Dementia care costs and outcomes
Literature review

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Executive summary

Aim

Our aim was to look for evidence on approaches that achieve better outcomes for people with dementia which are also attractive from an economic point of view.

Methods

We conducted electronic searches of key databases and websites in medicine, social care and economics in February 2011. Key words used for the search were ‘dementia’, ‘Alzheimer’s disease’, ‘vascular dementia’ combined with ‘cost’, ‘hospital’ and ‘home care’. Searches were limited to items published from 2005 onwards for databases, and from 2000 onwards for websites.

Narrative analysis was used to analyse the data. Literature reviews were privileged, and other study designs included only to fill gaps in the evidence base.

Results

Pharmacological interventions

Most of the literature reviews focused on medications, particularly on the acetylcholinesterase inhibitors (AChEI) and memantine. For mild-to-moderate Alzheimer’s disease, AChEI (donepezil, rivastigmine, and galantamine) appear to be cost-effective treatments from the NHS point of view (National Institute for Health and Clinical Excellence, 2011). Memantine is recommended as second-line treatment when people with mild-to-moderate Alzheimer disease do not respond to or have contraindications to the AChEI. For moderate-to-severe Alzheimer’s disease, memantine appears to be the most cost-effective treatment.

Antipsychotic medications are suggested in NICE-SCIE guidelines for England and Wales to treat non-cognitive symptoms in Alzheimer’s disease, vascular dementia, mixed dementia or dementia with Lewy bodies (DLB) with severe non-cognitive symptoms, but only after an individual risk-benefit assessment, due to the possible increased risk of cerebrovascular events (NICE-SCIE, 2011). We found no literature reviews on the cost-effectiveness of antipsychotic drugs in Alzheimer’s disease.

We are aware of some new pharmacological treatment studies that will report economic evidence in the next few months (each of them conducted independently of pharmaceutical companies). One of those studies looks at antidepressant medications, not previously examined in cost-effectiveness analyses.

Non-pharmacological interventions – individuals with dementia

Cognitive stimulation therapy (CST) offers ‘activities involving cognitive processing; usually in a social context and often group-based, with an emphasis on enjoyment of activities’ (NICE-SCIE, 2011). In a study in England, CST was offered to people
with mild-to-moderate dementia in group sessions run in care homes and day centres twice a week for eight weeks. The authors concluded that CST has the potential to be more cost-effective than usual care and support through its effects on cognition and quality of life (Knapp et al, 2006). No economic evaluation was found for CST as primary prevention intervention (Medical Advisory Secretariat, 2008).

Physical exercise programmes have been shown to be effective as primary prevention measures for older people with good cognitive functioning and as secondary prevention for older people with mild-to-moderate dementia (Medical Advisory Secretariat, 2008; Forbes et al, 2008). However, we found no economic evidence.

Some research attention has focused on the ‘tailored activity programme’ approach. Cost-effectiveness of tailored activity programmes compared to usual treatment is suggested by a randomised controlled trial carried out in the United States. The main reason for the result appears to be the programme’s effect in reducing carer time inputs (Gitlin et al, 2010).

A randomised controlled trial in the Netherlands concluded that occupational therapy was not only cost-effective but also cost-saving compared to usual care (Graff et al, 2008).

A study in Belgium, based on a decision tree design, found that F-fluoro-deoxyglucose positron emission tomography (FDG PET) is cost-saving when added to standard diagnostic approaches (Moulin-Romsee et al, 2005).

Although there is supportive clinical effectiveness on magnetic resonance imaging (MRI) and neuropsychological testing for individuals with minor cognitive impairment and mild dementia as diagnostic tools (SBU, 2008), no cost-effectiveness evidence is available (Hulstaert et al, 2009).

Evidence is also lacking on the cost-effectiveness of ginkgo biloba as a primary or secondary preventive intervention for people with mild cognitive impairment and mild dementia (Hulstaert et al, 2009).

**Interventions targeted on carers**

Respite care or short-term breaks may be offered in different forms: day-care services, in-home respite services, host-family respite, institutional (overnight) respite services, respite programmes, multi-dimensional carer-support packages and video respite (Arksey et al, 2004). Four studies were found that suggested that the day care might confer benefits that are similar or greater than those achieved through standard care.

The other area where there is some evidence is for psycho-educational support for carers. No significant change in cost or outcomes was reported when comparison was made to standard care (SBU, 2008).
Wilson et al (2009) concluded that befriending was neither effective nor cost-effective compared to standard care.

A quasi-experimental study of a psychosocial intervention for family carers in Sweden found that counselling sessions and conversation groups resulted in significant delays in nursing home placements for the people with dementia they were supporting, compared to standard care and support arrangements (Andren and Elmstahl, 2008).

Organisation of care and support

Direct payments transfer social care funding to service users, who then have the opportunity to spend their budgets on a range of services to meet their personal (care) needs. Variants of direct payments include individual and personal budgets.

There is no evidence on the economic impacts of direct payments or personal budgets specifically for people with dementia. The only two well-conducted economic evaluations for older people do not offer immediately encouraging support for this organisational arrangement (Arntz and Thomsen, 2011; Glendinning et al, 2006).

We found one review on cost-effectiveness of case management for individuals suffering from dementia and their carers, but it was unable to show any results, due to the dearth of studies and heterogeneity of the population studied (Pimouguet et al, 2010). However, there are three well-conducted studies that demonstrate the impact of care management arrangements on delayed institutionalisation, and which imply, even if they do not fully document economic pay-offs (Mittelman et al, 2006; Chien and Lee, 2008; Brodaty et al, 2009).

Individuals with dementia are known to have an elevated risk of co-morbid conditions, and hence could require more medical or social care. Better management of co-morbidity could have economic pay-offs. A study in the United States showed the higher costs compared with matched individuals without dementia (Kuo et al, 2008).

Discussion

Limitations

Our search for ‘grey literature’ in websites was confined to the United Kingdom; we would not anticipate finding much in governmental and non-governmental websites in other countries, but we were unable to check. Our task was to look at available literature reviews, and the quality of some of these was low. None presented findings supported by meta-analysis, but that is not surprising given the paucity of available primary data studies. We have endeavoured to extract relevant findings from individual studies.
Barriers and opportunities

There are few economic studies, and some of the completed studies are methodologically weak, making it hard to be confident about the conclusions that can be drawn from them.

