

## Supplementary Data

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# Cost of Dementia in the Pre-Enlargement Countries of the European Union

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This section of the manuscript provides detailed information regarding the methods, assumptions, and sources used to inform the cost of dementia across countries in the EU-15.

A variety of national sources of epidemiological and health care utilization data were used, including the World Health Organization (WHO), the Organisation for Economic Co-operation and Development (OECD), the Statistical Office of the European Communities (EUROSTAT), the World Bank Group, Alzheimer Europe, European Brain Council, the National Ministries of Health, National Statistical Institutes, and published articles and reports. In addition, health, social and informal care resource use information was sought from published cohort studies of dementia patients. Relevant studies were obtained by reviewing the references of four literature reviews evaluating dementia cost-of-illness studies [1–4], two of which were systematic [3, 4]. Furthermore, targeted searches in MEDLINE were undertaken, where necessary, using combinations of the following terms: ‘dement\*’, ‘Alzheimer\*’, ‘resource\*’, ‘unpaid’, ‘informal’, ‘cost\*’, ‘institut\*’ and the names of each individual country.

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## RESOURCE USE

### *Social care*

The proportion of people aged 65 years or more living in long-term care institutions was multiplied by the respective population size to inform 14 countries [5, 6]. In Finland, hospitals also provide long-term care of elderly patients [7], which is included both in long-term care statistics and in inpatient care statistics [5, 8]. Hence, to avoid double counting, the proportion of elderly patients living in residential/nursing care homes, rather than in hospitals, was obtained from National Census data [9]. The number of people aged 65 years or more institutionalized with dementia was estimated using country-specific data derived from a variety of sources [10–23]. For Luxembourg, due to lack of information, it was assumed that the prevalence of dementia in long-term care institutions would be the same as in Belgium.

### *Primary care*

The consultation rates of dementia patients were obtained from country-specific studies evaluating the resource use patterns of dementia patients in 8 countries: Belgium [11], Denmark [24], France [25], Germany [26], Ireland [27], Spain [28], Sweden [29],

and the UK [30]. For Finland, these consultation rates were obtained from a multinational study conducted in four Nordic countries including Finland [2]. These consultation rates were then applied to the number of dementia patients in each country.

However, consultation rates were not found for dementia patients in Austria, Greece, Italy, Luxembourg, the Netherlands and Portugal. The number of primary care consultations due to dementia in these countries was estimated using similar countries and their proportion of visits due to dementia out of all primary care visits. The number of primary care visits due to dementia in Luxembourg and the Netherlands was estimated using data from Belgium on the proportion of primary care visits due to dementia [31], which was then applied to the total number of primary care visits for any cause in Luxembourg and the Netherlands [32–34]. The total number of primary care visits due to dementia in Austria was informed by the German proportion of primary care visits due to dementia which was applied to the total number of primary care visits for any cause in Austria [32, 33]. Finally, the proportion of primary care visits due to dementia in Spain [35], was applied to the total number of primary care visits in Greece [32], Italy [32, 33], and Portugal [36] to obtain the number of primary care visits due to dementia in these three countries.

#### *Hospital outpatient care*

Consultation rates by dementia patients in Belgium [11], Denmark [24], Finland [2], France [25], Germany [26], Spain [28], Sweden [29], and the UK [30] were obtained using the same sources as those used to obtain dementia-specific primary care resource use. These consultation rates were then applied to the number of dementia patients in each country. For Ireland, however, as there was no information on outpatient care consultation rates by dementia patients, the proportion of total primary care visits due to dementia was applied to the total number of hospital outpatient care visits for any cause [37] in order to obtain the number of outpatient care visits due to dementia.

In order to obtain the number of outpatient care visits due to dementia in the remaining countries, the proportion of outpatient visits due to dementia in Belgium, Germany and Spain was obtained and applied to the total number of outpatient visits in Austria [32, 33], Greece [32, 33], Italy [32, 33], Luxembourg [32, 33], the Netherlands [34] and Portugal [36], in the same way as that used to obtain dementia-related primary care resource use in these countries.

#### *Accident & Emergency care*

The number of A&E visits per patient with dementia was obtained for Finland [2], Germany [26], Spain [28], Sweden [2] and the UK [38]. These were then applied to the number of dementia patients in each country. For countries with dementia-related primary care resource use information, but no dementia-related emergency care, i.e., Belgium, Denmark, France and Ireland, the proportion of primary care visits due to dementia was applied to the total number of A & E visits in each country [31, 37, 39, 40] to obtain the number of dementia-related A & E visits.

