are still being processed with some work on databases to be completed, with some data still needs to be entered into Access database. (See Next Steps). Few additional papers were found in Econlit for instance – in total 192 papers were initially identified – this was filtered down to 79 papers the majority of which were identified through Medline. Overall more than one third of papers focus on Alzheimer's Disease and Other Dementia's.

Our initial analysis also indicates that the evidence base on both the costs of informal care for Alzheimer's Disease and other dementias as well as the inclusion of informal care in estimates of costs in other areas is increasing with recent estimates identified across a number of European countries e.g. [20-23] as well as being a component of costs in some evaluations of drug and non-drug interventions e.g. [24-28]. In addition the literature on informal care costs from other parts of the world also continue to increase e.g. [29] There are also a number of studies which have sought to project the long term costs of Alzheimer's Disease and other dementia's across Europe and elsewhere– to varying extents these have sought to incorporate the costs of informal care [30].

Attempts to estimate the value of informal care can also been seen for other diseases and disabilities [31-33]. The techniques used may provide useful insights for future evaluations of the costs of dementia. There is also evidence of methodological development in the way in which the costs of informal care are both measured and valued [34]. Much of this work has been undertaken

within Europe, in particular the Netherlands where the use of contingent valuation and conjoint analysis as ways of eliciting the value of informal care have been recently assessed in caregivers of people living with severe arthritis [35-37]. Some specific work applying contingent valuation to informal carers of people with dementia can be identified [38].

Another approach is to look at the extent to which end of life transfer of assets compensates individuals for informal care activities [39]. There have also been some developments in the way in which caregiving activities are measured and in particular not only to more accurately identify time spent caring, but also to better identify subjective and objective burden[40] as well as 'process utility' or immediate rewards from the caregiving experience [41]. One continuing limitation generally appears to be a lack of information from the context of central and eastern Europe, although one small exploratory study of the costs of informal care for dementia in Turkey can be identified [42].

8.3.3.6 Next Steps

While we have made much progress in reviewing the literature, tasks still to be done include full analysis of existing articles retrieved as well as completion of the handsearch. A paper (and more detailed report) looking at recent innovations and continuing challenges in the valuation of informal care will be written. Information emerging out of this review will also be stored within an access database of papers that can be used to complement work being undertaken elsewhere in the project.

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8.3.4 Economic environment of Alzheimer's disease in France

Paul A Kenigsberg

8.3.4.1 Population and survival (1)

There were 800,000 dependent people in France in 1999. This number is expected to reach 1 million by the year 2030.

Age-related dependence is about 10% in men and women 80 years-old, and rapidly growing to reach 25% in men and 35% in women of 90 years-old. Projections of population have been made using a microsimulation model *(Destinie–modèle démographique économique et social de trajectoires individuelles simulées)* based on a representative sample of 170 000 individuals. Model

simulates transitions between states of dependence every year and takes into account the higher mortality of dependent persons. Event probabilities were derived through the HID survey (2). In a central scenario with stable morbidity, life years with dependence after 60 years old would remain stable for men and women. This means that onset of dependence and death date shift at the same rate. The number of dependent people corresponds to a 1.3% reduction of prevalence rate per year. In a pessimistic scenario, life years with dependence grow at the same rate as life expectancy at age 60, leading to a 0.8% prevalence rate per year. Part of additional life years would be life years with disability, life extension being enabled by technical and medical progress, as well as improvement of life conditions. The number of dependent people would grow by 26% between 2000 and 2030, to reach 1.04 million people (between 0.94 and 1.23 million depending on the scenario) . In all cases, increase would be faster after 2030 (baby boomers reaching ages of 80-85). The concept of life with disability does not take into account psychic disability, which obtained legal recognition very recently.

Only 6% of men and 16% of women live more than 5 years in dependence.

For dependent people, these proportions are 21% and 31%, respectively.

8.3.4.2 Assessment of dependence

The French administration has defined the necessary conditions for elderly, dependent people to be entitled to public monetary benefits, either at home or in an institution. People must be at least 60 years old. Autonomy assessment tool (national scale AGGIR - acronym for Autonomie, Gérontologie, Groupe Iso Ressource) (3) is based on 17 variables.

A set of 10 variables is used to describe domestic and social needs of dependent elderly people. These variables are not used in the calculation of public monetary benefits but are used to establish a personal assistance plan addressing budget and asset management, meal preparation, cleaning, transportation, purchasing, treatment follow-up, leisure activities.

Another set of 10 variables, related to physical and psychic autonomy loss, is used to segment patients into 6 iso-resource groups (groups consuming equal amounts of resources) :

- Group GIR 1 comprises elderly people confined to bed or armchair, with severely altered mental functions, needing essential and continuous presence of caregivers.
- Group GIR 2 concerns elderly people confined to bed or armchair, with intellectual functions not totally altered, in need of care for most activities of daily living. This group also comprises aging people with altered mental functions but still able to move.
- Group GIR 3 comprises elderly people with preserved mental autonomy, partially able to move, but needing assistance every day and several times a day for body care.
- Group GIR 4 concerns elderly people unable by themselves to stand up, lie down or sit, but who are able to move around their place when standing, sometimes requiring help for toilet and to get dressed. This group also concerns people with no locomotion problems but requiring help for body activities and meals.
- Group GIR 5 concerns elderly people only needing specific assistance for toilet, meal preparation and cleaning.

- Group GIR 6 concerns elderly people who did not lose their autonomy for essential activities of daily living.

8.3.4.3 Caregiver resource utilisation (4)

Resource utilisation for professionals and caregivers has been recently measured in a sample of 2,614 beneficiaries of public allowance for autonomy, according to living mode and level of dependence (see below) (5).

	average number of home caregiving hours delivered by informal and professional caregivers					
	professional aid only (33%)	informal aid only (4%)	mixed formal and informal aid			at least one aid (100%)
			together (63%)	professionals	informal	
Living mode alone	1h50	2h45	3h25	1h45	1h40	2h45
alone at home with other people	1h40	5h20	6h50	1h40	5h10	5h15
at another person's place or with other people in a housing	2h00	6h45	8h30	1h30	7h05	6h50
Level of dependence GIR 1	2h30	6h40	8h55	1h20	6h15	7h15
GIR 2	2h25	4h40	7h30	2h10	5h20	5h50
GIR 3	1h55	4h40	6h20	1h45	4h30	4h50
GIR 4	1h20	4h10	3h30	1h00	2h30	5h50
Total	**1h50**	**5h10**	**5h45**	**1h40**	**4h10**	**4h30**

8.3.4.4 Public funding for dependence

Public allowance for autonomy, set up in January 2002, allows partial funding for human assistance, technical assistance and specific housing installations for dependent people. It is granted only to people over 60 years old, belonging to groups GIR 1 to GIR 4, after individual medical and social assessment *(allocation personnalisée d'autonomie)*. Allowance tariffs are fixed by the Ministry of Social Affairs for both home assistance and institutional care. Allowance allocation is managed by local governments (Conseil Généraux). Allowance is granted upon first application for 76% of people asking for home assistance and 90% of people seeking institutional care.

A total of 971,000 persons were benefiting from a public autonomy allowance in June 2006, of whom 576,000 (59%) were living at home and 395,000 (41%) in institutions. For dependent persons living at home, 3% were assessed in GIR 1, 19% in GIR 2, 22% in GIR 3 and 56% in GIR 4. For dependent persons living in institutions, 16% were assessed in GIR 1, 43% in GIR 2, 16% in GIR 3 and 25% in GIR 4.

Maximum monthly allowances allocated to people belonging to the first 4 iso-resource groups were respectively 1,168 € (GIR 1); 1,001 € (GIR 2); 751 € (GIR 3); 500 € (GIR 4) (*January 2006 figures*). Average allowance granted by local governments was about 30% below the national maximum amount established by the Ministry of Social Affairs. Average monthly allowance for dependent people living at home was 476 €, raising with the level of dependence : 912 € (GIR 1); 724 € (GIR 2); 544 € (GIR 3); 341 € (GIR 4). Average monthly allowance for dependent people living in institutions was 402 € (478 € for combined GIR 1 and 2; 293 € for combined GIR 3 and 4).

There are no resource conditions for a dependent person to be entitled to the autonomy allowance (in accordance to equity principles), although a there is a co-payment based on the dependent person's income (because of shrinking government finances). An assistance plan is proposed to the dependent person, mentioning the level of co-payment. Costs of individual assistance plans use reference costs based on local governments tariffs.

For dependent people living at home, there is no co-payment when the dependent person's income is lower than 658 € per month (which is the case for 28% of dependent people living at home). There is a progressive co-payment until a monthly income of 2,622 €, then a 90% co-payment above this threshold.

For dependent elderly people living at home, local governments paid approximately 84% of individual assistance programs (average cost 476 € per month), with 16% co-payment from the dependent persons.

For dependent elderly people living in institutions, local governments covered only 68% of the dependence tariff (average 402 € per month; 478 € in GIR 1 or 2; 293 € in GIR 3 or 4).

Dementia-related dependence in the elderly has been studied in the PAQUID cohort (6). Dependence was assessed for basic activities of daily living among people above 75 years of age. Dependence for one of these activities requires external carer intervention. Among patients with dementia, 57% were dependent for at least one ADL and 14% were heavily dependent (dependence for 3 out of 4 activities – toilet, dressing, locomotion, feeding). About 14% of people above 75 years old were assessed as dependent (iso-resource groups GIR 1 to 4). Part of dementia was very important, as 72% of people assessed in GIR 1-4 groups showed dementia. This proportion reached 100% in the GIR 1 group (7). Among the heavily dependent people (2.8% of the study population), 88% had dementia.