Even when studies are methodologically sound, it can still be hard to draw out conclusions. For example, some studies only examine outcomes and costs over short time periods (relative to the typical duration of need). Studies that are conducted outside the UK may offer helpful pointers, but inter-country differences complicate the inferences.

Another difficulty could be the natural heterogeneity in the population of people with dementia and in their carers, and research studies tend to focus on particular subgroups. Of course, this does not stop generalisation within subgroups, as has been the case when bodies such as NICE and SCIE have prepared guidelines on pharmacological treatments.

In comparison to the wide range of potential economic impacts, a number of studies focus quite narrowly on health care costs. A common omission is the economic impact on carers and on the economy (if carers give up productive employment). Even when the economic losses associated with unpaid carers are measured, a problem could be that many are seen as not ‘cashable’ (at least in the short term). The age-old problem of silo budgets will likely remain a source of (overall) inefficiency, leading to poor co-ordination, cost-shifting and ‘problem-dumping.’ Budget cuts could make the challenge harder.

Even when the research evidence is available and relevant, there is an apparent reluctance to implement it by adjusting the treatment, care and support offered.

At the moment, there is almost no economic evidence (at least specifically focused on people with dementia) on ‘stepping-stone,’ ‘halfway’ or intermediate care arrangements which can sit between living in one’s home in the community and being admitted long-term to a care home or inpatient ward.

Evidence about the economic consequences of extending greater choice and control to older people is limited, for example through self-directed care.
# Glossary of terms

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
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<tr>
<td>AChEI</td>
<td>Acetylcholinesterase inhibitors</td>
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<td>ADL</td>
<td>Activities of daily living</td>
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<td>CST</td>
<td>Cognitive stimulation therapy</td>
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<tr>
<td>DLB</td>
<td>Dementia with Lewy Bodies</td>
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<tr>
<td>NHS</td>
<td>National Health Service</td>
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<tr>
<td>NICE</td>
<td>National Institute for Health and Clinical Excellence</td>
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<tr>
<td>PCT</td>
<td>Primary care trust</td>
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<tr>
<td>QALY</td>
<td>Quality-adjusted life year</td>
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<td>TAP</td>
<td>Tailored activity programme</td>
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Introduction

Alzheimer’s Society was asked by the All-Party Parliamentary Group (APPG) on Dementia to commission a review of available evidence on saving money in dementia care and delivering better outcomes for people with dementia. The overall intention was to establish a broader evidence pool that providers and commissioners of dementia care in the UK can draw on, which highlights positive examples of what can be achieved in dementia care with existing resources. It was also hoped that the work would inform national organisations about how this might be achieved, and encourage them to help spread good practice across the UK.

We were asked by Alzheimer’s Society to contribute to this work by carrying out a meta-review of research literature (UK and international) on economic aspects of dementia care, including studies that have examined:

- the costs of dementia care and support
- the cost-offsets from interventions (changes in total and component costs)
- cost-effectiveness (incremental costs and outcomes of interventions).

Our overarching aim, therefore, was to look for evidence on approaches that achieve better outcomes for people with dementia which are also attractive from an economic point of view.

There is no shortage of evidence that resources used to support people with dementia are not deployed to their best effect; for example, reports from the National Audit Office, Age Concern and Alzheimer’s Society in recent years provide many illustrations. We chose to focus our work on the positive side: to search for examples of good value care and support, where good outcomes are delivered at an acceptable cost. (The meaning of terms such as ‘good value’, ‘good outcomes’ and ‘acceptable cost’ will be discussed.) From this basis, we aim to draw out recommendations for commissioners and policy-makers, which we summarise at the end of this paper as a series of barriers and opportunities.
Methods

We were asked to address the following questions:

• Where is there evidence of opportunities to save money but ensure quality of life for people with dementia in:
  - hospitals?
  - their own homes?
  - care homes?

• What can be seen as the barriers to doing these things?

• Are there examples of areas taking a joined-up approach to commissioning dementia care, for example between the NHS and local authorities and other key stakeholders? Are there cost savings available and/or opportunities to improve quality of care through this type of approach?

• What is the evidence internationally of opportunities to save money but ensure quality of life for people with dementia in:
  - hospitals?
  - their own homes?
  - care homes?

• How far does the evidence found in this review show opportunity for cost savings in dementia care services in the UK?

Because of what we found from our search we have configured the presentation of the evidence slightly differently in the Results section.

We conducted electronic searches of key databases and websites in medicine, social care and economics in February 2011.

Electronic databases included PubMed/Medline, Embase, the Cochrane Library (Cochrane Reviews), PsycINFO, EconLit, Centre for Reviews and Dissemination (Database of Abstracts of Reviews and Effects, NHS Economic Evaluation Database, Health Technology Assessment).

Websites included the database of the National Institute for Clinical Excellence, the Social Care Institute for Excellence, the National Audit Office, the Royal College of Psychiatrists, the Royal College of General Practitioners, Alzheimer’s Society, the King’s Fund, Carers’ UK, the Mental Health Foundation, Age UK (formerly Age Concern and Help the Aged), and the Bradford Dementia Group at Bradford University.

Key words used for the search were ‘dementia’, ‘Alzheimer’s disease’, ‘vascular dementia’ combined with ‘cost’, ‘hospital’ and ‘home care’. Searches were limited to items published from 2005 onwards for databases, and from 2000 onwards for websites. Material published before those dates was identified only if deemed to be particularly significant.
References were screened by title/abstract at first, then by full text. Specific types of dementia besides Alzheimer’s disease were searched for, including ‘dementia with Lewy bodies’, ‘dementia in Parkinson's disease’, ‘dementia in human immunodeficiency virus (HIV) disease’. Very rare types of dementia linked to metabolic or neurological disorders were not specifically searched for but were not excluded, such as ‘dementia in Pick's disease’, ‘dementia in Huntington's disease’, ‘dementia in Creutzfeldt-Jakob disease’, ‘dementia in other specified diseases classified elsewhere’, and ‘unspecified dementia’. Evidence relating to mild cognitive impairment (MCI), which does not lead to a dementia diagnosis, was excluded.

We searched for papers with title and abstract available in English; and full-text in English or some foreign languages (French, Spanish, and Italian).

Studies were included if they:
• evaluated interventions
• included evidence on service use or costs
• were conducted in the UK or other developed countries
• targeted people with dementia or their carers.

We entertained all study designs (quantitative, qualitative, mixed methods, economic evaluations, systematic reviews, narrative reviews, comments and point of views). From the economic evaluation standpoint, we were interested in all study perspectives (defined below).

