# Scenarios of dementia care:

## What are the impacts on cost and quality of life?

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# EXECUTIVE SUMMARY

As the world population continues to age, so will the number of people with dementia continue to rise rapidly. This growing prevalence poses many challenges, including the economic challenge of how societies can ensure that treatment, care and support are provided at an affordable cost, whilst ensuring good quality of life for people with dementia and their families. The aim of this research is to examine the economic consequences of different ways to respond to this challenge.

We start with a fully costed description of care and support for people with dementia in the UK today, with which we then compare four alternative scenarios. Two of these scenarios represent arrangements that are worse than today, and two of them better. We use simulation modelling to compare these scenarios: our *aggregate model* estimates the overall cost and quality of life consequences over one year for the UK; and our illustrative *lifetime model* estimates the cost and quality of life impacts for a 'typical' individual from the point of onset of dementia until death.

Data to populate the models are taken from various UK and other sources, including epidemiological studies, descriptions of care and support patterns, randomised trials of specific interventions and expert opinion. Included in these sources are individual-level data from a dozen recent UK dementia trials and observational studies. Costs include both public expenditure and wider societal costs; we separate health, social care and unpaid (informal) carer costs. Outcomes are measured as gains in quality-adjusted life years (QALYs) by people with dementia. Although we are not able to measure quality of life changes for carers in our quantitative modelling, we comment on the likely impacts of different scenarios on carers where relevant.

Our new analyses suggest that the annual cost of dementia in the UK in 2015 (as measured for the purposes of these analyses) will be approximately £21 billion (at 2012/13 price levels). More than a third of this total is the (imputed) cost of unpaid care provided by family and other carers. The total divides into 20% health care costs, 45% social care costs (publicly and privately funded) and 35% unpaid care costs. Dementia also has major impacts for the quality of life of both the estimated 800,000 people with dementia in the UK in 2015 and their carers. This current care scenario provides the baseline against which we compare the other four scenarios.

The no-diagnosis scenario describes a situation where no one with dementia has their condition diagnosed, and no dementia-specific services are delivered. We are able to look only at the consequences of not having medications which alleviate the symptoms of dementia, and of not having community-based social care support for dementia. Other potential impacts of not diagnosing dementia include higher risk of crises, such as emergency hospital admission resulting from a fall, but we are not able to model these impacts. For this no-diagnosis scenario we find that the overall costs would be around £350 million higher than today's care and support arrangements, and outcomes would be slightly lower.

The diagnosis-only scenario occurs when people with dementia do get a diagnosis but then receive no dementia-specific post-diagnostic support. Our modelling was the same as for the no-diagnosis scenario except that now we need include the cost of carrying out a diagnosis. Overall costs would be £500 million higher than they are currently, and again outcomes would be worse.

Neither the no-diagnosis nor the diagnosis-only scenario could be seen as better than current arrangements in the UK. Two other scenarios are explored in anticipation that they would be better than current arrangements. The improved care scenario assumes that everyone with dementia will have their disorder diagnosed, treated and supported with interventions that have been shown through well-conducted research to be more effective and/or cost-effective than standard care. Four specific variants of 'improved' care are modelled:

- *If medications to alleviate the symptoms of dementia* are available to everyone with Alzheimer's disease, the effect would to save around £250 million in overall costs, comprising a saving of about £400 million in social care with a partially offsetting extra cost of £150 million for unpaid care.

- *If cognitive stimulation therapy* is delivered to everyone with mild or moderate dementia, there would be little difference in overall costs, with a slight shift from social care to health care costs.

- *If case management* is used to coordinate care then this would increase overall costs by around £225 million, comprising a saving of around £1.15 billion on health and social care costs but an increase of almost £1.4 billion in the imputed costs of unpaid care.

- Finally, if family carers of people with dementia were supported with a *coping intervention* then overall costs would be around £200 million higher than they are today, comprising a saving of £200 million on health and social care and increase of £400 million in unpaid care costs. There would however be significant improvements in carer quality of life.

We are not able to model what would happen if these improved interventions are delivered as a *combined* package of care (the 'stacking' assumption), because no studies have shown what the cumulative effects might be. Nevertheless, there is clearly a strong economic case emerging for improved care and support shown by these simple models, with cost savings and/or quality of life improvements.

Disease-modifying treatments are not yet available for dementia. We examine a number of purely hypothetical (but, we hope, plausible) variants. The economic case for such treatments will depend crucially on assumptions made about how and when the course of the disease is altered.

- We look first at a treatment that *slows progression, but with life expectancy unchanged*. People diagnosed with dementia receive treatment which prolongs time in both the mild and moderate cognitive impairment states by 10%, but with no extension in life expectancy (which implies a higher mortality rate than is currently observed in the severe state). This scenario would save the UK almost £0.8 billion per year if available today (equivalent to 4% of today's costs). 375,000 people with dementia and their carers would benefit.

- A variant of this approach assumes *slows progression and an improvement in life expectancy*. As with the previous variant, people diagnosed with dementia receive treatment which prolongs time in both the mild and moderate cognitive impairment states by 10% and increases life expectancy (through no rise in mortality rate in the severe state). The number of people with dementia would be 870,000 rather than 800,000, the cost would be £1,725 million higher and outcomes would be rather higher than under current patterns of care.

- A further variant *slows progression, reduces needs and improves life expectancy*. People diagnosed with dementia receive treatment which prolongs time in both the mild and moderate cognitive impairment states by 10%, reduces need and average weekly costs in those states by 13.5%, and increases life expectancy. The number of people with dementia would again be 870,000 rather than 800,000, the cost would now be only £125 million higher than today's arrangements, but outcomes (quality-adjusted life years gained) would be considerably higher.

- We also look at a disease-modifying treatment that *delays dementia onset*. If this was available for everyone and delayed onset by 12 months, with disease progression then running the same course as today, it would save the UK around £1.5 billion per year if available today (equivalent to 7% of today's costs). Around 800,000 people with dementia and their carers would benefit from the delayed onset.

- A variant of this approach assumes *delayed onset for as long as 36 months*. This could save the UK as much as £4.9 billion per year (23% of today's costs). Again 800,000 people with dementia and their carers would benefit from the delayed onset.

We must emphasise that all the figures in this report are indicative estimates. Every one of the scenarios examined required us to make numerous assumptions. The hypothetical nature of the disease-modifying scenarios makes their estimated impacts particularly uncertain.

Evidence-based care and support interventions are available today that can improve the quality of life of older people with dementia and their carers. They would not be particularly costly to offer to more people than currently receive them, and there would be important outcome gains. Targeting of these interventions could improve their effectiveness and cost-effectiveness.

However, to reduce the costs of care and support in more than relatively modest ways requires the development of new interventions. A treatment that delayed the progression of dementia from the mild to the moderate and severe stages could reduce, or at least slow the increase in, numbers of people with dementia and/or increase overall survival with dementia, and could lead to marked cost reductions.

A two-pronged response to the economic challenge of dementia is needed. We must continue to invest in treatment, care and support services that can improve the lives of people with dementia and their carers. And we must continue to search for disease-modifying treatments. The latter strategy offers the best hope for an affordable and effective response to rapidly growing global needs.

# 1.    INTRODUCTION

The growing number of people with dementia is both a huge global achievement and a growing global challenge. In most high-income countries, the combination of mid-Twentieth Century baby booms, public health initiatives and treatment breakthroughs have combined to produce a rapidly growing 'older' population. Population ageing is even faster in many low- and middle-income countries. Changes in technology, information and social structures over the past 100 years or more have also combined to give each successive generation yet higher expectations for living standards, and therefore also for what they have come to expect from health and social care systems.

The scientific, social and economic successes of recent decades should be celebrated for considerably extending life expectancy in most countries. At the same time, these successes have led to substantial increases in the prevalence of age-related conditions such as dementia. The growing prevalence of dementia poses challenges, including the economic challenge of how societies can ensure that treatment, care and support needed by individuals with dementia and their carers is provided at reasonable cost. Governments across the globe are urgently looking for affordable responses to the dementia challenge, whilst ensuring good quality of life for those people affected.

We report research conducted over the past 3 months which investigated the economic consequences of five different scenarios for dementia. The first scenario – and the baseline from which we make comparisons with the other scenarios – is the system of care and support for people with dementia in the UK today, including the current situation where only about half of all people with dementia have had their illness diagnosed. We compare today's arrangements with four scenarios. Two of these alternative scenarios represent arrangements that are likely to be seen as *worse* than the situation today: no diagnosis, and no post-diagnostic support.

The other two scenarios are assumed to be *better* than today's arrangements. In one, we examine what would happen if everyone with dementia is given '*improved*' care and support in the sense that the services provided have been shown through well-conducted research to deliver better outcomes and/or lower costs. We explore four variants to illustrate this 'improved' scenario, linked to better access to medications that alleviate the symptoms of dementia, psychosocial therapy, case management and support for family carers. The other scenario is more hypothetical: it assumes the availability of a disease-modifying treatment, although of course none has yet been developed or delivered anywhere across the world. We look at two main variants of this scenario, one which delays the onset of dementia and the other which slows its progression, and make different assumptions about life expectancy and support costs.

For each of these five scenarios we endeavour to estimate both the cost implications – by tracing through the effects on patterns of treatment, care and support, including from unpaid family and other carers – and the impact on health-related quality of life.

It must be emphasised that our estimates can only be *indicative*. None of the scenarios that we have looked at has previously been studied in a way that would easily generate evidence that would allow economic comparisons to be drawn; indeed, one of the scenarios is completely hypothetical. Our approach is therefore to simulate what would be likely to result (in terms of cost and quality of life) on the basis of available evidence from epidemiological, clinical and economic studies, and from administrative databases.

In the next section we set out our research aims, then in Section 3 describe our methods (the structure of our simulation models, the sources of data used to populate those models, and the ways in which we calculated prevalence, balance of care, costs and health-related quality of life). We follow that with a section on how we operationalise the various scenarios, converting evidence from epidemiological sources and trials so that cost and quality of life calculations can be made. In Section 5 we present our results, applying our models to each of the scenarios and their variants. Our final section draws some brief conclusions.

## 2. RESEARCH AIMS

Earlier this year, we were commissioned by the Department of Health for England to compare the economic consequences of four dementia care 'scenarios' (which we label B to E below) with current arrangements (labelled scenario A below):

Current care scenario: People with dementia and their carers receive care and support as currently provided in England (Scenario A).

No-diagnosis scenario: People with dementia do not have their condition diagnosed and so do not receive dementia-specific care (Scenario B).

Diagnosis-only scenario: People with dementia receive a diagnosis but get no (dementia-specific) post-diagnostic formal care or treatment (Scenario C).

Improved care scenario: People with dementia receive a diagnosis, followed by evidence-based, 'improved' care and support, where 'improvements' have been demonstrated in robust trials (Scenario D).

Disease-modifying scenario: One or more disease-modifying treatment or therapy is available that either slows the progression of dementia or delays its onset (Scenario E).

As we describe below, most of these scenarios have more than one interpretation (or 'variant').

Our interpretation of 'economic consequences' is to measure as wide a range of costs as possible – and certainly to include the costs of unpaid care by family and other carers – and to assess health-related quality of life in a way that allows us to assess the impact on quality-adjusted life years. We give more explanation of these components in the next section. Our quantitative estimates of health-related quality of life relate mainly to people with dementia, although we do also discuss possible impacts on their (unpaid) carers where the available evidence allows.

Our calculations of the comparative impacts of these various scenarios are grossed up to the UK as a whole. Treatment and care arrangements are broadly not very different across the constituent parts of the UK, and some of the data used to describe today's arrangements and to demonstrate the impact of 'improved' arrangements in fact drew on samples of people recruited from outside England. Although this is not ideal, we have no reason to believe that our generalisation from England to the whole of the UK has produced estimates that are significantly distorted.

## 3. METHODS: BUILDING THE MODELS

### Evidence review

We conducted a rapid review of available evidence in areas spanned by the scenarios: diagnosis, crisis because no diagnosis has been made, evidence-based ('improved') care and support, and disease-modifying treatments. Although we are particularly interested in data from and about the UK, we extended our search to look at care improvements from the wider international context. Our search was as comprehensive as the short timescale allowed (less than three months for the whole study). We also built on and updated a previous review of evidence on the cost-effectiveness of interventions (Knapp et al 2013).

### Modelling

We build our approach on models previously developed in the Personal Social Services Research Unit (PSSRU) at the London School of Economics and Political Science (LSE). Two models are used to generate estimates of the costs and benefits of the scenarios: an *aggregate model*, estimating cost and quality of life impacts in one year; and a *lifetime model*, estimating cost and quality of life impacts for a 'typical' person newly diagnosed

with dementia. In each case we assume that care arrangements and prices are as in 2012/13, and demographic patterns are as expected for the UK in 2015. We gross findings for England to the UK.

**The aggregate model**

The dementia aggregate model estimates the costs and outcomes for all older people in England with dementia. It is based on previous versions of the PSSRU aggregate long-term care model (Wittenberg et al 1998, 2001) and the PSSRU dementia care model (Comas-Herrera et al 2007). Figure 1 provides a simplified representation of the model.

**Figure 1: Aggregate dementia model structure**
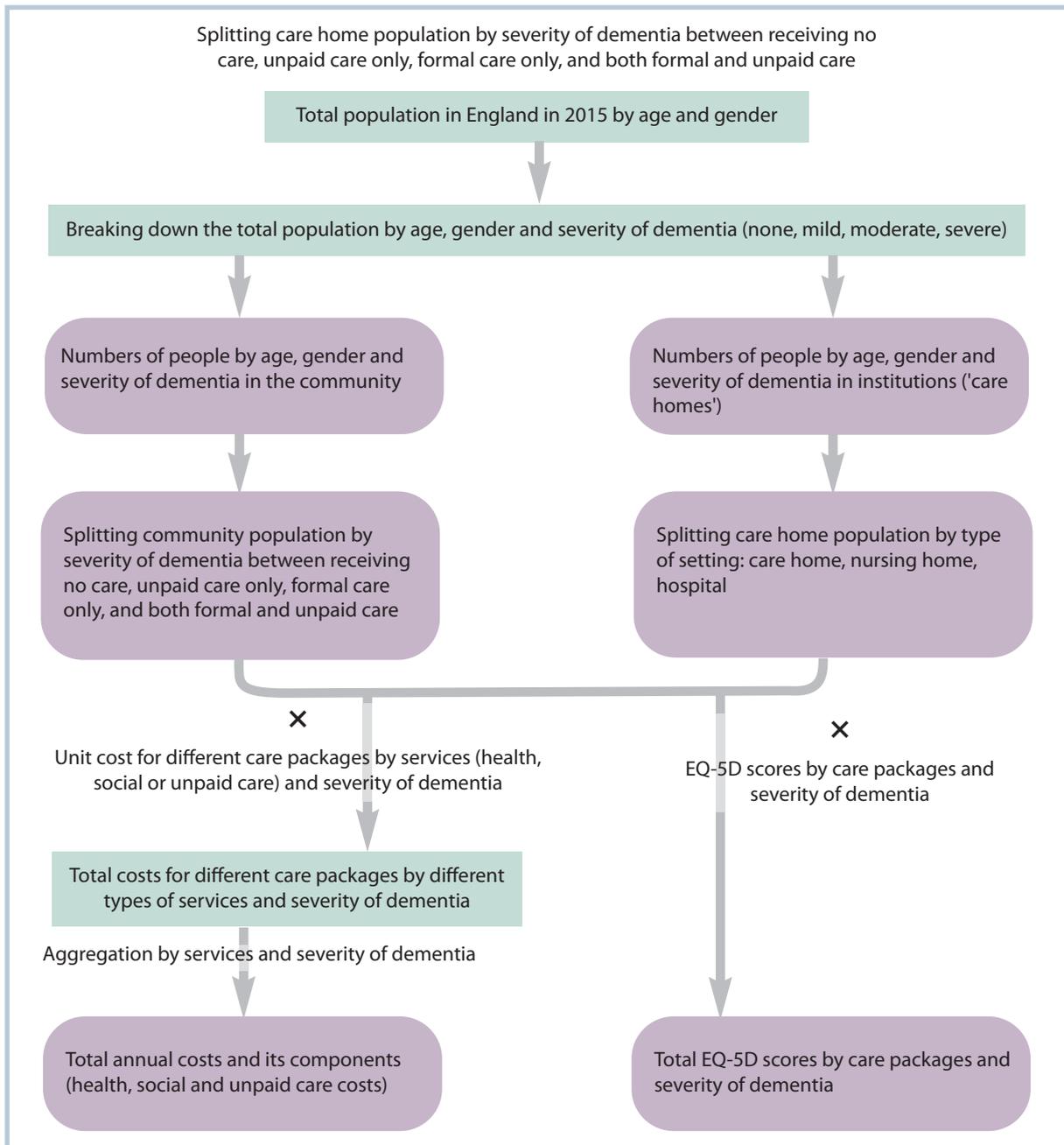
The model makes estimates of four key variables: number of older people with dementia, their receipt of unpaid and formal health and social care, the costs of this care (including opportunity costs of unpaid care), and the outcomes in terms of quality of life (measured using EQ-5D; see below). The model has four parts:

- the first divides the projected older population into cells by age, gender and severity of dementia;

- the second assigns people to different care settings and types of care: receiving no care, unpaid care only, formal community-based care only, both unpaid and community care, and residential care (mostly in residential care or nursing homes but in a few cases in hospital);

- the third estimates expenditures on care by attaching to each type of care for each severity category an average weekly cost; and

- the fourth estimates quality of life in a similar manner.

**The lifetime model**

Another way to show the impact of different scenarios is to look at a 'typical' older person with dementia. We therefore also estimate the lifetime costs and outcomes for a person experiencing recent onset of dementia. Our modelling relates to a person whose survival with dementia is 4.5 years from onset to end of life. We use a figure of 4.5 years since Xie et al (2008) found a population-based median survival for incident dementia of 4.5 years. Our estimates should be seen as indicative of likely lifetime costs and quality-adjusted life expectancy from onset of dementia for a person with this length of survival, which the Xie et al (2008) findings suggest relate broadly to a person experiencing onset when aged in their eighties. It should be noted that our estimates relate to the period from onset and not from diagnosis, which may be a considerable time after onset.

The model divides the overall period of 4.5 years between periods with mild, moderate and severe dementia. In some variants of scenario E in which onset or progression are delayed, the model lengthens or shortens the period of 4.5 years in line with the scenario. It then attaches average annual costs and average annual quality of life data to the durations in each severity state. Summing across severity states produces estimated lifetime costs and estimated quality-adjusted life years from onset.

**Sensitivity analyses**

The models inevitably require a large number of assumptions, especially as they have to draw from different sources and bridge gaps in the available data. At this stage we have not been able to conduct thorough sensitivity analyses, adjusting for all plausible variations in parameter values (and certainly not combinations thereof), but we did carry out calculations to ensure that the cost and quality of life figures generated were robust with respect to the key assumptions in the models. In Scenario E (disease modification) we report estimates from a range of different hypothetical assumptions.

The sensitivity analyses can also provide an understanding of the relative importance of different assumptions, for example when the estimates from a model are much more sensitive to small changes in some variables than in others. In principle, although not examined in this report, they can also tell us what are perhaps some of the key drivers of cost and quality of life consequences and differences.

**Population data**

The models use the 2012-based principal population projections for England, for 2012 and 2015 (Office for National Statistics 2013).