8.3.4.5 Costs

Tables and texts are official material from the Parliament report 2005 on Alzheimer's and related diseases : Cécile GALLEZ. Rapport sur la maladie d'Alzheimer et les maladies apparentées. Office Parlementaire d'évaluation des politiques de santé. Assemblée Nationale, n°2454, 2005.

8.3.4.5.1 Alzheimer's disease direct medical costs (million €) - disease-specific (other age-related expenses excluded)

Category	Health insurance	Families	Total	%
Visits	94,20	10,50	104,70	11,21
Drugs	173,00	13,00	186,00	19,91
Hospital	62,53	0,00	62,53	6,75
Home nursing	580,34	0,00	580,34	62,13
Total medical costs	910,07	23,50	933,57	100,00
%	97,48	2,52	100,00	

8.3.4.5.2 Direct medical costs per known diagnosed person

Category	Health insurance	Families	Total	%
Visits	256,50	28,50,	285,00	6,84
Drugs	344,90	24,37	369,27	8,87
Hospital	173,52	11,00	184,52	4,43
Home nursing	3 326,00	0,00	3 326,00	79,86
Total medical costs	4 100,96	63,87	4 164,79	100,00

8.3.4.5.3 Medico-social costs (million euros)

	Health insurance	Local govt (conseil général)	Families (dependence)	Families (housing)	Total	%
Home	9,12	1280,21	359,54	0,00	1648,87	18,39
Home assistance	*0,00*	*1280,21*	*193,24*	*0,00*	*1 473,45*	*89,36*
of which informal assistance	*0,00*	*128,02*	*19,32*	*0,00*	*147,35*	
Day facility	*5,04*	*0,00*	*3,95*	*0,00*	*8,99*	*0,55*
Temporary housing	*4,08*	*0,00*	*162,35*	*0,00*	*166,43*	*10,09*
Long term housing	2 410,50	858,58	381,93	3 666,54	7 317,55	81,61
Total	2 419,62	2 138,79	741,47	3 666,54	8 966,42	100,00
%	26,99	23,85	8,27	40,89	100,00	

8.3.4.5.4 Medico-social costs per person (€ per year)

Home assistance	Amount	%
For-profit home assistance	8 628,00	64,83
Public-funded dependence assistance	*5 088,00*	*58,97*
Of which family co-payment	*768,00*	*8,90*
Other paid assistance	*2 772,00*	*32,13*
Non-profit assistance	4 680,00	35,17
Total	13 308,00	100,00

8.3.4.5.5 Total costs of Alzheimer's disease (in million euros)

Category	Health insurance	Local govt (conseil général)	Families	Total	%
Medical	910,07	0,00	23,5	933,57	9,43
Medico-social	2 419,62	2 138,79	4 408,01	8 966,42	90,57
Home	*9,12*	*1 280,21*	*3 59,54*	*1 648,87*	*18,39*
Institution	*2 410,50*	*858,58*	*4 048,47*	*7 317,55*	*81,61*
Ensemble	3 330,12	2 138,79	4 431,51	9 900,00	100,00
%	33,64	21,60	44,76	100,00	

8.3.4.5.6 Total cost per patient with Alzheimer's disease

Category	Total	%
	Home	
Direct cost		
Visits	285,00	1,63
Drugs	369,00	2,11

Hospital	185,00	1,06
Home nursing	3 326,00	19,04
Public dependence allowance	5 088,00	29,12
Family co-payment	768,00	4,40
Other paid assistance	2 772,00	15,87
Indirect cost		
Informal assistance	4 680,00	26,79
Total home	**17 472**	**100,00**
	Institution	
Direct cost		
Visits	285,00	1,07
Drugs	369,27	1,38
Hospital	184,52	0,69
Care	6 560,00	24,60
Dependence	4 872	18,27
Housing	14 400	53,99
Total institution	**26 671,00**	**100,00**

8.3.4.5.7 Total expenses per person for Alzheimer's disease (euros)

Categories	Health insurance	Local govt (conseil général)	Families	Total	%
Medical	5 727	0	64	5 791	26,21
Medico-social	0	4 225	12 082	16 307	73,79
Home	*0*	*2 529*	*4 085*	*6 614*	*29,93*
Institution	*0*	*1 696*	*7 997*	*9 693*	*43,86*
Total	5 727	4 225	12 146	22 099	100,00
%	25,92	19,12	54,96	100,00	

Families are the principal payors, with a 54.96% co-payment.

Total medico-social expenses (16,307 €) is split into 12,082 € paid by families and 4,225 by the local government (conseil general). Health insurance is the major payor of the medical component, paying 5,271 over 5,791 €. For the poorest people, social aid from the local government alleviates in part this need of financing. This aid is submitted to resource conditions and recuperation on estate. Considering a monthly average pension of 830 € for women and 1,460 € for men above 85 years old, annual cost represents for a woman 10 months of pension in an institution and 5 months at home, and for a man 7 months in an institution and 5 months at home (8,9). Complementary financing is an issue for middle-class persons, with a low estate and a revenue consisting mostly of pensions.

8.3.4.5.8 Direct and indirect cost of Alzheimer's disease by level of severity

Severity is expressed by *mini-mental state examination* (MMSE).

- medium, MMSE >20 ;

- moderate, MMSE (16 - 20) et MMSE (11 - 15) ;

- severe, MMSE ≤ 10.

8.3.4.5.9 Direct and indirect individual cost by level of severity for Alzheimer's disease (in euros)

	Medium		Moderate		Severe			
	MMSE (>20)	%	MMSE (16 - 20)	%	MMSE (11 - 15)	%	MSSE (≤ 10)	%
Direct medical								
Medical	494	5	759	4	962	4	1 223	4
Nursing	4363	43	4 650	28	4 957	20	6 040	18
day facility	30	0	39	0	44	0	53	0
Direct medico-social								
temporary housing	521	5	705	4	828	3	1 024	3
For-profit assistance	4 537	44	7 199	43	11 535	46	15 718	47
Subtotal	**9 946**	**97**	**13 352**	**79**	**18 325**	**73**	**24 058**	**72**
Indirect medico-social								
Nonprofit assistance	291	3	3 526	21	6 836	27	9 333	28
Total	**10 237**	**100**	**16 878**	**100**	**25 161**	**100**	**33 391**	**100**

Nursing costs and for-profit assistance represent at least two thirds of total direct costs. Direct medical and medico-social costs represent 97% of costs for patients at medium stage and more than 70% for others. Direct and indirect costs increase with the severity of the disease, in accordance with results obtained previously by some authors (10-12)as others show a more flexible relation between indirect costs and disease severity (13).

This may be explained by the fact that patients at the most severe stage of disease are not necessarily requiring more surveillance or an institutional placement, which decreases indirect costs (14). Furthermore, impact of disease severity on indirect costs largely depends on the calculation method used.

8.3.4.5.10 Institutional cost according to severity - Medico-social costs in institution by level of dependence for Alzheimer's patients (in million €)

GIR	Local govt (conseil général)	Families	Total	%
GIR 1 and 2	49,23	18,57	67,80	65,58
GIR 3 et 4	19,21	13,14	32,34	31,38
Total	71,55	31,83	103,38	100,00
%	69,21	30,79	100,00	

8.3.4.6 *References*

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8.4 Annex 1: Conclusions from the group meeting of WP8, Luxembourg Feb 25 and work that should be started before the next group meeting in November later this year.

Participants: Anders Wimo, Hannu Valtonen, David McDaid, Krisztian Karpati, Alan Jacques, Annette Dumas.

Absent: Linus Jönsson, Laszlo Gulacsi.

1. Anders Wimo and Linus Jönsson will present a methodological background to COI-studies.

2. Anders Wimo and Linus Jönsson will have the main responsibility for the literature review of what is written about the cost of illness of dementia/AD with a focus on European studies. The presented costs in the studies will, if possible be divided into cost categories (e.g. direct medical costs, direct non-medical costs, indirect costs-informal care etc). AW and LJ will distribute the literature list to the other members of the WP. If it is OK from the Swedish HTA organisation SBU, AW will distribute the section of COI and cost-effectiveness to the group members (and to Rupert McShane in WP5).

Since WP4 will describe available resources for dementia care in the different EU countries, AW will have contact with the WP leader of this group.

3. Hannu Valtonen will present a background of welfare theory, utilization of resources occur in care systems including a theoretical discussion in terms of the relation between demands and supplies of care and needs of care and how resources are allocated. Our task is not to analyse cost-effectiveness studies, but we can discuss how much welfare that can be produced, given the resources. Hannu will also present a background theory for costing (opportunity costs, cost categories (e.g. in terms of direct medical resources, direct non medical resources, indirect costs, informal care.)

4. David McDaid will review informal care (quantification, costing), both in methodological terms and what is written about it in dementia care.

5. David will send an internet reference to a report (from WHO?) where the number of health care resources and long term institutional care is described in most European countries. The focus will be not only on present EU members states but also on potential new members. The information about community services is probably more limited. The next step, to identify to what extent resources are utilized by demented is more difficult. Population based studies may be a source. David also has a source in a project he was involved in where expenditures on mental disorders in official terms can be contrasted to the calculated economical burden.