Data analysis

Narrative analysis was used to analyse the data. All eligible references were included and grouped in four main categories:
• pharmacological interventions
• non-pharmacological interventions targeting individuals with dementia
• interventions targeting carers of individuals with dementia
• organisation of care and support.

Findings were analysed within each category. Literature reviews were privileged, and other study designs included only to fill gaps in the evidence base.

Economic questions and analyses

Healthcare, social care and other responses to the needs of people with dementia that are well-designed, well-co-ordinated and well-targeted will have significant impacts on the mental and physical health of those individuals, on their general well-being, and also on the well-being of their (unpaid) carers. Those health and other services are delivered by staff with some access to appropriate information and support, medications, psychological therapies and other interventions. Services and treatments can be delivered in people’s own homes or in specialist care or treatment settings. The problem is that there are not enough of those resources to meet all needs.
In the face of such scarcity, difficult decisions have to be taken about how to use available resources to achieve the best possible outcomes: how to alleviate symptoms, improve quality of life, get better access to everyday activities, secure greater efficiency in the delivery of support, or achieve a fairer distribution of available resources. These can all be seen as economic questions.

Figure 1 offers a simple framework to help us locate interventions, their health and other outcomes, and the consequences for resources and costs. On the left of this simple schema are treatments, care and support arrangements. Different interventions of these kinds will potentially have a range of effects on the health and well-being of individual people with dementia and their carers (shown in the middle column of Figure 1). Successful achievement of outcomes could in turn reduce the longer-term costs (shown in the right-hand column of Figure 1). For example, successfully delaying cognitive decline could reduce or delay the need for intensive use of health or social care services. Figure 1 is a hypothesis map, and much research has been undertaken to improve our understanding of the connections between the different elements within it.

<table>
<thead>
<tr>
<th>Interventions</th>
<th>Outcomes</th>
<th>Cost savings</th>
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<tbody>
<tr>
<td>Home care</td>
<td>Cognition</td>
<td>Lower reliance on family carers</td>
</tr>
<tr>
<td>Medication</td>
<td>Independence in daily living</td>
<td>Lower use of health care services</td>
</tr>
<tr>
<td>Psychological therapies</td>
<td>Social interaction</td>
<td>Lower use of social care services</td>
</tr>
<tr>
<td>Case management</td>
<td>Safety</td>
<td>Fewer out-of-pocket expenses</td>
</tr>
<tr>
<td>Occupational therapy</td>
<td>Behaviour changes</td>
<td></td>
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<tr>
<td>Community health care</td>
<td>Quality of life</td>
<td></td>
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<tr>
<td>Telecare</td>
<td>Carer quality of life</td>
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This same schema can then be used to identify the contributions that economics might play in helping us to understand and to improve the dementia care system. Economics tends to be associated most closely with the issues of cost, cost-offset, cost-effectiveness and incentives to bring about change. The arrows in Figure 2 represent those core economic issues. Cost questions are focused on what resources are used to provide treatment, care and support. Cost-offset questions ask how those costs compare with later savings that result because treatment and care have been successful. Cost-effectiveness questions are the most important, and look at the links between resources expended and outcomes achieved. Incentives questions ask about ways to encourage decision makers to pursue policies or practices that are more effective, efficient or fair. We say more about these economic questions below.

The underlying argument, therefore, is that interventions of various kinds might generate better outcomes, which in turn could lead to longer-term savings for
individuals and families, and/or for health and social care systems. This simple set of connections then gives rise to the need for a number of economic analyses, particularly relating to costs, cost-offset and cost-effectiveness.

**Figure 2: Economic questions**

Cost questions
One set of questions concerns the cost of supporting and treating people with dementia. We know that age-related health and care needs have enormous economic impacts today. A report published by Alzheimer’s Society, Dementia UK, looked at a range of economic, epidemiological, clinical and social aspects of dementia (Knapp et al, 2007). It included an estimate of the overall national cost of dementia: £17 billion. Accommodation accounted for 41 per cent of this total, health services 8 per cent, social care services 15 per cent and imputed costs for informal care support and lost employment 36 per cent. The economic impact on carers is often missed, yet we will see later that it is of importance in the interpretation of available evidence.

A second UK study has relevance too: Comas-Herrera et al (2007) found that, if expected trends in prevalence, staff costs and (unpaid) carer availability are overlaid onto England’s current care system, total health and social care expenditure will more than treble over a 30-year period. This represents an increase from about 0.6 per cent of gross domestic product to about 1 per cent, which is obviously a sizeable jump over a relatively short period. Although the projections by Comas-Herrera et al (2007) recognise the expected dwindling availability of family and other carers (because of falling fertility rates and rising female employment) and the likely increase in the salaries of care staff (because of labour market pressures), it is still an underestimate, since it does not factor in any improvements in access or in care quality.

Cost-offset questions
Age-related needs and disabilities generate costs because of their impacts on individuals’ abilities to work or look after themselves, their reliance on family or friends in the everyday activities of living, and their need for skilled treatment and
care from health care, social care and other systems. Calculating and aggregating these costs helps to draw attention to the overall volume of need and breadth of economic impact, but is descriptive rather than evaluative, because such an exercise says nothing about outcomes. Consequently, a decision-maker would have no idea from just these cost calculations what the benefits were of using resources in the way described.

One way to move beyond these descriptions is to compare the costs of action (ie, the costs of providing health and social care support) with the costs of inaction (ie, what would happen if no such support was available, or only at a lower level of intensity). This is a cost-offset study. For example, one could look to see whether physical exercise, social integration or stimulating activities can prevent or delay cognitive or behavioural decline in such a way as to reduce the need for care and support. A cost-offset study would then compare the costs incurred in delivering the interventions (such as a physical exercise programme) with the costs saved because people no longer need to use so many services or require so much help from family carers.

**Cost-effectiveness questions**

Cost-effectiveness analysis sits at the heart of economic evaluation. It does exactly what its name suggests: it calculates the difference between the resources used up by one intervention and the resources used up by some other intervention (summarised in terms of the costs), and then compares that cost difference with the difference in outcomes that are achieved in the two cases (in terms of their effectiveness). For example, if intervention A had better outcomes than intervention B, and if A also cost less than B, then it would be fairly straightforward to conclude that A was the more cost-effective of the two. However, complications arise when one of the interventions (let’s say it is A) is both more effective and simultaneously more expensive. Someone then needs to decide whether the better outcomes from intervention A are worth the higher cost when compared to intervention B, in turn requiring someone to place a value (implicitly or explicitly) on those outcomes. It hardly needs to be said that such a valuation is replete with difficulty, and especially in the areas of ageing and disability.