## Prevalence

The models assume that the overall prevalence of dementia by age, gender and severity remains as in the *Dementia UK* analyses (Knapp et al, 2007). An expert group was convened as part of that earlier study, and considered the six high-quality British surveys available at that time (Brayne and Calloway 1989; Clarke et al 1991; Livingston et al 1990; MRC CFAS 1998; O'Connor et al 1989; Saunders et al 1993). These surveys had been conducted in the 1980s and early 1990s and were dominated by the largest and most rigorous one, Cognitive Functioning and Ageing Studies (CFAS I) funded by the Medical Research Council. Because of variation in the estimates between the different studies, a Delphi survey was conducted as part of the *Dementia UK* study. A new prevalence estimate was published last year, based on a survey carried out in England in 2008–11, referred to as CFAS II (Matthews et al 2013). This suggested that there had been a decrease in age-adjusted prevalence (from 8.3% to 6.5% in the population aged 65 and over).

The total prevalence estimate employed in our study is 675,000 for England, this being the figure now assumed by the Department of Health, which we then gross up to the UK as a whole.

The overall numbers are divided between the institutional and household population through the following four steps:

- The estimated overall numbers of older people in care homes and hospitals are derived from the PSSRU at LSE long-term care model.

- 57.2% of males and 73.4% of females in care homes (and in long-stay hospital care) are assumed to have dementia, on the basis of CFAS findings.

- These numbers with dementia are then split by severity using information from the CANE trial (except that the proportion in the severe group was assumed lower and in the moderate group slightly higher than in CANE, to ensure that for severe dementia the care home group did not exceed the estimated total population with severe dementia; for more information on the CANE study see Orrell et al 2007).

- The numbers in care homes are then subtracted from the overall numbers to produce estimates of the numbers of older people with dementia living in the community.

## Patterns of care and support

We do not have up-to-date nationally representative epidemiological survey data, and so we need to estimate how the overall prevalent population of people with dementia is distributed between different severity groups. We employ the usual categorisation into mild, moderate and severe, usually by reference to MMSE data in the original datasets.

We also need to estimate how people in each of these severity groups are distributed across different care settings. We distinguish five different settings:

- no care or support,
- unpaid care and support (only),
- formal care and support (only) in the community,
- both unpaid and formal care and support in the community,
- in a care home.

We have explained earlier how the numbers in care homes and long-stay hospital care are estimated. Data from trials and some other UK sources are used to identify the patterns of care and support for each group of people with dementia in the community, cross-categorising severity (mild, moderate, severe) and care

setting (no care or support, unpaid care and support only, formal care and support in the community only, both unpaid and formal care and support in the community).

Services and support data for individual people with dementia were recorded in those trials, in all but one case using adapted versions of the Client Service Receipt Inventory (CSRI) completed by a family or professional carer (Beecham and Knapp 2001). Coverage in those studies was comprehensive across all services, including (but not confined to): inpatient stays, outpatient attendances, day hospital treatment, visits to social clubs, meals at lunch clubs, day care visits, hours spent in contact with community-based professionals such as community teams for older people, community psychologists, community psychiatrists, general practitioners, nurses (either practice, district or community psychiatric), social workers, occupational therapists, paid home help or care workers, and physiotherapists. Data were also collected in some studies on support from volunteers, befriending and telephone help-line support. In all studies, information was collected on unpaid support provided by family and friends.

We include in our dataset detailed information on about 1400 people with dementia and on more than 200 carers, collected from a dozen studies in which we had previously participated[1]. Consequently, much of our data (including on quality of life) comes directly from people with dementia or from carers. From the trials we use (retrospective) baseline data only (for both intervention and control groups). We first categorise everyone from the trials by severity and settings (e.g. formal only, unpaid care only etc.) and then exclude all people in severity/setting combinations that are in conflict with the exclusion/inclusion criteria for the trial. For example, some people in a trial of a carer intervention were recorded as 'formal care only', yet we knew that these people needed to have an unpaid carer to be included in the study. In another study of cognitive stimulation therapy for people with mild or moderate cognitive impairment we found a few people with severe dementia.

Data on hours of unpaid care provided by carers are available for co-resident and non-co-resident carers, and these are totalled. In some studies, co-resident carers had been asked to estimate the percentage of time they could spend away from the person with dementia (e.g. 0–25%, 25%–50%), and we take mid-points of these ranges and convert them into hours (assuming a waking day of 16 hours).

## Costs

The service use data collected in the individual studies noted above are converted to cost estimates. The studies from which data were drawn had used unit costs that reflect reasonably well long-run marginal opportunity costs, and generally came from sources in the public domain – mainly from the PSSRU volume (Curtis 2013) and the National Health Service Schedule of Reference Costs (for inpatient and outpatient costs). All costs are inflated to 2012/13 prices.

The costs are those of the total care and support used, not just those that can be directly attributed to dementia. It is not possible with the data available for this study to separate costs associated with treatment and care of dementia from those associated with treatment and care linked to other health or social care needs. Indeed, in a clinical context it would often be extremely difficult to separate the reasons for particular treatments and care arrangements. In a study with better data and more time, it would be possible to use multivariate statistical techniques to try to tease out the relative contributions of dementia and other conditions.

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1. These studies were SADD (Banerjee et al 2011,; Romeo et al 2013), some component studies within the SHIELD programme (Orrell et al 2014; D'Amico et al 2014; unpublished CSP data), DADE (Lacey et al 2012; Trigg et al 2014), EVIDEM (Lowery et al 2013; unpublished cost data), LASER-D (Livingston et al 2008), DOMINO (Howard et al 2012 for QOL data), CST (Spector et al 2003; Knapp et al 2006), CANE (Orrell et al 2007) and START (Livingston et al 2013; Knapp et al 2013).

It is notoriously difficult to estimate the number of hours spent by carers in the support of a relative or friend with dementia. Some of the time devoted by carers is taken up with hands-on care, some of it with 'supervision' to ensure that nothing untoward occurs. Our estimates are based upon time reported by carers in the various trials and other studies, using a fairly consistent wording in the interview schedules. We attach to each hour of self-reported unpaid care a cost that is approximated by the national minimum wage in England as an indication of the opportunity cost. Again, this is an area of difficulty, indeed sometimes controversy. Some imputations of the cost of unpaid care have used a higher hourly rate, such as the cost of substituting the unpaid care of family members with a home care worker employed by a health or social care agency. Clearly the assumptions made about the number of hours of unpaid care and the associated cost will work through to influence the cost of any scenario and therefore the comparative cost of alternative approaches to dementia care.

We are not able to include costs of services used by carers which might be associated with the strain of providing unpaid care. The primary reason for that exclusion is the paucity of data. However, in looking at one of the variants of the improved care scenario (a coping strategy for carers) we discuss the consequences for their use of services.