David also has another source: European services mapping schedule, contact person: Louis Salvador. This source describes different resources for the mentally handicapped in Europe, unclear whether dementia is included.

6. Krisztian Karpati will discuss further details with Laszlo Gulacsi about the planned questionnaire, where data about resource utilization of demented in Hungary will be collected. If possible, a staging of the patents in terms of dementia severity would be an advantage. It would probably be difficult to identify the proportion of demented in Hungarian nursing homes. Krisztian and Laszlo will also

contact collegues in other parts of Eastern Europe regarding resource utilization/cost studies of dementia/AD in these countries.

7. We also discussed the possibilities to present data that could be of value for policy discussions in Alzheimer Europe and with EU. Alan Jaques and Annette Dumas from AE stressed the need for information about the socioeconomic impact of younger people with dementia (both on the demented persons themselves and the nexts of kin). They also stressed the need for projections of future costs and the need for information of how many demented that live alone in different parts of Europe. Another important topic is alcohol related dementia even if it is difficult to get any figures of the economic impact.

Other issues are that a description of available resources for dementia care (such as day care, long term institutional care, special living arrangements for dementia, diagnostic resources) in the EU and how they are utilized (not necessarily costed). There are probably utilized in different ways in Europe and the relation between different formal resources and informal care is different to highlight. Even if it is not WP8:s task to present recommendations, the highlighting of differences are important. It is also of interest to present information to what extent resources are paid by the state/the public system and out of pocket by patients and nexts of kin. David has such information (?).

8. If it is judged as important to make investments in some kind of care in a country where this resource is limited/lacking, a special infrastructure for this resource (in its wide context: education-competence, buildings tec) may be needed with an investment cost, that need to be considered.

It was also considered as interesting to highlight the consequences of changes in transfer systems. With a societal perspective and with an opportunity cost approach, the net effect of transfers is zero, but it may be of interest for policy makers to have information on the effects on different parts of the care system.

9. Some new approaches were interesting, such as a system of vouchers to patients/caregivers (corresponding to 2/3 or 100% of residential care) in the Netherland (and UK??).

10. Alan Jacques from AE will write a short text about "what is unique with dementia in terms of use of resources". Alan will also check whether AE has information of the sellings and perhaps use (in terms of e g Defined daily doses DDDs) of the "antidementia drugs" (cholinesterase inhibitors, memantine) in the different EU countries. Otherwise AW will try to get this information, perhaps via EMEA. Alan J will also send an e-mail through the AE network in EU and ask for local and national studies (not available in Medline/Pubmed or similar) regarding dementia studies of costs, resource utilization and perhaps care organisation. If these studies are in the local languages, there is such competence in the group (Hannu in German, Krisztian in German, Annette Dumas in French, David in Spanish etc).

11. We do not know to what extent people with dementia are diagnosed in Europe. One option could be to present the content of a basic diagnostic investigation of suspected dementia and if it then is assumed that, say, 80% of the incident cases would be identified, what is the cost for this in different countries (with country specific costs) of Europe. This approach assumes that country specific incidence data are available in EU. It also assumes that time use and use of other resources are similar (there are probably local-national-inter national variations in the effectiveness of the

diagnostic process). AW will first communicate with WP5 regarding the diagnostic approach and then circulate it in our WP8. One policy approach could be to compare the estimate of diagnostic costs with the estimated total societal costs of dementia.

8.5 Annex 2: Conclusion from the EuroCoDe meeting in Brussels, WP8, Socio-economic impact, Nov 6, 2006.

Participants: Anders Wimo, David McDaid, Hannu Valtonen, Anders Gustavson (replacing Linus Jönsson), Alan Jaques, Paul Kenigsberg (new working member of the group)

Absent: Laszlo Gulacsi

The work in WP8 is proceeding well and as reported on the meeting, we will succeed in keeping the deadlines and deliverables. WP is also in need for later collaboration with particularly WP 4 (social support systems) and WP 7 (prevalence rates).

Specific tasks for group members

1. ALL: deadlines

a. Financial report: to Jean Georges

Jan 31 2007

Jan 31 2008

Feb 28 2009

The period for the first economic report is Jan 1, 2006 to December 31, 2006. This means that ASAP when the new year begins, you should start to prepare the report to Jean. I refer to the document that was presented by Jean Georges at the meeting.

b. Activity report: to Anders Wimo

The period for the first activity report is Jan 1, 2006 to December 31, 2006. Send activity report to Anders Wimo, who will edit it and send it to Jean Georges who needs it before Jan 31, 2007. This means that you should send it to Anders Wimo as early as possible in January 2007. It should include a brief report of what you have done so far , including the results of literature review (including references of papers, if possible with Endnote format).

Deliverable 1. 18 months from start Jan 1, 2006. In spring 2007: send 1st report of results of work.

Jan 31 2008

Feb 28 2009

2. Specific task for group members as discussed on the meeting

Anders Wimo, Linus Jönsson, Anders Gutavsson:

Present a definition of socioeconomic impact as defined in application and also definition(s) of cost of illness.

Present estimates of cost of illness of dementia in Europe, based on costing models, such as EBC, DWCD but also an update of published COI studies.

Send the EBC report to members of WP8.

Send references about informal care from the Swedish SBU report´s database to David McDaid (with cc to others).

Present available results regarding differences in costs of different types of dementia, such as AD, VaD, PDD.

Present costs of dementia diagnostics from two levels: basic diagnostics and extended diagnostics at the specialist level.

Reflect whether forecasts of cost of illness figures should be presented, based on demographic changes and assumptions of e.g similar cost patterns in the whole Europe as in the country with the highest COI per case.

Hannu Valtonen:

Classifie European countries health care and social care systems such as "Nordic welfare system", "Family based systems (Germany?)", "Market oriented systems" or something similar.

Comment on especially David´s work on informal care

David McDaid

Literature search with an update on informal care

Send us Search strategy in MESH terms

Describe costing methods of informal care

Discuss "new" components of informal care such as immigrants from eg Eastern Europe, Philippines, North Africa and real "black market" carers vs traditional carers such as spouses, children.

Describe a coming(?) voucher system in the UK?

Paper by Richard Harvey about the consequences of early onset dementia.

Quantitative data on informal care should be presented, but reflect whether costs for informal care should be calculated or not and if yes: how such data will be presented.

Alan Jacques

Use Alzheimer Europe´s network to describe care organisation for dementia in the different European countries

Describe the consequences for early onset of dementia for the families: lost income, costs of care etc.

Discuss the most important care activity if priorities must be set: early diagnostics? Quality of care?

Paul Kenigsberg

Send short CV to Anders Wimo

Make search in French databases regarding the socio-economic impact of dementia.

Organise translations of papers in French, but also Geerman and Italian.

Describe French system with taxation relief if private staff is employed to do social care (not nursing).

Make database search regarding differences in dementia care due to rural/urban living but also due to different socioeconomic status of patients and caregivers. Discuss search strategy with David.

Discuss the influence of disability and economic allowance from society due to that.

Present a simple figure for theory of change (based on hypothesis, identification of problems etc)

Lazslo Gulasci (Absent on meeting)

Present Eastern Europe patterns of dementia care.

LATER:

ALL: discuss methodological issues (informal care, comorbidity, younger demented, different care systems, rural/urban areas, Eastern Europe, diagnostics, migration)

ALL: discuss policy implications for presented figures : differences between countries/regions vs how care is organised. Recommendations for future research.

ALL: discuss with other WPs, particularly WP 4 and 7.

9 WP 9 – Risk factors and prevention

9.1 Background

Life expectancy still increases linearly, and the elderly part of the European population grows rapidly in relation to the young. Dementia grows even more rapidly, because it increases exponentially after age 65; it will become a great burden if nothing is done. Meta-analyses of studies done in developed countries have established dementia prevalence at around 1.5% at age 65 years, which doubles every four years to reach about 30% at 80 years *(Hofman 1991, Jorn 1987, Ritchie 1995)*. *Rocca et al. (1998)* reanalyzed previously reported data on the incidence of dementia and AD in Rochester, Minnesota, from 1975 through 1984, investigated time trends and also conducted a birth cohort analysis. The authors concluded that no major time trends are apparent for either dementia or AD. The stability of incidence over time is evidence against a simple environmental etiology for AD *(Rocca-Study)*.

Alzheimer's disease and other dementias are already a major public health problem among the elderly in industrialized countries. These dementias could also have a devastating impact on developing countries, whose populations are aging the most rapidly; by the year 2020, approximately 70% of the world's population aged ≥60 will be located in developing countries *(World Health Organization (WHO). Population ageing-a public health challenge. Fact Sheet No. 135. Geneva: World Health Organization, 1998)*. By 2020 the number of elderly people worldwide will reach more than 1000 million with over 700 million of them in developing countries. Estimated at 29 million today, the number of people affected by senile dementia in Africa, Asia and Latin America may exceed 55 million in 2020 *(AgeForum 1998 Annual Report).*

Incidence rates for dementia (including AD) appear to be lower in East Asia than in the United States or Europe *(Chandra et al. 2001)*. Considerable variations have been reported in incidence and prevalence rates of AD between countries *(Jorm, Jolly, 1998; Gao et al. 1998)*, but most investigators conclude that these variations in rates are mainly due to differences in study methods *(Corrada et al. 1995).*

In studies using identical methods like in Canada *(Canadian Study of Health and Aging, 1994)*, England and Wales *(Medical Research Council Cognitive Function and Ageing Study MRC CFAS, 1998)* or in different european contries *(Launer et al. 1999)* no local or national differences were identified.

