

Summary: Intervention & Options		
Department /Agency: Department of Health	Title: Impact Assessment of National Dementia Strategy	
Stage: Final	Version: 1.6	Date: 20/01/2009
Related Publications: Transforming the Quality of Dementia Care		

Available to view or download at: <http://www.dh.gov.uk>

Contact for enquiries: AJ Palethorpe

Telephone: 0113 25 46468

What is the problem under consideration? Why is government intervention necessary?

Most dementia is not diagnosed, or diagnosed late, too late for effective intervention and the prevention of harm. Services of proven effectiveness are not commissioned and people with dementia and their families are not aware of availability of local services. The effect is that people with dementia and their families experience a lower quality of life than they should; this includes recourse to premature or inappropriate use of residential care. The provision of accurate and consistent information and evidence is a public good that could most effectively and efficiently be delivered by Government. Central guidance to commissioners is necessary to ensure establishment for new services and systems.

What are the policy objectives and the intended effects?

The policy objective is to improve outcomes and the quality of life for people with dementia and their family carers by: 1. improving public and professional understanding enhancing help-seeking and help-offering; 2. providing diagnosis early in the illness so that available support and treatments (including those which will prevent harm later in the disease) can begin as soon as needed; and 3. quality improvements in dementia services following diagnosis through to the end of life. The intended effects include a reduction in the premature and/or inappropriate use of residential care.

What policy options have been considered? Please justify any preferred option.

Option 1 Do nothing - rely on the NHS and its partner organisations to take-up the challenges described in reports by the NAO, Audit Commission and others over the years.

Option 2 Implement all recommendations immediately

Option 3 Implement recommendations with the strongest evidence base, evaluate demonstration projects for those where more information is required on the costs and benefits of interventions.

Option 3 is preferred because it makes improvement where benefits are clear while implementing demonstration projects and evaluation to generate data on the benefits and costs of other interventions.

When will the policy be reviewed to establish the actual costs and benefits and the achievement of the desired effects? After 3 years – in October 2011.

Ministerial Sign-off For Final Impact Assessments:

I have read the Impact Assessment and I am satisfied that, given the available evidence, it represents a reasonable view of the likely costs, benefits and impact of the leading options.

Signed by the responsible Minister:



.....Date: 2 February 2009

Summary: Analysis & Evidence					
Policy Option: Full Implementation		Description: Implement all of the recommendations in the National Dementia Strategy over 5 years.			
COSTS	ANNUAL COSTS		Description and scale of key monetised costs by ‘main affected groups’		
	One-off (Transition)	Yrs	Primary care trusts and local authorities in respect of service developments and training, and DH in respect of information, analysis and national & regional support. Estimation of exact costs will require further development of the evidence base.		
		2			
	Average Annual Cost (excluding one-off)				
		10	Total Cost (PV)		
Other key non-monetised costs by ‘main affected groups’					
Costs to patients and their families of acquiring information and attendances. Costs to patients and their families of paying for their own home care from reduced residential care					
BENEFITS	ANNUAL BENEFITS		Description and scale of key monetised benefits by ‘main affected groups’		
	One-off	Yrs	Benefits in terms of improved quality of life for people with dementia and their families, and of greater job satisfaction for staff, are expected to be substantial but have not been monetised.		
	£				
	Average Annual Benefit (excluding one-off)				
	£		Total Benefit (PV)		£
Other key non-monetised benefits by ‘main affected groups’					
Benefits in terms of improved quality of life for people with dementia and their families and net savings for self-funders from reduced use of residential care (net of increased home care costs).					
Key Assumptions/Sensitivities/Risks It has not been possible to provide quantified or monetised benefits, due to shortage of evidence, but benefits are expected to be significant. Risk of implementation					
Price Base Year	Time Period Years	Net Benefit Range (NPV) £		NET BENEFIT (NPV Best estimate)	
What is the geographic coverage of the policy/option?				England	
On what date will the policy be implemented?				04/09	
Which organisation(s) will enforce the policy?				HCC/CSCI/CQC	
What is the total annual cost of enforcement for these organisations?				£ NIL	
Does enforcement comply with Hampton principles?				Yes	
Will implementation go beyond minimum EU requirements?				No	
What is the value of the proposed offsetting measure per year?				£ N/A	
What is the value of changes in greenhouse gas emissions?				£ Negligible	
Will the proposal have a significant impact on competition?				No	
Annual cost (£-£) per organisation (excluding one-off)		Micro	Small	Medium	Large
Are any of these organisations exempt?		Yes/No	Yes/No	N/A	N/A
Impact on Admin Burdens Baseline (2005 Prices)				(Increase - Decrease)	
Increase of	£	Decrease of	£	Net Impact	£
		Key:	Annual costs and benefits: Constant Prices		(Net) Present Value