As it was not possible to obtain information on the number of A & E visits due to any cause in Austria and Luxembourg, it was assumed that each patient with dementia would have the same A & E consultation rates as in Germany and Belgium, respectively. In order to obtain the number of A & E visits due to dementia in the remaining countries, the proportion of A & E visits due to dementia in Belgium, Germany and Spain was obtained and applied to the total number of A & E visits in Greece [41], Italy [42], the Netherlands [43] and Portugal [36], in the same way as that used to obtain dementia-related primary and outpatient care resource use in these countries.

#### *Hospital inpatient care*

Inpatient care was estimated from the number of dementia-related days in hospital, including day case admissions. The number of days in hospital, which included day cases, was obtained, for each country, from EUROSTAT statistics by primary diagnosis of dementia and Alzheimer's disease [8]. The only exception was Greece, for which no dementia-related hospitalisation information was available. The number of hospital bed-days due to dementia was therefore applied by using age and gender dementia-related hospital bed-day rates from Spain, and applying them to the Greek population, stratified by age and gender.

#### *Expenditure on medications*

The expenditure on dementia medications was derived from national sources such as National Drug Agencies, Social Security Systems or Prescribing Services for Belgium [44], Denmark [45], Finland [46], France [47], Germany [48], Italy [49], Luxembourg [50, 51], Netherlands [52], Portugal [53], Sweden [54], Spain [55] and the UK [56–59].

Supplementary Table 1  
Data sources for resource use in the EU-15, by country, 2007.

Country	Productivity			Health care					Long term care	
	Mortality	Morbidity	Informal care	Primary care	Outpatient visit	A & E visit	Inpatient day	Medication	People in long-term care	Cases with dementia
Austria	[73]	[87, 88]	Germany [64]	Germany, [32, 33]	Germany, [32, 33]	Germany [31]	[8]	Germany, [60, 61]	[5]	[10]
Belgium	[74]	[87, 88]	Sweden [65]	[11]	[11]	Primary care, [40]	[8]	[44]	[5]	[11]
Denmark	Sweden	[87, 88]	Sweden [66]	[24]	[24]	Primary care, [40]	[8]	[45]	[5]	[12]
Finland	[75]	[87, 88]	Sweden [67]	[2]	[2]	[2]	[8]	[46]	[9]	[13]
France	[76]	[87, 88]	Portugal [68]	[25]	[25]	Primary care, [39]	[8]	[47]	[5]	[14]
Germany	[77]	[87, 88]	Portugal [69]	[26]	[26]	[26]	[8]	[48]	[5]	[15]
Greece	Spain	[87, 88]	Belgium, Netherlands [70]	Spain, [32]	Spain, [32]	Spain, [41]	Spain	Portugal, [48]	[5]	[16]
Ireland	[78]	[87, 88]	Belgium, Netherlands [71]	[27]	Primary care, [27]	Primary care, [37]	[8]	Northern Ireland, [63]	[5]	[21]
Italy	[79]	[87, 88]	Belgium, Netherlands [72]	Spain, [32, 33]	Spain, [32, 33]	Spain, [42]	[8]	[49]	[5]	[22]
Luxembourg	Belgium	[87, 88]	Belgium, Netherlands [73]	Belgium, [32, 33]	Belgium, [32, 33]	Belgium	[8]	[50, 51]	[5]	Belgium
Netherlands	[80]	[87, 88]	Belgium, Netherlands [74]	Belgium, [34]	Belgium, [34]	Belgium, [43]	[8]	[52]	[5]	[17]
Portugal	Spain	[87, 88]	Belgium, Netherlands [75]	Spain, [36]	Spain, [36]	Spain, [36]	[8]	[53]	[5]	[23]
Spain	[81]	[87, 88]	Belgium, Netherlands [76]	[28]	[28]	[28]	[8]	[55]	[5]	[18]
Sweden	[82]	[87, 88]	Belgium, Netherlands [77]	[29]	[29]	[2]	[8]	[54]	[5]	[19]
UK	[83-85]	[87, 88]	Belgium, Netherlands [78]	[30]	[30]	[38]	[8]	[56-59]	[5]	[20]