## Expenditure breakdown by source

Health care costs are assumed to be met entirely by the NHS. Social care costs would be met partly by local authorities (municipalities) and partly by people with dementia themselves, either through self-funding their care or through user charges, but we have not split these costs. The costs of unpaid care fall to the carers, although they may receive social security benefits (especially Carers Allowance) and/or social services support in recognition of their caring role.

## Quality of life and QALYs

Quality of life is estimated from data collected in the trials and other studies using the EQ-5D (EuroQol Group 1990). This measure is widely used in the UK and many other countries to provide a generic summary (valid across different disease areas) of the impact on quality of life. EQ-5D has five dimensions of health-related quality of life: mobility, self-care, usual activities, pain/discomfort, and anxiety and depression. It is not a dementia-specific scale, and is therefore perhaps less sensitive to the experiences of people with dementia than we would like. (A tool such as the DEMQOL (Smith et al 2007) would have been preferable but has not been widely used until recently, and we had more data for the EQ-5D.) We applied societal weights (the York A1 Tariff; Dolan et al 1995) to the 243 possible health states obtained from the EQ-5D by combining ratings on the five domains to calculate utility values. Quality-adjusted life years (QALYs) were calculated by 'area under the curve' analysis, with linear interpolation between assessment points.

We use self-reported EQ-5D values for people with dementia. We do not combine this self-reported and proxy-reported EQ-5D.[2] We have some data from the trials on carer quality of life (again using EQ-5D, self-reported), but have not been able to model quantitatively the impact of different scenarios on the quality of life of carers. Relatively few studies have collected data that would allow such examination. We do, however, comment on carer quality of life implications of different assumptions, and refer to previous estimates of these impacts where they are available.

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2. There was one exception. From the DADE study for people with severe dementia we only have proxy EQ-5D scores. To estimate self-reported EQ5D scores (to be consistent with the other studies), we ran a regression for the subsample of the DADE study with mild or moderate dementia (for whom we had both self-report and proxy EQ5D scores). We regressed self-reported EQ-5D score as the dependent variable and the proxy score as an independent variable, along with a number of covariates: age, gender, whether or not the spouse was the main carer and the time (in years) since diagnosis of dementia. We then extrapolate to the group with severe dementia.

# 4. OPERATIONALISING THE SCENARIOS

These scenarios have not been previously studied or compared in the way that we are doing in this study, and so the evidence base from which we build our estimates is far from ideal. We therefore use a range of modelling techniques to examine the economic implications of different care and support arrangements, and extract data from a wide range of sources, including epidemiological studies, descriptions of patterns of care and support, randomised trials of specific interventions and expert opinion. Costs and quality of life gains are estimated by bringing together data from a dozen recent UK dementia trials and observational studies.

We operationalise Scenarios B and C and the four variants of Scenario D by moving people between severity categories and types of care, by amending the average weekly costs of care and by adding or subtracting the costs of diagnoses, medication and other interventions. We operationalise the variants of Scenario E by using amended prevalence rates of dementia to reflect delayed onset or delayed progression and by reducing the average weekly costs of care in some variants.

## The current care scenario (Scenario A)

Under this first scenario, people with dementia and their carers receive care and support as currently provided in England in 2012, with numbers 'up-rated' to the population projected for the UK for 2015. We include the following services and costs for the current system:

- diagnoses for the 50% of people with dementia who currently receive a diagnosis;

- assessment and reviews and care management on the basis that around one third of the total national costs as recorded in official local authority returns relate to people with dementia;

- medications for the estimated 15% of people with dementia who receive them, on the basis that the costs of medications are included in the costs reported in the trials;

- care home fees, at an estimated £500 per week for those in residential care homes and £600 per week for those in nursing homes;

- unpaid and formal care provided to people in care homes from outside their care home, as reported in the trials (baseline data, that is before randomisation);

- hospital care for the small numbers assumed to have a hospital as their primary residence, in accordance with data from the trials;

- unpaid and formal care for people with dementia living in the community, on the basis of data from the trials.

## The no-diagnosis scenario (Scenario B)

In this second scenario, people with dementia do not have their condition diagnosed and so do not receive dementia-specific care. We sought to operationalise this scenario by looking at three possibilities: (a) people with dementia no longer have access to medications that alleviate the symptoms of dementia; (b) dementia-specific community-based social care is no longer provided; and (c) crises occur. We assume that nobody has a diagnosis, and therefore the cost of the diagnosis itself is saved.

For the first of these three possibilities we take data on the effect of taking donepezil on cognitive impairment (measured by MMSE score) as reported by Bond et al (2012) and Howard et al (2012). We assume that 20% of people with mild or moderate cognitive impairment are currently taking donezepil or another dementia medication (117,600 people). There are of course a number of medications now used specifically to treat people with dementia. We have assumed for simplicity that patients are treated with donepezil only. This assumption is made purely to keep the modelling manageable, given the short timescale for this work.

Donepezil is now off patent in the UK, and the cost we assume in our calculations is the cost for the generic drug. The effect of donepezil on cognition is suggested to be on average 1.2 MMSE points over 6 months (Bond et al 2012) and 1.7 MMSE points over 12 months (Howard et al 2012). We use these trial-based findings to estimate the numbers of people with Alzheimer's disease who, because they would not be taking this medication, would be in a *higher* severity group, assuming a uniform distribution of people across MMSE scores within each severity group. Health care costs are reduced because of decreased spending on medications (£4.4 million over one year), although may increase in other areas.

For the second possibility, where dementia-specific community-based social care is no longer provided, we assume that this would only affect people who receive both formal and unpaid care in the community and have no ADL needs. We use estimates from CFAS I (MRC CFAS 1998) on the proportion of users of formal community care with cognitive impairment but no ADLs (average 16% across both genders). We assume that these 16% receiving unpaid and formal care would stop receiving it: those in the mild and moderate categories would move to a situation where they were receiving unpaid care only, and those in the severe category would move to care homes. Among those receiving both unpaid and formal care, social care unit costs are reduced by multiplying by 0.7 (due to lower use of services such as day care and respite care) and unpaid care is multiplied by 1.5 to reflect the greater number of hours now needed. Health care costs are increased by an amount equal to a proportion of the reduction in social care unit costs (reflecting Fernandez and Forder 2008). We also assume a decrease in social care assessments proportional to the decrease in social care users.

The third possibility is that crises will occur because dementia is not identified or treated. We are not able to find quantitative estimates of the impact, although consultation with a number of experts in the field identified quite a range of possible negative consequences, including higher risks of fires, gas explosions, domestic flooding, physical illness (as people do not take their medications and do not present with problems), self-neglect and weight loss (leading to falls and physical illness), unclaimed pensions (leading to problems with not paying bills, and so services could be cut off and there could be eviction threats), getting lost (exposure, hospital admission), vulnerability (money stolen, abuse), family breakdown, eviction for antisocial behaviour, disinhibition, and neglect for someone they are caring for. There could be worsening of quality of life for family members. These are potentially important impacts but we are not able to include them in our modelling.

### The diagnosis-only scenario (Scenario C)

In our third scenario, people with dementia receive a diagnosis (mean cost £650; Dixon et al 2014), but get no (dementia-specific) post-diagnostic formal care or treatment. This is identical to Scenario B except that we now add a cost for diagnosis, which we assume is conducted in a memory clinic and not in primary care. We assume that all incident dementia cases get a diagnosis, and not the people who were previously diagnosed (prior to the year under study). We do not add a cost for people who would have been assessed in a memory clinic but who did not then receive a diagnosis of dementia (i.e., we do not factor in how many people need to be assessed in order to identify all incident dementia cases), and so we are under-estimating the cost of this scenario.

We are not taking into account any decrement to quality of life – for the person with dementia or their family – that might follow from having a diagnosis but then receiving no post-diagnostic care.

### The improved care scenarios (Scenario D)

The next scenario describes a situation where people with dementia receive a diagnosis, followed by evidence-based, 'improved' care and support, where 'improvements' have been demonstrated in robust trials. In selecting which 'improvements' to model we have been guided by recommendations from the National Institute for Health and Care Excellence (NICE). These include: post-diagnostic support and care management; cognitive stimulation for all those with mild to moderate dementia; acetylcholinesterase

(AChE) inhibitors (donepezil, galantamine and rivastigmine for mild to moderate Alzheimer's disease) and memantine (an option for people with moderate Alzheimer's who are intolerant or have contraindication to AChE inhibitors, or severe AD); assessment of non-cognitive symptoms and behaviour that challenges (but no specific recommendations regarding treatment); the same access to palliative care and end of life care as the rest of the population; assessment of carers' needs; carer support interventions; and respite/short-break services, including day care, day and night sitting, adult placement and short-term or overnight placement in residential care.

In operationalising Scenario D, we are only able to look at a subset of the elements recommended by NICE because of data limitations. We also look at these possible improvements to care and support arrangements *one by one* rather than in combination, because available evidence does not tell us how the quality of life or cost impacts would 'stack up' if more than one of these improvements was introduced simultaneously. We assume 100% coverage following diagnosis.

We model four components of this 'improved care' scenario.

The first (called D1) assumes that everyone with Alzheimer's disease receives *donepezil*. We previously set out the processes used to generate estimates of cost and quality of life impacts when describing Scenario B (although now applied in reverse), and our main sources for the effectiveness evidence are the meta-analysis and model of Bond et al (2012) and the DOMINO trial for people with more severe dementia (Howard et al 2012). This improvement will increase health care costs in so far as more medications will be prescribed, but it slows disease progression, and so – in our model – alters the distribution of people across severity categories and care settings.

The second component (D2) assumes that everybody receives *cognitive stimulation therapy* (CST) in the mild or moderate state. CST is usually delivered over 7 weeks and has been shown to be effective and cost-effective (Spector et al 2003; Knapp et al 2006; Woods et al 2012). A recent trial shows that it is also effective and cost-effective over a further 16-week period as 'maintenance' therapy (Orrell et al 2014, D'Amico et al 2014). We assume from these trials that the effect of standard CST is to slow cognitive decline by 0.6 MMSE points over one year. The trials show that the intervention is likely to be cost-neutral in so far as the cost of intervention is compensated by decreased intensity of use of services, although there will be a shift in the distribution of costs between categories.

The third component that we look at is *case management* (D3). We were given early sight of a forthcoming Cochrane Review by Reilly et al (2014). Although this review awaits final sign-off, its conclusions suggest that case management reduces the likelihood of institutionalisation (which we interpret in the terms of our model as admission to a care home), although the findings over successive time periods are not unambiguous. Reilly et al (2014) do not find evidence of significant quality of life benefits for people with dementia or for carers. We assume that all older people newly experiencing onset of dementia receive a diagnosis, and that those with mild or moderate dementia living in the community are given (extra) case management at an assumed annual cost of £500 per person. The number of people with moderate or severe dementia living in a care home is estimated to reduce by 27.5% as a result of this intervention.

Finally we look at the *support provided to carers* (D4). The START study evaluated a coping strategy for carers and found significant effectiveness and cost-effectiveness gains over the 8-month period following the receipt of the intervention (Livingston et al 2013; Knapp et al 2013). We do not include carer service use costs or carer quality of life in our model because – generally across the various trials and other sources – we are not able to find sufficient data. However, the START study found that savings in carers' use of health services (£67 per carer over the evaluation period) partly offset the cost of the intervention itself (£232 per carer). If this kind of intervention were to reduce the likelihood of care home admission in the longer term – and we have made that assumption for the purposes of our modelling – then that would potentially affect both the quality of life of the person with dementia and the costs of their care. We assume that all older people newly experiencing onset of dementia receive a diagnosis, and that the carers of those with mild or moderate

dementia living in the community are given (extra) carer support. The number of people with moderate or severe dementia living in a care home is assumed to reduce by 5% as a result of the intervention.

### The disease-modifying scenario (Scenario E)

In our final scenario we examine the impact of one or more disease-modifying treatments being available, either to slow the progression of dementia or to delay its onset. We assume that all people with onset of dementia receive a diagnosis, and then that all receive the disease-modifying treatment at least while in the mild or moderate severity state. For the delayed-onset variants, the treatment might need to be prescribed more widely, for example to all older people thought to be at high risk of onset of dementia, although we do not cost that possibility in our models.

In calculating consequences for cost and quality of life, we assume that the disease-modifying treatments are already available, indeed have been available for a while. Unlike the analyses in another study that has very recently been completed by the Office of Health Economics (Lewis et al 2014), we are not looking at the impact of phasing in a disease-modifying treatment over a period of time, but assume that a steady state of availability has already been achieved.

We can make different assumptions about the cost of this new treatment itself. In Section 5 we show the impacts of a disease-modifying treatment under a range of different 'price' assumptions.

The nature and details of the five variants are outlined in Table 1 below. For delayed progression we assume 10% longer duration in the mild state and 10% longer duration in the moderate state. Scenarios E1 and E2 differ in terms of whether mortality rates rise in the severe state, holding survival from onset constant, or whether mortality rates in the severe state are unchanged, increasing overall survival from onset. Scenario E3 considers a case where the treatment reduces average levels of need within the mild and moderate states, allowing average weekly costs to fall. Scenarios E4 and E5 relate to delayed onset of dementia of one and three years respectively.