Health economists continue to develop the methodology of cost-effectiveness analysis (for example, see Drummond et al, 2005), and these approaches can be used in the dementia field, although the practical challenges of adaptation are sometimes significant.

The three key elements of cost-effectiveness – costs, effectiveness and trade-offs – need a little further explanation.

In cost-effectiveness analysis the aim is to measure costs of alternative actions as changes in the resources employed or used up, valued in monetary terms. Identification of costs becomes an important task in the context of dementia care because costs are more than just the accountancy value of the resources employed by health and social care providers. In the case of dementia, a sizable part of the overall cost falls to families, who might give up work or leisure time to provide unpaid care. It is also important that service costs are recognised across agency and sector boundaries.
Effectiveness is basically the difference between the level of unmet need prior to an intervention or action and the level of unmet need some time afterwards. A number of effectiveness (or outcome) domains should therefore be considered when evaluating dementia care and treatment.

Effectiveness measurement in social care appears to be a much greater challenge than in healthcare, where a measure of symptom reduction combined with a measure of health-related quality of life is often seen as sufficient. Broader concepts of quality of life might be needed in research relating to people with dementia. When developing measures of effectiveness it is important that patient/user views are central, even though they can often be difficult to obtain when people have severe symptoms. While symptom alleviation is the core clinical outcome, improving or maintaining quality of life might be the core concern for the person with dementia or their close family members.

If one intervention (say, a policy approach or a treatment strategy) is both more effective and more costly than another, which of them is the more cost-effective? Health economists have developed methods for considering the trade-offs between the better outcomes that follow from one intervention with the higher costs necessary to achieve those outcomes. The question is whether the additional outcomes are worth the higher costs. The purpose of a cost-effectiveness analysis is to highlight precisely what those trade-offs are. This takes us into difficult territory, because we need to blend the science of measurement and statistical analysis with personal preferences and value judgements about the ‘worth’ of these outcomes.

Research studies now often use a generic outcome measure (such as the Quality-Adjusted Life Year or QALY) to make comparisons easier across different clinical domains, and in countries such as England there are (national) benchmarks to provide some guidance. However, it must not be forgotten that trade-offs are necessarily based on (subjective) value judgements. In our review, we found one study, conducted in Spain, that had directly estimated willingness to pay for different policies for Alzheimer’s disease care (Negri et al, 2008). The authors found that societal demand to be significant for the programmes evaluated, with values highest for day centres, followed by home care, and then medium/long-stay centres. This study is quite interesting but does not particularly help with our task in this paper.
Results

We conducted a literature review of cost-effectiveness studies of interventions in dementia care. The studies that we found are most sensibly arranged under four heads:

- pharmacological interventions
- non-pharmacological interventions for individuals with dementia
- interventions targeted on carers
- organisation of care and support.

Pharmacological interventions

There is more economic evidence on pharmacological interventions than on any other area in the dementia field. One purpose of medication, of course, is to alleviate behavioural, cognitive and functional symptoms, but a particular interest in the literature is the possibility of slowing down the progression of the underlying disease dementia. From an economic standpoint, such an effect has the potential to reduce carer burden, lessen the rate of hospitalisation and delay long-term admission into institutional care, where costs often increase dramatically (Fillit, 2005; Fillit and Hill, 2005). Most cost-effectiveness-studies found in our review focus on drugs for Alzheimer’s disease.

Most of the literature reviews concern acetylcholinesterase inhibitors (AChEI) and memantine. The National Institute for Health and Clinical Excellence (NICE) (National Institute for Health and Clinical Excellence, 2011) recently updated previous NICE technology appraisal guidance on the use of acetylcholinesterase inhibitors and memantine for Alzheimer disease (National Institute for Health and Clinical Excellence, 2006; National Institute for Health and Clinical Excellence, 2009). Published economic evaluations were systematically reviewed since 2004 and results presented and commented upon by severity of disease. For mild-to-moderate Alzheimer’s disease, it was concluded that AChEI (donepezil, rivastigmine, and galantamine) were cost-effective treatments from the NHS point of view. Memantine represented a cost-effective use of NHS resources only as second choice, when people with mild-to-moderate Alzheimer disease were intolerant to or have contraindications to the use of AChEI. In fact, memantine generated fewer QALYs at a higher cost. For moderate-to-severe Alzheimer’s disease memantine appeared to be the most cost-effective treatment.

Notwithstanding the high quality of the NICE literature review, these results have a number of limitations. One limitation is that the number of cost-effectiveness studies is relatively scarce (12 for AChEI and 6 for memantine), which might look quite a good number in comparison to what is available for non-pharmacological interventions, but which is small relative to what is often available in quite different clinical areas. It is also small if one factors in that most of these studies have been funded and conducted by the manufacturers of the medications. Economic models for all pharmacological interventions were developed only by the Assessment Group, while two pharmaceutical companies focused on donezepil (Eisai/Pfizer) and memantine (Lundbeck).
The adaptation of the Assessment of Health Economics in Alzheimer's Disease (AHEAD) model used by NICE was contested by the original developers of the model because of the limited amount of data available for analysis (Getsios et al, 2007). Though the Assessment Group model was based on old data (1988-1999) and collected on a small sample, it was argued by NICE to be using the best available data.

Similarly, a previous literature review on AChEI and memantine (Cappell et al, 2010) found donepezil and rivastigmine to be cost-effective compared to placebo in mild to moderate, and memantine in moderate-to-severe Alzheimer's disease from a societal perspective (and so taking into account not only the impact on health and social care but the impacts on carers, for example). The authors of this well-conducted and independent review concluded that this result was largely due to the reduction in dependency and an increase in the proportion of carer time that was free of caregiving, results found in other literature reviews for donepezil and rivastigmine.

Other reviews have reached slightly different conclusions, but were conducted earlier and so would have covered the most recent medication trials. For example, the literature review that underpinned the 2006 NICE guideline found it difficult to reach a conclusion on the cost-effectiveness of AChEI for mild-to-moderate and memantine for severe Alzheimer's disease (Loveman et al, 2006). The literature review produced by the Belgian Health Care Knowledge Centre (Hulstaert et al, 2009) was similarly cautious because, in the researchers' view, of the quality of available studies. They argued that health benefits are often gauged by cognition and not as functional abilities, which they argued were pivotal in the decision to admit someone to institutional care. Hulstaert and colleagues noted that the coverage of outcome and cost measures differs across studies, making it hard to pool evidence. Studies have been conducted across a number of different countries, which might not be a problem when interpreting effectiveness evidence but can make it hard to ascertain the relevance of cost-effectiveness findings.