The assessment of rates of AD for different populations also could offer a powerful opportunity to explore risk factors for the disease. If populations could be identified with significantly different incidence rates of AD, the search for risk factors could be greatly enhanced by exploiting the diversity of their gentics and cultures, as well as their relative exposures to disease pathogens or environmentally noxious agents.

The discussion so far is concentrated on treatment, whereas prevention is neglected. Contrary to a widespread opinion prevention strategies in dementias are feasible. Genetic factors alone dominate the fate of cognition only in about 3% of the cases *(Kornhuber 2004)*. Because Alzheimer's disease accounts for more than 70% of all cases of dementia it is important to identify modifiable risk factors for the disease. A number of health, lifestyle, and environmental factors which have an influence on the incidence of dementia, have been identified.

9.2 Identifying risk factors

For some diseases it is easy to identify the etiologies, which makes it easier to take steps to prevent people developing the disease in the first place. This is particularly true for infectious diseases like measles where vaccination programmes have dramtically reduced the incidence of the disease.

For other diseases, the situation is much more complicated, particularly where the conditions develops over a long time, like many forms of dementia. A person's chances of developing the disease may be influenced by many interacting factors and it may be impossible to identify one single risk factor that is enough to cause the disease *(Alzheimer Scotland)*.

9.2.1 What are risk factors?

Risk factors are physical conditions, biological factors or behaviours which are more common in people who develop a particular disease than in those who don't. Risk factors are characteristics of a person (e.g. blood group) or environmental conditions (e.g. sunlight) which appear to have some relationship to the development of a disease. Other examples include exposures to a substance, family background or work history. In other words, a health-related risk factor is something that increases our chances that a particular disease is developing in us. The presence of these 'risk factors' is associated with an increased risk that the disease is present in a given individual.

Thus, a person who smokes is more likely to develop lung cancer than someone who does not smoke. But his does not mean that doesn't smoke causes lung cancer, just that more smokers get lung cancer than non smokers. This also underlines another issue about risk – risks are measured by looking at large numbers of people, not individuals, so what is true for a large population may not be true for an individual.

9.2.2 How are risk factors determined?

Two types of studies are used to determine risk factors. One approach is to monitor a group of healthy people over a long period of time and compare those who develop a disease with those who do not. Family factors as well as work histories and lifestyle factors, such as smoking, alcohol, diet etc. are examined and analysed in the disease and non-disease groups.

In the second approach, people who already have the condition or disease under investigation, such as Alzheimer's disease, are compared with people who are otherwise similar, but do not have the disease. Information is gathered on personal and family characteristics, as well as past exposures which may have occurred through lifestyle and work. Risk factors are those particular exposures and characteristics which are significantly more frequent in the diseased than the non-diseased group.

It is important to remember that risk factors are not causes. No single study can verify a link between a disease and a specific factor. Repeated investigations are necessary before a link can be established.

9.2.3 What are the risk factors for dementia?

Several key risk factors for dementia have been identified:

- Age
- Genetics

- Gender
- Vascular problems
- Lifestyle and environment

Of these factors, age, genetics and gender (what we are) cannot be controlled or modified while medical history, lifestyle and environment (what we do) have the potential to be modified *(Alzheimer Scotland)*.

9.3 Genetic risk factors

9.3.1 Family history of dementia

Some genetic risk factors have been identified, but only a small proportion of AD cases can be explained by specific gene mutations. Emprical support for specific environmental risk or protective factors has often been incosistent *(Hendrie HC 1998)*. There is considerable evidence that familial factors play an important role in the etiology of AD. The risk of dementia and AD has been shown to be increased among persons with a family history of dementia, but contradictory results exist as well *(Launer et al., 1999)*.

Life table analyses have shown a cumulative risk of dementia to first-degree realtives of AD cases of approximately 50% by age 90, while relatives of purported control subjects had a much lower cumulative risk. Because only about one-third of people meeting neuropathological criteria for AD present with dementia prior to death *(Ashford et al. 2002)* some individuals classified as controls will also carry the disease.

9.3.2 Twin studies

Twin studies offer a special design for teasing apart the relative importance of genetic and environmental influences.

Studies of AD amont thwin pairs over age 70 provide the strongest support for genetic causation. Monozygotic twin pairs show higher concordance rates for AD than dizygotic twin pairs *(Räiha et al. 1996; Bergem et al. 1997; Gatz et al. 1997)*, and estimates of AD heritability from these studies are in the 60-80% range *(Table 1 Ashford et al. 2002)*.

Table 1

Estimated heritabilities of AD from 2 twin studies

Study	Mean age	MZ concordance	DZ concordance	Heritability
Study of Dementia in Swedish Twins	78 years	75.0%	25.9%	.74
Norwegian Twin Registry Study	80 years	83.0&	46.0%	.61

Given the variable age of onset among monozygotic twins with the disease, these heritability figures may represent underestimates of the true heritability. Although the ratio of the concordance rates in monozygotic and dizygotic twins in these studies was approximately 2:1 as would be expacted from a genetically inherited disease, the concordance estimates can be reduced by death prior to diagnosis in unaffected twins, leading to lower heritability estimates *(Ashford et al. 2002)*.

Large intra-pair differences in age of onset suggest that environmental factors are also important in determining whether and when an individual may develop dementia. Nongenetic risk factors might be the focus for interventions to reduce disease risk or delay disease onset.

9.3.3 Genes

Genes may be related to disease in two ways: through autosomal-dominant mutations, in themselves sufficient to cause the disease alternatively, gene variations (polymorphisms) may indirectly increase disease risk without being sufficient in themselves to cause the disorder. This latter group are referred to as susceptibility genes. Familial AD refers to small numbers of cases (at least 5% of all cases), in which there is a clear pattern of autosomal dominant inheritance. Such clear patterns usually are associated with an age of onset before 60 years of age. The disease usually starts in the 40's and 50's. Extensive research carried out over the past two decades has isolated a number of autosomal-dominant genes related to AD, notably APP mutations on chromosome 21 *(Tanzi et al. 1987; Goate et al. 1991)*, the presenelin 1 gene on chromosome 14 *(Sherrington et al. 1995)*, and presenelin 2 on chromosome 1 *(Sherrington et al., 1995)*. These mutations have principally concerned early onset AD, and only explain a small proportion (less than 1%) of total cases *(Ritchie & Dupuy, 1999)*.

Some susceptibility genes are also currently being studied, of which polymorphisms of the apolipoprotein E gene have received the most attention, with earliest clinical reports suggesting it to be present in about 90% of late onset cases (which occur predominantly after 60 years old and do not have an apparent autosomal dominant mode of inheritance).

Meta-analysis of recent epidemiological studies has shown that while ApoE ε4 is more common in all forms of AD than in controls, it is specifically related to the late onset rather than the early onset variant. In controls, the prevalence of at least one ApoE ε4 allele is 14% as compared to less than 30% in early sporadic and familial forms, rising to 37% in late sporadic and familial forms, rising to 37% in late sporadic cases and reaching 48% in late familial cases *(VanGool et al. 1995)*. ApoE ε4 is thus seen to be mostly strongly associated with late onset familial cases of AD *(Ritchie und Dupuy, 1999)* and it is the clearest genetic factor that has been associated with non-familial or "sporadic" AD, which constitutes at least 95% of all cases *(Ashford et al. 2002).*

ApoE ε4 has a prevalence of 15% in European populations, with 8% for ApoE ε2 and 77% for Apo E ε3. Cross-cultural epidemiollogical studies have shown that the prevalence of ApoE ε4 is highly variable across populations, being most common in Africa and Scandinavia (over 20%), and least common in Japan and China (6-12%). Populations of African origin are observed to have among the highest occurrence *(Kalaria et al., 1997; Osuntokun et al., 1995)*. Within Europw a north/south gradient has been observed, with higher rates being observed in the north, with an estimated 23% in Finland descending through 9% in southern Spain. *(Eggertsen et al. 1993; Gerdes et al. 1992; James et al. 1993 ; Muros et al. 1996).*

The human apolipoprotein E gene is localized on chromosome 19 *(Ritchie et al. 1999).*

There are three types of ApoE: ApoE ε2, ApoE ε3 and ApoE ε4. Apo E has a central role in lipid metabilism and has long been a centre of interest for researching vascular pathologies.

The ApoE ε4 allele represents a major risk factor for AD in different ethnic groups, across ages between 40 and 90 years, and in both men and women *(Farrer et al., 1997).* Having one copy of the ApoE ε4 gene increases a person's risk of developing Alzheimer's disease by up to four times. Someone with two copies of ApoE ε4, one from each parent, has a 10 times greater risk and earlier age of onset than individuals who inherited one ε4 allele *(Corder et al. 1994)*; but only about 2% of the population have two copies of ε4.

The most common form of the gene is ε3. About 60% of the population have two copies of ApoE ε3 and are at average risk, which, means that about half will develop the disease by their late 80s.

About one in six people have at least one copy of ApoE ε2. This form of the gene delays the onset and decreases the risk of AD *(Corder et al. 1994)*. The lowest risk is for people who have two copies of ApoE ε2 *(Roses, 1996)*

It is important to recognise that this gene affects risk and is not a predictor of whether someone will develop Alzheimer's disease. Although ApoE ε4 increases the risk of developing the disease it does not make it certain. Many people who develop Alzheimer's disease do not have an ApoE ε4 gene, and some with the ε4 type do not develop the disease.