Supplementary Table 2  
Unit costs in the EU-15, by country, 2007

Country	Productivity losses		Informal care			Health and Social care						
	Yearly earnings		Hourly earnings			GP visit (€)	Outpatient visit (€)	A & E visit (€)	Inpatient day (€)	Year in long term care (€)	Sources (€)	
	Males (€)	Females (€)	Active carers (€)	Inactive carers (€)								
Austria	41,409	28,676	18	9	26	80	116	497	20,882	[89-94]		
Belgium	39,721	35,038	20	8	22	39	79	390	22,196	[90, 91, 95-98]		
Denmark	56,910	45,282	27	14	17	55	142	654	60,559	[90, 91, 99-101]		
Finland	38,756	31,332	19	9	43	203	243	452	34,619	[90, 91, 102-105]		
France	34,303	28,317	16	8	23	26	95	489	19,981	[90, 91, 93, 106]		
Germany	42,600	32,600	19	8	37	45	53	387	21,000	[90, 102, 107-109]		
Greece	28,546	19,317	12	4	23	61	64	196	15,600	[90, 91, 110-113]		
Ireland	46,484	36,058	21	9	47	162	196	582	37,428	[90, 91, 114-116]		
Italy	31,163	25,223	15	10	22	68	69	373	16,889	[90, 91, 110, 117-120]		
Luxembourg	47,543	39,110	24	10	36	57	70	474	54,297	[90, 91, 94, 121,122]		
Netherlands	41,442	31,776	20	8	24	77	56	398	23,220	[90, 91, 123-125]		
Portugal	16,710	13,174	8	3	31	59	76	219	19,277	[23, 90, 91, 126-128]		
Spain	24,582	17,851	11	4	18	57	123	338	16,776	[90, 91, 129-131]		
Sweden	38,418	31,368	18	12	66	296	248	380	41,745	[90, 91, 132-134]		
UK	49,247	32,443	20	9	38	148	114	397	40,414	[90, 91, 135, 136]		

Supplementary Table 3  
Resource units in the EU-15, by country, 2007

Country	Mortality losses				Productivity losses				Informal care (thousands)						Health and social care (thousands)							
	Deaths		Working years lost*		Working years lost		Hours of informal care		Active carers		Inactive carers		GP visit		Out-patient visit		A & E visit		Hospital bed-day		Long-term institutional care, years	
	Males	Females	Males	Females	Males	Females	Males	Females	Active carers	Inactive carers	GP visit	Out-patient visit	A & E visit	Hospital bed-day	Long-term institutional care, years							
Austria	274	696	55	90	770	268	77,348	114,670	4,316	724	128	278	44									
Belgium	1,225	2,595	478	495	922	293	81,272	149,966	2,289	166	111	204	51									
Denmark	1,595	3,618	262	207	617	218	37,974	199,872	718	226	50	25	19									
Finland	1,432	3,306	568	680	501	206	40,946	238,399	364	86	11	1,968	8									
France	7,583	17,532	2,693	3,578	5,161	1,997	483,350	691,954	12,406	3,308	567	569	457									
Germany	4,207	9,699	1,673	1,275	7,969	2,779	738,841	1,131,672	42,480	9,912	1,416	801	600									
Greece	1,737	2,658	456	455	1,093	277	166,959	290,463	744	898	87	155	13									
Ireland	238	495	105	65	382	112	39,284	112,980	612	117	61	28	6									
Italy	4,657	9,951	1,586	1,490	5,556	1,472	654,135	1,851,202	11,237	4,173	366	323	212									
Luxembourg	42	91	37	31	43	13	2,645	4,667	66	13	4	9	2									
Netherlands	1,972	5,295	585	475	1,721	553	120,241	157,582	2,976	200	98	180	59									
Portugal	1,677	3,374	404	410	850	310	164,494	286,175	1,554	636	135	21	20									
Spain	6,502	14,091	1,670	1,513	4,217	1,166	573,545	1,207,651	9,977	3,443	351	439	134									
Sweden	3,706	7,710	438	343	1,049	385	58,106	318,360	1,755	145	23	102	66									
UK	6,865	16,553	2,025	1,933	6,073	2,140	641,814	1,248,212	10,017	659	391	3,594	305									
Total EU-15	43,712	97,664	13,035	13,040	36,924	12,189	3,880,954	8,003,825	101,511	24,706	3,799	8,696	1,996									

Note: The working year lost\* links with: \*Does not take into account unemployment or inactivity rates.

Supplementary Table 4  
Resource use rates in the EU-15, by country, 2007

	Working years lost due to mortality per 1,000 early-onset dementia patients		Working years lost due to morbidity per 1,000 early-onset dementia patients		Health care resource use per dementia patients				Institutionalisation rate amongst dementia patients $\geq 65$ years of age
	Male	Female	Male	Female	GP visit	Outpatient visit	A & E visit	Hospital bed-day	
Austria	8	13	109	38	34	6	1	2	36%
Belgium	52	54	101	32	14	1	1	1	32%
Denmark	44	35	103	36	9	3	1	0	25%
Finland	110	131	97	40	5	1	0	25	11%
France	52	69	100	39	12	3	1	1	47%
Germany	23	18	112	39	30	7	1	1	45%
Greece	46	46	110	28	5	5	1	1	8%
Ireland	34	21	123	36	15	3	1	1	15%
Italy	29	27	102	27	10	4	0	0	20%
Luxembourg	102	86	119	36	11	2	1	2	36%
Netherlands	38	31	113	36	14	1	0	1	29%
Portugal	43	44	91	33	9	4	1	0	13%
Spain	45	41	113	31	14	5	0	1	20%
Sweden	44	34	105	39	11	1	0	1	43%
UK	35	33	105	37	10	1	0	4	34%
Total EU-15	37	37	106	35	16	4	1	1	33%