There is a pervasive problem that long-term data are generally lacking. These same weaknesses were highlighted by Geldmacher (2008) in a brief review. Another limitation emphasised out by Hulstaert et al is the point we made earlier: that it is obviously in the interest of a pharmaceutical company to show positive results against usual care for its product.

**Antipsychotic medications** are suggested in the NICE-SCIE guidelines for England and Wales for treating non-cognitive symptoms in Alzheimer's disease, vascular dementia, mixed dementia or dementia with Lewy Bodies (DLB) with severe non-cognitive symptoms, but only after an individual risk-benefit assessment due to the possible increased risk of cerebrovascular events (NICE-SCIE, 2011).

The newer antipsychotic drugs (so-called atypical or second-generation antipsychotics) have been shown to be as effective as first-generation antipsychotics and to have fewer side-effects, but the possible increase in cardiovascular risk has to be taken into account. We found no literature reviews on
the cost-effectiveness of antipsychotic drugs in Alzheimer’s disease. A single study, based on a Markov (simulation) model shows that a second-generation antipsychotic (olanzapine) is cost-effective compared to doing nothing for the treatment of agitation and psychosis in individuals with Alzheimer’s disease living in the community (Kirbach et al, 2008). Conversely, a randomised controlled trial found that second-generation antipsychotics (olanzapine, quetiapine, risperidone) analysed as a group, were not cost-effective compared to placebo for the treatment of agitation, psychosis, and aggression in individuals with Alzheimer’s disease living in the community (Rosenheck et al, 2007). This well-conducted United States study (the CATIE-D study) found that, while health benefits (QALYs and other measures of function: quality of life, activities of daily living, and dependence) were equivalent, health costs were significantly lower in the placebo group. However, the short follow-up period (nine months) did not allow the researchers to examine long-term outcomes or costs (for example, stemming from side-effects, or longer-term delays to institutionalisation).

We are aware of some new studies of pharmacological treatment that will report new and salient economic evidence in the next few months (each of them conducted independently of pharmaceutical companies). One of those studies looks at antidepressant medications, not previously examined in cost-effectiveness analyses as far as we can tell.

Non-pharmacological interventions – individuals with dementia

We found relatively little economic evidence on non-pharmacological interventions for individuals with dementia. Intervention areas were covered by extant evidence: group-based cognitive stimulation, physical exercises programmes, and tailored activity programmes.

Cognitive stimulation therapy (CST) offers, ‘activities involving cognitive processing; usually in a social context and often group-based, with an emphasis on enjoyment of activities’ (NICE-SCIE, 2011).

CST has been shown to be effective as primary prevention for older people with good cognitive functioning and as secondary prevention for older people with mild-to-moderate dementia (Medical Advisory Secretariat, 2008). The recent literature reviews by the Ministry of Health and Long-Term Care in Ontario (Medical Advisory Secretariat, 2008) and by the Belgian Health Care Knowledge Centre (Hulstaert et al, 2009) identified only one randomised controlled study evaluating the cost-effectiveness of a CST programme as secondary prevention intervention (Knapp et al, 2006). In this English study, CST was offered to people with mild-to-moderate dementia in group sessions run in care homes and day centres twice a week for eight weeks. The sessions focused on senses, remembering the past, people and objects, and everyday practical issues. There were limitations to the study, but the authors concluded that CST has the potential to be more cost-effective than the usual care and to support through its effects on cognition and quality of life. Costs for people receiving CST were not significantly higher than costs for the usual care group. The study limitations included the small sample (91 people in the intervention group and 70 in the control group) and short follow-up period (eight weeks), and so long-term outcomes are not known. Only people with mild-to-
moderate dementia living in care homes or attending day centres were included, which makes it hard to generalise the results to other dementia severity levels or to people living in the community and not using congregate care facilities. Indeed, one possibility is that it may have been the social interaction between group participants that generated the positive outcomes rather than the CST itself. Each of these limitations is being addressed in two current English studies, and new economic evidence will be generated and published over the coming two to three years.

No economic evaluation was found for CST as primary prevention intervention (Medical Advisory Secretariat, 2008).

Physical exercise programmes have been shown to be effective as primary prevention measures for older people with good cognitive functioning and as secondary prevention for older people with mild-to-moderate dementia (Medical Advisory Secretariat, 2008; Forbes et al, 2008). They have the potential to delay the onset or slow the evolution of dementia. They are suggested in England and Wales as part of a care plan in order to promote and maintain independence in people with dementia (NICE-SCIE, 2011). We found no economic evidence at all.

Some research attention has focused on the tailored activity programme approach. This is a home-based intervention consisting of eight sessions of structured occupational therapy over four months, targeted to provide individuals with dementia with activities tailored to their cognitive and functional capabilities, and to train carers in the use of those activities.

So far it appears that the programme has only been trialled in the United States. It comprises six home contacts and two telephone contacts, and is organised around three phases. In phase 1, abilities are evaluated by the occupational therapist; in phase 2, three activities tailored to the individual with dementia capabilities are developed, the individual trained and the caregivers instructed on strategies to adopt; and in phase 3, once the three activities have been mastered, the occupational therapists help to generalise the strategies to other care activities. It aims to address the difficulty that some dementia patients encounter as their illness progresses of becoming less tolerant of environmental stimuli.

Cost-effectiveness of tailored activity programmes compared to usual treatment is suggested by a randomised controlled trial carried out in the United States. The main reason for the result appears to be tailored activity programme’s effect in reducing carer time inputs (Gitlin et al, 2010). However, it was unclear from the study how carers decide to spend the non-caregiving time that is ‘released’ or whether this improves carer health. Moreover, the sample size was small (60 patient-carer pairs, four of whom dropped out) and there was no collection of data beyond four months.