Recently, large-scale clinical series and population studies monitoring incident cases of AD have observed that even in late onset familial AD, a large proportion of cases (23-68%) do not have an ApoE ε4 allele *(Lucotte et al. 1994; Henderson et al. 1996; Ritchie et al. 1996).*

While more research needs to be done to determine the relationship between the ApoE gene and vascular dementia, it is known that there are other genes which contribute to a person's risk of developing other conditions which are linked to vascular dementia, such as diabetes, high blood pressure and high cholesterol *(Alzheimer Scotland)*.

It is now recognized that ApoE is not the 'cause' of AD, but rather an important link in a biological chain of events, AD itself appearing less like a single disease process and more the result of the failure of diverse neuronal compensatory and repair mechanisms to deal with multiple ageing-related aggressions. An interactive effect with ApoE in Alzheimer's disease has now been demonstrated in relation to a number of other risk factors. That is, the ApoE ε4/AD association has been shown to be much stronger in the presence of a number of other factors, notably a family history of senile dementia *(Zubenko et al. 1994; Jarvik et al. 1995)*, female gender *(Jarvik et al. 1995),* younger age *(Corder et al. 1994; Ritchie et al., 1996)*, oestrogen loss *(Tang et al. 1996)*, atherosclerosis *(Hofman et al. 1997)*, herpes virus *(Itzhaki et al. 1997)*, white matter lesions *(Skoog et al. 1998)* and head injury *(Mayeux et al. 1995)*.

At the present time, the greatest risk for AD is considered to result from the co-occurrence of ApoE ε4 and atherosclerosis *(Hofman et al. 1997).* ApoE ε4 has been proposed to modify the effects of various vascular and lifestyle related factors for cognitive functioning and dementia, so that the ApoE ε4 carriers might be more vulnerable to various adverse environmental factors, e.g. blood pressure and alcohol.

9.4 Non-genetic risk factors

9.4.1 Ageing

Age is the most important known risk factor for AD. The risk of developing the disease doubles every five years over age 65.

Dementia may occur at any age, although rarely below the age of 60. It becomes more common with increasing age, affecting one person in 20 aged over 65; one in five over 80; and one in three over 90.

The estimated annual incidence of Alzheimer's disease in the population was 0.6% (95% CI, 0.3%-0.9%) for persons aged 65 to 69 years, 1.0% (95% CI, 0.6%-1.4%) for persons aged 70 to 74 years, 2.0% (95% CI, 1.3% to 2.7%) for persons aged 80 to 84 years, and 8.4% (95% CI, 3.7%-13.1%) for persons aged 85 years and older. The incidence of Alzheimer's disease is substantial and is approcomately 14 times higher among persons older than 85 years compared with those between 65 and 69 years of age *(Herbert et al. 1995).*

Ageing has been consistently shown to be the major risk factor for Alzheimer's disease and other dementias.

Although age is the most significant risk factor that we know about, dementia is not an inevitable part of ageing. There are other risk factors that increase or reduce our likelihood of developing dementia. These might be environmental, genetic or lifestyle factors *(Alzheimer Scotland)*.

9.4.2 Gender

It has been suggested that the prevalence of AD is higher in women than in men *(Rocca et al. 1991; Rocca et al. 1999)*; it is not clear whether this difference is due to biology, to the fact that women tend to live longer or to their behaviour*(Alzheimer Scotland)*.

Variations in the results of studies of AD prevalence and incidence in defined populations were likely due more to methodological factors than to actual differences in the effect of sex on disease risk. A number of studies have found a higher prevalence of AD among women *(Fratiglioni et al. 1997)*, but many had small sample size and lacked tests for statistical significance. On the other hand, studies from Herbert et al. 2001 and Rocca et al. 1998 provide evidence against a sex difference in the risk of AD.

Vascular dementia is more common in men than women across all age groups. This may be because risk factors for vascular dementia, such as high blood pressure and heart disease, are more common in men *(Alzheimer Scotland)*.

Overall, 66% of people with dementia are female. However, the proportion varies with age group: women account for only 37% of people with dementia between 65 and 69, but 79% of people with dementia aged 90 and above *(Alzheimer Scotland)*.

9.4.3 Vascular risk factors

Recent epidemiological evidence suggests an association between AD and vascular risk factors such as arterial hypertension, diabetes mellitus, general atherosclerosis and atrial fibrillation *(Schmidt et al. 2000)*.

9.4.3.1 Hypertension

There is fairly strong epidemiological evidence that hypertension (*high blood pressure*) at midlife and possibly also in late-life is associated with increased risk of all types of dementia, as well as vascular dementia and Alzheimer disease *(Rigaud et al. 2000; Birkenhäger et al. 2001)*.

Blood pressure is always given as two numbers, the systolic and diastolic pressure. Both are important. The blood pressure is at its highest when the heart beats, pumping the blood into the arteries. This is called systolic pressure. When the heart relaxes, between beats, the blood pressure falls. This is called diastolic pressure*.

A blood pressure of 140/90mmHg or higher is considered *high blood pressure*. If one or both numbers are usually high, you have high blood pressure*.

Categories for Blood Pressure Levels in Adults (in mmHg, measured in millimeters of mercury, a unit for measuring pressure)*:

Category	Systolic (first or top number)	Diastolic (second or bottom number)
Normal	Less than 120	Less than 80
High blood pressure		
Stage 1	140-159	90-99
Stage 2	160 or higher	100 or higher

*www.nhlbi.nih.gov/health/dci/Diseases/Hbp/HBP_WhatIs.html

Skoog et al. (1996) reported in a longitudinal population-based study on elderly persons that those who developed AD had higher systolic blood pressure than non-demented individuals 10-15 years prior to the onset of the disease. Interestingly, blood pressure declined during the years prior to dementia onset. This may explain the inverse association between blood pressure and risk of dementia found in some cross-sectional studies. Other population-based studies such as the Honolulu Aging Study *(Launer et al. 1995)* and the Framingham Study *(Elias et al. 1993)* have also demonstrated that high blood pressure precedes cognitive impairment in individuals without symptoms or signs of cerebrovascular disease.

Treatment of high blood pressure in old age has been shown in several studies to reduce the risk of cognitive decline and dementia. In one 4 year randomised controlled trial, long-term antipypertensive therapy reduced the risk of dementia by 55%, from 7.4 to 3.3 cases per 1000 patient-years (43 vs 21 cases). Bosch et al. (2002) looked at people with a high risk of stroke and found that those given a blood pressure lowering drug had a 41% less risk of cognitive impairment in the next 2 years, through the evidence from randomised controlles trials is not equivocal.

In a randomized, double-blind, placebo-controlled trial conducted among 6105 people with previous stroke or transient ischemic attack, the researchers gave participants either a drug to lower blood pressure or a matching placebo. They found that those who had the treatment and had another stroke had a reduced risk of cognitive impairment or dementia. This suggests that reducing the impact of brain damage from strokes could reduce the risk of dementia in the future *(Alzheimer Scotland)*.

9.4.4 Cholesterol

Cholesterol is a fatty substance (a lipid) which is essential to healthy life. It is mostly produced in the liver, but is also provided from the food a person eats. Cholesterol is carried in the bloodstream as lipoproteins. Low-density lipoprotein (LDL) cholesterol is called "bad" cholesterol, because elevated LDL levels are associated with an increased risk of coronary artery (heart) disease. Conversely, high-density lipoprotein (HDL) cholesterol is called the "good cholesterol" because HDL cholesterol levels are associated with less coronary disease *(www.medterms.com/script/main/art.asp? articlekey=2710)*.

High levels of cholesterol at midlife has been shown to be associated with an increased risk of dementia and Alzheimer disease. Shorter term follow-up studies or cross-sectional studies have reported no association or even an inverse association. Some research has suggested that people taking drugs called statins to lower their cholesterol levels have a lower risk of developing dementia and Alzheimer disease, but the evidence on this is insufficient and contradictory at the moment.

9.4.5 Diabetes mellitus

Diabetes mellitus is a group of metabolic diseases characterized by high blood sugar (glucose) levels, which result from defects in insulin secretion, or action, or both *(www.medicinenet.com/diabetes_mellitus/page3.htm)*.

Cross-sectional and prospective *(Xu et al. 2004)* studies provide substantial evidence that diabetes is associated with cognitive impairment. With regard to dementia, some diabetic complications and comorbidities are implicated as risk factors for dementia and Alzheimer disease. An association between diabetes mellitus and increased risk of dementia has been found in both prospective studies and cross-sectional studies *(Xu et al. 2004)*.

The evidence on the association between diabetes and AD specifically are somewhat inconsistent but generally supportive of a positive association.

A number of cross-sectional studies indicate that diabetes mellitus is associated with Vascular dementia, but not with AD. The population-based prospective study in Sweden and the Canadian Study of Health and Aging (CSHA) demonstrate that diabetes is associated with Vascular dementia independent of other vascular diseases, but not with Alzheimer disease.

By contrast, longitudinal data from the Rotterdam study show that diabetes is associated with an increased risk of Alzheimer disease, particularly if subjects were treated with insulin. This findings may reflect greater risk of dementia in more severe diabetes. Patients on insulin treatment may have more severe diabetes, or a longer history of diabetes. Such people are thus longer exposed to diabetes related risk factors, through contradictory results exist as well. Leibson et al. found no effect of diabetes duration on dementia risk.