**Table 1: Description of Scenario E variants**

| Scenario | Severity prevalence | Cost by severity and care type |
|---|---|---|
| E1. Progression delayed: 10% longer in mild state and 10% longer in moderate state; mortality in severe state rises, keeping overall survival constant | Increased prevalence in mild and moderate states; greatly reduced prevalence in severe state | No change by severity state and type of care |
| E2. Progression delayed: 10% longer in mild state and 10% longer in moderate state; mortality rate in severe state does not rise, increasing survival | Increased prevalence in mild and moderate states; marginally reduced prevalence in severe state | No change by severity state and type of care |
| E3. Progression delayed: 10% longer in mild state and 10% longer in moderate state; mortality rate in severe state does not rise, increasing survival | Increased prevalence in mild and moderate states; marginally reduced prevalence in severe state | Average weekly costs of community care in mild and moderate groups reduced by 13.5% (see Results section) |
| E4. Onset of dementia delayed by one year | Reduced prevalence rates in all states: rate for age 75 applied to age 76 (etc.) | No change by severity state and type of care |
| E5. Onset of dementia delayed by three years | Reduced prevalence rates in all states: rate for age 75 applied to age 78 (etc.) | No change by severity state and type of care |

## 5. RESULTS

We estimate that there are around 800,000 older people with dementia in the UK. It should be noted that this excludes the relatively small number of people aged under 65 with early onset dementia. The total comprises around 440,000 people with mild dementia (MMSE 26 to 21), 260,000 with moderate dementia (MMSE 20 to 10), and 100,000 with severe dementia (MMSE under 10).

We estimate that around 225,000 older people in the UK will experience onset of dementia in 2015. The ratio of the numbers with dementia to this estimate of new cases might suggest that average survival of older people from onset of dementia is less than 4 years. However, this would be an under-estimate since the numbers of new cases of dementia have likely been rising as the overall numbers of older people have been increasing.

There are around 285,000 older people with dementia in care homes in the UK and an assumed 8,000 whose primary residence is a hospital. Of the remaining 510,000 people with dementia, we expect, on the basis of evidence from the trials, that some 85,000 receive no care, 85,000 receive unpaid care only, 130,000 receive formal care services only and 210,000 receive both unpaid and formal care.

Our analyses suggest that the cost of dementia among older people in the UK is approximately £21 billon (at 2012/3 prices). This comprises around £4,150 million health care costs, £9,550 million social care costs (publicly and privately funded) and £7,450 million implicit cost of unpaid care. This amounts to 20% health care, 45% social care (publicly and privately funded) and 35% unpaid care. (The cost of unpaid care is calculated at national minimum wage for time inputs reported by carers.) This figure of £21 billion is likely an under-estimate, and we will be revisiting this figure in work funded by the Alzheimer's Society which will be reported later in 2014.

We estimate that under current patterns of care the lifetime cost of care is around £125,000 over a period of 4.5 years from onset of dementia in a person's eighties to end of life, and that the quality-adjusted life expectancy is around 3.55 years from onset. These estimates should be treated with great caution.

### Impact of Scenarios B and C

Scenarios B and C, while not affecting the overall number of older people with dementia, would lead to an increase in the proportions with moderate and severe dementia. Scenario B would be around £350 million more costly than the current pattern of care (Scenario A), and Scenario C would be around £500 million more costly. Outcomes would be slightly lower.

**Table 2: Annual costs for current care and support, no-diagnosis and diagnosis-only (Scenarios A, B, C)**

| | ANNUAL COSTS IN 2015 (£, millions, 2012 prices, UK) | | | |
|---|---|---|---|---|
| VARIANTS OF THE SCENARIO | Health care | Social care | Unpaid care | Total |
| Current care and support (Scenario A) | 4,150 | 9,550 | 7,470 | 21,160 |
| No-diagnosis scenario (Scenario B) | 4,190 | 9,970 | 7,350 | 21,510 |
| Diagnosis-only scenario (Scenario C) | 4,330 | 9,970 | 7,350 | 21,650 |

**Impact of Scenario D**

The four variants of Scenario D would also not affect the overall number of older people with dementia, but D1 (medication) and D2 (cognitive stimulation therapy) would lead to an increase in the proportion with mild dementia. The costs of these scenarios are set out in Table 3. Relative to current patterns of care, the differences would be: D1 around £250 million less costly, D2 broadly the same cost, D3 (case management) around £225 million more costly and D4 (carer support) around £200 million more costly.

The estimated impact on outcomes of these scenarios is modest. That may be partly because we have used a relatively crude measure (QALYs generated from the generic EQ-5D) and did not look at symptom alleviation or other more clinical measures. The modest impact is certainly partly a consequence of limitations in the data available for our modelling, and because our modelling is not able to take into account changes in quality of life (or indeed costs) within severity-setting cells. Nor are we measuring the effects on carer quality of life, which is, for example, an important gain found in the START study by Livingston et al (2013). A further consideration is that careful targeting of the interventions on those individuals most likely to benefit from them – if it was possible to identify such individuals – would be likely both to improve outcomes and to reduce costs. More work is required to explore the outcomes in a more refined manner than was possible within the time available for this study.

We should emphasise that we have examined these four scenarios independently of one another, and have not attempted to aggregate the cost and outcome impacts. There is no reason why the four interventions modelled under Scenario D should not be delivered together, but we have no way of estimating whether the combined effect would be a simple addition of the individual effects. (Orrell et al, 2014, show that there can be added benefits of combining cognitive stimulation therapy and acetylcholinesterase inhibitor medications.)[3]

**Table 3: Annual costs for base case and improved care scenarios**

| VARIANTS OF THE SCENARIO | ANNUAL COSTS IN 2015 (£, millions, 2012 prices, UK) | | | |
|---|---|---|---|---|
| | Health care | Social care | Unpaid care | Total |
| Current care and support (Scenario A) | 4,150 | 9,550 | 7,470 | 21,160 |
| Improved care: donepezil (Scenario D1) | 4,140 | 9,160 | 7,620 | 20,920 |
| Improved care: cognitive stimulation (Scenario D2) | 4,300 | 9,340 | 7,530 | 21,160 |
| Improved care: case management (Scenario D3) | 4,060 | 8,480 | 8,840 | 21,380 |
| Improved care: carer support (Scenario D4) | 4,200 | 9,310 | 7,850 | 21,370 |

3. A more ambitious study is currently underway that will provide a more robust platform of models than possible here, and therefore more robust estimates of cost, quality of life and other outcome consequences. At the 2013 Dementia Summit, the UK Government announced new research studies, one of which (led from the LSE) has recently started, and will allow more detailed modelling of future costs and outcomes for different care and support arrangements for dementia. This is the MODEM study: 'A comprehensive approach to modelling outcome and cost impacts of interventions for dementia. It is funded by the ESRC and NIHR. The MODEM study is developing a comprehensive, integrated, quantitative set of models to estimate current and future needs, and the outcomes and costs of interventions aimed at meeting them. It will be completed in early 2018. Please contact Adelina Comas-Herrera (a.comas@lse.ac.uk) for details.

**Impact of Scenario E**

Scenarios E1 to E3 relate to delayed progression of dementia from mild to moderate states, and from moderate to severe states, but with no delay in initial onset. Our cost findings are set out in Table 4. E1 is almost £800 million cheaper than current patterns of care (Scenario A) and would produce slightly better outcomes. This is because there would be only some 32,000 people with severe dementia in comparison with slightly over 100,000 at present. The scenario does however assume that the mortality rate in the severe state would be higher than currently, such that overall survival with dementia would not rise.

Scenario E2 is similar to E1 but assumes that the mortality rate for severe dementia would not rise and instead survival would rise, by around 0.35 years. The number of people with dementia would be 870,000 rather than 800,000, the cost would be £1,725 million higher than under current patterns of care, and outcomes would be noticeably. We estimate that the lifetime cost of care would be around £135,000 over a period of 4.85 years, in comparison with £125,000 over 4.5 years under current patterns of care. There would be a gain of about 0.31 quality-adjusted life years per person over this period. These estimates should be treated with great caution.

E3 is similar to E2 but assumes that the average weekly cost of community-based care (formal and unpaid) for people with mild or moderate dementia would be lower than at present. This is on the basis that the new treatment might reduce average levels of need within the mild and moderate severity states as well as prolonging their duration. A fall of around 13.5% in weekly costs renders this scenario broadly cost-neutral in comparison with current arrangements before considering the cost of the new treatment itself. The number of people with dementia would again be 870,000 rather than 800,000, the cost would be only £125 million higher than currently, and outcomes would be the same as for E2. The estimated lifetime cost would be similar to the current system but survival and quality-adjusted life years from onset would be as per Scenario E2.

Scenarios E4 and E5 assume delays to the onset of dementia by one year and three years respectively, with progression after onset unchanged from what happens at present. The estimated numbers of people with

**Table 4: Annual costs for base case and disease modifying scenarios**

| | ANNUAL COSTS IN 2015 (£, millions, 2012 prices, UK) | | | |
|---|---|---|---|---|
| VARIANTS OF THE SCENARIO | Health care | Social care | Unpaid care | Total |
| Current care and support (Scenario A) | 4,150 | 9,550 | 7,470 | 21,160 |
| Slowed progression, life expectancy unchanged (E1) | 3,920 | 8,480 | 7,970 | 20,370 |
| Slowed progression, life expectancy increased (E2) | 4,520 | 10,190 | 8,180 | 22,890 |
| Slowed progression, life expectancy increased, weekly costs reduced (E3) | 4,190 | 9,930 | 7,170 | 21,280 |
| Delayed onset by 1 year (E4) | 3,910 | 8,850 | 6,900 | 19,660 |
| Delayed onset by 3 years (E5) | 3,240 | 7,360 | 5,650 | 16,250 |

Note: Some figures might not add up due to rounding

dementia would be around 740,000 and 610,000 respectively, rather than the present 800,000. Costs would be £1.5 billion lower (7% of current cost) for E4 and £4.9 billion lower (23% of current cost) for E5 than under current patterns of care. Lifetime costs would be somewhat lower than at present for E4 and more substantially lower for E5, since survival with dementia would be lower from later onset. There would be quality-adjusted life year gains from both scenarios, particularly E5.

We have not included a cost for the disease-modifying treatment itself, and the figures in Table 4 assume that the treatment would be free to purchase or deliver. If the cost was £100 per patient year, then the annual cost of delivery for Scenarios E1, E2 and E3 would be £75 million across the UK as a whole, and if the annual cost per patient was £1,000 the total bill would be £750 million, which would seriously eat into any savings elsewhere in the health and social care systems. For scenarios E4 and E5, the treatment cost would depend on how many older people needed to be offered (and then accepted) the new medication to ensure that the average delayed onset of one year or three years could be achieved.

## 6. CONCLUSIONS

In December 2013, Health Ministers from the G8 countries and the UK Prime Minister met in London for a Dementia Summit, and subsequently issued both a Declaration and a Communique. These two documents spelt out clearly the challenges so often experienced by people living with dementia, their families and other carers, and emphasised the need for concerted action in many domains. Central to national or international efforts to improve the lives of people with dementia and other carers must be timely diagnosis followed by appropriate treatment, care and support. Also central to such efforts must be the search for ways to prevent or slow down the progression of dementia.

We have shown that evidence-based care and support interventions are available that improve the quality of life of older people with dementia and their carers. They would not cost very much more to offer to larger numbers of people than is currently the case. If it was possible to target those interventions on people with dementia and carers for whom the benefits are most likely to be achieved then this would also help to bring down the overall costs. A word of caution is important here: some of the scenarios would result in a shift of cost from formal services to unpaid carers (i.e. would require family and other carers to provide more unpaid hours of support). The availability and willingness of carers to offer this greater increased supply must be considered.

We have also shown that to reduce the costs of care and support in more than a small way will require the development of new interventions. It may be that new ways to deliver care and support currently being introduced but not yet evaluated would offer important cost or outcome gains, and it is very important that the search continues until such time as a disease-modifying treatment becomes available. However, on the basis of our (hypothetical) calculations, it will take a treatment that delays dementia onset to substantially alter the level of costs. Such a treatment would lead to a reduction – or at least a slower increase – in the numbers of people with dementia and therefore in the costs of caring for them, while also improving quality of life. Medication that delayed the progression of dementia from the mild to the moderate and severe stages could reduce, or at least slow the increase in, numbers of people with dementia and/or increase overall survival with dementia, but with smaller impacts on cost.

The figures from our analyses show clearly the need for a two-pronged response to the economic challenge of dementia. We need to continue to invest in treatment, care and support that can improve the lives of people with dementia and their carers, both now and over the coming years. Those interventions may not significantly reduce the overall costs of care, but could significantly improve quality of life. The second prong is to continue to invest in basic and clinical research to find disease-modifying treatments. The latter strategy offers the best hope for an affordable and effective response to rapidly growing global needs.

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