A second economic study of physical exercise looked at occupational therapy at home for people with mild-to-moderate dementia living in the community, and also examined the consequences for carers. A randomised controlled design was used in this study in Holland, and found occupational therapy to be not only cost-effective but also cost-saving compared to usual care (Graff et al, 2008). The
intervention consisted of ten one-hour sessions at home, delivered over five weeks. The first stage was evaluation of the severity of the individual's disability and its effects on activities of daily living, and selection of those meaningful daily activities that they wanted to improve. One subsequent possibility was modification of the home and environment, and to teach the individual with dementia compensatory and environmental strategies. Carers were also trained to use effective supervision. The economic evaluation found this occupational therapy approach was cost-saving (with savings mainly accruing as a result of reductions in informal care) and 'yielded significant and clinically relevant improvements in daily functioning in patients and sense of competence in carers' (Graff et al, 2008, p.7 online). The study has limitations: it was not double-blind, it had a short (three-month) follow-up, and there were questions about representativeness of study participants. But none of these appears to be a major problem, and the results should be seen as robust and relevant.

A study carried out in Belgium, based on a decision tree design, found that F-fluoro-deoxyglucose positron emission tomography (FDG PET) is cost-saving when added to standard diagnostic approaches because it has the potential to delay cognitive decline by allowing the more accurate prescription of medications (Moulin-Romsee et al, 2005). Decision tree studies are generally weaker than randomised trials, and so the findings should be treated with a little caution. Nevertheless, the findings warrant further consideration.

Although there is supportive clinical effectiveness on magnetic resonance imaging (MRI) and neuropsychological testing for individuals with minor cognitive impairment and mild dementia as diagnostic tools (SBU, 2008), no cost-effectiveness evidence is available (Hulstaert et al, 2009).

Two other areas that we looked at generated no further economic evidence. A systematic literature review of non-pharmacological interventions to prevent wandering in individuals with dementia in comparison to usual care reported no relevant cost-effectiveness studies (Robinson et al, 2006; Robinson et al, 2007). Evidence on the cost-effectiveness of ginkgo biloba as a primary or secondary preventive intervention for people with mild cognitive impairment and mild dementia is also lacking (Hulstaert et al, 2009).

We are aware of a number of studies currently underway that are looking at the cost-effectiveness of some of the above and other non-pharmacological interventions for people with dementia. Some will be reporting in 2011.

**Interventions targeted on carers**

Better support for family and other unpaid carers has been a policy emphasis for some years now, but the evidence on what works remains quite modest. The responsibility of caring for someone with dementia can have a big impact on health (especially mental health), employment opportunities, related entitlements (such as pension) and income. Effective interventions targeted on the individual with dementia certainly have the potential to reduce a carer's ‘burden’ somewhat, although until quite recently most research studies tended not to look at cost-effectiveness by reference to carer effects.
Here we concentrate on carer-targeted initiatives such as financial support (tax or pension credits, and direct payments), employment-friendly policies (such as flexible working and paid care leave), respite breaks and psychosocial or psycho-educational support.

Given the key role that unpaid family and other carers play in supporting people with dementia, a breakdown in that relationship can often lead to short- or long-term admission of the person with dementia into a care home or hospital, both of which generate high costs for either the state or the family. One would therefore expect some potential for carer interventions to prove cost-effective, but in fact we found comparatively little evidence on the cost-effectiveness of such interventions. What evidence there is concentrates on two broad types of intervention: respite care and psycho-educational support.

**Respite care or short-term breaks** may be offered in different forms: day-care services, in-home respite services, host-family respite, institutional (overnight) respite services, respite programmes, multi-dimensional carer-support packages, and video respite (Arksey et al, 2004). Given this variety it has been hard to draw clear conclusions from the available evidence. Indeed, a report from the Ministry of Health and Long-term Care in Ontario (Medical Advisory Secretariat, 2008) found only two substantial reviews of the economic literature on respite care: a Cochrane review by Lee and Cameron (2004) and a review for the National Institute for Health Research by Arksey and colleagues (2004). The latter is the more useful for present purposes. We also found a few further studies but no further reviews since 2004.

Arksey et al (2004) offer a very helpful and comprehensive review, covering a range of dimensions, including economic. One area where researchers found economic evidence was for day care (‘planned’, not emergency): four studies were of good enough quality to include, two of which, ‘suggested that day care might be cost-saving’, while the other two, ‘suggested that day care might provide greater benefits but at a higher cost as compared to standard care. All four studies suggested that the benefits of day care might be similar or greater than those achieved through standard care’ (Arksey et al, 2004, p.52). One study was found that examined the cost-effectiveness of multi-dimensional carer-support packages, conducted in Canada in the 1980s (Drummond et al, 1991). That study concluded that cost per QALY for the support package was quite favourable compared to other health care interventions. No economic evidence was found for in-home respite, host-family respite, institutional/overnight respite (and little evidence that it reduced the demand for long-term placements), respite programmes (multiple forms of respite and short-term breaks) or video respite.

The other area where there is some evidence is for **psycho-educational support** for carers. The Belgian Health Care Knowledge Centre identified only two literature reviews on cost-effectiveness of caregiver support (Hulstaert et al, 2009). The first is the one produced by the Swedish Council on Technology Assessment in Health Care (SBU, 2008) and based on one short-term (primary data) study and two long-term economic models of non-pharmaceutical interventions for carers. Support was broadly defined as programmes of counselling, education, emotional support, and
contact provided to carers. No significant change in cost or outcomes was reported when comparison was made to standard care.

The second literature review, produced by the National Institute of Health and Clinical Excellence in collaboration with the Social Care Institute for Excellence (NICE-SCIE, 2006), reached no conclusion on the cost-effectiveness of interventions for caregivers of demented individuals comparative to standard care, because of the scarcity of evidence and the heterogeneity of the five available economic evaluations.

There have been some more recent interesting studies (but not reviews). Charlesworth et al (2008) evaluated a befriending intervention in which trained befrienders were matched with carers and given one-to-one emotional support. Wilson et al (2009) report the associated cost-effectiveness study. The researchers concluded that the befriending intervention was neither effective nor cost-effective compared to standard care. A new study by some of the same team of an ‘expert carer’ programme – with some similarities to befriending – is due to report in the next few months.

A quasi-experimental study of a psychosocial intervention for family carers in Sweden found that counselling sessions and conversation groups resulted in significant delays in nursing home placements for the people with dementia they were supporting, compared to standard care and support arrangements (Andren and Elmstahl, 2008). Another study was conducted in the United States, evaluating a multi-component intervention that included, ‘modules focusing on information, safety, caregiver health and well-being, and behaviour management for the care recipient’ (Nichols et al, 2008). Twelve individual sessions were delivered in the caregivers’ home (nine sessions) and through telephone (three sessions), supplemented by five telephone-administered support-group sessions of five to six caregivers (Nichols et al, 2008, p.414). Their randomised trial revealed a significant difference in care-giving hours: each additional hour of care-free time for carers costs just under $5 per day. In other words, the intervention would be viewed as cost-effective if funders were prepared to pay this amount per day, or an extra $893 over the six-month period. The authors lament the short duration of their study (6 months), and refer to earlier work by Brodaty and Peters (1991) in Australia that demonstrated cost-savings over 39 months from a multi-component residential training programme for carers.