Supplementary Table 5  
Research funding for brain disorders and dementia in the EU-15

	Brain disorders, (thousands) (€)	Dementia, (thousands)* (€)
Austria	2,737	182
Belgium	7,104	474
Denmark	8,241	549
Finland	6,191	413
France	105,573	7,038
Germany	73,238	4,883
Greece	3,056	204
Ireland	30,056	2,004
Italy	47,706	3,180
Luxembourg	376	25
Netherlands	33,559	2,237
Portugal	3,531	235
Spain	27,308	1,821
Sweden	18,311	1,221
UK	291,570	19,438
European Commission	93,986	6,266
Total EU-15	752,544	50,170

\*Calculated assuming that the proportion of total research funding for brain disorders devoted to dementia across the 28 European countries, estimated by Sobocki et al. (2006) to be 6.7%, was the same in each EU-15 country.

To obtain dementia medication expenditure in the remaining three countries, the proportion of Nervous System (ATC code N) pharmaceutical expenditures due to dementia medications in Germany, Portugal and Northern Ireland, was multiplied to the total expenditure in Nervous System pharmaceuticals in Austria [60, 61], Greece [62], and Ireland [63], respectively.

### Informal care

The time spent by relatives and friends providing unpaid care for dementia sufferers was obtained from country-specific studies evaluating the informal care patterns of dementia patients in 10 countries: Belgium [64], France [65], Germany [66], Ireland [67], Italy [68], the Netherlands [69], Portugal [70], Spain [71], Sweden [72] and the UK [38]. The time spent providing informal care was then multiplied by the number of dementia cases living in the community and annualized.

In the five countries for which no country-specific data were identified, extrapolations between similar countries were made. Therefore, we assumed that the hours of informal care provided in Austria would be the same as in Germany, for Denmark and Finland we assumed these to be the same as for Sweden, for Greece the same as for Portugal and finally, for Luxembourg the same as for Belgium and the Netherlands.

The average hours of informal care given to each dementia patient was then multiplied by the number of people with dementia living in the community and annualized. The total number of hours of informal care provided was distributed according to the employment status and gender of the carer. Informal care provided by employed carers was valued using the gender-specific average wage in each country. Care provided by unemployed, inactive or retired carers was valued using the minimum wage or, for those countries with no minimum wage, the wage of the worst paid sector.

In a number of studies, the employment status of the carer was not reported. Therefore, to determine the employment status of the carer we used information from each study on the carer's relationship with the patient (spouse, son/daughter, son/daughter in law, sibling, other relative or friend) and the gender of the carer. Due to the advanced age of dementia patients, we assumed that spouses, siblings and friends providing the care would typically be aged 65 years of age or more, and therefore be retired. If care was being provided by either the patients' children or their children's spouses, then it was assumed that these informal carers would be under 65 years of age. Using gender-specific economic activity and unemployment rates for each country, we then determined the proportion of these carers who were employed or unemployed/economically inactive.

#### Mortality losses

Age and gender specific deaths, where the main cause was either dementia or Alzheimer's disease, were obtained from mortality databases for Austria [73], Belgium [74], Finland [75], France [76], Germany [77], Ireland [78], Italy [79], the Netherlands [80], Spain [81], Sweden [82] and the UK [83–85]. For Greece and Portugal, for which no dementia-specific mortality estimates were identified, age and gender dementia-specific death rates from Spain were multiplied by the population, stratified by age and gender, of these two countries to obtain the number of deaths due to dementia. In a similar way, Swedish and Belgian age and gender dementia-specific death rates were used to estimate the number of death due to dementia in Denmark and Luxembourg.

#### Morbidity losses

The number of cases of early onset dementia (i.e. before 65 years of age) in each of the 15 EU countries was obtained from the ADI report and applied to the under 65 years of age population estimates for each of the 15 countries [6]. Using age and gender specific unemployment and economic activity rates [86], we estimated the expected number of early onset dementia patients that would be in employment if employment rates were the same as those for the general population.

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