Summary: Analysis & Evidence						
Policy Option: 3 mix of implementation and demonstrations			Description: Implement those recommendations where benefits are clear and evaluate other areas where benefits are clear			
COSTS	ANNUAL COSTS		Description and scale of key monetised costs by ‘main affected groups’ Primary care trusts and local authorities in respect of service developments and training, and DH in respect of information, analysis and national & regional support.			
	One-off (Transition)	Yrs				
	£ 12.2 millions	2				
	Average Annual Cost (excluding one-off)					
	£155.2 millions	10	Total Cost (PV)		£ 1.386 billions	
Other key non-monetised costs by ‘main affected groups’						
BENEFITS	ANNUAL BENEFITS		Description and scale of key monetised benefits by ‘main affected groups’ Benefits in terms of improved quality of life for people with dementia and their families, and of greater job satisfaction for staff, are expected to be substantial but have not been monetised.			
	One-off	Yrs				
	£					
	Average Annual Benefit (excluding one-off)					
	£		Total Benefit (PV)		£	
Other key non-monetised benefits by ‘main affected groups’ Improved quality of life for people with dementia and their families, and greater job satisfaction for staff. Savings for self-funders from reduced use of residential care (net of increased home care cost). Improved policy implementation because of learning from the demonstration sites.						
Key Assumptions/Sensitivities/Risks It has not been possible to provide quantified or monetised benefits, due to shortage of evidence, but benefits are expected to be significant. Additional costs may be incurred depending on implementation decisions following demonstration and further evidence gathering. These costs (and benefits) will be subject to further Impact Assessments as appropriate.						
Price Base Year	Time Period Years	Net Benefit Range (NPV) £		NET BENEFIT (NPV Best estimate)		
What is the geographic coverage of the policy/option?				England		
On what date will the policy be implemented?				04/09		
Which organisation(s) will enforce the policy?				HCC/CSCI/CQC		
What is the total annual cost of enforcement for these organisations?				£ N/A		
Does enforcement comply with Hampton principles?				Yes		
Will implementation go beyond minimum EU requirements?				No		
What is the value of the proposed offsetting measure per year?				£ N/A		
What is the value of changes in greenhouse gas emissions?				£ N/A		
Will the proposal have a significant impact on competition?				No		
Annual cost (£-£) per organisation (excluding one-off)			Micro	Small	Medium	Large
Are any of these organisations exempt?			Yes/No	Yes/No	N/A	N/A
Impact on Admin Burdens Baseline (2005 Prices)				(Increase - Decrease)		
Increase of	£	Decrease of	£	Net Impact		£
			Key:	Annual costs and benefits: Constant Prices		(Net) Present Value

Introduction

- 1.1 This document assesses the economic impact of the recommendations of the National Dementia Strategy. Key elements of the overall strategy include: a public information initiative on the causes and symptoms of dementia (to encourage people who suspect a problem to come forward earlier), advice on risk-factors and what an individual can do to reduce them, provision of services to diagnose and treat dementia, training for health and social care professionals in the recognition of signs and symptoms, and work to support regulation and inspection of service-providers and the identification of existing evidence and, therefore, areas for future research efforts.
- 1.2 The Strategy was published in draft form for consultation in June 2008. The consultation period ended on 11 September. The final version reflects the contributions made by many hundreds of individuals with a wide range of experience of living with, and working to support, people with dementia. Overwhelmingly, respondents supported the objectives described in the draft strategy but a significant number of respondents wished greater emphasis to be given to the links to the Carer's and End of Life Care strategies and to the role that housing provision and telecare/assistive technology can play in supporting people with dementia and their carers.
- 1.3 We are grateful, in particular, to Jeni Beecham of the Personal Social Services Research Unit for her invaluable contribution towards the development of this Impact Assessment.
- 1.4 This Impact Assessment describes the problems under consideration (Section 2) and why it is considered necessary for the Government to intervene (Section 3).
- 1.5 It then outlines the policy objectives for a National Dementia Strategy, and the intended outcomes (Section 4).
- 1.6 In Section 5, we set out the evidence, principal costs and benefits of the National Dementia Strategy.
- 1.7 Our expectation is that improved services for people with dementia and their families will deliver improved quality of life for both patient and carer. These benefits cannot readily be monetised.
- 1.8 However, in order to indicate the economic costs and benefits involved, it is necessary to make some assumptions about what 'costable' inputs might be required to implement the recommendations and bring about the outcomes described in the strategy.
- 1.9 It should be stressed that this assessment is our best estimate of the gross economic costs of achieving the objectives described in the Strategy, on the following assumptions
 - every locality starts from the same place
 - they will each will implement the Strategy in the same way and within the same timeframe.
- 1.10 This is different from an assessment of the amount of additional resource that might have to be found to deliver those objectives that are costed here. We know, for example, that the NHS and Local Authorities in England invested at least £1.8 billion in Older People's Mental Health services in 2006/07¹, and that total investment in all adult mental health services by the NHS in England was over £5.5 billion in 2007/08². These are significant sums and it is certain, although we are not able to quantify it, that a proportion of the current level of resource is already invested in dementia services or could – by service reconfiguration – be made available for reinvestment in modernised, responsive services of the kind described in the Strategy. Similarly, investment across health and social care economies in education and training are significant and it is probable that some of that resource is already – or could be – targeted at the needs identified here.

- 1.11 The demonstration, evaluation and review work that is planned for the initial stages of the Strategy is, in large part, intended to establish the difference between the economic cost and the extent to which any additional investment is necessary and represents value for money. This evidence will be used to inform decisions about relative priorities for investment in health and community support services from 2011/12 onwards.
- 1.12 The strategy is assumed to be implemented over a five year period. However, the pace of nature of implementation will inevitably vary, depending on local circumstances, the level and development of services within each NHS and local authority area. The strategy itself makes this clear. There is no expectation therefore that all areas will be able to implement the strategy within five years. Implementation will also depend on review of evidence from pilots and further development of the evidence base, including the precise scale and nature of costs and benefits. Where applicable, these will be subject to separate impact assessments in the future.

What is the problem?

Overview

- 2.1 In their report on the subject, the House of Commons Committee of Public Accounts³ cited the following:
 - in 2006, only 5 people in 1,000 aged 65-69 had a diagnosis of dementia against an expected prevalence of 13
 - of people aged over 80 years, only 60 of an expected prevalence of 122 in 1,000 had a diagnosis.
- 2.2 In addition to under-diagnosis, there is evidence that people with dementia have:
 - increased delayed discharge from and readmission to hospital
 - premature admission to care homes
 - a lack of appropriate services
- 2.3 Reports from the NAO and the PAC, and other commentators, have consistently identified the causes of these failures of care include a widespread misunderstanding – and even fear – of dementia that leads people to believe that it is intrinsic to the aging process and untreatable. This leads people to believe – entirely mistakenly – that there is ‘no point’ in diagnosing the disease.
- 2.4 This essential misunderstanding is often the trigger for subsequent service failures because facilities are not established, staffed (with appropriately skilled staff) or commissioned for those people who can and do have needs but have not been identified. In addition, those services that are commissioned are directed towards the care of people who are severely affected meaning that there are very few services focussed on early diagnosis and intervention.
- 2.5 The number of people with dementia, and so the number of people caring for a person with dementia, is already substantial; and growing. There are an estimated 700,000 people with dementia in the UK now and this is projected to double in the next thirty years.
- 2.6 However, the evidence points to a widespread public and professional misunderstanding of what dementia is, what are its causes, the burden of disease for people with dementia and for their family carers, the degree to which some dementia is preventable and how effective specialist care can be in enabling people to live well with dementia, preventing harm and crises, easing the burden for all.
- 2.7 This misunderstanding is not confined to individuals with dementia and their family carers; it is shared by non-specialist health staff and those that those who commission and provide services.
- 2.8 Finally, these misunderstandings are not limited to lack of information. A lot of what is ‘known’ is factually incorrect. For example, it is widely assumed that dementia is a natural part of the aging process and so inevitable; it is not.
- 2.9 In a number of areas the evidence-base for the interventions is weak (or absent).
- 2.10 The costs for some of the important outcomes of this Strategy have, or will be, addressed in complementary strategies and so – to avoid double-counting the costs and the benefits – are not addressed in detail in this Assessment. Specifically

- the End of Life Care Strategy describes a generic model for all adults at the end of life and also describes the end of life trajectory for a person with dementia⁴
- the New Deal for Carers makes a number of explicit references to the needs of people caring for people with dementia⁵
- Lifetime Homes, Lifetime Neighbourhoods includes the need for suitable accommodation for people with dementia⁶

and the Impact Assessments for those strategies take account of the costs and benefits.

Specific areas for attention

- 2.11 Poor public and professional awareness, a lack of diagnosis, late diagnosis, poor navigation in the system, poor quality care in general hospitals and care homes.

Why is Government intervention necessary?

- 3.1 The Department of Health is responsible for setting the policy and funding for health care, including for older people's mental health and long-term conditions. The Department also has responsibility for policy on adult social care – including policy for carers – and provides Councils with about 15 per cent of adult social care spending through specific grants.
- 3.2 The Department of Health has made clear the priority for improving care for people with dementia and their families in past policy documents such as the National Service Framework for Older People. However, there has been little progress in this area as shown by the NAO and PAC reports on dementia care.
- 3.3 Information that makes clear the nature and size of the health and social care challenge posed by dementia has become available in the last two years (e.g. that dementia costs £17 billion per year), along with evidence that interventions can be clinically and cost effective but are not deployed. Government action is required to address the shortfall on information, evidence and funding.
- 3.4 In the light of these findings, and the undisputed forecasts of the increasing scale of the burden of disease as the population ages, Ministers and the Chief Executive of the NHS have identified dementia as a national priority requiring an approach targeted at the specific failures – of public and professional understanding, of training and of service provision – that have been identified. In particular, the Department of Health will take up the challenge set out in the NAO report to “... *champion and coordinate improvements in dementia services as an explicit part of its approach to improving health and social care, including providing strong and transparent leadership for dementia management.*”⁷

Policy objective and intended effects

- 4.1 The policy objectives of the National Strategy can be summarised as improving outcomes for people living with dementia through:
- providing a strategic framework against which local services can secure quality improvements to dementia services, and address health inequalities relating to dementia;
 - providing advice and guidance for health and social care commissioners, strategic health authorities (SHAs), local authorities, hospitals, and primary care trusts (PCTs) in the planning, development and monitoring of services; and
 - providing a guide to high-quality health and social care services to inform the expectations of those affected by dementia and their families.
- 4.2 The intended effects are to
- maximise opportunities for harm prevention
 - improve the quality of life of people with dementia, and their families
 - reduce the premature and/or inappropriate use of residential care
- 4.3 The Strategy is not a detailed practice guideline; that was published by NICE-SCIE in 2006⁸ (although it is unclear what the impact of services for people living with dementia has been because of this). It will however raise public and professional awareness of dementia (what it is and what it isn't) and – by setting out a description of what better, more pro-active dementia care looks like and costs – promote the configuration and re-configuration of services so that the experience of health and social care services of people living with dementia are of the same high standard everywhere in England.
- 4.4 The Strategy describes a number of objectives, based on the findings of the NAO Report *'Improving services and support for people with dementia'*, the NICE-SCIE Guideline, the recommendations of the Strategy's External Reference Group of key stakeholders, the conclusions reached by the professionals on the Strategy Working Group, and the strong and consistent responses from the many hundreds of people who responded to the national consultation.

Policy Options

- 5.1 The 17 objectives in the National Dementia Strategy are derived directly from the evidence base, best clinical practice guidelines and the lived experience of people with dementia and their carers communicated to the Department during the strategy development and the consultation. The objectives each also form part of a coherent whole programme of quality improvement and there is a high degree of complementarity, synergy and added value that accrues from the set as a whole.
- 5.2 The degree of consensus on the content of the programme and on what needs to be done should not be underestimated. This is a consensus shared by clinicians, people with dementia and their carers, social care, researchers and the third sector that the objectives are the right ones and that they will work. This was a clear finding of the development phase of the strategy and from extensive formal consultation. There is no doubt in the field that all the objectives are needed. There are however reasonable questions in some cases about how to achieve some of these. This is reflected in the strategy and this Impact Assessment in the use of demonstration projects and evaluation to generate data on what might be best to commission.
- 5.3 The proposed implementation of the objectives has been profiled to ensure that the consequences of each are taken into account. So for example, the public information campaign can signpost people to memory services as they are established and the improved community services can play in once those identified as having dementia have progressed in severity so that they require such care. The danger of creating demand by one action and not delivering the service change needed to meet this demand has been identified and dealt with in the temporal profiling of the initiation of the objectives.
- 5.4 Option 1 is to do nothing. By definition, it has no additional costs or benefits. This would mean relying on the NHS and its partner organisations to take-up the challenges described in the reports by NAO, Audit Commission and others over the years. In practice the paucity of services has been made clear in successive reports over the years and yet the weaknesses persist. The public and specifically people with dementia are themselves unaware of their own needs so not in a position to lobby their commissioners.
- 5.5 Options considered are:
- Option 2: start implementing all recommendations immediately.
 - Option 3: implement recommendations with the strongest evidence base, set up and evaluate demonstration projects for those where more information is required on the costs and benefits of interventions.
- 5.6 It follows therefore that any interventions suggested in the strategy that require evidence from the demonstration sites are ideas to be tested and evaluated, not a statement of policy or a commitment to specific actions in the future. It is also essential to bear in mind that
- the scope and range of existing services will differ locality to locality, and so each will be starting from a different point, **and**
 - decisions on which elements of the strategy will be commissioned, and over what time period, are matters for local determination, **and**
 - each locality is responsible for identifying what existing resource is – or could be made – available to invest in their local Strategy.
- 5.7 It is essential to bear in mind that the delivery of the overall strategy cannot be achieved by any one agency; the NHS and its partners in Local Government and providers of home and residential care (including not-for-profit and the voluntary sector) must all work together if we are to effect the changes people with dementia and their families need. This

Assessment therefore describes the economic impact for all partners, some of whom will recover any **new** or **additional** costs directly attributable to cost incurred in improving existing services or developing and delivering new services under contracts between themselves and commissioners.

Evidence base for recommendations

O1: Public information to increase public and professional awareness

5.8 The problem is lack of information or misinformation

- people wait up to three years before reporting symptoms of dementia to their doctor⁹
- 70 per cent of carers report being unaware of the symptoms of dementia before diagnosis¹⁰
- 64 per cent of carers report being in denial about their relative having the illness¹¹
- 58 per cent of carers had believed the symptoms to be just part of ageing¹²
- only 31 per cent of GPs believe they have received sufficient basic and post-qualifying training to diagnose and manage dementia¹³
- 50 per cent of the public believe that there is a stigma attached to dementia¹⁴
- people over 65 are more worried about developing dementia (39 per cent) than cancer (21 per cent), heart disease (6 per cent) or stroke (12 per cent)¹⁵

5.9 Bearing in mind that about one-half of all cases of dementia have a vascular component (i.e. vascular dementia or mixed dementia), there is an opportunity to minimise the effects of dementia, or prevent it altogether for some people through health promotion messages on diet and lifestyle.

5.10 Campaigns concerning general health conditions in adults have been successful in back pain (decline in medical pay-out claims, increase in GP knowledge, positive shift in beliefs) and in knowledge about emergency contraception (Buchbinder et al, 2001; Trussell et al, 2001). For Northern Ireland, the Health Promotion Agency also report good outcomes from their campaign to increase activity levels in adults and TV campaigns were particularly in reaching young people (www.healthpromotionagency.org.uk). A recent review of population studies on public beliefs and attitudes toward mental illness found just six of the 43 studies included information on dementia (Angermeyer and Dietrich, 2005).

5.11 We also have evidence from Scotland's multi-media "See me" campaign. Total expenditure on the campaign was £2,293,000 plus an initial grant in Year 1 (2001-2002) of £500,000. Of the total, 73 per cent was spent on direct campaign costs. Over 100 local organizations and groups have been involved and each year the campaign reached more than 75 per cent of the populations surveyed. By 2004, the Scottish Executive's public attitudes survey showed improved rates of positive attitudes to mental health problems and a reduction from 32 per cent to 17 per cent of those who agree that people with mental health problems are dangerous. There has been a 57 per cent decline in derogatory terms used by the media. (www.seemescotland.org).

- 5.12 Total expenditure on the DH-funded *Mind Out for Mental Health* campaign between 2000-01 and 2003-04 was £3,473,000 (Hansard written answers 2001-2005). The subsequent 5-year NIMHE strategy *Shift* started 2004. The one-year report on media attitudes to mental health problems between 2005 and 2006 showed little change (Mind Over Matter 2, 2007). The Defeat Depression Campaign (DDC; 1992 to 1996) run by the Royal College of Psychiatrists was aimed at both the general public and GPs. Small (five -10 per cent) but significant positive changes in public attitudes were found over time (Paykel et al, 1998). Almost two-thirds of GPs reported being aware of the DDC (Rix et al, 1999). There was no impact from DDC and increased prescription of anti-depressants on the number of days of 'incapacity' recorded by the Department of Social Security (Moncrieff, 1999).
- 5.13 We have concluded that a two-tier approach is likely to be the most effective. The 'top tier' would comprise a national campaign aimed to contribute to change in public and professional knowledge and attitudes. This would include concerted efforts with media personnel to influence the representation of mental health in the media. This is likely to be costly because a key target audience would be younger people, for whom television has been shown to be particularly effective. The top tier would also include a focussed campaign for GPs through their professional media.
- 5.14 The second tier would be the work organised and delivered locally, working with key partner organisations – including the voluntary sector – to develop tailored messages for local populations on what services are available as they are commissioned and come on stream, how to access and what to expect from them.
- 5.15 Based on the evidence and experience of other public information campaigns - primarily *See me* (Scottish Executive multi-media campaign on public attitudes to mental health), *Mind out for Mental Health* (Department of Health), the *Defeat Depression campaign* (Royal College of Psychiatrists) – we estimate that the optimum costs of local campaigns would be **£1 million a year in Year 1** (including the costs of publicity to re-inforce the launch), and then **£3.5 million in Year 2**. Funding beyond Year 2 (2010/11) is entirely dependent on the evidence from the demonstration sites. We have assumed that the upper limit for future costs would be **£4m a year from Year 3 onwards**, assuming that these elements of information campaigns will be delivered locally as services are configured, matching supply with demand.

O2: Early diagnosis and intervention

- 5.16 For those people with dementia now, and for those who will get it in the future, services need to be pro-active. People need to be empowered to present themselves for diagnosis when signs and symptoms become apparent rather than wait. GPs and others need to know where they should send people for diagnosis.
- 5.17 Evidence suggests that
- early provision of support at home can decrease institutionalisation by 22 per cent¹⁶
 - even in complex cases and where the control group is served by a highly skilled mental health team, case management can reduce admission to care homes by 6 per cent¹⁷

- older people's mental health services can help with behavioural disturbance, hallucinations and depression in dementia reducing the need for institutional care¹⁸
- carer support and counselling at diagnosis can reduce care home placement by 28 per cent¹⁹
- early diagnosis and intervention improves quality of life of people with dementia²⁰; and
- early intervention has positive effects on the quality of life of family carers²¹.

5.18 Based on the evaluation of the Croydon Memory Service we have estimated that the development of memory clinics nationally would cost health and social services around £220 million a year. This excludes the savings from reduced use of residential care that would be associated with implementing such services. In the longer-term, savings to social services could be of the order of £130 million a year. There would also be savings to individuals (i.e. for those who would fund their residential care privately).

5.19 In its 2008/09 operating framework the Department stated that such services were cost effective and that it would publish the detailed analysis supporting this. The case was published as annex four of the consultation paper on the National Dementia Strategy, published in June 2008. The details of the cost effectiveness analysis are available there and as a peer reviewed publication²².

O3: Good quality information for those diagnosed with dementia and their carers

5.20 The problem is the absence of good quality information to be given to people with dementia and their carers.

5.21 **Policy option:** provision of a set of information materials of relevance at different stages of dementia, for those with different types of dementia and those with different problems in dementia. The alternative of a formal "information prescription" was considered in the consultation document and rejected based on high cost and the need for information to be renewed for individuals as the disease progresses and different challenges emerge.

5.22 The centrality of good quality information given in such a way as to be accessible to patients and carers in enabling them to direct their own care is clear. Every person diagnosed with dementia and their carers need to be provided with good quality, relevant information on the illness and on the availability of local services.

5.23 **Benefits:** Overall, good quality information is valued by patients as an aid to decision-making but it should come in a variety of formats. People prefer to use it alongside discussions with a trusted professional. Involving users in designing information packs improves quality. