



ASSESSING THE SOCIOECONOMIC
IMPACT OF ALZHEIMER'S DISEASE
IN WESTERN EUROPE AND CANADA

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ABOUT THE REPORT

Assessing the socioeconomic impact of Alzheimer's in western Europe and Canada is a report by The Economist Intelligence Unit, sponsored by Eli Lilly, which examines how healthcare systems and governments in western Europe and Canada are responding to the growing pressures that Alzheimer's disease and other dementias are placing on their economy, society and healthcare systems.

The findings of this report are based on research carried out by The Economist Intelligence Unit and include insights from leading dementia experts in academia and the medical profession, as well as patient association leaders. This information was gathered in December 2016 and January 2017 through an in-depth interview process. The insights from these interviews appear throughout the report and country profiles, which are included in this report. Our research consists of a cost analysis of dementia in six countries—Canada, France, Germany, Italy, Spain and the UK. We initially conducted an epidemiological review to determine the number of dementia patients in 2016 and then estimated the dementia costs based on the most relevant—and most recently published—data.

We would like to thank the following interviewees (listed alphabetically) for sharing their insights and experience:

- Charles Alessi, senior dementia adviser, Public Health England
- Elena Andradas, director general, Directorate General of Public Health, Quality and Innovation, Spanish Ministry of Health, Social Policy and Equality
- Melissa Aquino, psychologist and specialist in neuropsychology and cognitive disease, Italian Alzheimer's Association (AIMA)
- Debbie Benczkowski, chief operating officer, Alzheimer's Society Canada
- Claudine Berr, research director, Institut National de la Santé et de la Recherche Médicale (Inserm), France
- Lutz Frölich, head, Department for Geriatric Psychiatry, Central Institute of Mental Health, Medical Faculty Mannheim, University of Heidelberg, Germany
- Serge Gauthier, director, Alzheimer's Disease Research Unit, McGill University Research Centre for Studies in Aging, Canada
- Jean Georges, executive director, Alzheimer Europe
- Fabrizio Giunco, medical director, Istituto Palazzolo, Fondazione Don Carlo Gnocchi, Istituto di Ricovero e Cura a Carattere Scientifico (IRCCS), Italy
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- Jöel Jaouen, president, France Alzheimer

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- Frank Jessen, director, Clinic for Psychiatry and Psychotherapy, University Hospital Cologne, Germany
- Monika Kaus, chair, German Alzheimer Association (DAzG)
- Martin Knapp, director, Personal Social Services Research Unit; professor of social policy, London School of Economics and Political Science (LSE); and director of NIHR School for Social Care Research, UK
- Hans Helmut König, specialist in the economy of health, University of Hamburg, Germany
- Giuseppe Lacidogna, neurologist, neuropsychologist, Policlinico Universitario Agostino Gemelli (Hospital), Italy
- Gill Livingston, professor of psychiatry of older people, University College London; and honorary consultant old-age psychiatrist in Camden and Islington NHS Foundation Trust
- Pablo Martínez-Lage, director of neurology, Centre for Research and Advanced Therapies, Fundacion CITA-alzheimer Fundazioa, Spain
- Matthew Norton, director of policy and strategy, Alzheimer's Research UK
- Jesús Rodrigo, executive director, Spanish Confederation of Associations of Families of People with Alzheimer's and other Dementias (CEAFA), Spain
- Paolo Maria Rossini, director, Department of Neurosciences, Policlinico Universitario Agostino Gemelli (Hospital); and professor of neurology, Università Cattolica del Sacro Cuore, Italy
- Christophe Roy, director of social missions, France Alzheimer
- Liz Sampson, reader, University College London, Marie Curie Palliative Care Research Department; and consultant in liaison psychiatry, North Middlesex University Hospital, UK
- Samir K Sinha, director of geriatrics, Sinai Health System and the University Health Network Hospitals, Toronto, Canada
- Theresa Tam, interim chief public health officer, Public Health Agency of Canada
- Lluís Tárraga, chief executive officer, Fundació ACE, Spain
- Pietro Davide Trimarchi, neuropsychologist, Istituto Palazzolo, Fondazione Don Carlo Gnocchi IRCCS, Italy
- Ketty Vaccaro, head of health and welfare, Censis, Italy
- Petra Weritz-Hanf, head of Division 303 "Healthy Aging Dementia Support", Federal Ministry for Family Affairs, Senior Citizens, Women and Youth, Germany

The Economist Intelligence Unit bears sole responsibility for the content of this report. The findings and views expressed in the report do not necessarily reflect the views of the sponsor. Sarah Murray was the author of the report, and Edel McCormack was the editor.

EXECUTIVE SUMMARY

To assess the socioeconomic burden of Alzheimer's and other dementias as well as the associated challenges facing policymakers, governments and society, The Economist Intelligence Unit has conducted a study of six countries—Canada, France, Germany, Italy, Spain and the UK—to examine the strategies and policies that governments and other key organisations are devising and implementing in their attempts to tackle the socioeconomic impact of these diseases.

Key findings and identified needs

- **Rapidly ageing populations are adding to the rising number of people with dementia.** This is putting severe pressure on countries' healthcare systems and budgets, and importantly also on families and informal caregivers. If current levels of informal care are to continue, governments will need to increase the amount of support they give these carers in order to manage the rising number of people with Alzheimer's disease. According to Jean Georges, executive director of Alzheimer Europe, "better support and training for carers is needed so they are better able to provide care at home, which would save substantial costs to governments in the long run".
- **The cost of dementia is mounting.** The global societal and economic cost was estimated at US\$818bn in 2015, or 1.09% of global GDP, according to Alzheimer's Disease International.
 - The majority of direct medical costs fall on the health system of each country we studied. Based on our analysis, the UK shoulders the highest direct medical cost, whereas Germany and Italy carry the lowest. Direct costs of dementia are shared between families and the public system, but indirect costs fall entirely on families. This leads to a very high private economic burden of dementia. In our analysis, we have determined that in all European countries more than one-half of the cost falls on the families.
 - These indirect costs are in addition to the emotional burden of the disease, which has a major impact on those caring for someone with Alzheimer's. Many caregivers are under growing stress and can suffer from anxiety, depression and other debilitating effects. Ketty Vaccaro, head of health and welfare at Censis, argues that the big question is how long the informal care model—based on the key role of the family—will last.
- **Developing national strategies on dementia is necessary to improve co-ordination across service providers.** In many countries healthcare and social care systems operate in silos with separate sources of funding. This not only increases costs but also results in lower quality of care, because dementia affects both a person's health and their ability to function in society. "Improving the situation of people with dementia and their carers depends on what has been called a 'welfare mix', which means the co-ordinated efforts of market, state and civil society, including self-help

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organisations," explains Monika Kaus, chair of the German Alzheimer Association. Moreover, national strategies will help to inform regional policies.

- **More research is needed.** This not only relates to the development of medicines and medical technologies that can prevent or slow the onset of dementia, but also to the production of data that can inform policies on preventive measures and facilitate an increase in the rate of accurate and timely diagnosis. Rates of early diagnosis need to be increased as a means of improving the outlook for patients and helping to cut expenditure by avoiding costly hospitalisation and institutional long-term care. According to Theresa Tam, interim chief public health officer at the Public Health Agency of Canada, necessary measures include "providing the tools and information that people need to recognise the disease to promote early diagnosis, since that makes a difference in terms of delaying some of the impact".
- **There is a lack of understanding between what people consider symptoms of old age and what are, in fact, indicators of Alzheimer's.** One way to tackle this is by raising awareness of the condition and education about what Alzheimer's is—its symptoms and its impact on those that suffer from it and those around them. "The fight against Alzheimer's disease and related illnesses requires a change of view of society as a whole. Awareness of the general public is therefore a priority for the years to come," explains Jöel Jaouen, president of France Alzheimer.

INTRODUCTION

The global population is ageing rapidly. Between 2015 and 2030 the number of people aged 60 years or over is expected to grow by 56%, from 901m to 1.4bn, and by 2050 the population of older persons worldwide is forecast to more than double in size to approximately 2.1bn.¹ One of the leading challenges posed by an ageing population is the care and management of age-related diseases, especially dementia. Dementia is a general term used to describe brain disorders that cause a gradual deterioration of the functional and social capacity of a person. This steady decline is caused by a variety of underlying diseases, most commonly Alzheimer's disease, and includes varying degrees of memory loss and difficulties with a person's understanding, judgment or use of language.²

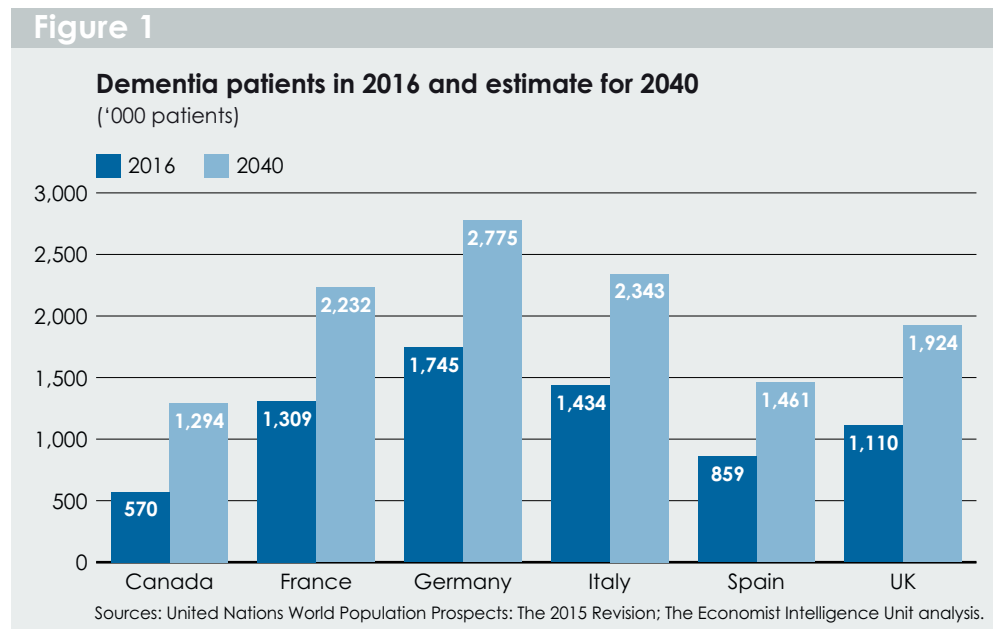
Alzheimer's disease, also simply referred to as Alzheimer's, is the most common form of dementia, accounting for 60-80% of all dementia cases.³ According to the Alzheimer Cooperative Valuation in Europe (ALCOVE) project, a network of 30 partners from 19 EU member states that aims to improve knowledge on dementia and its consequences, the terms Alzheimer's and dementia are sometimes used interchangeably, with leading organisations such as Alzheimer's Disease International (ADI) and Alzheimer Europe representing all dementias, and not just Alzheimer's disease.

Alzheimer's is a slowly progressive brain disease that begins before clinical symptoms emerge.⁴ There are a number of reasons why a person develops Alzheimer's,⁵ but the main risk factors are unmodifiable characteristics such as family history, genetic predisposition and age, which is the greatest risk factor of all.⁶ As the disease progresses, these symptoms usually escalate to include language impairments, difficulties with planning and organising, and a growing sense of confusion and deterioration. Eventually, many people experience increased fragility, severe memory loss and difficulties in walking and swallowing. Moreover, the disease affects each person differently, with no two experiences alike.

In 2015 ADI estimated that someone in the world developed dementia approximately every three seconds.⁷ It is estimated that in 2016 some 47m people worldwide were living with dementia, a figure that is projected to rise to more than 131m by 2050.⁸

According to the OECD, dementia is already the second-largest cause of disability for the over-70s and costs an estimated US\$645bn per year globally. This increase is steadily taking its toll on families, caregivers and national healthcare and social care systems. The World Health Organisation (WHO) estimated this burden at US\$604bn a year in 2012 and predicted that these costs would increase faster than the prevalence.⁹ The global societal and economic cost was estimated at US\$818bn in 2015, or 1.09% of global GDP, according to ADI.¹⁰ Moreover, it estimates that by 2018 dementia costs will increase to US\$2trn.¹¹

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¹ United Nations, *World Population Ageing 2015*. http://www.un.org/en/development/desa/population/publications/pdf/ageing/WPA2015_Report.pdf

² NHS choices, *Dementia guide: About dementia* [Internet]. England: gov.uk; [cited 21 November 2016]: <http://www.nhs.uk/conditions/dementia-guide/pages/about-dementia.aspx>

³ Alzheimer's Association, 2016 Alzheimer's disease facts and figures, *Alzheimer's and Dementia*, 2016;12(4):459-509.

⁴ Rajan KB, Wilson RS, Weuve J *et al*, "Cognitive impairment 18 years before clinical diagnosis of Alzheimer disease dementia", *Neurology*, 2015;85(10):898-904.

⁵ Alzheimer's Association, 2016 Alzheimer's disease facts and figures.

⁶ OECD, *Addressing Dementia: The OECD Response*, OECD Health Policy Studies. Paris: OECD Publishing, 2015

⁷ Alzheimer's Disease International, *Dementia Statistics*. <https://www.alz.co.uk/research/statistics>

⁸ Alzheimer's Disease International, *World Alzheimer Report 2016*. <https://www.alz.co.uk/research/WorldAlzheimerReport2016.pdf>

CHAPTER 1: THE BURDEN OF ALZHEIMER'S DISEASE

A major consequence of the world's ageing population and the upsurge in life expectancy is a marked increase in the number of people living with dementia. There are several types of dementia, the most common being Alzheimer's disease. The development of Alzheimer's begins before clinical symptoms emerge. Two key pathologies, known as amyloid plaques and tau tangles, appear in the brain of a person with Alzheimer's 10-20 years before symptoms emerge.¹² At present, there is no single simple test that can identify the disease and the level of clinical impairment, making it extremely difficult to diagnose. However, several new, regulatory-approved imaging agents are now available that can confirm the presence or absence of amyloid pathology in patients.

Treatments available for Alzheimer's and other types of dementia, pharmacologic and non-pharmacologic, may temporarily alleviate symptoms, but no intervention has so far been able to alter the course of the disease. In addition, the distress of a dementia diagnosis and the awareness of what will happen to the individual can lead to anxiety and depression.

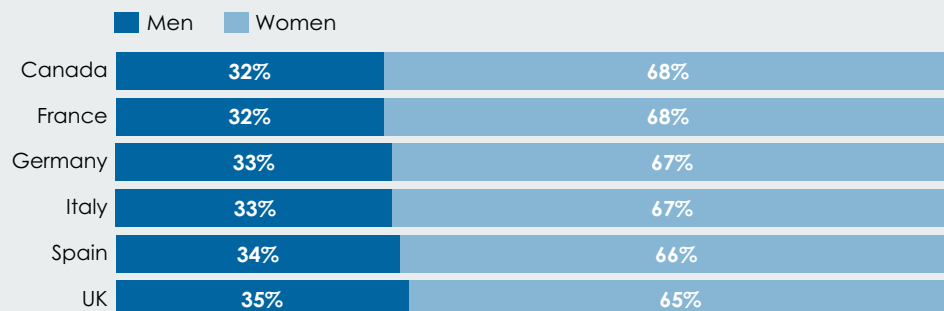
According to Alzheimer Europe, approximately 30-60% of people with dementia are probably not diagnosed. Similarly, according to a recent global systematic review and meta-analysis, the pooled rate of undetected dementia is 61.7%, clearly highlighting the issue of underdiagnosis.¹³

When analysing dementia on a gender basis, the prevalence of dementia is higher in women than in men across the globe.¹⁴ In the six countries analysed in this study, the ratio of cases in women versus men is 2:1.¹⁵ Alzheimer's disease and other dementias were the fourth-largest cause of disability in women aged 60 years or older worldwide

Figure 2

Dementia cases by gender, 2016

(%)



Source: Dementia in Europe Yearbook 2013, 2012 population statistics from the United Nations, Canadian Study of Health and Aging (1994).

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in 2012, and the eighth-largest cause of disability in men of the same age group.¹⁶ Moreover, Alzheimer's disease and other dementias were the seventh-largest cause of death in women aged 60 years and above.¹⁷

In the following sections we explore the emotional burden of Alzheimer's and the direct and indirect costs incurred as a result of the disease. This will provide an overview of present and future challenges that Alzheimer's poses to healthcare systems.

The emotional burden

The role of informal caregivers

The burden of caring for someone with Alzheimer's is often a cause of considerable emotional stress for caregivers, especially informal caregivers who are looking after a family member. The diminished ability of people with Alzheimer's to communicate and carry out daily activities can be particularly challenging for those around them, placing both physical and mental strains on carers. "People who are looking after someone with dementia are very likely to develop anxiety and depression," says Gill Livingston, professor of psychiatry of older people at University College London. In addition, the symptoms of Alzheimer's, such as agitation and aggression, can add a different layer of complexity to the challenge of taking care of someone with dementia.

Among the countries analysed in this report, Italy represents an example where the informal care burden of dementia is extremely high, making it essential to improve the social care system to support families. According to Censis, a socioeconomic research institute, Italy's national strategy on dementia addresses these issues, with part of the strategy focusing on promoting the empowerment of people with dementia and their carers. Moreover, it includes commitments to provide support to carers and recommendations to involve them in every phase of the disease, from diagnosis to treatment. Although these commitments are an example to other countries of how the role of informal caregivers can be established as a priority for policymakers, governments will need to back up this support with adequate funding at each level.

With healthcare systems under financial pressure, the role of informal caregivers is fundamental. According to the OECD, informal care is the most important source of care for people with long-term care needs in OECD countries, and more than 10% of people aged 50 or over provide informal care to family members and friends with functional limitations.

The impact of Alzheimer's on daily life

Stigma and the inability to continue to work are the two major areas that impact a person who has been diagnosed with Alzheimer's disease. "It is not uncommon that the moment someone is diagnosed with a condition like dementia, they lose their job," says Charles Alessi, senior dementia adviser to Public Health England. According to a 2016

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study by the UK's Alzheimer's Society, almost two-thirds of respondents felt a diagnosis would mean that "life is over", while almost one-half worried that people would think they were "mad". The study also found that more than one-half would delay seeking a dementia diagnosis for up to a year or more, often as a result of these doubts and fears.

A lack of understanding of the disease on the part of friends and colleagues outside the family network can sometimes result in people avoiding those with Alzheimer's, even when their cognitive decline is at a relatively mild stage. This can be particularly challenging for those who are still in employment. "It makes them unable to work, or they experience social isolation and stigma in the office," says Debbie Benczkowski, chief operating officer at Alzheimer's Society Canada.

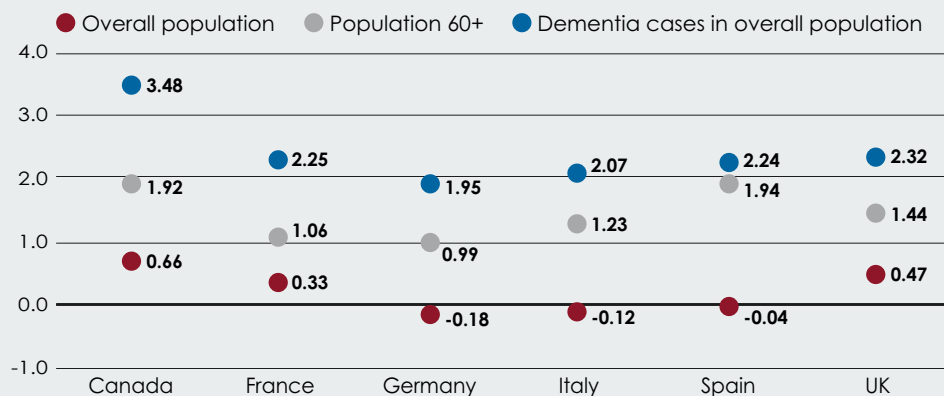
For those still in employment, loss of income is life-changing. In Canada, for example, one survey found that more than 40% of those with Alzheimer's disease and dementia below the age of 65 reported being permanently unable to work.¹⁸ The same survey estimated that, on average, men with Alzheimer's disease and dementia would lose 16 years in full health and women 15.5 years in full health owing to disability and premature death.

Prevalence of dementia

An increase in ageing populations means that more people are at risk of developing dementia. The overall population in Canada, for example, is expected to increase only slightly, but the share of those aged over 60 is predicted to grow to a much greater extent. According to research conducted by The Economist Intelligence Unit for this report, this means that—assuming constant prevalence rates and no breakthroughs in prevention or therapy—the number of people with dementia will more than double.

Figure 3

Estimated 2016-2040 compound growth of population and dementia cases by country (%)



Sources: Dementia in Europe Yearbook 2013; Canadian Study of Health and Aging United Nations World Population Prospects: The 2015 Revision; The Economist Intelligence Unit estimates.

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In Germany, the number of people living with dementia is projected to increase from 1.7m in 2016 to 2.8m by 2040, and in Italy, if current prevalence rates are maintained, the number of those with dementia is projected to increase from 1.4m to 2.3m by 2040, whereas the overall population is expected to decrease in both countries over that period.

Our analysis is based on the assumption that prevalence rates of dementia will be constant until 2040. However, recent studies have suggested that prevalence might be decreasing. This could be partly due to the growing attention being paid to optimum health early in life.^{19,20} These studies highlight the need to fully understand the changes in the prevalence rate so as to prevent the increase in the burden estimated in our analysis.

Table 1. Projection of number of dementia cases in 2040 in thousands of people

Age bands	Canada	France	Germany	Italy	Spain	UK
30-59	17	30	36	25	19	33
60-64		20	27	21	21	22
65-69	108	63	72	71	57	62
70-74		131	210	154	114	148
75-79	468	251	427	289	211	274
80-84		452	653	468	346	417
85-89	702	556	668	545	360	429
90 and older		729	683	770	334	540
Affected population	3.0%	3.2%	3.6%	4.0%	3.2%	2.6%
Total number of cases	1,294	2,232	2,775	2,343	1,461	1,924

Source: Dementia in Europe Yearbook 2013, Canadian Study of Health and Aging United Nations World Population Prospects: The 2015 Revision

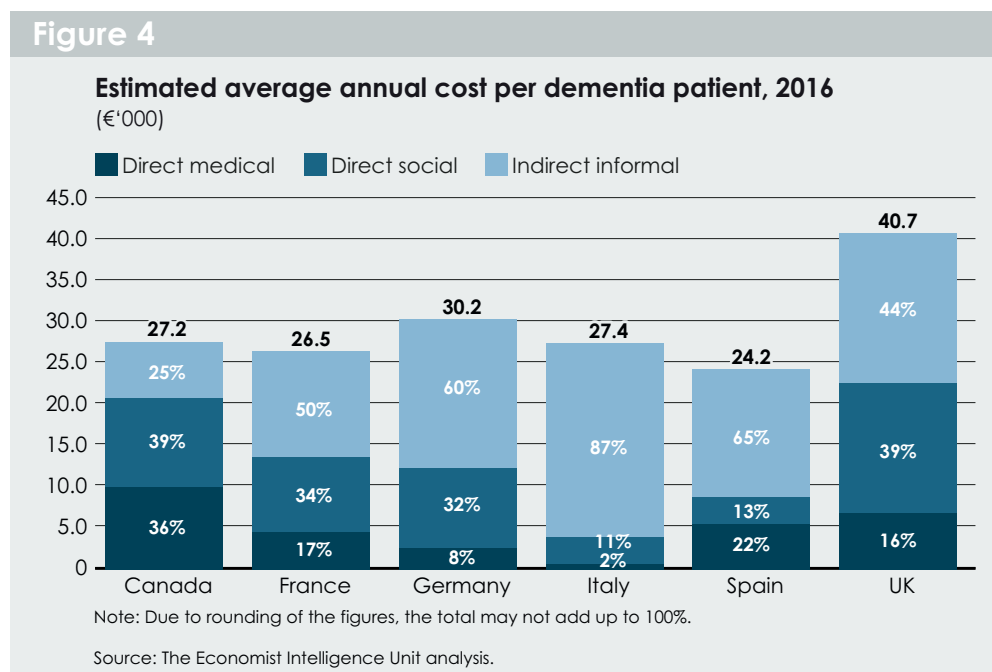
Dementia costs

Financially, the cost of dementia on health and social care systems is becoming progressively onerous owing to the rise in the number of people with Alzheimer's as an overall percentage of the population. Costs can be divided into direct and indirect costs. Direct costs arise from measures to prevent, diagnose or attempt to manage the disease, and they can be subdivided into medical care costs and social care costs.

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Indirect costs are not medical expenses but instead account for losses such as income, productivity and opportunity.

Dementia was estimated to cost the EU15 (the member states before the accession of ten candidate countries in 2004) €189bn in 2007. Of this, 68% was accounted for by informal care, 26% by social care, 5% by healthcare and 1% by productivity losses.²¹ According to our analysis, the UK has the highest average annual cost per patient, at €40,695 (US\$45,032). This is followed by Germany at €30,179 and Italy and France at €27,419 and €26,510 respectively.



Direct costs

There are two types of direct costs: direct medical, which are healthcare costs, and direct social, which are the costs of formal social care. Healthcare costs include the cost of physician visits, visits to or by nurses, hospital admissions and medication.

The six countries in this study all operate universal healthcare systems, with variations. Therefore, the majority of direct medical costs fall on the health systems. Dementia cost analysis is usually limited to dementia-related medicines such as anticholinesterases and NMDA receptor antagonists. However, dementia patients may also take medicines to help manage other non-cognitive symptoms associated with the disease, such as anxiolytics, hypnotics and antidepressants.

In addition, a number of direct medical costs relate to interventions such as physical therapy, speech therapy and memory stimulation. However, there is limited evidence of success, and they do not prevent disease progression.

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Based on our analysis, the UK bears the highest direct medical cost at national level, at €7.4bn. By contrast, Germany and Italy have the lowest direct medical costs among the countries analysed.

Direct social costs, the second type of direct costs, reflect the expenditure of formal care—professional home care, day-centre visits or nursing-home expenses. Direct social costs can be partly covered by the country's health system, local authorities or social benefits when available, and are also partly covered by the dementia sufferer and his or her family.

Although many countries with national public healthcare systems operate universal healthcare coverage, other forms of care, such as home care and social care, often impose a heavy burden on people with dementia and their families. In Germany—where about 60% of people with Alzheimer's and other dementias live in private homes and 40% in nursing homes—an important tool is the country's system of long-term care insurance (LTCI), which was introduced in 1995 as part of the country's social security system.²² However, even then not all costs are covered, according to Ms Kaus of the German Alzheimer Association. "People have to pay relatively high costs," she explains, and "under certain circumstances [families] are obliged to pay".

Indirect costs

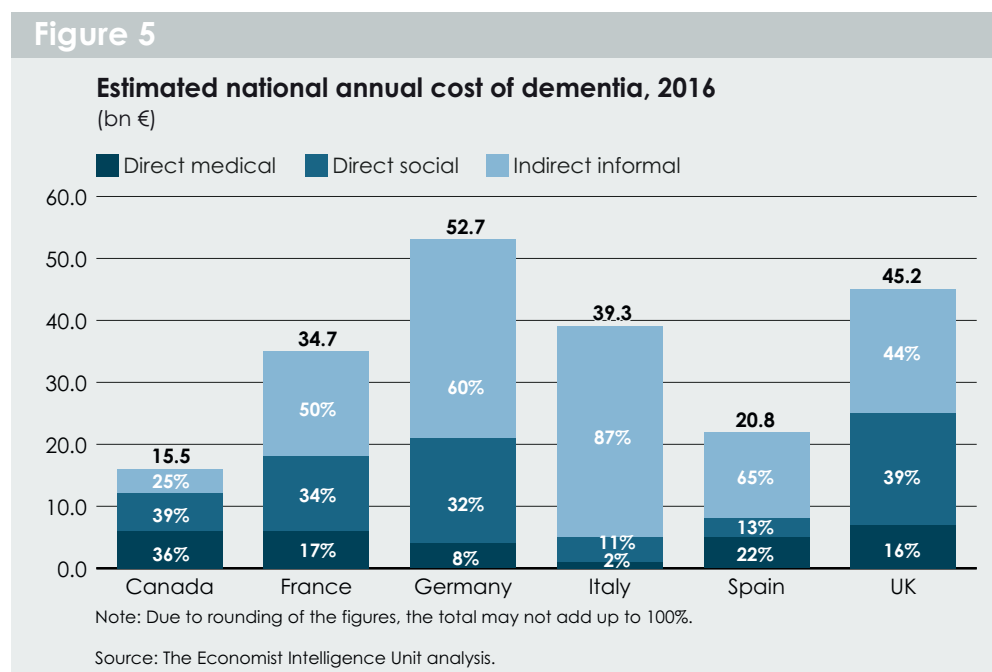
Indirect costs are lost earnings as a result of premature disability, expenses following the death of a person with dementia, and opportunity costs incurred by informal caregivers. Informal caregivers are often family members, but they can also include friends or charity workers who are not paid to provide assistance. Informal caregivers incur a loss of time when providing care, time that could be used for work or leisure activities, which may cost them a promotion or prevent them from looking after their own fitness and health.

It is challenging to determine indirect costs, as this is not money spent but rather money or opportunities lost because the person with dementia cannot keep their job, or because an informal caregiver needs to take time off from work or sacrifice their own free time to care for someone with the disease. Since people usually develop symptoms of dementia close to or after retirement, indirect productivity costs of patients are often considered negligible and excluded from cost of dementia analyses. For the purpose of our analysis, indirect costs of dementia are the opportunity costs of informal caregivers.

In general, the monetary value of lost income and the damage to caregivers' health and wellbeing is hard to determine, resulting in indirect informal costs often being excluded from economic models of disease. Yet social and informal costs create the heaviest burden for countries, says Jesús Rodrigo, the executive director of the Spanish Confederation of Associations of Families of People with Alzheimer's and other Dementias (CEAFA). "The main problem is not the disease itself," he notes. "It's the consequences of Alzheimer's for family carers and the whole of society."

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Our analysis has found indirect informal costs to be the largest cost component in all European countries, reaching €23,768 (87%) per patient in Italy and €15,724 (65%) per patient in Spain. According to Ketty Vaccaro, head of health and welfare at Censis, Italy's large informal care cost is partly attributable to the fact that Italy's National Health Service is more focused on treating acute diseases than managing the needs of those with chronic conditions. "It is necessary to build a real reorganisation of services as soon as possible, with special attention to chronic diseases and long-term care and new strategies to finance it," Ms Vaccaro says.



The private burden

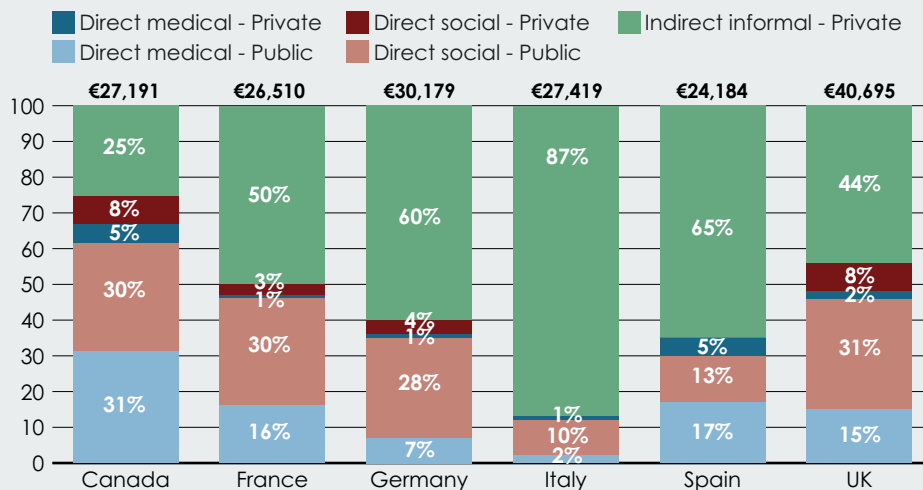
Direct costs of dementia are shared between families and the public system, but indirect costs fall entirely on families. This leads to a very high private economic burden of dementia. In our analysis we have determined that in all five European countries more than half of the cost falls on the families. This reaches €14,342 in France and €19,475 in Germany, for example. In Canada the burden on families is much lower at 38%, which represents €10,451 per patient.

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Figure 6

Split of annual average cost of dementia per patient, 2016

(%)



Note: Due to rounding of the figures, the total may not add up to 100% and direct social private costs in Italy and Spain are 0%.

Source: The Economist Intelligence Unit analysis.

⁹ WHO, *Dementia: a public health priority*, 2012. http://apps.who.int/iris/bitstream/10665/75263/1/9789241564458_eng.pdf?ua=1

¹⁰ Alzheimer's Disease International, *Dementia Statistics*.

¹¹ Alzheimer's Disease International, *World Alzheimer Report 2015*.

¹² <https://www.nia.nih.gov/alzheimers/publication/2011-2012-alzheimers-disease-progress-report/primer-alzheimers-disease-and>

¹³ Lang L, Clifford A, Wei L *et al*, "Prevalence and determinants of undetected dementia in the community: a systematic literature review and a meta-analysis", *BMJ Open*, 2017;7:e011146. doi:10.1136/bmjopen-2016-011146

¹⁴ Alzheimer's Association, *Alzheimer's Disease Facts and Figures*, 2014. Includes a special report on women and Alzheimer's disease. https://www.alz.org/downloads/Facts_Figures_2014.pdf

¹⁵ *Dementia in Europe Yearbook 2013*; 2012 population statistics from the United Nations; Canadian Study of Health and Aging (1994).

¹⁶ United Nations, *World Population Ageing 2015*. http://www.un.org/en/development/desa/population/publications/pdf/ageing/WPA2015_Report.pdf

¹⁷ Ibid.

¹⁸ Public Health Agency of Canada, *Mapping Connections: An Understanding of Neurological Conditions*, 2014. <http://www.phac-aspc.gc.ca/publicat/cd-mc/mc-ec/assets/pdf/mc-ec-eng.pdf>

¹⁹ Wu YT, Fratiglioni L, Matthews FE *et al*, "Dementia in western Europe: epidemiological evidence and implications for policy making", *The Lancet Neurology*, 2016;15(1):116-24.

²⁰ Langa KM, Larson EB, Crimmins EM *et al*, "A Comparison of the Prevalence of Dementia in the United States in 2000 and 2012", *JAMA Internal Medicine*, 2016, 2017;177(1):51-58.

²¹ Luengo-Fernandez R, Leal J and Gray AM, "Cost of dementia in the pre-enlargement countries of the European Union", *Journal of Alzheimer's Disease*, 2011;27(1):187-96.

²² German Alzheimer Association, *Dementia and long-term care: An analysis based on German health insurance data*, 2014. [http://www.alzheimersanddementia.com/article/S1552-5260\(14\)02103-7/abstract](http://www.alzheimersanddementia.com/article/S1552-5260(14)02103-7/abstract)

CHAPTER 2: BARRIERS TO ADDRESSING A GROWING PUBLIC HEALTH CHALLENGE

In addressing Alzheimer's disease and other dementias, policymakers are confronted with a number of hurdles. These range from low rates of diagnosis, fragmented health and social care systems, increasing pressure on informal caregivers and the stigma associated with dementia. Many of these challenges are intertwined. For example, the poor co-ordination of healthcare and social care makes it difficult for informal caregivers to access essential services to support them in caring for people living with dementia.

Low rates of diagnosis

Despite the widespread impact of the disease and evidence that early diagnosis can improve the outlook for people with Alzheimer's and caregivers, many people do not receive a formal diagnosis.²³ In general, the detection of dementia is not clearly identified as being within the capacity of non-specialist services.²⁴ This, coupled with the fact that dementia is often considered a normal part of ageing by some healthcare staff, adds to low levels of diagnosis.²⁵ Moreover, denial on the part of those who have dementia plays an important role in timely diagnosis rates. According to Alzheimer's Disease International, in the majority of high-income countries only 40-50% of people living with dementia have received a diagnosis. Nonetheless, a key finding in our study is that a significant improvement in early diagnosis rates is needed in all six countries. In Canada, for example, more than half of those living with dementia have not been diagnosed, according to Samir K Sinha, director of geriatrics, Sinai Health System and the University Health Network Hospitals, Toronto.

Although rates of diagnosis remain low, our research finds that recommendations for improving early diagnosis are included in some national dementia strategies. In France, the prioritisation of early diagnosis was an integral component of its 2004-08 plan. The emphasis on diagnosis has continued in its national neurodegenerative diseases plan for 2014-19, which includes multiple neurodegenerative diseases such as Alzheimer's, Parkinson's and Huntington's disease.²⁶ "We have a very good network for diagnosis with engaged professionals," says Christophe Roy, director of social missions at France Alzheimer. "This is a huge achievement of the Alzheimer's plan."

Poor co-ordination of health and social care

In addition to the need for earlier diagnosis, co-ordination between healthcare and social care is another key area with room for improvement. In all of the countries in this report, a separation between healthcare and social care presents barriers to addressing

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the needs of people with Alzheimer's and their carers. The separation of these systems is especially problematic for Alzheimer's owing to the physical constraints of the disease and the sizable social challenges it presents, such as the inability to live independently with progressing disease severity.

For these reasons, co-ordinating the strategies of both systems is crucial to provide the complex range of social and medical interventions patients need. However, "it's a problem in all countries", says Jean Georges, executive director of Alzheimer Europe. "You don't always see a co-ordinated approach of making sure there are linkages between the two sectors." He goes on to say that while many countries have universal healthcare, social care is not always included in this. "Long-term care also needs to be funded and better supported," he explains.

In the UK, for example, separate systems delivering healthcare and social care make it difficult to determine "to what extent is dementia care considered to be a healthcare responsibility or how much of it is a social care responsibility", comments Martin Knapp, director of the Personal Social Services Research Unit and professor of social policy at the London School of Economics and Political Science (LSE), as well as director of the National Institute for Health Research (NIHR) School for Social Care Research. However, on a positive note, Matthew Norton, director of policy and strategy at Alzheimer's Research UK, says that "things are moving forward", with a transfer of some of the budget of the National Health Service (NHS) to social care, although he adds that "it has just scraped the surface". Nevertheless, in some parts of the country fundamental changes are taking place. The Greater Manchester devolution agreement, signed in 2014, aims to create a more integrated health and social care system. Within this, dementia has been made a major priority for health and social care reform in the Greater Manchester Combined Authority area.²⁷

Operating in silos is not exclusively a UK problem. In Germany, there is a sharp division between medical and social care that results in limited concerted action, according to Lutz Frölich, head of the Department for Geriatric Psychiatry at the Central Institute of Mental Health, Medical Faculty Mannheim at the University of Heidelberg. Nevertheless, Germany's strong social support system—boosted after recent adjustments to the LTCI system—recognises the damage caused by dementia and provides financial support to those affected by the disease.

Spain suffers from a similar lack of integration. "Inside the ministry there are closed doors," says Mr Rodrigo. "Alzheimer's disease is not only a health and social problem, but while you have the same ministry at the national level, both issues are treated differently, and people from the health system don't talk to people from the social system."

The absence of a strong organisation between both systems has a considerable knock-on effect on the level of care a person suffering from Alzheimer's can receive.

Informal caregivers under increasing stress

As demonstrated throughout this report, a considerable burden is often placed on families caring for someone with Alzheimer's. However, informal care is the most important support system for people with long-term care needs in OECD countries. "It is estimated that an average of four hours per day is spent by caregivers [providing support]," says Jöel Jaouen, the president of France Alzheimer. "The care system for Alzheimer's disease today relies heavily on their involvement."

In 2013 Statistics Canada, the national statistics office, stated that 28% of the population aged 15 or over were informal carers; of these, 6% were providing care to those with Alzheimer's disease and other dementias.²⁸ Given estimates by the Public Health Agency of Canada (PHAC) that the number of Canadians with Alzheimer's disease and dementia who are likely candidates for informal care will almost double between 2011 and 2031, this is a major cause for concern. Yet Ms Benczkowski argues that "there's little support for family caregivers. There are support groups, but it's spotty and not consistent across the country".

Meanwhile, changes in society mean that countries may not be able to rely on informal care as heavily as in the past. According to Mr Jaouen, in a poll conducted by France Alzheimer eight out of ten caregivers said they had difficulty reconciling their working lives and caregiving activities.

Given these difficulties, policymakers will have to devise new ways of providing them with support. Ms Vaccaro stresses that a wide range of support is needed in Italy. "It requires not only an improvement in the availability of public services, especially at home, and co-ordination of healthcare and social care, but also financial support for caregivers," she says.

As reported by the WHO, an important form of support for caregivers is information and training. First, they need to have access to information that will help them understand the characteristics and course of the disease, as well as the resources that are available to them. Second, training in how to care for people with the disease is critical, including how to prevent or manage challenging behaviour.²⁹

In fact, insufficient training for caregivers remains a barrier to managing dementia. This is the case in Spain, according to Pablo Martínez-Lage, director of neurology at the Centre for Research and Advanced Therapies at Fundacion CITA-alzheimer Fundazioa. "There are no teams really trained to communicate a diagnosis," he says. "There are no teams to inform caregivers about what the behavioural symptoms are, how to approach them, or what drugs are available to treat them."

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²³ Alzheimer Europe, *Dementia in Europe Yearbook*; with a focus on national policies relating to the care and support of people with dementia and their carers, as well as the prevalence of dementia. Luxembourg: Alzheimer Europe, 2013.

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²⁵ Ibid.

²⁶ Ministère des Affaires sociales de la Santé et des Droits des femmes, *Plan Maladies Neuro-Dégénératives 2014-2019*. Paris, 2014.

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²⁸ Sinha, M, *Portrait of caregivers, 2012*. Canada: Statistics Canada, Ministry of Industry, 2013.

²⁹ WHO, *Supporting informal caregivers of people living with dementia, 2015*. http://www.who.int/mental_health/neurology/dementia/dementia_thematicbrief_informal_care.pdf

CHAPTER 3: MULTI-PRONGED SOLUTIONS

To address the challenges discussed in Chapter 2 comprehensively, it is essential that governments look to create and implement far-reaching dementia policies. In addition to strategies that make dementia a national priority, countries must also take a number of other steps to address the disease. These include funding, or encouraging funding, for research to find treatments that can slow the disease's progress or prevent its occurrence, providing care for those already living with dementia, and working to raise awareness of the disease through initiatives such as dementia-friendly communities or other campaigns.

Collaboration between institutions can accelerate progress in tackling dementia. Several joint initiatives by the EU have brought together experts from ministries, civil society and academia. One example of this is the EU Joint Programme–Neurodegenerative Disease Research (JPND), which aims to increase co-ordinated investment between participating countries with the goal of funding research that can find cures for and enable the early diagnosis of neurodegenerative diseases.³⁰

The first item listed in the Paris Declaration, which sets out the political priorities of the European Alzheimer movement, is an appeal for national governments to identify Alzheimer's as "a major public health challenge and develop national action programmes". This call to action is reinforced by Alzheimer Europe's recommendations on the distribution of social support to people with dementia and carers. Moreover, it invites governments to establish national action plans for dementia care and reserve the necessary funds to carry them out.³¹

The development of national plans and strategies

Among the countries included in this report, national dementia plans and strategies are now in place in the UK and Italy. However, approaches differ, with some countries, such as Spain and France, creating specific strategies focused on dementia, while others are implementing broader strategies that include all neurodegenerative diseases.³² According to Mr Georges, regardless of whether or not they have a national strategy in place, all six countries in this study have seen positive developments in the past years in having dementia recognised as a national issue.

In the UK, the Prime Minister's Challenge on Dementia 2020 concentrates on advancing research, boosting the provision of care and raising public awareness. In addition, the government has pledged to invest over £300m (US\$340m) in research, and this is expected to double by 2025.³³

Italy's national strategy, approved in 2014, includes calls for commitments to research and prevention, the promotion of care guidelines, an integrated network of services

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and training, and information for informal caregivers. However, Ms Vaccaro argues that the strategy has limited impact. "The real weakness is that this plan has no specific funding, and the risk is that it will be difficult to go from planning to implementation," she warns. Moreover, she explains that in Italy healthcare policies are implemented at a regional level, and financial resources are unevenly spread across the country.

Spain took a different approach when it launched its national strategy for all neurodegenerative diseases in 2016. The *Estrategia en Enfermedades Neurodegenerativas del Sistema Nacional de Salud*³⁴ is designed to improve diagnosis for all neurodegenerative diseases, increase the personal attention given to patients, and establish respite programmes for caregivers.³⁵ At the same time, CEAFA has been pushing for a specific dementia strategy.³⁶ Mr Rodrigo argues that because responsibility for funding and delivering healthcare is devolved to each region, a national strategy devoted to dementia could unify policies and best practices. "We have 17 different regions, all of which have their own competences in health and social issues," he explains.

To promote the idea of a national strategy focused on dementia, a National Dementia Group established by the Institute of Ageing (IMSERSO), which is independent of the Ministry of Health, Social Services and Equality, is soliciting input from a wide range of sectors. The group, says Mr Rodrigo, brings together stakeholders ranging from medical professionals and social care experts to researchers, lawyers and economists. In light of the costs of the disease, he stresses the urgency of this work. "For us, Alzheimer's is a health priority, but also a social priority. The national health and social system has not enough awareness of the magnitude of the problem."

The revision of the French national dementia strategy in 2014 to cover all neurodegenerative diseases³⁷ has enabled the sharing of resources and best practices among professionals working to manage neurodegenerative diseases. However, an issue raised by Mr Roy is that the government has not increased the budget. "At the end of the day, this has decreased the resources available for Alzheimer's," he says.

Nonetheless, the absence of a national plan does not necessarily mean that countries are failing to make progress in tackling the disease. Canada, for example, is without a national dementia strategy, but its 2014 National Dementia Research and Prevention Plan³⁸ outlines many of the federal investments that address dementia, according to the PHAC. Moreover, the idea of a national strategy is gaining momentum. In November 2016 the Senate Committee on Social Affairs, Science and Technology published a report entitled "Dementia in Canada: A National Strategy for Dementia-Friendly Communities",³⁹ which recommended that the government create and implement a national dementia strategy.

The absence of a national strategy in Germany does not prevent the country from addressing the needs of people with Alzheimer's. Its system of LTCI provides robust social support by recognising the impairments caused by dementia and providing financial

support to those in need. However, streamlining and collaboration opportunities exist, something that a national strategy could address. "Many people feel that the system is not transparent and is bureaucratic," says Ms Kaus.

Although the regions of Bavaria, Saarland, Rhineland-Palatinate and Schleswig-Holstein have developed regional dementia plans,⁴⁰ Ms Kaus contends that "Germany is lagging behind other European countries concerning a national dementia strategy". She points out that the Alliance for People with Dementia,⁴¹ whose partners are leading organisations in fields that include welfare, medicine, civil engagement, employers and unions, has a goal of agreeing on a national dementia strategy by 2018.

Investment in research

Research and development (R&D) into Alzheimer's and other forms of dementia has several sources of funding, ranging from corporations to foundations. "What's really encouraging is that at the EU level there's recognition of the need to exchange knowledge and learn from one another and now and again pool resources when it comes to funding research, for example," says Mr Georges.

In fact, through its plans on dementia the UK government aims to increase the proportion of people with a dementia who take part in research to 10% by 2020.⁴² On top of this, UK policymakers are also encouraging investment in research from different sources. In 2015 the Dementia Discovery Fund was launched with US\$100m from investors such as the Department of Health, Alzheimer's Research UK and major pharmaceutical companies to invest in the development of novel therapeutic approaches.⁴³ The fund aims to invest more than US\$200m over 15 years. Dr Norton stresses the importance of this collaborative approach. "Government funding can be a catalyst and can provide the guidance for other money to follow," he says.

Risk reduction and preventive research are also important areas where investments are being made. In Germany, explains Ms Kaus, part of the work of the Deutsches Zentrum für Neurodegenerative Erkrankungen (DZNE, the German Centre for Neurodegenerative Diseases), which is funded by the Federal Ministry of Education and Research, is to develop new preventive and therapeutic approaches.

Supporting awareness

Given the importance of informal care as part of managing the growing number of people with dementia, key organisations are looking at ways to support the community of family caregivers and others.

In Germany, LTCI offers employees ten days temporary leave from work for organising care when an unexpected need arises.⁴⁴ During this time the insurance pays 90% of their income. In France, Mr Roy states that "the government has made a huge effort to

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develop a comprehensive system to support family carers [from counselling, national training and capacity-building programmes to support groups], and in parallel has developed throughout the country day-care centres for people with Alzheimer's to allow family carers to have some respite."

By contrast, Italy has more work to do in this area. "The role of social assistance services, such as integrated home care or day care, is very limited, and there are large differences between regions and local health units," says Ms Vaccaro. Recent research by Censis showed that only 10% of people with Alzheimer's had integrated home care, and 12.5% had access to day care.⁴⁵

Even in countries where long-term care is funded by government, informal caregiving will remain an important tool, filling the gaps in public funding. In Canada, says Ms Benczkowski, long-term care is governed and funded by provincial legislation, with a variety of services and cost coverage plans offered across the country. Some provinces, she explains, cover part of the costs for a nursing home or other specialised residential care facilities or none, depending on the circumstances.

Access to training is also fundamental for informal caregivers. In France, free training sessions are largely financed by the National Solidarity Fund for Autonomy (CNSA), an agency of the French state that provides financial support and funding for support services to people who can no longer function independently. In the past seven years more than 20,000 people have been trained using this programme, according to France Alzheimer. Strengthening informal care helps governments save money, says Mr Georges. "If there's not the right level of support at home, patients often stay longer in hospital," he explains.

As countries recognise the potential of the community to contribute to managing dementia, some are introducing new strategies for engaging local groups. These efforts are creating what are generally referred to as "dementia-friendly communities".

In 2016 the German Alzheimer Association launched "Demenz Partner", a campaign influenced by the Dementia Friends initiative of the UK's Alzheimer's Society. The campaign gives people basic information about dementia and how to behave when interacting with people with dementia. In addition, following the recommendations of Alzheimer's Disease International, Italy has created a pilot project for a dementia-friendly community in Abbiategrasso, a small town near Milan, based on the same principles.⁴⁶

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- ³¹ Alzheimer Europe, National Dementia Strategies. <http://www.alzheimer-europe.org/Policy-in-Practice2/National-Dementia-Strategies>
- ³² JPND Research, What is neurodegenerative disease? <http://www.neurodegenerationresearch.eu/about/what/>
- ³³ The Prime Minister's challenge on dementia 2020. https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/507981/PM_Dementia-main_acc.pdf
- ³⁴ http://www.msps.es/organizacion/sns/planCalidadSNS/pdf/Est_Neurodegenerativas_APROBADA_C_INTERTERRITORIAL.pdf
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CONCLUSION

The nature of dementia—a disease that requires a wide range of social and medical interventions—provides complex challenges for governments, particularly given the rising numbers of people affected. Policymakers need to focus not only on research, but also on increasing rates of diagnosis and on ensuring that informal care is robust and can meet demand.

Some experts argue that more needs to be spent on managing the disease. “It is time for the authorities to reverse the logic and finally consider the expenses incurred in the fight against Alzheimer's disease as an investment for the future and not as a cost,” says Mr Jaouen of Alzheimer France. “In the absence of strong measures financed by major means, increasing the number of sick people will only increase costs for society as a whole.”

Nevertheless, the past decade has yielded signs of progress, with the disease moving higher on the policy agenda. A number of countries are developing national dementia strategies, and across Europe initiatives have been launched to enable ministries of health, academics and others to collaborate on research and policy recommendations and to learn from each other.

Countries still face a number of hurdles, from underdiagnosis to a lack of co-ordination between healthcare and social services. However, recognition of the challenge Alzheimer's presents is increasing. “Today the situation is much better,” says Ms Kaus of the German Alzheimer Association. “Politicians, the medical professions and the general public understand more and more that dementia will be a major problem for the next decades.”

Moreover, others see positive momentum in the way policymakers are tackling Alzheimer's and other dementias. “I see a note of hope when you look at where the disease was ten years ago,” says Mr Georges of Alzheimer Europe. “That's very positive.”

APPENDIX

Methodology

The number of dementia cases in 2016 was estimated based on the prevalence reported in the Canadian study of health and ageing⁴⁷ (Table A1), prevalence reported in the Dementia in Europe Yearbook 2013,⁴⁸ and population estimates from the United Nations (Table A2).⁴⁹ The number of people suffering from dementia in 2040 was estimated using the current national prevalence rate and population projections per age band from the United Nations (Figure 1 and Table 1).⁵⁰

We searched published and grey literature to identify relevant academic studies and reports on cost of dementia. The search was pragmatic and targeted in scope and was designed to provide a selection of publications that could contribute to determine cost of dementia in 2016 in Canada, France, Germany, Italy, Spain and the UK.

We used the following search approaches:

- bibliographic database search in Medline and Embase (Embase.com);
- grey literature search, including searches of organisations' websites and Google advanced search; and
- supplementary search techniques, for example, reference-harvesting and related articles searches.

We searched the Medline and Embase databases using relevant subject headings and free text terms in the title and abstract. Searches were not designed to be comprehensive, but rather were focused on identifying articles published between January 2010 and December 2016, when the search was completed.

Our search focused on identifying three components of dementia costs:

- direct medical costs (healthcare costs, eg the cost of primary care, hospital inpatient care, hospital outpatient care and medication);
- direct social costs (costs of formal care, which can be professional home care, day-centre visits or nursing-home expenses); and
- indirect informal costs (opportunity cost of informal caregivers).

We focused on aggregated data (national cost) and excluded studies owing to unclear or non-comparable methodologies, such as studies where the elements of each cost component (direct medical, direct social or indirect informal costs) were not clear or consistent. Of the resulting literature, we collected data from the most recent source for each cost component of each country. This resulted in three national cost components per country, with data ranging from 2007 to 2014 (Figure A1).^{51, 52, 53, 54, 55, 56} We determined average cost per patient using reported prevalence in the year of data.

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We assumed that dementia medical costs increased at the same rate as healthcare spending growth. Therefore, we inflated direct medical costs to 2016 using healthcare spending real growth per country, which was determined based on figures from The Economist Intelligence Unit's databases. We assumed social care costs increased at the same rate as GDP per head, so we inflated direct social costs and indirect informal costs based on GDP per head growth from year of data to 2016, also determined based on Economist Intelligence Unit data. This allowed us to determine the average annual cost per patient in 2016. Using the estimated number of dementia patients in 2016 (Table A2), we determined national cost of dementia in 2016.

We further split the cost of dementia into public, or government, spending and private spending, which is the expenditure from family and friends. This split has not been previously determined for dementia. We assumed that dementia direct medical costs are split between public and private spending in the same way as other medical expenditure. Therefore, we used the World Health Organisation (WHO) out-of-pocket (OOP) expenditure as a percentage of total expenditure on health in 2014, the latest available split,⁵⁷ to determine private spending on dementia direct medical costs (Figure A2). We assumed that dementia formal social care follows the same public-private split as national social care, and we determined the private spending on direct social costs of dementia with the OECD social private (mandatory and voluntary) expenditure share.⁵⁸ We attributed indirect informal costs entirely to private pockets (families and friends).

Our analysis was based on assumptions that, despite being sensible, may contribute to some level of uncertainty. One of the limitations of the methodology is the assumption that dementia prevalence will remain the same until 2040. In fact, recent studies suggest that dementia prevalence is decreasing,^{59,60} but this trend still needs validation. Cost per patient was determined based on aggregated data, which may also be a limitation. However, these costs were the clearest and most comparable data identified and allowed us to determine average cost per patient using estimated numbers of patients in the year of the data.

Each country included in this analysis has its own health and social care system, and the characterisation of dementia cost depends on the budget used to finance care. For example, what in some countries belongs to the health system and is therefore classified as direct medical cost can in other countries be the responsibility of the social care system, being classified as direct social cost. This might explain differences in the split of dementia costs across countries.

The inflation of costs to 2016 was based on an increase of medical costs at the same rate as healthcare spending, and an increase of social care costs at the same rate as GDP per head. While these assumptions are logical, there is an associated uncertainty. This also applies to the public and private split of dementia cost.

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This analysis presents the strengths of looking at studies with similar methodologies, which allows comparison. Each cost component and all methods were clearly defined, something we encourage others to do.

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⁴⁹ United Nations Department of Economic and Social Affairs - Population Division, *World Population Prospects: The 2015 Revision*. <https://esa.un.org/unpd/wpp/DataQuery/>

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⁵⁹ Wu YT, Fratiglioni L, Matthews F *et al*, "Dementia in western Europe: epidemiological evidence and implications for policy making", *The Lancet Neurology*, 2016;15(1):116-24.

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Figure A1

Methodology to determine dementia costs in 2016

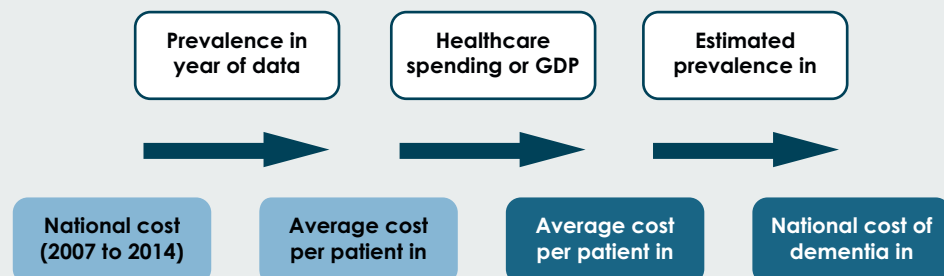


Figure A2

Methodology to determine public/private split of dementia costs

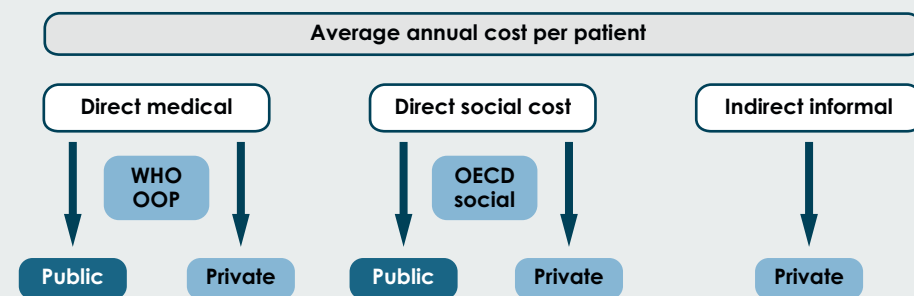


Table A1. Prevalence of dementia per age band (%).

Age bands	Canada	France	Germany	Italy	Spain	UK
30-59	0.1	0.1	0.1	0.1	0.1	0.1
60-64		0.6	0.6	0.5	0.6	0.6
65-69	2.4	1.6	1.6	1.6	1.6	1.6
70-74		3.5	3.6	3.5	3.5	3.6
75-79		7.1	7.7	7.4	7.2	7.4
80-84	11.1	15.3	15.9	15.8	15.4	16.1
85-89		25.1	26.4	26.4	25.5	26.2
90 and older	34.5	42.4	43.5	40.6	31.8	40.2

Source: Dementia in Europe Yearbook 2013, 2012 population statistics from the United Nations, Canadian Study of Health and Ageing (1994).

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Table A2. Dementia cases in 2016 in thousands of people.

Age bands	Canada	France	Germany	Italy	Spain	UK
30-59	16	31	44	33	26	32
60-64		22	31	20	15	19
65-69	83	61	66	59	37	57
70-74		90	146	105	70	101
75-79	196	153	323	201	116	158
80-84		289	403	329	217	251
85-89	275	319	393	351	228	246
90 and older		344	337	336	150	245
Affected population	1.6%	2.0%	2.2%	2.4%	1.9%	1.7%
Total number of cases	570	1,309	1,745	1,434	859	1,110

Source: Dementia in Europe Yearbook 2013, Canadian Study of Health and Aging (1994), United Nations World Population Prospects: The 2015 Revision, EIU analysis.

Table A3. Projection of number of dementia cases in 2040 in thousands of people.

Age bands	Canada	France	Germany	Italy	Spain	UK
30-59	17	30	36	25	19	33
60-64		20	27	21	21	22
65-69	108	63	72	71	57	62
70-74		131	210	154	114	148
75-79	468	251	427	289	211	274
80-84		452	653	468	346	417
85-89	702	556	668	545	360	429
90 and older		729	683	770	334	540
Affected population	3.0%	3.2%	3.6%	4.0%	3.2%	2.6%
Total number of cases	1,294	2,232	2,775	2,343	1,461	1,924

Source: United Nations World Population Prospects: The 2015 Revision, EIU analysis.

ASSESSING THE SOCIOECONOMIC IMPACT OF ALZHEIMER'S IN WESTERN EUROPE AND CANADA

Table A4 - Estimated annual cost of dementia, EUR, 2016.

Country	Cost per patient (EUR)				Society cost (million EUR)			
	Direct medical	Direct social	Indirect informal	Total	Direct medical	Direct social	Indirect informal	Total
Canada	9,781	10,504	6,907	27,191	5,575	5,987	3,937	15,499
France	4,425	8,900	13,185	26,510	5,793	11,650	17,259	34,702
Germany	2,440	9,736	18,003	30,179	4,258	16,989	31,416	52,663
Italy	681	2,970	23,768	27,419	976	4,259	34,084	39,319
Spain	5,345	3,114	15,724	24,184	4,591	2,675	13,507	20,774
UK	6,656	15,971	18,069	40,695	7,388	17,728	20,056	45,172

Table A5 - Split of annual average cost of dementia per patient, EUR, 2016.

Country	Public costs (EUR)		Private costs (EUR)		Indirect informal - Private	Total
	Direct medical - Public	Direct social - Public	Direct medical - Private	Direct social - Private		
Canada	8,450	8,290	1,330	2,214	6,907	27,191
France	4,145	8,023	281	877	13,185	26,510
Germany	2,118	8,587	322	1,149	18,003	30,179
Italy	537	2,836	144	134	23,768	27,419
Spain	4,062	3,069	1,283	45	15,724	24,184
UK	6,008	12,558	648	3,413	18,069	40,695

SOCIOECONOMIC IMPACT OF ALZHEIMER'S AND OTHER DEMENTIAS CANADA

March 2017

- In 2016 some 600,000 people in Canada—about 1.6% of the overall population—were estimated to be living with dementia.
- There is no national dementia strategy in Canada, but some provinces are working on their own strategies.
- Average annual cost per dementia patient is estimated at €27,191, of which a share of 38% falls on families.
- In Quebec, nurses are starting to be formally involved in dementia care, and in Ontario new models of primary care are being implemented.
- Political will, structured care pathways and co-ordination between services are needed to improve dementia care in Canada.

About this document

To better understand the socioeconomic impact of Alzheimer's disease and other dementias, The Economist Intelligence Unit has conducted a cost analysis of dementia in six countries.¹ First, an epidemiological analysis was conducted, involving an estimation of the number of dementia cases in Canada in 2016 based on the prevalence reported in the *Canadian Study of Health and Aging*² and population estimates from the UN.³ Then, dementia cost in Canada in 2016 was estimated based on an update of published data^{4,5} and on Economist Intelligence Unit data on healthcare and GDP growth. The cost of dementia was split into either public (government) spending or private spending, which involves expenditure from family and friends, based on public-private cost splits from the World Health Organisation (WHO) and the Organisation for Economic Co-operation and Development (OECD).^{6,7} A projection of the number of patients in 2040 was made based on UN population estimates and assuming the prevalence rate is maintained.

For the purpose of writing this document, The Economist Intelligence Unit conducted interviews in December 2016 and January 2017 with:

- Serge Gauthier, director, Alzheimer's Disease Research Unit, McGill University Research Centre for Studies in Aging; and
- Samir K Sinha, director of geriatrics, Sinai Health System and the University Health Network Hospitals, Toronto.

ASSESSING THE SOCIOECONOMIC IMPACT OF ALZHEIMER'S IN WESTERN EUROPE AND CANADA

This country summary is part of a report on dementia entitled *Assessing the socioeconomic impact of Alzheimer's in western Europe and Canada*.

Population living with dementia

In 2016 the total population in Canada was estimated to be 36m; of these, 6m were aged 65 years and above.⁸ Based on analysis by The Economist Intelligence Unit, 600,000 people, about 1.6% of the national population and mostly over the age of 65, were estimated to be living with dementia in Canada in 2016.⁹ The general population is expected to grow by 0.7% per year, reaching 42.5m by 2040. If prevalence proportions per age group are maintained, the number of people living with dementia is expected to grow at the much faster rate of 3.5% per year, increasing to 1.3m by 2040. Population dynamics is the driver behind the projected increase in the number of dementia patients. Canada's population is expected to grow faster than the populations of European countries, and this overall growth may be the driver behind the anticipated rise in the number of dementia cases.



In 2016, 600,000 people in Canada were estimated to be living with dementia.

National strategy and community initiatives

There is currently no national strategy for dementia in Canada, and according to Samir K Sinha, "there has not been a clear and specific commitment from the elected liberal government towards a national dementia strategy". Serge Gauthier believes the lack of a national strategy until now could be due to the political landscape in Canada, as "healthcare is the responsibility of provinces and territories, so it has always been difficult for the federal government to have a national policy that will be agreed upon by all the provinces and territories". A private member of parliament has proposed an act—Bill C-233—concerning the development of a national plan for Alzheimer's disease and other dementias, which is expected to receive federal approval following the support of the majority of the members of parliament seen so far.

In an effort to improve patient care, the Senate of Canada has recently published a report on dementia in the country that includes recommendations for a national dementia strategy.¹⁰ Recommendations cover the need to promote awareness, provide housing support and increase research funds. Dr Sinha believes that overall the recommendations are "narrow in nature" and present limitations. As an example he mentions the amendment to the Caregiver Tax Credits, which suggests that Caregiver Tax Credits become income-based. However, it does not consider certain flaws, such as the fact that current support is for family-related caregivers only.

ASSESSING THE SOCIOECONOMIC IMPACT OF ALZHEIMER'S IN WESTERN EUROPE AND CANADA

Some provinces of Canada have developed provincial dementia plans. Quebec, for example, developed an Alzheimer's plan in 2009.¹¹ Among its recommendations the plan called for investment in the training of healthcare professionals, which has since helped to improve the quality of care.

In 2014 a federal initiative in the field of dementia research—the Canadian Consortium on Neurodegeneration in Aging (CCNA)—was launched.¹² This is a five-year funding project which brings together more than 350 researchers and clinicians from around the country to provide the “research infrastructure for not just basic research and clinical research but also looking [at care] differences between parts of the country and seeing if care can be improved through education of family doctors or working with more memory clinics”, says Professor Gauthier.

In addition to building the necessary infrastructure and workforce, it is important to raise dementia awareness. This has, in fact, been central to the aims of the Alzheimer Society of Canada. In recent years the society has run the Dementia Friends Canada campaign, funded by the federal government. This campaign focuses on providing information on dementia and building environments inclusive of people living with dementia, which is essential in improving their quality of life. In 2015 the Alzheimer Society of British Columbia developed a Dementia-Friendly Communities Local Government Toolkit to help to understand and develop these communities.¹³ Sports figures have been involved in raising dementia awareness, such as former ice hockey player Henri Richard and former player and coach Al Arbour, who have made their dementia diagnoses public. The different awareness campaigns have had positive results; according to Professor Gauthier, compared with five years ago more adults over 60 have shown interest in observation studies, particularly non-pharmacological prevention such as memory training. As a result, diagnoses can now be made earlier than was possible ten years ago.

Informal care of dementia patients is usually provided by a loved one. The Alzheimer Society of Canada and other associations organise training and support groups for informal caregivers. The Alzheimer Society provides brochures and publications to help caregivers. The Caregiver Network (TCN), for example, is an online learning network supported by different companies and organisations that focuses on caregivers, although it is not exclusively dedicated to dementia.¹⁴ In addition to the information provided on the website, TCN hosts educational events in collaboration with other



The Senate of Canada has recently published a report on dementia in the country that includes recommendations for a national dementia strategy.

associations. Despite these initiatives, experts believe there is not enough support for caregivers in Canada, and Professor Gauthier adds that the family doctor should be involved in helping caregivers, stating it “should be part of management of dementia to look for depression or fatigue in the caregivers and treating it”.

Looking after patients

In Canada, care for dementia patients is highly variable around the country; different provinces have different resources and approaches to dementia, leading to inconsistent patient support. In some areas of the country, particularly in urban areas with more advanced medical facilities, dementia patients are looked after by neurologists, geriatricians and psychiatrists in a specialist multidisciplinary approach. However, this approach is not rolled out across the country, and even when it exists, nurses are frequently left out. But according to Professor Gauthier this is currently being addressed in Quebec, where the formal involvement of nurses is now being implemented. Ontario is currently developing its second dementia strategy and improving primary care for dementia; Dr Sinha says some promising models of primary care for people with dementia are being implemented in that province.



“Up to 50% of Canadians who actually have a diagnosis of dementia are not disclosed their own diagnosis.”

In order to support dementia care, the Canadian Consensus Conference on the Diagnosis and Treatment of Dementia¹⁵ is responsible for writing guidelines on the diagnosis and treatment of dementia. These guidelines, which are relevant for all health professionals treating dementia, are issued approximately every five years, showing a proactive approach to dementia care in Canada. However, according to Dr Sinha, more than half of the people living with dementia have not been diagnosed, and “up to 50% of Canadians who actually have a diagnosis of dementia are not disclosed their own diagnosis”, which reflects the general state of dementia care.

There are several nursing homes in Canada, including public residences that do not require any private co-pay. The nursing homes usually have Alzheimer's care units for dementia patients but are not dementia-only institutions. Although the family of the patient makes the decision to transfer the patient to a nursing home, the physician and social worker may also be involved in the process. In fact, care of dementia patients in Canada is handled by local care networks, and it is the social worker who interacts the most with the family. According to Professor Gauthier, there is currently a shift to palliative care at home.

ASSESSING THE SOCIOECONOMIC IMPACT OF ALZHEIMER'S IN WESTERN EUROPE AND CANADA

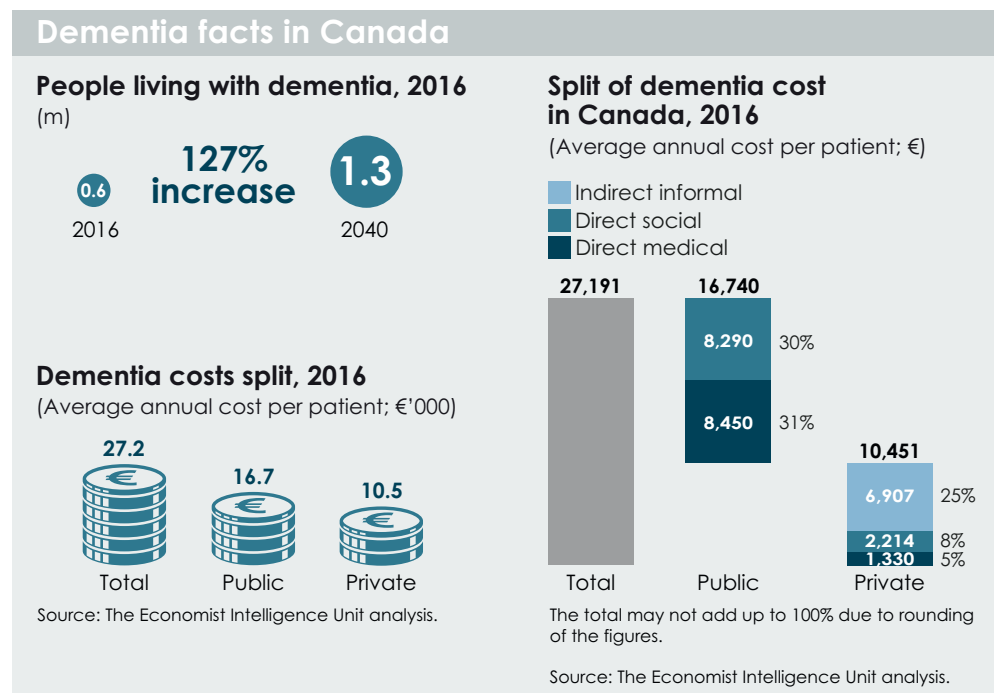
Cost of dementia in Canada

We have estimated the average annual cost per dementia patient in Canada to be €27,191, based on an update of published data.^{16,17,18} The majority of the costs fall on social care (64%), but unlike in the European countries included in this study, Canada seems to have an even distribution of costs across the different components. Direct social costs, which are the costs of professional social care, account for 39%, and indirect informal costs, which are opportunity costs of informal caregivers, account for 25%. Healthcare costs, represented by direct medical costs, account for 36% of the cost per patient. The out-of-pocket share of medical expenditure in Canada is estimated to be 14%,¹⁹ and the private share of formal social care costs is estimated to be 21%.²⁰ The government carries the majority of the costs of dementia patients, with 38% falling on the families, mostly driven by informal care. Dementia costs in Canada were estimated to be €15.5bn in 2016.



Dementia costs in Canada were estimated to be €15.5bn in 2016.

Several reports on the cost of dementia in Canada, funded by dementia societies, pharmaceutical industry and the government, have been published in recent years.^{21,22} Therefore, it is believed the government of Canada is aware of the economic burden of dementia.



Needs to improve dementia care

We estimated that 600,000 people were living with dementia in Canada in 2016. If prevalence rates are maintained, this number is projected to increase to 1.3m by 2040. In order to reduce prevalence and improve diagnosis rates, it is important to raise awareness of the disease and of the role cardiovascular risk factors play in the development of dementia. Dementia care is highly variable across Canada, with different provinces providing different care and varying levels of support. The provinces of Quebec and Ontario are focusing on improving dementia care—in Quebec through the training of healthcare professionals and the involvement of nurses and in Ontario through the development of new models of primary care. A national dementia strategy is needed so that all patients are looked after. It is essential to implement care pathways across the country and to ensure better co-ordination between different professionals in order to improve the quality of life of people living with dementia and their families.

¹ Economist Intelligence Unit analysis. See Appendix for methodology.

² Canadian study of health and aging: study methods and prevalence of dementia, *Canadian Medical Association Journal*, 1994;150(6):899-913.

³ United Nations Department of Economic and Social Affairs - Population Division, *World Population Prospects: The 2015 Revision*. <https://esa.un.org/unpd/wpp/DataQuery/>

⁴ Alzheimer Society of Canada, *Rising tide: The impact of dementia on Canadian society*, 2010.

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- ⁵ Manuel DG, Garner R, Finès P *et al*, "Alzheimer's and other dementias in Canada, 2011 to 2031: a microsimulation Population Health Modeling (POHEM) study of projected prevalence, health burden, health services, and caregiving use", *Population Health Metrics*, 2016;14(37).
- ⁶ WHO, Global Health Observatory data repository, Health expenditure ratios, by country, 1995-2014: Out-of-pocket expenditure as a percentage of total expenditure on health. <http://apps.who.int/gho/data/node.main.75>
- ⁷ OECD Social Expenditure Database (SOCX): Social private (mandatory and voluntary) expenditure share. <http://www.oecd.org/social/expenditure.htm>.
- ⁸ United Nations Department of Economic and Social Affairs - Population Division, *World Population Prospects: The 2015 Revision*. <https://esa.un.org/unpd/wpp/DataQuery/>
- ⁹ Economist Intelligence Unit analysis. See Appendix for methodology.
- ¹⁰ The Standing Senate Committee on Social Affairs, Science and Technology. *Dementia in Canada: A National Strategy for Dementia-friendly Communities*, Senate of Canada, 2016.
- ¹¹ Comité d'experts, "Relever le défi de la maladie d'Alzheimer et des maladies apparentées: une vision centrée sur la personne, l'humanisme et l'excellence: rapport", Santé et services sociaux Québec, 2009.
- ¹² Canadian Consortium on Neurodegeneration in Aging. CCNA-CCNV. <http://ccna-ccnv.ca/en/>
- ¹³ Alzheimer Society of B.C., "How can my local government become dementia friendly?", 2016. <http://www.alzheimer.ca/en/bc/About-dementia/Dementia-friendly%20communities/DFC%20Local%20Government%20Toolkit>.
- ¹⁴ The Caregiver Network, *Alzheimer's Disease and Dementia*, 2015. <https://thecaregivernetwork.ca/about/>
- ¹⁵ Gauthier S, Patterson C, Chertkow H *et al*, "Recommendations of the 4th Canadian Consensus Conference on the Diagnosis and Treatment of Dementia (CCCDTD4)", *Canadian Geriatrics Journal*, 2012;15(4):120-6.
- ¹⁶ Economist Intelligence Unit analysis. See Appendix for methodology.
- ¹⁷ Alzheimer Society of Canada, *Rising tide: The impact of dementia on Canadian society*, 2010.
- ¹⁸ Manuel DG, Garner R, Finès P *et al*, "Alzheimer's and other dementias in Canada, 2011 to 2031: a microsimulation Population Health Modeling (POHEM) study of projected prevalence, health burden, health services, and caregiving use", *Population Health Metrics*, 2016;14(37).
- ¹⁹ WHO, Global Health Observatory data repository, Health expenditure ratios, by country, 1995-2014: Out-of-pocket expenditure as a percentage of total expenditure on health. <http://apps.who.int/gho/data/node.main.75>
- ²⁰ OECD Social Expenditure Database (SOCX): Social private (mandatory and voluntary) expenditure share. <http://www.oecd.org/social/expenditure.htm>.
- ²¹ Alzheimer Society of Canada, *Rising tide: The impact of dementia on Canadian society*, 2010.
- ²² Alzheimer Society of Canada, *Prevalence and Monetary Costs of Dementia in Canada: Population Health Expert Panel*, 2016.

These country summaries do not aim to present a thorough description of all national programmes and initiatives in support of dementia. Instead, we present examples of these activities to illustrate the level of national engagement with dementia. Sara C Marques and Annie Pannelay were the authors of these summaries.

SOCIOECONOMIC IMPACT OF ALZHEIMER'S AND OTHER DEMENTIAS FRANCE

March 2017

- In 2016 some 1.3m people in France—about 2% of the overall population—were estimated to be living with dementia.
- The Plan Maladies Neuro-Dégénératives 2014-2019 is a national strategy for multiple neurodegenerative diseases that replaced the previous dementia-specific plans.
- Average annual cost per dementia patient is estimated at €26,510, of which a share of 54% falls on families.
- The national healthcare system has designed consultations dedicated to memory and cognitive testing. These should be used more frequently to improve diagnosis rates further.
- France has good dementia diagnosis and care pathways, but better co-ordination between services and professionals is needed to improve the quality of life of dementia patients.

About this document

To better understand the socioeconomic impact of Alzheimer's disease and other dementias, The Economist Intelligence Unit has conducted a cost analysis of dementia in six countries.¹ First, an epidemiological analysis was conducted, involving an estimation of the number of dementia cases in France in 2016 based on the prevalence reported in the *Dementia in Europe Yearbook 2013*² and population estimates from the UN.³ Then, dementia cost in France in 2016 was estimated based on an update of published data^{4,5} and on Economist Intelligence Unit data on healthcare and GDP growth. The cost of dementia was split into either public (government) spending or private spending, which involves expenditure from family and friends, based on public-private cost splits from the World Health Organisation (WHO) and the Organisation for Economic Co-operation and Development (OECD).^{6,7} A projection of the number of patients in 2040 was made based on UN population estimates and assuming the prevalence rate is maintained.

For the purpose of writing this document, The Economist Intelligence Unit conducted interviews in December 2016 with:

- Claudine Berr, research director, Institut National de la Santé et de la Recherche Médicale (Inserm)

ASSESSING THE SOCIOECONOMIC IMPACT OF ALZHEIMER'S IN WESTERN EUROPE AND CANADA

- Etienne Hirsch, director, Institute for Neurosciences, Cognitive Sciences, Neurology and Psychiatry (ITMO); and associate director, Institut du Cerveau et de la Moelle Epinière; and
- Christophe Roy, director of social missions, France Alzheimer.

This country summary is part of a report on dementia entitled *Assessing the socioeconomic impact of Alzheimer's in western Europe and Canada*.

Population living with dementia

In 2016 the total population in France was estimated to be 64.7m, of whom 12.5m were aged 65 years and above.⁸ Based on Economist Intelligence Unit analysis, 1.3m people, about 2% of the national population and mostly over the age of 65, were estimated to be living with dementia in France in 2016.⁹ While the general population is projected to see a small increase by 2040, the number of people living with dementia is expected to increase to 2.2m if prevalence proportions per age group are maintained, growing at 2.3% per year, compared with 0.3% growth per year for the general population. Population dynamics is the driver behind the estimated increase in the number of dementia patients.



In 2016, 1.3m people in France were estimated to be living with dementia.

National strategy and community initiatives

In 2001 France was the first European country to develop a national dementia strategy. The strategy was updated in 2004 and again in 2008, and the main priority of the 2008-2012 plan¹⁰ was to improve diagnosis. Professor Etienne Hirsch says one of the strengths of the plan was “reinforcing the organisation of care [pathways] across the country”. In 2014 the dementia-specific plan was replaced with the Plan Maladies Neuro-Dégénératives 2014-2019, a national strategy combining multiple neurodegenerative diseases, including Alzheimer's, Parkinson's and multiple sclerosis.¹¹ According to Etienne Hirsch, “the basis of this plan is that there are common mechanisms in terms of pathophysiology in all these neurodegenerative disorders”, so combining them in one plan brings “the advantage of having a global approach for these disorders from a research standpoint and also from an organisational standpoint”. However, some dementia experts oppose this approach because of the heterogeneity of the patients included in the plan.

Among the strengths of the national strategy on neurodegenerative diseases is the expansion of the research focus from basic and clinical research in dementia to social sciences and technological innovations. Other strengths are the aim of continuing to

improve access to the health system across the country and the effort to involve lay organisations, such as France Alzheimer, which are now part of discussions and collaborative projects. Professor Hirsch believes the government of France “is fully aware [of the burden of dementia], and this is why it has launched successive plans on dementia and now on neurodegenerative disorders”. He adds that of the 96 measures defined in the plan, several are close to implementation, but others are only in the early stages. One of the goals of the strategy is to develop a society that is respectful and inclusive of people living with dementia, and with that develop the concept of dementia-friendly communities.

Dementia awareness campaigns are also essential to help create environments that are inclusive of people living with dementia. France Alzheimer has been very active in this regard; among its initiatives is the Village Alzheimer[®],¹² an event that includes

conferences and workshops and was held for the fourth time in Paris in 2016. Public figures supporting the dementia cause in France usually do so in private. Exceptions do happen, though: one example of public involvement of celebrities with dementia is the colouring book for adults by the model Clémentine Levy with well-known collaborators, such as the French fashion designer Jean-Charles de Castelbajac.¹³ Profits of the book feed back into Alzheimer's research. Books for children explaining various aspects of dementia have also been produced in France, such as *Ma grand-mère perd la tête* (My grandmother is losing her head).^{14,15}

In addition to working towards raising dementia awareness, France Alzheimer also organises activities to support informal caregivers, who are usually family members. These activities range from information sessions and support groups to relaxation workshops.¹⁶ This is an example of the co-operation between the association and the government, as the latter provides funding for these initiatives. According to Claudine Berr, the Alzheimer-specific national plan had developed the concept of supporting carers, but this is not clearly laid out in the new plan. “The caregiver needs to be [pro]active,” she adds.

Looking after people living with dementia

The care pathway of dementia patients in France varies with the patient or disease characteristics, such as severity and presence of comorbidities. It also varies with the extent to which the general practitioner and the family are involved. The general practitioner usually performs the first screening for dementia. Instead of a general consultation, they have the option to use special “long consultations”, designed for



In 2014 the dementia-specific plan was replaced with a national strategy combining multiple neurodegenerative diseases, including Alzheimer's, Parkinson's and multiple sclerosis.

ASSESSING THE SOCIOECONOMIC IMPACT OF ALZHEIMER'S IN WESTERN EUROPE AND CANADA

memory and cognitive testing, to screen patients. According to Professor Hirsch, the long consultations are not used as often as they should be as the funds available for long consultations are not entirely spent. Therefore, “one of the objectives of the plan is to advertise for these [consultations] to stimulate the GPs [general practitioners] to use this system”. He adds that one challenge for the implementation of the long consultations is the low availability of general practitioners in some areas, particularly rural areas, which limits the time available per patient.

Despite these limitations, Christophe Roy says that in France “we have a very good network for diagnosis, with engaged professionals”. After initial screening by the family doctor, dementia patients are usually referred to a memory clinic or directly to a specialist, who could be a neurologist, geriatrician or psychiatrist, to confirm the diagnosis and initiate treatment. According to Dr Berr, co-ordination between all professionals involved in dementia care is needed to improve the quality of life of people living with dementia. Memory clinics and some hospitals do offer multidisciplinary and co-ordinated care to dementia patients, but this approach is more likely to be available in a tertiary level of care—regional specialised centres, where people with complex diagnoses, such as aggressive dementia or early onset cases, are looked after. These specialised centres also include research units focused on carrying out clinical trials.

Day-care centres for people living with dementia in France are available for patients with mild or moderate forms of the disease and are designed to provide them with the opportunity to interact with other people and participate in educational activities. Patients with severe behavioural deficits might be institutionalised in special units with more specialised staff and activities.

In France, there are institutes to assist patients and caregivers with the co-ordination of dementia care. These are called Maisons pour l'autonomie et l'intégration des malades d'Alzheimer (MAIA—Houses for Autonomy and Integration),¹⁷ and they have been set up in pre-existing centres such as hospitals or patient associations. In another endeavour to assist dementia care, the Fondation Médéric Alzheimer has developed an online tool with the contact information of institutions useful for the care of Alzheimer's patients in the various French departments, from places of diagnosis to day centres, nursing homes and MAIA platforms.¹⁸



“We have a very good network for diagnosis, with engaged professionals.”



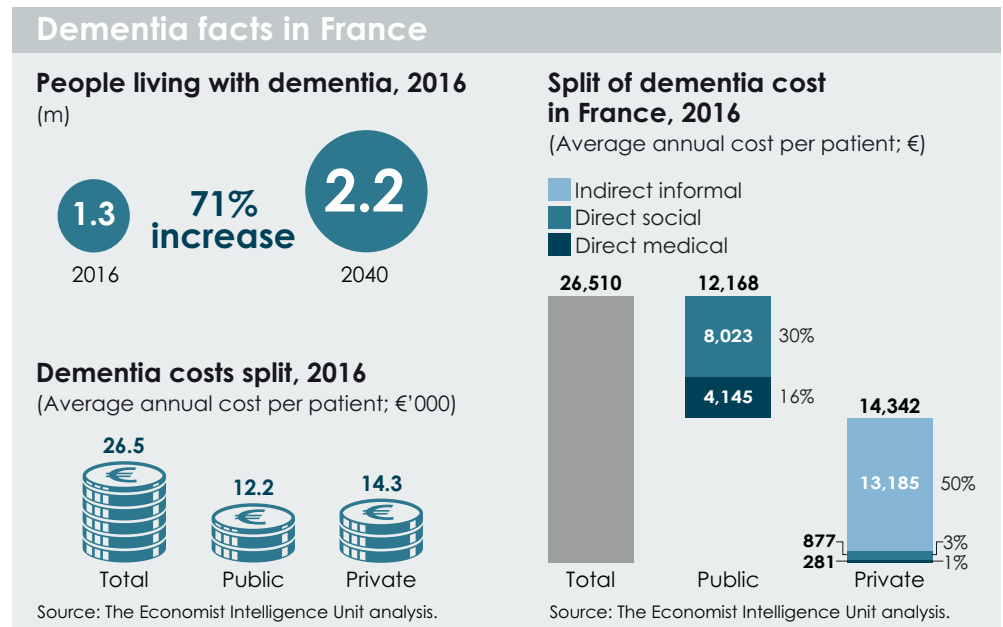
In France, there are institutes to assist with the co-ordination of dementia care and to provide support to caregivers.

ASSESSING THE SOCIOECONOMIC IMPACT OF ALZHEIMER'S IN WESTERN EUROPE AND CANADA

Cost of dementia in France

We have estimated the average annual cost per dementia patient in France to be €26,510 based on an update of published data.^{19,20,21} The majority of the expenses fall on social care; indirect informal costs, which represent the opportunity costs of caregivers, account for 50% of the average cost per patient, while 34% pay for direct social costs (costs of professional social care). Direct medical costs, which are healthcare costs, account for 17% of the cost per patient. France has a low private burden on medical and formal social expenditure, as only 6% of the medical cost and 10% of formal social care are estimated to fall on the families.^{22,23} However, as indirect informal costs fall entirely on families, a total of 54% of the overall cost is borne privately. Therefore, families are strongly impacted by dementia economically. Dementia costs in France were estimated to be €34.7bn in 2016.

In 2015 the Fondation M d ric Alzheimer published a report on the medical and informal care cost of Alzheimer's in France and highlighted the complexity of determining the social costs of the disease, which contribute greatly to the overall cost.²⁴ The report highlights that detailed analyses of social care are needed to accurately identify Alzheimer's costs.



Needs to improve dementia care

We estimated that 1.3m people were living with dementia in France in 2016. If prevalence rates are maintained, this number is expected to increase to 2.2m by 2040. The French healthcare system has designed consultations dedicated to memory and cognitive testing; these should be used consistently to improve dementia diagnosis in France further. Dementia care pathways have been developed in France, and it is necessary to consolidate their use to ensure support for all patients across the country. Improved co-ordination between professionals involved in dementia care and the development of dementia-friendly programmes are essential to provide people living with dementia and their families with a better quality of life.

¹ Economist Intelligence Unit analysis. See Appendix for methodology.

² Alzheimer Europe, *Dementia in Europe Yearbook*, with a focus on national policies relating to the care and support of people with dementia and their carers, as well as the prevalence of dementia. Luxembourg: Alzheimer Europe, 2013.

³ United Nations Department of Economic and Social Affairs - Population Division. *World Population Prospects: The 2015 Revision*, custom data acquired via website. United Nations, 2016. Available from: <https://esa.un.org/unpd/wpp/DataQuery/>

⁴ Luengo-Fernandez R, Leal J, Gray AM, "Cost of dementia in the pre-enlargement countries of the European Union", *Journal of Alzheimer's Disease*, 2011;27(1):187-96.

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⁵ Bérard A, Gervès C, Fontaine R *et al*, "Combien coûte la maladie d'Alzheimer?", Fondation Médéric Alzheimer, 2015.

⁶ WHO, Global Health Observatory data repository, Health expenditure ratios, by country, 1995-2014: Out-of-pocket expenditure as a percentage of total expenditure on health. <http://apps.who.int/gho/data/node.main.75>

⁷ OECD, Social Expenditure Database (SOCX): Social private (mandatory and voluntary) expenditure share. Available from: <http://www.oecd.org/social/expenditure.htm>.

⁸ United Nations Department of Economic and Social Affairs - Population Division. World Population Prospects: The 2015 Revision, custom data acquired via website. United Nations, 2016. Available from: <https://esa.un.org/unpd/wpp/DataQuery/>

⁹ Economist Intelligence Unit analysis. See Appendix for methodology.

¹⁰ Ministère du Travail, de l'Emploi et de la Santé, Plan Alzheimer et maladies apparentées 2008-2012.

¹¹ Ministère des Affaires sociales de la Santé et des Droits des femmes, Plan Maladies Neuro-Dégénératives 2014-2019. Paris, 2014.

¹² France Alzheimer & Maladies Apparentées, "Un Village Alzheimer à Paris", June 2016. Available from: <http://30ans.francealzheimer.org/node/471>

¹³ Lévy, C, "Carnet de coloriages", *Le Cherche-Midi*, 2015.

¹⁴ Dreyfuss C, *Ma grand-mère perd la tête*. Editions Thierry Magnier, 2004.

¹⁵ More examples can be found on: <http://www.alzjunior.org/lectures/>

¹⁶ France Alzheimer & Maladies Apparentées, "Etre aidé". Available from: <http://www.francealzheimer.org/etre-aid%C3%A9>

¹⁷ Caisse nationale de solidarité pour l'autonomie MAIA. Available from: <http://www.cnsa.fr/parcours-de-vie/maia>

¹⁸ Fondation Médéric Alzheimer, *Annuaire National*. Available from: <http://www.annuaire-med-alz.org/>

¹⁹ Economist Intelligence Unit analysis. See Appendix for methodology.

²⁰ Luengo-Fernandez R, Leal J, Gray AM, "Cost of dementia in the pre-enlargement countries of the European Union", *Journal of Alzheimer's Disease*, 2011;27(1):187-96.

²¹ Bérard A, Gervès C, Fontaine R *et al*, "Combien coûte la maladie d'Alzheimer?", Fondation Médéric Alzheimer, 2015.

²² WHO, Global Health Observatory data repository, Health expenditure ratios, by country, 1995-2014: Out-of-pocket expenditure as a percentage of total expenditure on health. <http://apps.who.int/gho/data/node.main.75>

²³ OECD Social Expenditure Database (SOCX): Social private (mandatory and voluntary) expenditure share. <http://www.oecd.org/social/expenditure.htm>.

²⁴ Bérard A, Gervès C, Fontaine R *et al*, "Combien coûte la maladie d'Alzheimer?", Fondation Médéric Alzheimer, 2015.

These country summaries do not aim to present a thorough description of all national programmes and initiatives in support of dementia. Instead, we present examples of these activities to illustrate the level of national engagement with dementia. Sara C Marques and Annie Pannelay were the authors of these summaries.

SOCIOECONOMIC IMPACT OF ALZHEIMER'S AND OTHER DEMENTIAS GERMANY

March 2017

- In 2016 some 1.7m people in Germany—about 2.2% of the overall population—were estimated to be living with dementia.
- There is no national dementia strategy in Germany. Some regions have developed regional plans and are working towards implementing them.
- Average annual cost per dementia patient is estimated at €30,179, of which a share of 65% falls on families.
- The long-term care insurance (LTCI) system, revised in 2016, acknowledges the impairment caused by dementia and provides financial support to patients.
- More political effort and better co-ordination between medical care and social care services are needed to improve dementia care in Germany.

About this document

To better understand the socioeconomic impact of Alzheimer's disease and other dementias, The Economist Intelligence Unit has conducted a cost analysis of dementia in six countries.¹ First, an epidemiological analysis was conducted, involving an estimation of the number of dementia cases in Germany in 2016 based on the prevalence reported in the *Dementia in Europe Yearbook 2013*² and population estimates from the UN.³ Then, dementia cost in Germany in 2016 was estimated based on an update of published data⁴ and on Economist Intelligence Unit data on healthcare and GDP growth. The cost of dementia was split into either public (government) spending or private spending, which involves expenditure from family and friends, based on public-private cost splits from the World Health Organisation (WHO) and the Organisation for Economic Co-operation and Development (OECD).^{5,6} A projection of the number of patients in 2040 was made based on UN population estimates and assuming the prevalence rate is maintained.

For the purpose of writing this document, The Economist Intelligence Unit conducted interviews in December 2016 and January 2017 with:

- Lutz Frölich, head, Department for Geriatric Psychiatry, Central Institute of Mental Health, Medical Faculty Mannheim, University of Heidelberg;
- Frank Jessen, director, Clinic for Psychiatry and Psychotherapy, University Hospital Cologne; and

ASSESSING THE SOCIOECONOMIC IMPACT OF ALZHEIMER'S IN WESTERN EUROPE AND CANADA

- Petra Weritz-Hanf, head of Division 303 "Healthy Aging, Dementia Support", Federal Ministry for Family Affairs, Senior Citizens, Women and Youth.

This country summary is part of a report on dementia entitled *Assessing the socioeconomic impact of Alzheimer's in western Europe and Canada*.

Population living with dementia

In 2016 the total population in Germany was estimated to be 80.7m, of whom 17.3m were aged 65 years and above.⁷ Based on Economist Intelligence Unit analysis, 1.7m people, about 2.2% of the national population and mostly over the age of 65, were estimated to be living with dementia in Germany in 2016.⁸ While the population of Germany is expected to see a small decline by 2040, the number of people living with dementia is projected to increase to 2.8m if prevalence proportions per age group are maintained, growing at 2% per year, compared with a decrease of 0.1% per year for the general population. Population dynamics is the driver behind the estimated increase in the number of dementia patients.



In 2016, 1.7m people in Germany were estimated to be living with dementia.

National strategy and community initiatives

In Germany there is a clear separation between medical and social care. Lutz Frölich believes "this distinction, which is a systematic problem in a way, limits concerted action", such as the development of a national strategy. In fact, there is no national dementia plan in Germany, although the regions of Bavaria, Saarland, Rhineland-Palatinate and Schleswig-Holstein have developed regional dementia plans.⁹⁻¹² According to Petra Weritz-Hanf, the first three regions are currently implementing their plans, and implementation in Schleswig-Holstein is scheduled to start soon. The regional plans cover important areas such as action to improve awareness, early diagnosis and enabling support in the home, but their scope is not very detailed, and there seems to be little public awareness of the development and implementation of the plans. A federal programme for the support of dementia patients, the Allianz für Menschen mit Demenz (Alliance for People with Dementia), was established in 2012.¹³ The programme focuses on ageing with dignity and high-quality health services and care, and it brings together public agencies and dementia-supporting organisations. Frank Jessen believes the Alliance is a good start, but it cannot replace a national dementia plan, and "the financial support is not sufficient".

Germany has a good social support system, especially since the 2016 reform of the long-term care insurance (LTCI) system, which now acknowledges the impairment caused

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by dementia and provides financial support to those suffering from the disease. Ms Weritz-Hanf says that a general collaboration between all actors in the field of dementia in Germany is still missing: "We have a beginning with the Alliance for People with Dementia, but our goal is a national strategy." The federal government is seen as lacking dedication to implement changes to improve dementia care. Its main focus regarding dementia has been the founding in 2009 of the Deutsches Zentrum für Neurodegenerative Erkrankungen (DZNE—German Centre for Neurodegenerative Disorders), a large research institution which focuses on developing new preventive and therapeutic approaches. The DZNE also conducts research on the care of dementia patients in rural areas, where the availability of specialists is low.



A general collaboration between all actors in the field of dementia in Germany is still missing.

In addition to the national Alliance for People with Dementia, local alliances are also being established. One of their goals is to reduce the stigma associated with the disease, which, Professor Frölich says, is still a problem despite the clear improvement compared with ten years ago. The local alliances and other associations, such as Aktion Demenz,¹⁴ work towards developing dementia-friendly communities, and there are now around 500 of these communities in Germany. However, local experts believe the definition of "dementia-friendly community" or related projects is not clear, and some initiatives do not result in concrete action. There are considerable improvements that need to be made to achieve a large-scale, dementia-friendly environment. In an additional effort to decrease stigma, the Federal Ministry for Family Affairs, Senior Citizens, Women and Youth has funded campaigns organised by the Deutsche Alzheimer Gesellschaft

(German Alzheimer Association), such as the "Demenz Partner" (Dementia Friend) campaign launched in 2016. Campaigns to increase awareness and decrease stigma associated with dementia have also been run at a regional level. Public figures have been involved with this cause, such as German politicians and celebrities. For example, in 2012 Rudi Assauer, who managed the football club Schalke 04 in the 1980s, made his Alzheimer's diagnosis public. He has since created a dementia foundation, the Rudi Assauer Gemeinnützige Initiative Demenz und Gesellschaft (the Rudi Assauer Non-profit Initiative for Dementia and Society), which aims to raise awareness, reduce stigma and promote support for family members.



Rudi Assauer, who managed the football club Schalke 04 in the 1980s, made his Alzheimer's diagnosis public in 2012.

ASSESSING THE SOCIOECONOMIC IMPACT OF ALZHEIMER'S IN WESTERN EUROPE AND CANADA

Informal care of dementia patients, which is usually provided by a loved one, constitutes a great burden of dementia in Germany.¹⁵ Therefore, it is important to develop training and support programmes for informal caregivers. Free opportunities run by non-profit associations as well as hospitals, nursing homes and churches are available, but these initiatives are organised locally and not rolled out nationally.

Looking after people living with dementia

There is no clear dementia care pathway in Germany. Dementia is not a specialist-only disease, so general practitioners (GPs) can make the diagnosis and manage the disease. Alternatively, they can send the patient to a specialist, usually a neurologist or psychiatrist. Following diagnosis, the specialist can take care of the patient or send them back to their GP for disease management. A third diagnosis pathway is available in urban areas with large hospitals, which provide services in "memory clinics". Patients are referred to such clinics by their GP or specialist, or they can go directly without a referral if they have private medical insurance. Memory clinics focus on diagnosis and are not usually prepared for long-term care. Therefore, patients are sent back to their GP or a specialist. Unfortunately, GPs do not always identify dementia and, according to Professor Frölich, a large share of patients who are not referred to a specialist go undiagnosed.

There are several services available to dementia patients in Germany, such as speech therapy, cognitive training, occupational therapy and counselling. Usually, the larger the city, the more developed the infrastructures and service options. GPs are not always aware of the services available to dementia patients, so patients can reach out to "social contact points" for information, but they are not guided through the system. "What we don't have yet are [...] case managers, like nurses or social workers who co-ordinate the entire process of care," says Professor Jessen, mentioning that there are some ongoing pilot projects to develop such a role, which he believes would improve dementia care. Multidisciplinary care is not always available; some patients are offered different services, but they are frequently not co-ordinated.

There are several day-care centres and nursing homes for dementia patients in Germany, and "more and more effort is being made to specialise these houses for dementia patients", or to set aside some sections of the nursing homes, says Professor Jessen. Professor Frölich believes the system in Germany has several strengths, namely on the social care front, but there is definitely room for improvement.

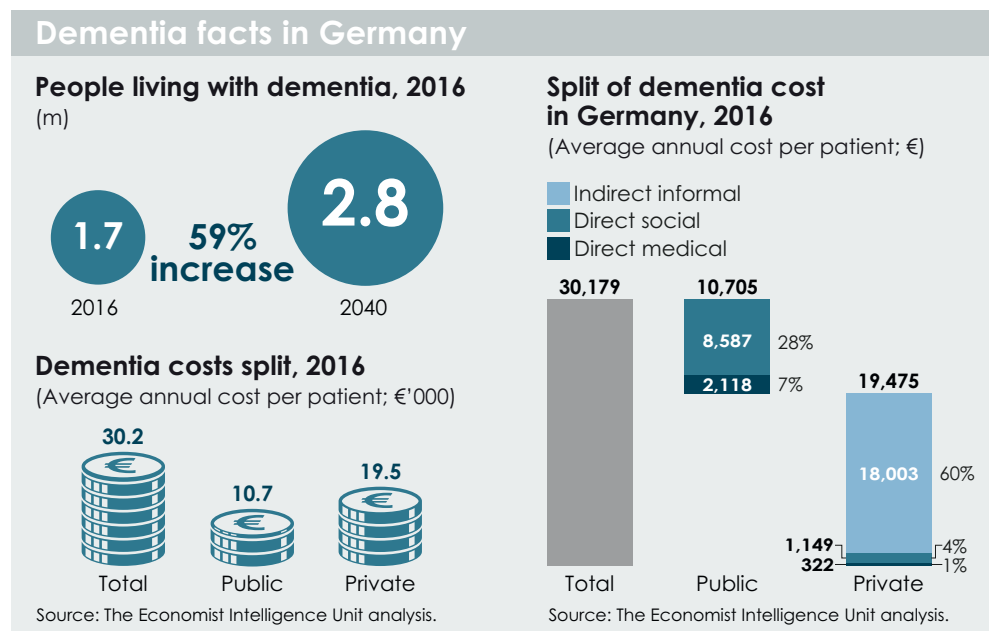


Professor Frölich believes the system in Germany has several strengths, namely on the social care front.

Cost of dementia in Germany

We have estimated the average annual cost per dementia patient in Germany at €30,179 based on an update of published data.^{16,17} The majority of the expenses (92%) are accounted for by social care, with 60% of the average cost per patient represented by indirect informal costs, which are opportunity costs of caregivers, and 32% paying for direct social costs (costs of professional social care). Direct medical costs, which are healthcare costs, account for 8% of the cost per patient. Germany has a relatively low private burden on medical and formal social care expenditure, with 13% of the medical cost and 12% of formal social care cost falling on the families.^{18,19} However, as the very high indirect informal care costs fall on family and friends, a share of 65% of the overall cost is borne privately. Therefore, families are strongly impacted by dementia economically. Dementia costs in Germany were estimated to be €52.7bn in 2016.

The GERAS Study, an investigation into the burden of Alzheimer's disease in France, Germany and the UK, confirmed that the cost of dementia increases with the severity of the disease.^{20,21} New results estimate that in Germany, in the first year after diagnosis, annual cost per patient ranges from €15,850 to €33,710 in mild and severe Alzheimer's respectively.²² In the third year following diagnosis, costs range from €23,940 to €32,360 in mild and severe Alzheimer's respectively, confirming that costs increase with disease progression, while in severe disease they are maintained over time. In line with our assessment, the authors estimate that informal care costs are the main cost at all stages of dementia.



Needs to improve dementia care

We estimated that 1.7m people were living with dementia in Germany in 2016. If prevalence rates are maintained, this number is expected to increase to 2.8m by 2040. The clear separation between medical and social care in Germany may have hindered the development of a national dementia strategy. The federal government has not focused on dementia strategies but has funded a large research institution that conducts clinical and care research. It is important to raise awareness of the disease and its risk factors to attempt to reduce the prevalence and improve diagnosis. The main strength of dementia care in Germany is social care, although there is a need for case managers to guide the patient through the system and improve the quality of life of patients and their families.

¹ Economist Intelligence Unit estimate. See Appendix for methodology.

² Alzheimer Europe, *Dementia in Europe Yearbook*, with a focus on national policies relating to the care and support of people with dementia and their carers, as well as the prevalence of dementia. Luxembourg: Alzheimer Europe, 2013.

³ United Nations Department of Economic and Social Affairs - Population Division, *World Population Prospects: The 2015 Revision*, custom data acquired via website. United Nations 2016. Available at: <https://esa.un.org/unpd/wpp/DataQuery/>

⁴ Luengo-Fernandez R, Leal J and Gray A, "Cost of dementia in the pre-enlargement countries of the European Union", *Journal of Alzheimer's Disease*, 2011;27(1):187-96.

⁵ WHO, Global Health Observatory data repository. Health expenditure ratios, by country, 1995-2014: Out-of-pocket expenditure as a percentage of total expenditure on health. <http://apps.who.int/gho/data/node.main.75>

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⁶ OECD, Social Expenditure Database (SOCX): Social private (mandatory and voluntary) expenditure share. <http://www.oecd.org/social/expenditure.htm>.

⁷ United Nations Department of Economic and Social Affairs - Population Division, *World Population Prospects: The 2015 Revision*, custom data acquired via website. United Nations 2016. Available at: <https://esa.un.org/unpd/wpp/DataQuery/>

⁸ Economist Intelligence Unit estimate. See Appendix for methodology.

⁹ Bayerisches Staatsministerium für Arbeit und Sozialordnung Familie und Frauen, "Demenz-strategie Bayern", Munich, 2012.

¹⁰ Kirchen-Peters S and Hielscher V, "Gemeinsam für ein demenzfreundliches Saarland - Erster Demenzplan des Saarlandes". Saarbrücken: Ministerium für Soziales, Gesundheit, Frauen und Familie des Saarlandes, 2015.

¹¹ Ministerium für Soziales, Arbeit, Gesundheit und Demografie des Landes Rheinland-Pfalz, "Demenzstrategie". Available at: <https://msagd.rlp.de/de/unsere-themen/gesundheits-und-pflege/pflege/demenzstrategie/>

¹² Ministerin für Soziales, Gesundheit, Wissenschaft und Gleichstellung des Landes Schleswig-Holstein, "Demenzplan für Schleswig-Holstein erstellen und umsetzen", 2016.

¹³ Bundesministerium für Familie, Senioren, Frauen und Jugend, "Allianz für Menschen mit Demenz". Available at: <http://www.allianz-fuer-demenz.de/informationen/die-allianz.html>

¹⁴ Aktion Demenz, *Demenzfreundliche Kommune*. Available at: <http://www.aktion-demenz.de/home/143-demenzfreundliche-kommune-.html>

¹⁵ Economist Intelligence Unit estimate. See Appendix for methodology.

¹⁶ Ibid.

¹⁷ Luengo-Fernandez R, Leal J and Gray A, "Cost of dementia in the pre-enlargement countries of the European Union", *Journal of Alzheimer's Disease*, 2011;27(1):187-96.

¹⁸ WHO, Global Health Observatory data repository. Health expenditure ratios, by country, 1995-2014: Out-of-pocket expenditure as a percentage of total expenditure on health. <http://apps.who.int/gho/data/node.main.75>

¹⁹ OECD, Social Expenditure Database (SOCX): Social private (mandatory and voluntary) expenditure share. <http://www.oecd.org/social/expenditure.htm>.

²⁰ Wimo A, Reed CC, Dodel R *et al*, "The GERAS Study: a prospective observational study of costs and resource use in community dwellers with Alzheimer's disease in three European countries - study design and baseline findings", *Journal of Alzheimer's Disease*, 2013;36(2):385-99.

²¹ The GERAS study is supported by Eli Lilly and Company. A link to authors' disclosures is included in the Wimo (2013) publication.

²² Jacobs T, Kraemer S, Saure D *et al*, "Ressourcenverbrauch und Kosten der Alzheimer-Demenz für Patienten und Pflegenden in Deutschland – 36-Monatsdaten der GERAS-Beobachtungsstudie". Poster presented at the Deutsche Gesellschaft für Psychiatrie und Psychotherapie, Psychosomatik und Nervenheilkunde, November 23rd-26th 2016, Berlin, Germany.

These country summaries do not aim to present a thorough description of all national programmes and initiatives in support of dementia. Instead, we present examples of these activities to illustrate the level of national engagement with dementia. Sara C Marques and Annie Pannelay were the authors of these summaries.

SOCIOECONOMIC IMPACT OF ALZHEIMER'S AND OTHER DEMENTIAS ITALY

March 2017

- In 2016 some 1.4m people in Italy—about 2.4% of the overall population—were estimated to be living with dementia.
- The Italian Ministry of Health launched its first Dementia National Plan in 2014. Eleven regions have established regional committees to work on the implementation of the plan.
- Average annual cost per dementia patient in Italy is estimated at €27,419, of which a share of 88% falls on families.
- The government of Italy provides dementia patients with financial benefits, and patients and their families then seek care services. The benefits are not enough to cover all needs.
- Implementation of the national plan and rolling out good dementia care practice with case managers will be needed to improve dementia care in Italy.

About this document

To better understand the socioeconomic impact of Alzheimer's disease and other dementias, the Economist Intelligence Unit has conducted a cost analysis of dementia in six countries.¹ First, an epidemiological analysis was conducted, involving an estimation of the number of dementia cases in Italy in 2016 based on the prevalence reported in the *Dementia in Europe Yearbook 2013*² and population estimates from the UN.³ Then, dementia cost in Italy in 2016 was estimated based on an update of published data⁴ and on Economist Intelligence Unit data on healthcare and GDP growth. The cost of dementia was split into either public (government) spending or private spending, which involves expenditure from family and friends, based on public-private cost splits from the World Health Organisation (WHO) and the Organisation for Economic Co-operation and Development (OECD).^{5,6} A projection of the number of patients in 2040 was made based on UN population estimates and assuming the prevalence rate is maintained.

For the purpose of writing this document, The Economist Intelligence Unit conducted interviews in December 2016 and January 2017 with:

- Fabrizio Giunco, medical director, Istituto Palazzolo, Fondazione Don Carlo Gnocchi, Istituto di Ricovero e Cura a Carattere Scientifico (IRCCS);

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- Giuseppe Lacidogna, neurologist, neuropsychologist, Policlinico Universitario Agostino Gemelli (Hospital);
- Paolo Maria Rossini, director, Department of Neurosciences, Policlinico Universitario Agostino Gemelli (Hospital) and professor of neurology, Università Cattolica del Sacro Cuore; and
- Pietro Davide Trimarchi, neuropsychologist, Istituto Palazzolo, Fondazione Don Carlo Gnocchi, IRCCS.

This country summary is part of a report on dementia entitled *Assessing the socioeconomic impact of Alzheimer's in western Europe and Canada*.

Population living with dementia

In 2016 the total population in Italy was estimated to be 59.8m; of these, 13.6m were aged 65 years and above.⁷ Based on Economist Intelligence Unit analysis, 1.4m people—about 2.4% of the national population and mostly over the age of 65—were estimated to be living with dementia in Italy in 2016.⁸ While the population in Italy is expected to see a small decline by 2040, the number of people living with dementia is projected to increase to 2.3m if prevalence proportions per age group are maintained, growing at 2.1% per year, compared with a decrease of 0.1% per year for the general population. Population dynamics is the driver behind the projected increase in the number of dementia patients.



In 2016, 1.4m people in Italy were estimated to be living with dementia.

National strategy and community initiatives

In 2014 the Italian Ministry of Health developed the first Dementia National Plan.⁹ According to Pietro Davide Trimarchi, some of the strengths of the plan are its aim of increasing disease knowledge and awareness, the integration of services between diagnosis and the post-diagnosis phase, and the focus on research of evidence-based efficacy guidelines for management of the disease. However, the lack of detailed patient rehabilitation and inclusion services are shortfalls of the plan. There are 19 regions and two autonomous provinces in Italy, and each one is responsible for implementing the dementia plan. Paolo Maria Rossini explains that the lack of funding for each region to implement the plan is an additional weakness of the strategy.

The Italian Dementia National Plan is currently being put into practice, with 11 regions having established a regional committee to ensure its implementation. Objectives of the committees include the definition of diagnostic and therapeutic care pathways, the provision of training for healthcare professionals, and assisting the development of

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Centri per Disturbi Cognitivi e Demenze (CDCDs—Centres for Cognitive Disease and Dementia). The CDCDs are slowly replacing the Unità di Valutazione per l'Alzheimer (UVA—Alzheimer's Evaluation Units), which have been developed since 2000 and are mainly for diagnosing and monitoring dementia, offering limited intervention options.

There is an increasing awareness of the burden of dementia in Italy, as shown by a recent effort to strengthen care of patients. The Disegno di Legge (Law of Stability) was revised in November 2016, and non-self-sufficient individuals living with Alzheimer's disease are now entitled to funds. According to Professor Rossini, "central authorities seem to have understood the social alert linked to the progressive ageing of the population and the resulting increase in chronic diseases, such as dementia".

In order to have a better trained healthcare workforce in Italy, some dementia educational activities have been funded by the national health services and the Ministry of Health. Dr Trimarchi highlights the training of general practitioners in the area of Milan under the scope of REMIND, a dementia diagnosis and management project. Giuseppe Lacidogna mentions a one-year project promoted by the Italian Psychogeriatric Association. The course involved sessions in 13 regions, and it had learning objectives that included overcoming stigma, limiting carelessness of services, and focusing on the right of patients to remain in their own home for as long as possible.

In addition to educating healthcare professionals and making infrastructure and support available, Fabrizio Giunco highlights the global need to improve diagnosis and to learn to deal with a pre-symptomatic diagnosis of dementia. Professor Rossini adds: "A cultural revolution is needed in this regard." The dementia regional committees and patient associations have run dementia campaigns to increase awareness, promote patient autonomy and prevent the isolation of dementia-affected families. A short film on the story of a man living with Alzheimer's disease entitled "Lettere a mia figlia" (Letters to my daughter), with the famous Italian actor Leo Gullotta playing the main character, premiered in November 2016 and is up for the David di Donatello award. The film is expected to help raise dementia awareness. Despite the campaigns seen around the country, Professor Rossini explains that no co-ordinated campaign has been launched in Italy, in contrast to campaigns on cancer and metabolic diseases.

According to Dr Giunco, the sense of community and family in Italy is very strong, and therefore discrimination against people living with dementia is minimised. It is important to ensure that people with dementia live in inclusive environments, such as dementia-friendly communities. Italy is currently taking steps towards developing these environments. The Federazione Alzheimer Italia is undertaking the first such project in



Eleven regions have established a regional committee to ensure implementation of the Dementia National Plan.



The project *Noi con voi, ambasciatori per l'Alzheimer* has been recognised with the European Foundations' Initiative on Dementia award in 2014.

Abbiategrosso, a small town near Milan.¹⁰ Other initiatives aiming to develop an environment supportive of people living with dementia and their families are the Alzheimer Cafe projects in Milan,¹¹ run by different associations, the hotline Linea verde Alzheimer¹² (Green-line Alzheimer) and the project *Noi con voi, ambasciatori per l'Alzheimer* (Us with you, ambassadors for Alzheimer's) run by the King Carlo Alberto refuge in Luserna San Giovanni.¹³ This initiative offers members of the community the opportunity to become "ambassadors for Alzheimer's" by participating in key activities, including home-care service and educational events. It has been formally recognised, receiving the European Foundations' Initiative on Dementia (EFID) award in 2014.

Informal care of dementia patients, usually provided by a loved one, is very common in Italy. It is therefore essential to develop training and support programmes for informal caregivers. Several training opportunities are available, organised by municipalities or associations such as the Federazione Alzheimer Italia, the Associazione Italiana Malattia di Alzheimer (AIMA), the Alzheimer Uniti Roma Onlus and SOS Alzheimer. These associations provide online educational material and organise themed meetings with the help of healthcare experts, from neurologists to nurses and occupational therapists. The hospital Policlinico Universitario Agostino Gemelli in Rome, for example, provides help to caregivers in support groups led by a psychologist.

Looking after people living with dementia

People in Italy usually see a general practitioner when they have memory difficulties. When dementia symptoms are present, the general practitioner refers the patient to a specific service, such as a UVA or CDCD. Patients usually see a neurologist when they are 65-75 years old, or a geriatrician if they are over 75. In specialised clinics, patients undertake cognitive assessments and blood and neuroimaging analyses. When the dementia diagnosis is confirmed, the patient starts standard symptomatic pharmacological therapy and cognitive training.



Dementia care in Italy "is different from other European countries because the minister of health and the government choose to give money to people instead of services", creating a "do-it-yourself system".

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Some UVAs offer a multidisciplinary care approach, but this is not available in all units. The CDCDs, on the other hand, have been designed to offer this comprehensive care to all patients.

There are care services available to enable patients to remain at home, such as home services, day-care centres and psychological consultations. Home-care services, however, usually follow a general approach instead of being dementia-specific. When the disease progresses, the patient might be institutionalised in a nursing home. Dementia patients in Italy receive financial benefits—not directly because they have dementia, but according to their level of dependence. Then they manage their own care with their families. Dementia care in Italy “is different from other European countries because the minister of health and the government choose to give money to people instead of services”, creating a “do-it-yourself system”, says Dr Giunco. He adds: “Home-care services and formalised community services reach fewer elderly than in other European countries, leaving relatives and caregivers mostly alone when planning care.” Experts believe the benefits are not sufficient to cover the needs of people living with dementia. “In the advanced phases of disease”, Dr Giunco continues, “caregivers tend to use major services in a ‘shopping-around’ way, which makes it difficult for health entities and regional governments to manage budgets, care pathways and proper use of emergency and hospital services.” In order to respond to patients' needs, more institutional centres are needed in Italy, and in the north of the country this is expected to be addressed through a requalification of old nursing homes, according to Dr Lacidogna. “The health and social-care services for frail elderly are among the great challenges that the Italian society is facing,” he says.

In specialised centres in Italy dementia patients are sometimes assigned a case manager, usually a social worker, who co-ordinates care provided by other professionals. Case managers are useful to help with the fragmented system in Italy, where there are weak links between the national health system, social care and private providers.

Dementia care varies by region in Italy, leading to inequalities across the country. For example, an electronic dementia record exists in the Veneto region,¹⁴ which includes medical information about the patient and social aspects of care. According to Professor Rossini, one of the main goals of the Dementia National Plan is to “create, reorganise and strengthen a network of services and resources”. This should include the roll-out of initiatives such as electronic dementia records at a national level, which would ultimately improve dementia care in the country.



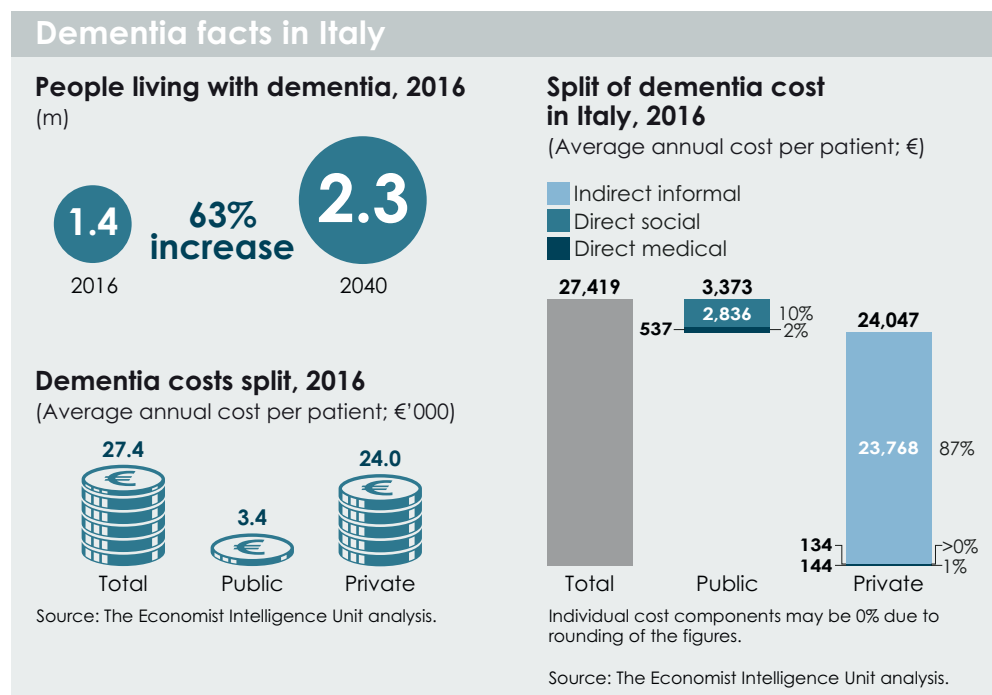
A dementia electronic record exists in the Veneto region; it includes medical information of the patient and social aspects of care.

ASSESSING THE SOCIOECONOMIC IMPACT OF ALZHEIMER'S IN WESTERN EUROPE AND CANADA

Cost of dementia in Italy

We have estimated the average annual cost per dementia patient in Italy to be €27,419, based on an update of published data.^{15,16} The majority of these expenses are accounted for by social care costs, particularly indirect informal costs, which are the opportunity costs of informal caregivers and carry 87% of the average cost per patient. Direct social costs, which are costs of professional care, account for 11% of the cost per patient, and direct medical costs, which represent healthcare costs, for 2%. In Italy, 21% of medical expenditure and 5% of formal social care are borne by the families.^{17,18} However, as indirect informal costs fall on the families and they are very high, 88% of the overall cost is borne privately. Therefore, families are strongly impacted by dementia economically. Dementia costs in Italy were estimated to be €39.3bn in 2016.

The Fondazione Centro Studi Investimenti Sociali (Censis—Centre for Social Studies and Policies) and AIMA have recently published a collaborative report on the cost of Alzheimer's disease in Italy.^{19, 20} They determined very high average costs per patient, with the highest share represented by indirect costs. Costs do not align with similar European countries; indirect costs were reported to be much higher in this report in Italy. Costs were identified through surveys and the different methodology poses limitations to the comparison with other studies.



Needs to improve dementia care

We estimated that 1.4m people were living with dementia in Italy in 2016. If prevalence rates are maintained, this number is expected to increase to 2.3m by 2040. It is important to raise awareness of dementia and improve diagnosis rates. The UVAs are being replaced with CDCDs, which are centres capable of more specialised dementia care, and some patients are assigned a case manager. However, this is not common practice yet, which shows that while there are good examples of dementia care in Italy, they need to be rolled out nationally to improve dementia care consistently across the country. The informal care burden of dementia is high in Italy. It is therefore essential to improve the social care system so families can learn to rely on it and see their opportunity cost reduced. It is equally essential to improve the links between healthcare and social care in Italy to enhance the quality of life of people living with dementia and their families.

ASSESSING THE SOCIOECONOMIC IMPACT OF ALZHEIMER'S IN WESTERN EUROPE AND CANADA

- ¹ Economist Intelligence Unit estimate. See Appendix for methodology.
- ² Alzheimer Europe, *Dementia in Europe Yearbook*; with a focus on national policies relating to the care and support of people with dementia and their carers, as well as the prevalence of dementia. Luxembourg: Alzheimer Europe, 2013.
- ³ United Nations Department of Economic and Social Affairs - Population Division. World Population Prospects: The 2015 Revision, custom data acquired via website. United Nations 2016; [cited 28 October 2016]. Available at: <https://esa.un.org/unpd/wpp/DataQuery/>
- ⁴ Luengo-Fernandez R, Leal J and Gray AM, "Cost of dementia in the pre-enlargement countries of the European Union", *Journal of Alzheimer's Disease*, 2011;27(1):187-96.
- ⁵ WHO, Global Health Observatory data repository. Health expenditure ratios, by country, 1995-2014: Out-of-pocket expenditure as a percentage of total expenditure on health. <http://apps.who.int/gho/data/node.main.75>
- ⁶ OECD, Social Expenditure Database (SOCX): Social private (mandatory and voluntary) expenditure share. Available at: <http://www.oecd.org/social/expenditure.htm>.
- ⁷ United Nations Department of Economic and Social Affairs - Population Division. World Population Prospects: The 2015 Revision, custom data acquired via website. United Nations 2016; [cited 28 October 2016]. Available at: <https://esa.un.org/unpd/wpp/DataQuery/>
- ⁸ Economist Intelligence Unit estimate. See Appendix for methodology.
- ⁹ Presidenza del Consiglio dei Ministri Conferenza Unificata. Piano nazionale demenze. Strategie per la promozione ed il miglioramento della qualità e dell'appropriatezza degli interventi assistenziali nel settore delle demenze. Italy: *Gazzetta Ufficiale*, No. 9, 2015.
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- ¹² Associazione Italiana Malattia di Alzheimer, "Linea Verde Alzheimer". Available at: <http://www.alzheimer-aima.it/lineaverde.htm>
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- ¹⁵ Economist Intelligence Unit estimate. See Appendix for methodology.
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- ¹⁸ OECD, Social Expenditure Database (SOCX): Social private (mandatory and voluntary) expenditure share. Available at: <http://www.oecd.org/social/expenditure.htm>.
- ¹⁹ AIMA, Censis. L'impatto economico e sociale della malattia di alzheimer: rifare il punto dopo 16 anni. 2016.
- ²⁰ This report was supported by Eli Lilly and Company.

These country summaries do not aim to present a thorough description of all national programmes and initiatives in support of dementia. Instead, we present examples of these activities to illustrate the level of national engagement with dementia. Sara C Marques and Annie Pannelay were the authors of these summaries.

SOCIOECONOMIC IMPACT OF ALZHEIMER'S AND OTHER DEMENTIAS

SPAIN

March 2017

- In 2016 some 900,000 people in Spain—about 1.9% of the overall population—were estimated to be living with dementia.
- A national healthcare strategy for neurodegenerative diseases, which was first launched in 2016, now needs to be implemented in each autonomous region.
- Average annual cost per dementia patient is estimated at €24,184, of which a share of 71% falls on families.
- There are public and private institutions providing good dementia care in Spain, creating examples of care that could be rolled out to other institutions in the country.
- A bigger budget, political will and better co-ordination between health and social services and healthcare professionals is needed to improve dementia care in Spain.

About this document

To better understand the socioeconomic impact of Alzheimer's disease and other dementias, the Economist Intelligence Unit has conducted a cost analysis of dementia in six countries.¹ First, an epidemiological analysis was conducted, involving an estimation of the number of dementia cases in Spain in 2016 based on the prevalence reported in the *Dementia in Europe Yearbook 2013*² and population estimates from the UN.³ Then, dementia cost in Spain in 2016 was estimated based on an update of published data^{4,5} and on Economist Intelligence Unit data on healthcare and GDP growth. The cost of dementia was split into either public (government) spending or private spending, which involves expenditure from family and friends, based on public-private cost splits from the World Health Organisation (WHO) and the Organisation for Economic Co-operation and Development (OECD).^{6,7} A projection of the number of patients in 2040 was made based on UN population estimates and assuming the prevalence rate is maintained.

For the purpose of writing this document, The Economist Intelligence Unit conducted interviews in December 2016 and January 2017 with:

- Elena Andradas, director general, Directorate General of Public Health, Quality and Innovation, Spanish Ministry of Health, Social Policy and Equality;

ASSESSING THE SOCIOECONOMIC IMPACT OF ALZHEIMER'S IN WESTERN EUROPE AND CANADA

- Pablo Martínez-Lage, director of neurology, Centre for Research and Advanced Therapies, Fundacion CITA Alzheimer Fundazioa;
- Jesús Rodrigo, executive director, Spanish Confederation of Associations of Families of People with Alzheimer's and other Dementias (CEAFA); and
- Lluís Tárraga, chief executive officer, Fundació ACE.

This country summary is part of a report on dementia entitled *Assessing the socioeconomic impact of Alzheimer's in western Europe and Canada*.

Population living with dementia

In 2016 the total population in Spain was estimated to be 46.1m; of these, 8.8m were aged 65 years and above.⁸ Based on Economist Intelligence Unit analysis, 900,000 people—about 1.9% of the national population and mostly over the age of 65—were estimated to be living with dementia in 2016.⁹ While the population of Spain is projected to see a small decline by 2040, the number of people living with dementia is expected to increase to 1.5m if prevalence proportions per age group are maintained, growing at 2.2% per year, compared with a decrease of 0.04% per year for the general population. Population dynamics is the driver behind the estimated increase in the number of dementia patients.



In 2016, 900,000 people in Spain were estimated to be living with dementia.

National strategy and community initiatives

In 2016 the Spanish Ministry of Health, Social Services and Equality published the first national strategy for neurodegenerative diseases.¹⁰ The strategy has yet to be approved and implemented by each of the 17 autonomous regions. Elena Andradas states that the Ministry is “currently working on [...] implementation aspects and follow-up indicators”. One strength of the strategy is the bringing together of all agents involved in the care of dementia patients, from healthcare services to social care services and patient associations. The strategy also outlines an improved care pathway focused on the patient. Dr Andradas highlights several advantages of launching a strategy combining multiple neurodegenerative diseases, namely the fact that the diseases have similar pathologic processes and all require palliative care, stating that “the joint approach facilitates the management, accessibility and efficiency of resources to reach all who need them, and it also helps raise awareness and train professionals”. Pablo Martínez-Lage has an opposing view regarding the combining of several neurodegenerative diseases in one plan: “A global strategy on all neurodegenerative diseases won't be as efficacious as an initiative that is specific on Alzheimer's disease

ASSESSING THE SOCIOECONOMIC IMPACT OF ALZHEIMER'S IN WESTERN EUROPE AND CANADA

because [...] patients are very heterogeneous and require different approaches regarding diagnosis, treatment and social care."

Patient representatives call for greater dementia awareness within the government, despite experts from both the private and the public sector agreeing on the achievements made until now and the next steps. It is possible that there is still a lack of understanding of the situation from the perspective of the government. For example, Jesús Rodrigo believes there is no consensus regarding the real scale of dementia in Spain, concluding: "It's very difficult to fight the disease if we don't know the magnitude of the problem." The Spanish Confederation of Associations of Families of People with Alzheimer's and other Dementias (CEAFA) has formed a partnership with the health ministry and aims to put dementia higher up the political agenda.^{11,12} The national strategy makes it clear that the ministry is not solely responsible for dementia care, but no other institutions are singled out for this. Therefore a national policy that holds the government and each autonomous region accountable to dementia patients is still lacking in Spain.



"It's very difficult to fight the disease if we don't know the magnitude of the problem."

The national strategy on neurodegenerative diseases also aims to raise awareness. So far, dementia awareness campaigns have mainly been run by CEAFA and family associations; for example, CEAFA runs an annual campaign on September 21st, World Alzheimer's Day. In 2016 the Fundación Pasqual Maragall in Barcelona, a research foundation, released a video to help raise awareness and fund research "for a future without Alzheimer's", featuring children imagining what it would be like to live to the age of 100.¹³ Pasqual Maragall, who gives his name to the foundation, is a former Spanish politician and president of the autonomous government of Catalonia. He revealed in 2007 that he had been diagnosed with dementia and created the foundation to help beat the disease. This is an example of a public figure in Spain who revealed his personal battle, thereby helping to increase dementia awareness.

In addition to running awareness campaigns, CEAFA and family associations in Spain are also involved in the development of communities that are inclusive of people living with dementia, and some municipalities are also trying to become more supportive. However, according to Dr Martínez-Lage, the initiatives of municipalities are very formal and do not translate into action. Informal care of dementia patients, which is usually provided by a loved one, is very common in Spain, making it essential to develop support programmes for informal caregivers. Some training or support programmes are available through family associations, and a few municipalities are slowly developing initiatives. One example is the programme "Cuidar al Cuidador" (Taking Care of the Caregiver) in Madrid,¹⁴ which includes group sessions led by a psychologist and training

sessions led by occupational therapists. These initiatives represent an improvement in the support of caregivers in Spain, but they are not rolled out nationally. Dr Martínez-Lage says: "Physicians are not very well trained to detect caregiver burden syndrome, [...] a lot of training is needed in that respect," adding that the mental health network in Spain might not yet be at a stage where it is ready to help caregivers. According to Dr Andradas, one of the objectives of the Ministry of Health is to look after informal caregivers.

Looking after people living with dementia

When patients present with dementia symptoms in Spain, the primary-care physician refers them to a specialist, usually a neurologist or, less commonly, a geriatrician or psychiatrist. Blood and neuroimaging testing is performed for diagnostic assessment, and dementia treatment can include pharmacological treatment, rehabilitation, cognitive stimulation or occupational therapy. However, there is no clear care pathway in Spain. Dr Andradas highlights the need for individual care plans for each patient, mentioned in the national strategy, and the establishment of specific care pathways in each autonomous region. According to Dr Martínez-Lage, the diagnosis process can take up to 30 months, which can be due to "a combination of attitudes of the general population, [...] the lack of training of primary care assistants and specialists [...] and the failures of the system".



"Physicians are very keen to prescribe non-pharmacological therapies, but less than half of caregivers are aware of the existence of these therapies."



According to Pablo Martínez-Lage, "physicians are not very well trained to detect caregiver burden syndrome, [...] a lot of training is needed in that respect".

First, the general population is usually not aware of dementia symptoms and may take a long time to visit a physician. Second, healthcare professionals need to be trained on dementia, and in this regard Dr Andradas explains: "There is a strategy on training of professionals, and some of the objectives are raising awareness and providing training in primary care." Among the problems in the healthcare system in Spain are the long waiting lists and the unequal access to specialised dementia diagnosis units, which are not evenly spread around the country. Dementia units are available in hospitals, but they frequently lack a comprehensive approach as their care strategies are focused on pharmacological treatment. The health ministry highlights that there is

some co-ordination between different services, and efforts are being made to keep improving this. Dr Martínez-Lage adds that “the role of neuropsychologists, the role of nurses [and] the role of social workers should also be emphasised”. He mentions a paradox in Spain: “Physicians are very keen to prescribe non-pharmacological therapies, but less than half of caregivers are aware of the existence of these therapies, which are mostly given in social care centres, and many of them are run by family associations.”

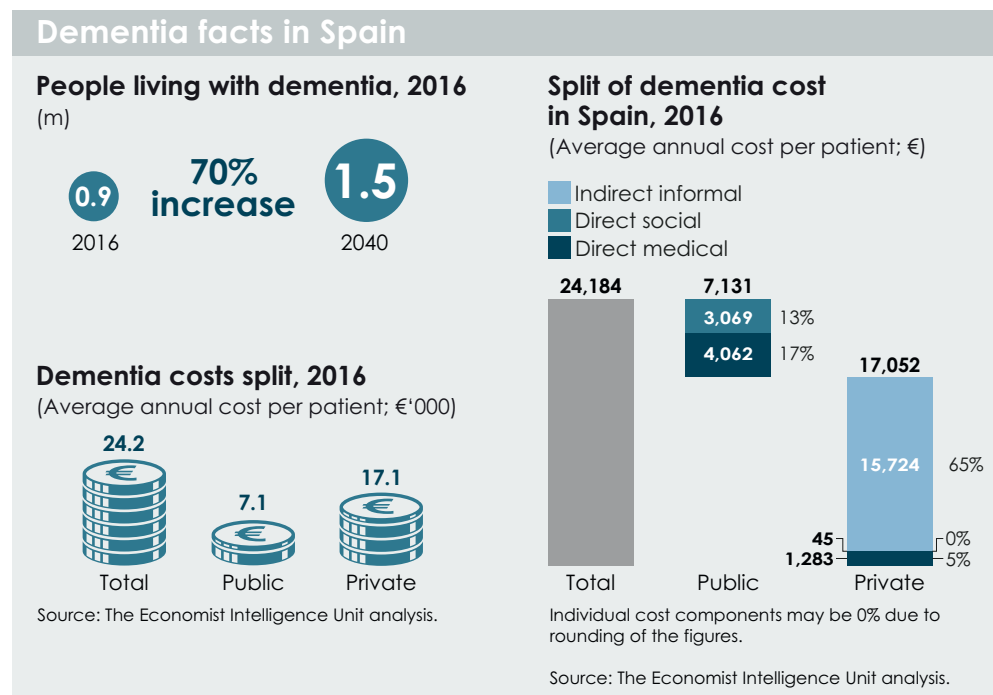
In Spain there are both public and private institutions to manage dementia. The Hospital de la Santa Creu i Sant Pau in Barcelona, for example, has a memory clinic that enjoys a national and international reputation for dementia research. In the private sector another example of best practice in dementia, also in Barcelona, is the non-profit Fundació ACE, which offers patient-focused and integrated care to people living with dementia and supports the families and informal caregivers. Patients can access this clinic with a referral from their general practitioner, in which case access to the clinic services is free of charge. If dementia has already been diagnosed but patients want to confirm their diagnosis at the clinic, they may need to make out-of-pocket payments if they do not want to visit their general practitioner again. According to Lluís Tàrraga, around 97% of the patients seen at Fundació ACE access the clinic through the national social security system. The clinic saw 6,769 patients in 2015, of whom 2,009 were new patients, and it has 205 day-care places.¹⁵

There are other institutions in Spain that provide good care for dementia patients, but it is important to note that this is not consistent across the country. For example, the autonomous regions of Spain have different resources available. This can be seen in GDP per capita, which in 2015 ranged from €16,166 in Extremadura to €31,812 in Madrid.¹⁶

Cost of dementia in Spain

We have estimated the average annual cost per dementia patient in Spain at €24,184, based on an update of published data.^{17,18,19} The majority of the expenses fall on social care, with 65% of the average cost per patient financing indirect informal costs, which are opportunity costs of informal caregivers, and 13% paying for direct social costs (costs of professional social care). Direct medical costs, which are healthcare costs, account for 22% of the cost per patient. Spain has a low private burden on formal social expenditure, estimated at 1%,²⁰ while out-of-pocket medical expenditure, estimated at 24%, is considerable.²¹ In combination with indirect informal costs, the total private share of cost per patient is 71%. Therefore, families are strongly impacted by dementia economically. Dementia costs in Spain were estimated to be €20.8bn in 2016.

ASSESSING THE SOCIOECONOMIC IMPACT OF ALZHEIMER'S IN WESTERN EUROPE AND CANADA



Needs to improve dementia care

We estimated that 900,000 people were living with dementia in Spain in 2016. If prevalence rates are maintained, this number is expected to increase to 1.5m by 2040. The recently launched strategy on neurodegenerative diseases includes relevant recommendations, but it will be difficult to get it approved and implemented across the country. A national policy is needed to improve the social care system in Spain and to alleviate the high informal care burden of dementia. It is also important to raise awareness of the disease and improve diagnosis rates and co-ordination between all professionals involved in dementia care. Spain has good examples of patient-focused care models that can be rolled out to other regions to improve the quality of life of dementia patients and their families.

¹ Economist Intelligence Unit analysis. See Appendix for detailed methodology.

² Alzheimer Europe, *Dementia in Europe Yearbook*; with a focus on national policies relating to the care and support of people with dementia and their carers, as well as the prevalence of dementia. Luxembourg: Alzheimer Europe, 2013.

³ United Nations Department of Economic and Social Affairs - Population Division. *World Population Prospects: The 2015 Revision*, custom data acquired via website. United Nations 2016. Available at: <https://esa.un.org/unpd/wpp/DataQuery/>

⁴ Luengo-Fernandez R, Leal J and Gray AM, "Cost of dementia in the pre-enlargement countries of the European Union", *Journal of Alzheimer's Disease*, 2011;27(1):187-96.

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- ⁸ United Nations Department of Economic and Social Affairs - Population Division. World Population Prospects: The 2015 Revision, custom data acquired via website. United Nations 2016. Available at: <https://esa.un.org/unpd/wpp/DataQuery/>
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- ¹⁴ Portal web del Ayuntamiento de Madrid. Cuidar a quienes cuidan - Curso 2016/17. Ayuntamiento de Madrid. Available at: <http://www.madrid.es/portales/munimadrid/es/Inicio/Ayuntamiento/Servicios-Sociales/Mayores/Cuidar-al-cuidador-Curso-2014-15?vgnnextfmt=default&vgnnextoid=a53f10e21f566210VgnVCM2000000c205a0aRCRD&vgnnextchannel=c432de1f33872210VgnVCM2000000c205a0aRCRD#>
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- ¹⁹ Parés-Badell O, Barbaglia G, Jerinic P *et al*, "Cost of disorders of the brain in Spain", *PLOS ONE*, 2014;9(8).
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- ²¹ WHO, Global Health Observatory data repository. Health expenditure ratios, by country, 1995-2014: Out-of-pocket expenditure as a percentage of total expenditure on health. Available at: <http://apps.who.int/gho/data/node.main.75>

These country summaries do not aim to present a thorough description of all national programmes and initiatives in support of dementia. Instead, we present examples of these activities to illustrate the level of national engagement with dementia. Sara C Marques and Annie Pannelay were the authors of these summaries.

SOCIOECONOMIC IMPACT OF ALZHEIMER'S AND OTHER DEMENTIAS UNITED KINGDOM

March 2017

- In 2016 some 1.1m people in the UK—about 1.7% of the overall population—were estimated to be living with dementia.
- England, Scotland and Northern Ireland have developed national dementia strategies, while Wales is currently working on a strategy.
- Average annual cost per dementia patient in the UK is estimated to be €40,695 (£35,349), of which a share of 54% falls on families.
- A lot of time and effort is spent on dementia research in the UK, examples of which are the development of the Dementia Discovery Fund and the Dementia Research Institute.
- Greater awareness, more training of healthcare professionals and better support from public-sector services are needed to improve the care of people living with dementia further.

About this document

To better understand the socioeconomic impact of Alzheimer's disease and other dementias, the Economist Intelligence Unit has conducted a cost analysis of dementia in six countries.¹ First, an epidemiological analysis was conducted, involving an estimation of the number of dementia cases in the UK in 2016 based on the prevalence reported in the *Dementia in Europe Yearbook 2013*² and population estimates from the UN.³ Then, dementia cost in the UK in 2016 was estimated based on an update of published data⁴ and on Economist Intelligence Unit data on healthcare and GDP growth. The cost of dementia was split into public (government) spending or private spending, which involves expenditure from family and friends, based on public-private cost splits from the World Health Organisation (WHO) and the Organisation for Economic Co-operation and Development (OECD).^{5,6} A projection of the number of patients in 2040 was made based on UN population estimates and on the assumption that the prevalence rate is maintained.

For the purpose of writing this document, The Economist Intelligence Unit conducted interviews in December 2016 with the following experts:

- Martin Knapp, director, Personal Social Services Research Unit, professor of social policy, London School of Economics and Political Science (LSE); director of NIHR School for Social Care Research;

ASSESSING THE SOCIOECONOMIC IMPACT OF ALZHEIMER'S IN WESTERN EUROPE AND CANADA

- Gill Livingston, professor of psychiatry of older people, University College London; honorary consultant old-age psychiatrist in Camden and Islington NHS Foundation Trust;
- Matthew Norton, director of policy and strategy, Alzheimer's Research UK; and
- Liz Sampson, reader, University College London, Marie Curie Palliative Care Research Department; and consultant in liaison psychiatry, North Middlesex University Hospital.

This country summary is part of a report on dementia entitled *Assessing the socioeconomic impact of Alzheimer's in western Europe and Canada*.

Population living with dementia

In 2016 the total population in the UK was estimated to be 65.1m; of these, 11.7m were aged 65 years and above.⁷ Based on Economist Intelligence Unit analysis, 1.1m people—about 1.7% of the national population and mostly over the age of 65—were estimated to be living with dementia in the UK in 2016.⁸ While the population of the UK is expected to see a small increase by 2040, the number of people living with dementia is expected to increase to 1.9m if prevalence proportions per age group are maintained, growing at 2.3% per year, compared with 0.5% growth per year for the general population. Population dynamics is the driver behind the projected increase in the number of dementia patients.



In 2016, 1.1m people in the UK were estimated to be living with dementia.

National strategy and community initiatives

Each country in the UK has its own health system and healthcare strategies. In 2009 England developed a national dementia strategy,⁹ defining 17 objectives to improve the quality of dementia services. The strategy focuses on three main themes: raising awareness and understanding, early diagnosis and support, and living well with dementia. In 2012 the prime minister of the UK acknowledged dementia as a major health and social care issue and launched The Prime Minister's Challenge on Dementia in England, a document which lays out key commitments that build on the national strategy.¹⁰ This "Challenge" aimed to improve dementia care and research by 2015. Since the launch of the national strategy and challenge, diagnosis rates and care services have improved, dementia-friendly programmes have been developed and research has been funded. In 2015 a new dementia "Challenge" aiming at further improvement was launched.¹¹ This document highlights efforts being made towards creating a better trained National Health Service (NHS) and social-care workforce, as well as building a dementia-friendly generation through raising awareness in younger people. It aims to make England the best country in the world for dementia care and

research. The ambitious goals of the challenge will “not [be] achieved overnight, but there are efforts being made to improve the societal perspectives of dementia”, says Martin Knapp. Among the strengths of the challenge are “putting more money into research”, according to Liz Sampson, and “the emphasis on the need to pay attention to people, today and in the immediate future, who have dementia”, according to Professor Knapp. On the other hand, Dr Sampson identifies the lack of focus on social care as the main weakness, adding that the challenge “is quite focused on medication and drug trials and it doesn’t really think so much about the actual care needed by the people who are living with dementia at the moment”. Professor Knapp adds that it is important to “make sure that the policy is emphasising the need to get care and support services to be better today”. The government has tried to improve dementia diagnosis rates further, but Professor Knapp says: “Providing additional training to primary healthcare professionals in relation to dementia has perhaps not had sufficient emphasis.”



The Prime Minister’s Challenge on Dementia 2020 has the goal of making England the best country in the world for dementia care and research.

In 2013 Scotland launched its second national dementia strategy,¹² which focuses on diagnosis, care and community support. The 2016-2019 strategy has yet to be published, although a proposal with key priorities was made available at the beginning of 2016.¹³ Among the objectives of the proposal are to prioritise dementia end-of-life care; to redesign care services; and to support the development of dementia-friendly initiatives. Northern Ireland also has its own dementia strategy, first launched in 2011.¹⁴ The strategy calls for improved diagnosis, improved services to patients and carers, and research into the causes of the disease and treatment options. It also introduces the development of mental health legislation. The new Mental Capacity Act of Northern Ireland,¹⁵ approved in 2016, outlines the creation of lasting powers of attorney. This may apply to dementia patients depending on the extent of their disability, which shows an additional effort in the country to support people living with dementia. In 2011 the Welsh government published the National Dementia Vision for Wales, which highlighted the support available for people living with dementia and some of the government's commitments.¹⁶ A draft for the first dementia national strategy was open for consultation until April 2017.¹⁷

The UK is focusing on dementia research. In 2015 a collaboration between charities, industry and the government formed the Dementia Discovery Fund (DDF).¹⁸ The DDF raised US\$100m to address the unmet medical needs of dementia, and it aims to invest over US\$200m over 15 years to support the creation of novel disease-modifying drugs in partnership with universities, academic institutions and the biotechnology and pharmaceutical industry. In 2016 the UK Dementia Research Institute (DRI) was

ASSESSING THE SOCIOECONOMIC IMPACT OF ALZHEIMER'S IN WESTERN EUROPE AND CANADA

announced as a £250m investment into dementia research by the Medical Research Council, the Alzheimer's Society and Alzheimer's Research UK (ARUK).¹⁹ This centre will be led from University College London and is expected to help to further knowledge on dementia and improve dementia care. While clinical research initiatives are essential, "we need an additional investment into social care, in improving and professionalising the social care sector", says Matthew Norton from ARUK.

Several associations have run dementia awareness campaigns in the UK, from national associations such as the Alzheimer's Society and ARUK, to international ones, such as Alzheimer's Disease International (ADI). "World Rocks against Dementia in 2017" is an example of a UK event supported by ADI that will lead a global campaign.²⁰ The Alzheimer's Society runs campaigns such as "Worried about your memory" and "Dementia Friends". The Dementia Friends initiative,²¹ for example, aims to change the way people think about dementia by teaching them to make people with dementia feel understood and included. In order to become a dementia friend, they need to attend one information session or watch a video online. Independent organisations and communities can also register with the programme. When successful, they can use a dementia-friendly symbol that is given to dementia friends as a badge. Well-known people in the UK have also taken on the role of promoting dementia awareness, such as the British comedian Terry Jones and the late novelist Terry Pratchett, which, according to Gill Livingston, has helped to make the disease less stigmatising than before.



In 2016 the UK Dementia Research Institute (DRI) was announced as a £250m investment into dementia research by the Medical Research Council, the Alzheimer's Society and Alzheimer's Research UK.

Among the initiatives to decrease the stigma of dementia is the development of dementia-friendly communities—environments inclusive of people living with dementia that aim to help them remain active, included and independent. There are several dementia-friendly communities in the UK, for example in East Lothian in Scotland.²² Although the UK ranks number one in a quantitative and qualitative palliative care analysis,²³ Dr Sampson believes dementia-friendly communities are not fully prepared for end-of-life care, adding: "It's one of the areas where people are a lot less aware."

Informal care of dementia patients, usually provided by a loved one, constitutes a great burden of dementia. It is important to develop training and support programmes for caregivers. According to experts, there are several training opportunities in the UK, namely in clinics specialised in the assessment, diagnosis and management of dementia, called memory clinics. Recently, a new coping intervention has been

developed. Called START (STrategies for RelaTives), it is an eight-session programme that has been shown to decrease anxiety and depression in carers.^{24,25} The dementia strategy of England recommends that carers receive support in this form or something similar.

Looking after people living with dementia

In the UK, patients see their general practitioner before seeing a specialist. This is the norm, although some private health insurance plans make it possible to see the specialist directly. When patients have a referral for a specialist they can go to a hospital, private practice or memory clinic. In the UK, dementia belongs to the psychiatry specialty. Therefore, psychiatrists are the main specialists that look after these patients; neurologists are usually only involved with younger dementia patients or patients with unusual symptoms, and geriatricians are also involved less often. Although there are more than 200 memory clinics in England, in 2014 the average waiting time from receipt of referral by the memory clinic to dementia diagnosis was 14 weeks, ranging from two to 56 weeks.²⁶ The long waiting times previously reported led to an audit of 11 clinics that identified action for service improvement, such as reviewing referral protocols and the role of specialist nurses.²⁷

Following diagnosis, dementia patients are offered pharmacological intervention, but no clear care pathway is implemented across the country, according to both Professor Knapp and Dr Sampson. Cognitive stimulation therapy is a non-pharmacological intervention reported to be available in around two-thirds of memory clinics.²⁸ It is a



Technological help such as gas, heat and movement alarms that run through the telephone line are available.

programme of several sessions, where structured discussions and activities, including word puzzles or games, take place. Memory clinics provide different services to help people living with dementia, such as psychological support and memory strategies or advice. In these clinics, different professionals are involved in the care of dementia patients, such as nurses, occupational therapists and psychologists, who work in a multidisciplinary environment. The role of dementia nurses has been developed in recent years, namely in the form of Admiral Nurses in the UK—registered nurses specialised in dementia who give practical, clinical and emotional support to patients and their families.²⁹ This service is in a more advanced stage in England, but other UK countries



No clear care pathway is implemented across the country.

also have teams available. For example, recruitment for an Admiral Nurse team in Swansea, Wales was initiated in February 2017.³⁰ When social workers are involved in dementia care, they assist in finding home care, applying for financial benefits and designing management plans to help patients stay independent and keep living in the community for as long as possible, says Professor Livingston. This support may include setting up financial plans, making housing and eating arrangements and dealing with the prevention of fire accidents. It may also include the installation of technological help such as gas, heat and movement alarms that run through the telephone line. Professor Livingston highlights that more practical help is needed, namely with giving power of attorney to a member of the family so that they have the legal right to make decisions for the patient. According to experts, the multidisciplinary approach to dementia is not consistently available across the country.

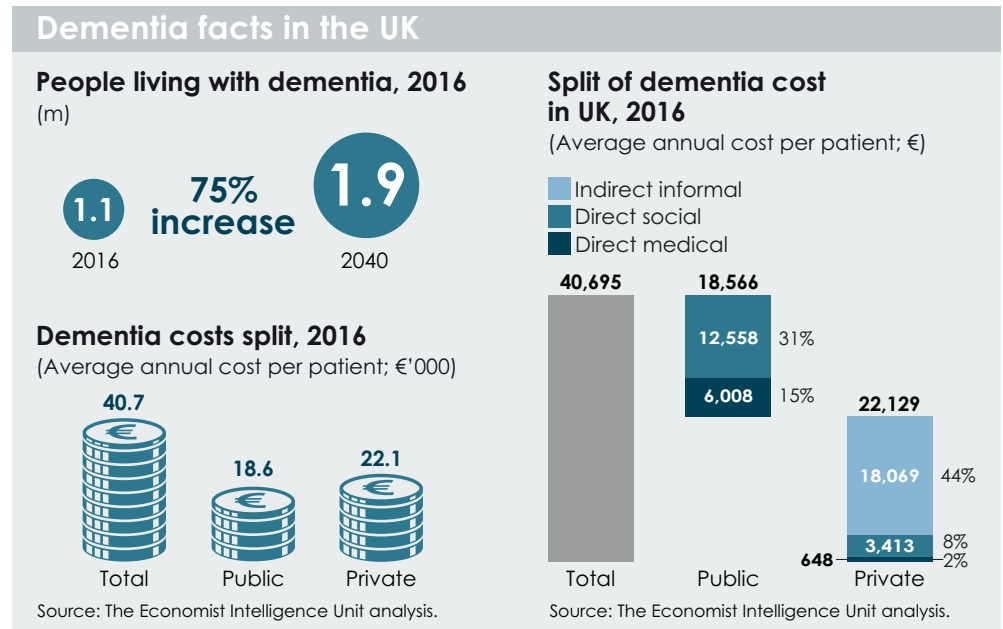
There are several good nursing homes in the UK, and no single model is repeated throughout the country. According to Professor Livingston, even when nursing homes are not specifically designed for people living with dementia, about 70% of nursing-home residents have some form of dementia.

Cost of dementia in the UK

Based on an update of published data, we have estimated the average annual cost per dementia patient in the UK to be €40,695 (£35,349),^{31,32} the highest cost among the countries analysed here. Indirect informal costs, the opportunity costs of informal caregivers, carry the highest share of the cost at 44%, while 39% is accounted for by direct social costs (costs of professional social care). Direct medical costs, which are healthcare costs, are only 16% of average cost per patient. Families bear the indirect informal costs and also 21% of direct social costs³³ and 10% of direct medical costs.³⁴ This leads to a share of 54% of the cost per patient to be borne by patients and families. Therefore, families are strongly impacted by dementia economically. Dementia costs in the UK were estimated at €45.2bn (£39.3bn) in 2016.

A recent 18-month study on the burden of dementia in France, Germany and the UK, the GERAS study, looked at 526 patients in the UK and confirmed that cost of dementia increases with severity of disease.^{35,36} Confirming our findings, the GERAS study found that informal care costs are estimated to be the main contributor to cost per patient in all stages of the disease. The *Dementia UK: Update* report,³⁷ published by the UK's Alzheimer's Society in 2014, also estimated that people with moderate or severe dementia have a higher average cost if they live in the community as opposed to living in an institution owing to the greater indirect informal costs. This report highlighted the need for high-quality data that reflect the real demographics to fully support decision-making.

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Needs to improve dementia care

We estimated that 1.1m people were living with dementia in the UK in 2016. If prevalence rates are maintained, this number is projected to increase to 1.9m by 2040. To improve diagnosis rates, it is important to raise awareness of dementia and ensure that healthcare professionals benefit from better and more targeted training. The UK is dedicated to dementia research, which is illustrated by the establishment of the Dementia Discovery Fund and the Dementia Research Institute. It is important that memory-clinic services are improved and that best-care models are rolled out nationally to reach all dementia patients. It is essential to improve and implement a national policy to define healthcare and social-care responsibilities and to make services available to dementia patients soon after diagnosis. The UK delivers good palliative care, but improvements are needed.³⁸ It is important to make end-of-life care resources available for dementia patients to support patients and families until the end.

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These country summaries do not aim to present a thorough description of all national programmes and initiatives in support of dementia. Instead, we present examples of these activities to illustrate the level of national engagement with dementia. Sara C Marques and Annie Pannelay were the authors of these summaries.

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