The relation between dementia and diabetes mellitus could either be explained through vascular disease or by nonvascular effects of diabetes.

9.5 Lifestyle risk factors

While the evidence for genetic factors is strong, there has been considerable study of environmental factors that might be associated with AD.

9.5.1 Aluminium

Aluminium is clearly a neurotoxic substance. It is generally thought of as the light silvery metal used to make pots and pans. Aluminium is a naturally occurring element that makes up about 8% of the surface of the earth and is present in water and the air. Because it is extremly common in the environment it is very difficult to know how much of it we are taking in.

The epidemiological observations relating aluminium to the incidence of Alzheimer's disease can be interpreted in the light of the experimental, clinical, and pathological findings.

The epidemiological findings fall into three groups:

First, those relating heavy exposure to aluminium by inhalation to mental impairment: these suggest that exposure sufficient to cause a large increase in the body burden of aluminium is neurotoxic, but not that it causes progressive dementia or Alzheimer's disease. Secondly, the observations relating Alzheimer's disease, dementia, or mental impairment to aluminium in water supplies or medicaments applied to the skin or taken by mouth: these provide some evidence that levels of aluminium in drinking water near the top of the recommended range are associated with an increased risk of Alzheimer's disease, and possibly only, if the pH of the water is low. Thirdly, there are the observations relating aluminium in soil and water to a neurological syndrome that has some similarities with Alzheimer's disease and is found only in some islands of the west Pacific.

In 1973, the first report of increased concentrations of Aluminium in the brains of patients with Alzheimer disease was published *(Crapper DR et al.1973)*. Considerable evidence exists that Aluminium may play a role in the aetiology or pathogenesis of Alzheimer's disease. What is not clear from the pathological findings is whether Alzheimer's disease is associated with either heavy exposure to aluminium or an accumulation of aluminium in the brain. First, the neuropathological lesions produced by the injection of aluminium and associated with acute aluminium dementia differ from those found with Alzheimer's disease *(Krishnan SS et al. 1987; Letterman RD 1988; Doll, R. 1993)*; e. g. no neurofibrillary tangles are found with acute aluminium dementia *(Doll R, 1993)*. Secondly, the association between the cerebral content of aluminium and Alzheimer's disease is controversial. On the one hand, Candy et al. (1984) and Perry and Perry (1985) have reported that abnormal amounts of alumino-silicates are present in the senile plaques characteristically associated with the disease. On the other hand, others have suggested that these findings are artefacts or the results of an inadequate choice of controls *(Letterman RD et al. 1988; Martyn CN et al. 1992; Martyn CN et al. 1989)*.

The combined experimental, clinical, and epidemiological evidence suggests that aluminium is neurotoxic in humans, but not that it is a cause of Alzheimer's disease. The preponderance of evidence is against a significant role for environmental aluminium as a cause for AD. Most older people do not get Alzheimer' disease despite the widespread presence of aluminium in the environment *(Alzheimer Scotland)*

9.5.2 Nutrition and Semiluxury food

Caloric Intake has been shown to affect aging in animals and possibly in humans *(Weindurch R, Sohal RS 1997)*. It has been reported that individuals with dementia change their food choices and increase their caloric intake *(Keene JM, Hope T 1997)*, eating less protein and more sweets than

controls without dementia *(Mungas D et al. 1990)*. Several studies *(Kalmijn et al. 1997; Luchsinger et al. 2002)* have shown an association between higher intake of total calories and fats in elderly individuals without dementia and higher risk of Alzheimer disease, particularly in carriers of the APOE ε4 allele *(Luchsinger et al. 2002)*. In contrast, *Barberger-Gateau et al. (2002)* have shown that elderly people who eat seafood or fish at least once a week are at lower risk of developing dementia. The Rotterdam study found similar results *(Kalmijn et al. 1997)*. The n-3 fatty acids contained in fish oils could reduce inflammation in the brain and may have a specific role in brain development and regeneration of nerve cells *(Morris et al., 2003)*.

9.5.3 Antioxidants/Vitamin C and E

One hypothesis that accounts for both the heterogeneous nature of Alzheimer disease and the fact that aging is the most obvious risk factor is that free radicals are involved. The probablility of this involvement is supported by the fact that neurons are extremely sensitive to attacks by destructive free radicals. Free radicals are a by-product that occurs when the body uses oxygen. They are harmful and can cause damage inside the cells of the body. Environmental factors such as cirgarette smoke or pollution can increase the level of free radicals in the body. Antioxidants are the body's defence system against free radicals, as they mop up these destructive molecules *(Alzheimer Scotland)*.

The danger from free radical damage increases with age. Some researchers think that the destructive effect of free radicals may be one of the causes of brain cell death in Alzheimer's disease. This has led to interest in whether increasing antioxidant intake through diet or vitamin supplements could provide any protection against Alzheimer's disease *(Alzheimer Scotland)*.

Several findings suggest that oxidative stress may play an important role in the pathogenesis of Alzheimer disease. Oxidative stress in brains of patients with Alzheimer disease is indicated by elevated cerebral levels of endogenous antioxidants that scavenge free radicals *(Grundman M 2000)*. In vitro studies have suggested that exogenous antioxidants reduce the toxicity of ß-amyloid in the brain of Alzheimer patients *(Behl C 1997; Christen Y 2000)*. Based on these findings it has been hypothesized that antioxidants from food may reduce the risk of Alzheimer disease. Studies which examined the longitudinal relationship between antioxidants from supplements and risk of Alzheimer disease found conflicting results *(Morris et al. 1998; Masaki et al. 2000).* It has been reported that vitamin C supplement use might decrease the risk of Alzheimer disease *(Morris et al. 1998)*; and that vitamin E and C supplements in combination has been associated with occurrence of Alzheimer disease *(Zandi et al. 2004)*.

The Cache County Study, a cross-sectional and prospective study of dementia, found that the use of vitamin E and vitamin C supplements in combination was associated with occurrence of AD *(Zandi et al. 2004)*, whereas other studies found no association between the supplemental intake of both vitamin C and E prior to diagnosis and a reduced risk for Alzheimer disease, but association with Vascular dementia was observed *(Masaki et al. 2000)*. Sano et al. (1997) investigated the association between supplemented antioxidant intake and Alzheimer disease in patients who were already diagnosed with Alzheimer disease, using data from a randomized controlled trial. They found

that patients taking vitamin E supplement had a slower progression of Alzheimer disease than patients taking placebo.

However, Luchsinger et al. analyzed data from 980 elderly subjects in the Washington Heights-Inwood Columbia Aging Project (WHICAP) who were free of dementia at baseline and were followed for a mean time of four years to analyse the association between the intake of antioxidant vitamins in supplemental or dietary (nonsupplemental) form or in both forms and the risk of incident Alzheimer disease. In this study, neither supplemental, dietary, nor total intake of carotens and vitamin C and E was associated with a decreased risk of Alzheimer disease (Luchsinger et al. 2003).

There is evidence that measurement of specific risk factors in midlife better predicts late-life cognitive impairment, because the measures are less influenced by preclinical disease (Launer et al. 1995). Thus some studies have studied the association between dementia and dietary patterns measured in midlife. The Honolulu-Asia Aging Study (HAAS), a prospecitve community-based study of elderly Japanese-American men that has been followed for research purposes for more than 30 years, showed that midlife dietary intake of beta-carotene, falvonoids, and vitamin E and C was not related to the incidence of dementia and its subtypes in late life (Laurin et al. 2004).

Others have investigated the association between the intake of antioxidants from food and the risk of Alzheimer disease. The results from a population-based cohort study *(Engelhart et al. 2002)* with a mean follow-up period of six years suggested that high intake of vitamin C and vitamin E from food might be associated with a lower incidence of Alzheimer disease. They found that those who had the highest intake of Vitamin E had a 43% lower risk of developing Alzheimer's disease compared with the people who had the lowest intake. There was a slight association between high intake of Vitamin C and risk of Alzheimer's disease. The results from the Chicago Health and Aging project showed that those with the highest intake of vitamin E from food, but not from vitamin supplements, had a 70% lower risk of developing Alzheimer's disease *(Morris et al. 2002)*. This reduced risk was only found in those people who did not have the ApoE ε4 gene. Vitamin C did not seem to offer any protection *(Morris et al. 2002)*.

Results on vitamin intake from food and risk of dementia, however, may not be comparable with results on supplement use for several reasons. First, studies on supplements use are prone to bias, because people using supplements may either have more health-seeking behaviour *(Kirk et al. 1999 aus Luchsinger et al. 2002)* or more health problems *(Bender et al. 1992 aus Luchsinger et al. 2002)*. Second, supplement intake is generally of shorter duration than intake of antioxidants from food which reflects long-term intake. Finally, antioxidants from supplements are consumed in a very high dose either with or without other substances, whereas antioxidants from food are always simultaneously consumed with other nutritients. This might lead to differences in absorption or biological activity between these two forms of antioxidants intake *(Bronner F 1993 aus Luchsinger et al. 2002)*.

There are several biological mechanisms that could explain a possible relationship between antioxidants from food and Alzheimer disease. First, antioxidant nutritients, including beta carotene, vitamin E, and vitamin C, are among the body's natural defense mechanisms against oxidative stress. Food sources of beta carotene include e.g. sweet potatoes, carrots, kale, spinach, turnip

greens, winter squash and fresh thyme. Beta-carotene is probably the most well known of the carotenoids, a phytonutrients family that represents of the one most widespread groups of naturally occurring pigments *(http://www.whfoods.com/genpage.php?tname=nutrient&dbid=125)*. Vitamin C is found in citrus fruits, berries, tomatoes, and various vegetables. Vitamin E is found particularly in foods like vegetable oils, nuts and seeds *(Alzheimer Scotland)*. The antioxidant nutritients may thereby decrease lipid peroxidation *(Abd el-Fattah AA et al. 1998, O'Donnell et al. 1998, Giray B et al. 2001)* and the oxidation of proteins *(Subramaniam R et al. 1998; Zhang P, Omaye ST 2000)*, inhibit the production of reactive oxygen species *(Bagchi D et al. 1998; Cardoso SM, Pereira C, Oliveira CR 1998; Tagami M et al. 1999)*, prevent mitochondrial dysfunction *(Subramaniam R et al. 1998; Bertoni-Freddari et al. 1995)* and DNA fragmentation *(Bagchi D et al. 1998; Tagami M et al. 1998)*, reduce the aggregation of of ß-amyloid *(Behl C 1997; Christen Y 2000)*, apoptosis *(Tagami M et al. 1999; Huang HM, Ou HC, Hsieh SJ 2000; Ahlemeyer B, Krieglstein J 2000)* and neuronal cell death *(Yallampalli S, Micci MA, Taglialatela G 1998; Sen CK, Khanna S, Roy S, Packer L 2000; Behl C 1997; Christen Y 2000)*. These are important neuropathological features in Alzheimer disease and by preventing the genesis of these features, the risk of Alzheimer disease might be reduced. Second, because Alzheimer disease is associated with both atherosclerosis and cardiovascular risk factors *(Hofman et al. 1997; Breteler MMB 2000 aus Luchsinger et al. 2002)* and oxidative processes are involved in atherosclerosis *(Witztum JL, Steinberg D, 1991 aus Luchsinger et al. 2002)*, high intake of antioxidants could also decrease the risk of dementia by reducing the risk of atherosclerosis.

9.5.4 Folate (Folic Acid) and Vitamin B12

Plasma total homocysteine has emerged as a major vascular risk factor. Homocysteine is a sulfur amino acid in the blood whose metabolism is closely related to that of the vitamins folate, B6, and B12. Too much of it can damage blood vessels and it has also been linked with dementia *(Malouf M, Grimley EJ, Areosa SA 2003)*. Folate and other B vitamins, including Vitamins B6 and B12 help process and lower levels of homocysteine. Fortified cereals, green leafy vegetables, orange juice, yeast extract and liver are all good sources of folate. There is evidence that having too little folate may contribute to the cognitive impairment of some older people's brains. This may result in reversible damage or possible increase the risk of Alzheimer's disease and Vascular dementia *(Alzheimer Scotland)*.

Low levels of folate and vitamin B12 might be related to an increased risk of Alzheimer disease *(Morris MS, 2003; Wang et al. 2001; Maxwell CJ, Hogan DB, Ebly EM 2002)*, because vitamin B12 is necessary for the conversion of homocysteine to methionine, and vitamin B12 or folate deficiency can increase homocysteine level due to slowed methylation reaction *(Hutto BR 1997; Bottiglieri T 1996)*. But there is no evidence currently that folate or vitamin B12 deficiency is associated with the neuropathologic hallmarks of Alzheimer disease. The lack of interaction between the two vitamins in relation to dementia occurrence may be explained by the common metabolic mechanisms of these two vitamins *(Bottiglieri T 1996)*. It is not yet known whether increasing your intake of folate either through diet or by taking supplements will reduce the risk of developing dementia. More research is

necessary to fully understand what benefits folate may have in protecting the brain *(Malouf M et al. 2003)*.

Several cross-sectional studies have shown that elevated plasma homocysteine levels have been associated with an increased risk of aterosclerotic sequelae, including death from cardiovascular causes *(Bots ML et al. 1997; Bostom AG et al. 1999)*, carotid atherosclerosis *(Selhub J et al. 1995)*, coronary heart disease *(Bostom AG et al. 1999; Stampfer MJ et al. 1992)*, and clinical stroke *(Perry et al. 1995; Kalmijn S et al. 1999)*. Stroke and atherosclerosis, in turn, increase the risk of clinical Alzheimer disease *(Hofman A et al. 1997; Snowdon DA et al. 1997)*. Hyperhomocysteinemia has been related to endothelial dysfunction *(Welch GN, Loscalzo J 1998),* cerebral microangiopathy *(Fassbender K et al. 1999)*, impaired nitric oxide activity *(Chao GL, Kuo TL, Lee YT 2000)*, and increased oxidative stress *(Starkebaum G, Harlan JM 1986)*; all factors associated with the aging of the brain *(McCann SM 1997; Beal ME 1995)*. These observations led to the hypothesis that elevated plasma homocysteine may be a risk factor for dementia and Alzheimer's disease. If this hypothesis is valid, it would be a modifiable risk factor, since elevated plasma homocysteine levels can be lowered by supplementation with folic acid *(Wald DS et al. 2001)*. The results from a prospective, observational study indicated that an increased plasma total homocysteine level is a independent risk factor for the development of dementia and Alzheimer's disease *(Seshadri S et al. 2002)*. Does this mean that high levels of homocysteine actually cause dementia? At the moment, researchers simply do not know; the high levels of homocysteine found could be a result of Alzheimer's disease rather a cause *(Alzheimer Scotland)*.

9.5.5 Overweight and Obesity

The National Institutes of Health (NIH) defines overweight in terms of the body mass index (BMI). The BMI is a person's weight in kilograms (kg) divided by their height in meters (m) squared. Overweight is a BMI of 27.3% or more for women and 27.8% or more for men, while obesity is defined as a BMI of 30 and above, according to the NIH.

The prevalence of overweight and obesity is more than 50% among adults in Europe and the United States, with the highest prevalence observed among adults 50 years and older *(Flegal KM et al. 1998; Visscher TL et al. 2000)*.

Overweight and obesity constitute a major public health problem because of adverse effects on vascular health. Since overweight and obesity increase risk of vascular disorders, both may be risk factors for Alzheimer's disease and Vascular dementia. Few long-term follow-up studies have examined this hypothesis:

Whitmer et al. (2005) tried to measure association between obesity in middle age (measured by body mass index and skinfold thickness) and risk of dementia in later life. What was particularly important about this study was the numer of subjects involved (more than 10.000 US men and women) and the length of the study (27 years). The participants were assessed between 1964 and 1973 when they were aged 40 to 45 and were assessed again between 1994 and 2003 to see whether any had developed dementia. People who had been obese in middle age had a 74% increased risk of dementia while the lifetime dementia risk in those who were overweight was 35% higher compared with those of a normal weight. One plausible reason for an increased risk of dementia with adiposity is through diabetes and cardiovascular disease as both these conditions increase the risk of dementia *(Elias PK et al. 1997; Curb JD et al. 1999)*. Yet, adjustment for

prevalence of cardiovascular disease and diabetes at mid-life and later did not attenuate the association. Perhaps adiposity works together with other risk factors to increase neurodegenerative disease.

Swedish researchers found that for every 1.0 increase in BMI in women aged over 70 years, the risk of Alzheimer's disease increased by 36%. The association between a high body mass index and dementia was found only in women. This may be partly explained by there being more obese women than men in the study, but it may also have something to do with a metabolic phenomenon in women (eg. estrogen) or sex differences in body fat distribution.

The prevention of overweight and obesity, even at greater ages, might be important for the prevention of dementia.

Several studies have shown that patients with Alzheimer disease have a lower weight and body mass index than the control patients. These observation has lead to the assumption that low BMI could be a risk factor for dementia. The weight loss seems to occur during the pre-clinical phases of dementia. The Honolulu-Asia Aging Study showed that the weight loss begins before the onset of the clinical syndrome and accelerates by the time of diagnosis among persons with dementia *(Stewart R et al., 2005)*. An population-based study from Southern California showed that weight loss precedes mild to moderate dementia. Further, the results from *Buchman et al. (2005)* showed that declining BMI was associated with increased risk of incident Alzheimer disease and increased rate of cognitive decline. These studies support a relationship between lower BMI and risk of dementia. A possible explanation is that a lower BMI may be an early clinical sign of the disease rather than a risk factor as such. Another explanation is that weight loss may occur before dementia is diagnosed *(McKhann G et al. 1984)* and may be the consequence of functional alteration in instrumental activities of daily living, which can occur in the very early stages of the disease *(Menzel HJ, Utermann G 1986)*.

Only a few studies have investigated the association between fat intake and the risk of dementia. It has been reported that high saturated fat and cholesterol intakes might be risk factors for Alzheimer disease, particularly among individuals carrying the apolipoprotein E ε4 allele *(Luchsinger et al. 2002, Laitinen et al., 2006)*.

9.5.6 Smoking

Older family and case-control studies have found that smoking has a protective effect against developing Alzheimer's disease *(Graves AB et al., 1991; van Duijn et al., 1995)*. In contrast, others have argued that the results reported by case-control studies were a consequence of survival bias rather than a true protecitve effect of smoking *(Riggs JE 1993)*. Thus, any lower rates of Alzheimer's disease among smokers may have little or nothing to do with any protective quality of smoking. *Wang et al. (1999)*, for example, found that a history of smoking was associated with increased mortality among patients with dementia, but not controls. Hence, patients with dementia who have been smokers may be eliminated earlier from the population and, as a consequence, would be under-represented in cross-sectional samples *(Wang HX et al. 1999 , Debanne SM et al. 2000)*. Smoking has a robust negative effect on survival. This can be illustrated with findings reported by *Doll et al. (1994)*. They found that 83% of male non-smokers and 60% of the smokers reached the age of 70 years; 57% of the non-smokers survived to age 80 years compared with only 26% of the smokers *(Doll R et al. 1994)*.

In the early 1990s results from family and case-control studies suggested a protective effect of smoking. The possible protective effect of smoking on the development of Alzheimer's disease has been attributed to an as yet unclear neuroprotective effect of nicotine and nicotinic drugs (*White HK 1999*; *Zanardi et al. 2002*). Nicotine is "an alkaloid (a nitrogen-containing chemical) made by the tobacco plant or produced synthetically… Nicotine has powerful pharmacologic effects (including increased heart rate, heart stroke volume, and oxygen consumption by the heart muscle) as well as powerful psychodynamic effects (such as euphoria, increased alertness, and a sense of relaxation). As is now well known, nicotine is also powerfully addictive." *(www.medterms.com/script/main/art.asp?Articlekey=22807)*

Alzheimer's disease affects neurotransmitter systems, particularly the cholinergic system. Nicotine is a cholinergic agonist. Evidence is accumulating that direct stimulation of nicotinic acetylcholine receptors may represent an effective target for the treatment of Alzheimer's disease *(Newhouse PA et al. 1997)*. In addition to direct stimulation of nicotinic receptors, nicotine may provide cascading effects via stimulation of the release of a variety of transmitters involved in cognitive function, including acetylcholine, norepinephrine, dopamine, serotonin, and glutamate *(Wonnacott S et al. 1989; McGehee DS et al. 1995)*.

Recent findings from cohort studies seem to indicate that smoking increases risk of dementia in general and of Alzheimer's disease in particular (*Ott A et al., 1998; Wang HX et al. 1999)*. Some speculate that the nicotinic effects of smoking improve cognitive functioning *(Jones GMM et al. 1992)*. Others suggest that the increased frequency of cardiovascular and cerebrovascular illnesses among smokers *(Skoog I 1998)* is likely to increase the risk of Alzheimer's disease in later life *(Esiri MM et al. 1999)*.

Several studies have shown that compared with never or past smokers, current smoking increased the risk of Alzheimer's disease significantly *(Ott A et al. 1998, Launer LJ et al. 1999)*. Similarly results exists as well for Vascular dementia *(Almeida OP et al. 2002)*. Launer et al. performed a pooled analysis of four European population-based prospective studies of individuals 65 years and older *(Launer LJ et al. 1999)*. They found also an significantly increased risk of Alzheimer's disease in current smokers. Ott and colleagues reported that current smoking was associated with a doubling of the risk of dementia and Alzheimer's disease *(Ott A et al. 1998)*. Interestingly, findings from several studies have shown that there is an increased risk of dementia and Alzheimer's disease associated with smoking in those without the APOE ε4 allele *(Ott A et al. 1998; Van Duijn CM et al. 1995; Merchant C et al. 1999)*.

9.5.7 Alcohol drinking

Alcohol consumption is known for its psychotropic effects. Psycho-stimulation is associated with a relaxation of inhibitions: cognitive tasks are done more quickla, with a feeling of easiness but with an increased error rate. Cognitive impairment is frequently observed in heavy drinkers and visuomotor capacity, memory or abstract thinking are affected. Excessive alcohol consumption can lead to alcohol related brain damage; severe loss of short-term memory and is responsible for alcoholic dementia, also named Korsakoff's syndrome. This disease is due to the lack of vitamin B1, frequently associated with malnutrition in heavy drinkers.

It is generally thought that light to moderate alcohol consumption may lower the risk of cognitive decline and dementia *(Espeland MA et al., 2005; Orgogozo JM et al. 1997; Huang W et al. 2002)*.

The health benefit may be mediated by a protective effect against vascular disease, as moderate alcohol consumption lowers the risk of stroke as well as subclinical infarcts and white matter disease on brain imaging *(Sacco RL et al. 1999; Mukamal KJ et al. 2001)*.

The findings from the Rotterdam Study suggested that light-to-moderate alcohol consumption is associated with a reduced risk of dementia in people aged 55 years and older *(Ruitenberg A et al., 2002)*. A further study found that risk of dementia increased with rising alcohol consumption for those people who carried the ApoE ε4 allele *(Anttila T et al., 2004)*. One possible explanation could be that individuals with the ε4 allele have less effective neural repair mechanisms *(Mahley RW et al. 2000)*, and thus they would be more susceptible to the deleterious effects of alcohol.

There is insufficient evidence to promote alcohol to nondrinkers as a means of reducing dementia risk. However, there may be benefits for those who enjoy drinking alcohol in moderation *(Alzheimer Scotland)*.

Other studies have shown that a history of heavy drinking or alcohol abuse might be associated with an increased occurrence of dementia and Alzheimer disease *(Thomas VS et al. 2001; Saunders PA et al. 1991; Kim JM et al. 2002)*, however, contradictory findings exist as well.

Recommended maximum weekly alcohol limits are 14 units for a woman and 21 units for a man *(http://news.bbc.co.uk/1/hi/uk/3303805.stm)*. One unit is considered to be 8g of alcohol. Often units are quoted as being one small glass of wine, half a pint of beer or one pub measure of spirits *(http://news.bbc.co.uk/1/hi/uk/3303805.stm)*.

9.6 Appendix 1: Minutes of EuroCode WP9 meeting in Luxemburg 25 – 26.02.2006

Present: Jim Jackson, Tiia Ngandu, Lutz Frölich

Absent: Istvan Degrell, Heike von Lützau-Hohlbein, Frans Verhey

Month 1:

According to our milestones, we have finalized the research methodology and have detailed the content of the literature search.

Month 1: Methodology finalization at meeting:

We will screen world-wide studies not only European and we will search public databases, e.g. PubMed. We will draw on textbooks for identification of risk factors, and include data from reports which are available to WP members (e.g. SBU report from Miia Kivipelto).

We will restrict ourselves to a detailed report on "Treatable" risk factors and only mention briefly "Non-treatable" risk factors. This means that we will review the data only on those risk factors amenable to intervention and in the second part, will review the intervention studies on those risk factors. A brief table will be devoted to non-treatable risk factors.

As a first step, we have identified the following potential risk factors (list not complete):

Alcohol / smoking / occupation-dependent risk factors / physiological / pathophysiological risk factors / Activity dependent risk factors / Nutrition dependent risk factors

It was decided that several points are to be explained:

Definitions: Risk factors and prevention (primary, secondary, tertiary prevention).

We will deal only with primary and sexondary prevention intervention studies (diagnosis, methodology). Specific methodological problems of intervention studies in dementia shall be made clear. Level of evidence for intervnetion studies. Specific problems of outcome criteria.

Explanation of efficacy of intervnetions: "attributable risk" (ANDREAS SEIDLER as consulatant)

Alcohol as a risk factor / protective factor in dementia and the diagnosis of alcohol-dementia (ISTVAN?)

The problem of MCI will be dealt with by the WP on diagnosis/treatment, not by our WP.

1.3 Appendix 2: Minutes of EuroCoDe WP9 meeting in Brussels 06.11.2006

Present: Frans Verhey, Jim Jackson, Heike von Lützau-Holbein

The following comments were made on the individual slides:

- Incident and prevalence increase with age up to age 85 (slide 6), if there is a levelling off at this age, this will have implications for the Prevention WP
- Familial aggregation (slide 7), need to explain very clearly that this is increased risk and not inevitable, we would also add that genetic testing should not be routinely offered because it is difficult for people to use the revealed information, also noted that there is no simple test to assess risk.
- Diabetes (slide 8), this is a rapidly changing field, therefore there is a particular need to keep up with the latest information, should risk factors for diabetes be listed as risk factors for dementia? Does well regulated diabetes reduce risk for dementia?
- Hypertension (slide 8), is there any evidence for intervention studies?
- Cardiovascular disease – also need to cover cerebrovascular illness (see the Rotterdam study)
- Folate/vitaminB12 (slide9), needs explanation as in Good for you, good for your brain.
- Inflammatory factors (slide 10), needs cross reference to later statement that side effects made this not suitable for treatment
- Aluminium (slide 10), it could state that no evidence has been found of this effect, it was an artifact in the original study
- Obesity and nutrition (slide 11), needs to keep in touch with the latest studies
- Smoking (slide11), more could be said including the link with cerebrovascualar disease
- Occupational exposure (slide 12), add pesticides
- Low level occupation etc (slide12), cross reference to higher education (slide 14), also consider social-economic explanations
- NSAIDs (slide 13), we felt the statement may be too positive, one trial discontinued because of side-effects, also the reference mentioned may not be the right one
- Under pharmacological factors (slide13), there also ought to be statements about lithium and cortisone, both would not be recommended as dementia therapies

- Alcohol (slide14) , need to explain light/moderate drinking – be more specific about the number of glasses
- Leisure time activities (slide 14) could be expanded to include mental stimulation and social activities
- Summary (slide 15), need to explain that it is worthwhile following the recommendations even though the evidence is only moderately strong
- Some doubts about omega-3 oil and fish because although good for you, the dementia evidence is not strong.

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