The shortage of high-quality evidence on interventions to support carers may be due in part to methodological limitations in some of the studies that have been conducted, the definition of respite care and the wide range of interventions, the variety of needs both for people with dementia and their carers, and the range of outcome measures employed across the literature.

Organisation of care and support

Research attention in relation to the organisation of care and support has concentrated on three main areas: direct payments, care management, and co-ordinated responses to co-morbid conditions.
Direct payments transfer social care funding to service users, who then have the opportunity to spend their budgets on a range of services to meet their personal (care) needs. Variants of direct payments have been tried in different countries and with different labels (individual budgets, self-directed support, and now, in the UK, personal budgets and personal health budgets). The primary aim is to offer greater choice and control over services to people with assessed needs for support. However, take-up rates for direct payments have been and remain low for older people (relative both to the number of people eligible for them, and to other groups of people with long-term needs). There have been very few evaluations compared, and especially for people with dementia.

There is no evidence on the economic impacts of direct payments or personal budgets specifically for people with dementia, but the only two well-conducted economic evaluations for older people do not offer especially encouraging support for this organisational arrangement.

In Germany, Arntz and Thomsen (2011) concluded that cash payments crowded-out informal care activity, and did not appear to be cost-effective. In England, the evaluation of the individual budgets pilot programme showed that costs were no different compared to standard care arrangements, but outcomes were marginally worse for older people with individual budgets (Glendinning et al, 2006). There were a number of reasons for expecting outcomes to be better for older people over time, and with better preparation and support for holding personal budgets. Longer-term evaluation findings are due in the near future from a team at York University. Analysis of the impacts of individual budgets on carers suggested better outcomes at equivalent costs, compared to standard care and support arrangements (Glendinning et al, 2009). Again these results relate to older people as a group rather than people specifically with dementia.

A second area where we were able to find some evidence was for (community-based) care management (other labels used are case management and co-ordinated care/case management). We found one review on cost-effectiveness of case management for individuals suffering from dementia and their carers was not able to show any results due to the dearth of studies and heterogeneity of the population studied (Pimouguet et al, 2010). Only three randomised controlled studies conducting an economic analysis of case management programmes for people with dementia were identified by these reviewers, spanning rather different populations and settings. Pimouguet and colleagues argue that no conclusion can be drawn about the economic impacts of care management, although our reading of the evidence that they review would lead to a different conclusion. It is true that there have been few studies that are called economic evaluations and that report impacts on costs or budgets, and that some are weak in design. However, there are a few well-conducted (and in some cases long-term) studies that demonstrate the impact of care management arrangements on delayed institutionalisation, and which imply, even if they do not fully document, economic pay-offs (Mittelman et al, 2006; Chien and Lee, 2008; Brodaty et al, 2009).

One study of interest because of its robust design evaluated the cost of a co-ordinated care management intervention for dementia in the USA (Duru et al,
Patients with dementia were assigned a care manager responsible for assessing problems at home and then reassessing them every six months using internet-based care management software, developing a care plan, and referring on to primary care and community agencies for specific treatment and care services. While the intervention was not cost-saving compared to standard care, the authors concluded that co-ordinated care management was cost-effective from both payer and social planner perspectives because of improvements in patient and carer outcomes, and because their measure of dementia care quality was significantly better too. In common with most care/case management studies, the focus was on people living in community settings.

Individuals with dementia are known to have an elevated risk of co-morbid conditions, and hence could require more medical or social care. Better management of co-morbidity could have economic pay-offs. One study in the United States showed the higher costs compared with matched individuals without dementia (Kuo et al, 2008). The most prevalent co-morbidities are psychiatric conditions (depressive, bipolar and delusional disorders), ischemic or unspecified stroke, hip fractures/dislocations. For example, psychiatric conditions are five times more prevalent among people with Alzheimer’s disease than matched controls, and costs are 1.5 times higher. This is undoubtedly an underestimate because these researchers only included costs recorded in the Medicare database and medical and pharmaceutical claims.

In the UK, it has been suggested that a quarter of acute NHS hospital beds is occupied by people with dementia. In the dementia hospital (DEMHOS) research in the UK, the main causes of hospitalisation in individuals with dementia were falls (14 per cent), broken/fractured hip (12 per cent), urine infection (9 per cent), chest infection (7 per cent) and stroke (7 per cent) (Alzheimer's Society, 2009). Hospital stays were longer for people with dementia than for other patients, with expected higher costs. In a study that the Personal Social Services Research Unit carried out for the National Audit Office, we found that earlier discharge and better management of hip fracture in demented patients could save between £64 million and £102 million a year in England (Henderson et al, 2007; and National Audit Office, 2007).
Discussion

The ageing of the world population – an amazing achievement attributable in large part to higher standards of living, public health initiatives and treatment breakthroughs – is generating major challenges for health, social care, employment, pensions, housing and other systems. Dementia exemplifies very well this changing reality, given the steep age-gradient on its prevalence, and the many personal, familial, social and economic implications. Projecting forward from today’s care and support arrangements shows how future costs will soar. For example, as noted earlier, expected trends in prevalence, staff costs and (unpaid) carer availability will lead to substantial increases in health and social care spending unless the system of provision is altered or there are major breakthroughs in prevention or disease course (Comas-Herrera et al, 2007).

Aims of this review

Against this background, we were asked to look at evidence on economic aspects of dementia care, and particularly the cost-effectiveness of interventions to treat, care for and support people with dementia or their carers, and also the potential for cost savings.

Summary findings

What strategies are there for reducing the projected future costs of treatment and care, and improving the outcomes generated from committed resources? There are many strategies, but only a few of them have been examined in economics research. In our search we looked for evidence relating to prevention of dementia, better or earlier diagnosis, interventions that might delay symptom progression, interventions to reduce symptom consequences, support for carers, improvement of cross-agency working and better end-of-life care.

Taking the broadest perspective, strategies for cost-containment and cost-effectiveness improvements include primary prevention of dementia or action to delay its onset (perhaps through physical exercise, social integration and stimulating activities – as protective factors – or better public health more generally, such as reducing smoking). We found almost no economic evidence in this area.

We also found no cost-effectiveness evidence on end-of-life care for people with dementia, and only one study of costs (McCrone, 2009).

Better support for family and other unpaid carers has attracted more attention in recent years, and has been the focus of quite a bit of research. A few economic evaluations have been carried out, but confined to a narrow range of options: day care, psycho-educational interventions and befriending. For a host of other carer-support possibilities (including a host of respite programmes, flexible employment arrangements and financial support) we could not find robust economic evidence.
Similarly, there has been little evaluation of the cost-effectiveness of strategies to alter the organisation of care and support: some evidence on direct payments (personal budgets) and some on care/case management. The latter area is quite encouraging, particularly with suggestions of longer-term cost-effectiveness. The need for better management of the clinical and social care responses to co-morbidity is increasingly being recognised, but there is very little economic evidence. What evidence there is – such as our own work on hip fractures for the National Audit Office – points to potentially sizeable savings and cost-effectiveness gains.

We found more cost-effectiveness evidence on non-pharmacological and pharmacological therapies, with the largest collection of evidence relating to dementia medications such as acetylcholinesterase inhibitors (AChEI) and memantine. The accumulated evidence (well summarised by NICE and SCIE, 2011), plus findings from new studies to be published later this year, offer helpful pointers to better and affordable dementia treatment (AChEI for mild-to-moderate disease, and memantine for moderate-to-severe disease). More evidence is needed on the widespread use of antipsychotics and antidepressants by people with dementia. There is only a small amount of evidence on non-pharmacological treatments (cognitive stimulation therapy and tailored activity programmes).

Limitations

Our search for ‘grey literature’ in websites was confined to the United Kingdom; we would not anticipate finding much in governmental and non-governmental websites in other countries, but we were unable to check. Our task was to look at available literature reviews, and the quality of some of these was low. None presented findings supported by meta-analysis, but that is not surprising given the paucity of available primary data studies. We have endeavoured to extract relevant findings from individual studies.

Barriers and opportunities

What are the opportunities for and the barriers to achieving better value for money in dementia care?

From this review we would identify the following:

- There are few economic studies, and some of the completed studies are methodologically weak, making it hard to be confident about the conclusions that can be drawn from them.

- Even when studies are methodologically sound, it can still be hard to draw out conclusions. For example, some studies only examine outcomes and costs over short time periods (relative to the typical duration of need). Studies that are conducted outside the UK may offer helpful pointers, but inter-country differences complicate the inferences. Even if clinical evidence ‘travels well’ between countries (although cultural differences should not be overlooked), economic evidence is highly dependent on the organisation, funding and incentives in health and social care systems.
• Another difficulty could be the natural heterogeneity in the population of people with dementia and their carers, and research studies tend to focus on particular subgroups (most typically distinguished by severity of dementia symptoms, or excluding people with co-morbidities, or concentrating only on co-resident carers). This makes it hard to know whether published findings can be generalised to other subgroups.

• Of course, this does not stop generalisation within subgroups, as has been the case when bodies such as NICE and SCIE have prepared guidelines on pharmacological treatments. Here the economic evidence is quite good, with new studies due to report very soon, quite possibly opening up new opportunities for value for money improvements.

• In comparison to the wide range of potential economic impacts, a number of studies focus quite narrowly on health care costs. A common omission is the economic impact on carers and on the economy (if carers give up productive employment). The broader the perspective of the study the more useful it should be. Given the pivotal role of family and other carers in dementia care, such omission (of costs and/or outcomes) is unacceptable.

• Even when the economic losses associated with unpaid carers are measured, a problem could be that many are seen as not ‘cashable’ (at least in the short term). The time that a carer spends in support of someone with dementia might not generate any immediate tangible costs, although over time the impact on the carer’s health could result in higher health service use by them, and carer ‘burn-out’ very often leads to care home or hospital admission for the cared-for person, at considerable cost to the individual, family or state.

• Even when the research evidence is available and relevant, there is an apparent reluctance to implement it by adjusting the treatment, care and support offered. The delays are probably greater in social care than health care, given the role that NICE has tended to play in preparing evidence-based guidelines. In social care, changes to care and support would often require investment by independent sector providers, some of whom feel especially squeezed as a result of what they would see as tough fee bargaining by councils. They are already quite low spenders on staff training, and jobs in care homes and day centres are generally low-paid and low-status. Cognitive stimulation therapy is an example of an intervention that has fairly good evidence in support of its effectiveness and cost-effectiveness, albeit over relatively short periods. That evidence ought to offer an opportunity to providers and commissioners to reap economic gains, but apparently only 10 per cent of PCTs and mental health trusts commission or deliver cognitive stimulation therapy (data from a FOI request sent to trusts and passed on to us).

• Budget cuts could make the challenge harder. NHS and local authority commissioners will be looking for treatment, care and support arrangements that are affordable in an increasingly difficult fiscal climate. They will therefore be attracted by interventions that appear to be cost-saving, and might find it hard to spend on interventions that are cost-effective (in the sense that the outcomes are worth paying for) only if they need to commit greater expenditure.
• People with dementia usually experience deteriorations in both health and capacity for self-care, and so both health and social care support is needed. The boundaries between the two systems have long been a source of difficulty, and it might be even harder in the immediate future for hard-pressed NHS and local authority commissioners to invest in better collaboration unless it can be shown to generate fairly immediate economic gains. The age-old problem of **silo budgets** will likely remain a source of (overall) inefficiency, leading to poor co-ordination, cost-shifting and ‘problem-dumping.’ The boundaries with other systems (such as housing, pensions and transport) are also relevant.

• At the moment, there is almost no economic evidence (at least specifically focused on people with dementia) on ‘stepping-stone,’ ‘halfway’ or **intermediate care** arrangements which can sit between living in one’s home in the community and being admitted long-term to a care home or inpatient ward. Extra-care housing and extended respite care are other options.

• Evidence about the economic consequences of extending greater choice and control to older people is limited, for example through **self-directed care**. What little evidence there is (for example, about personal budgets) is not especially encouraging. However, it was not clear from the individual budgets pilot, for example, that council staff had adequately prepared older people for holding their own budgets, and the potential economic benefits could be rather greater. They might also offer a way to circumvent health-social care boundary difficulties. The benefits for carers from the individual budgets evaluation were quite pronounced. Yet, it is still the case that very few older people currently have direct payments.
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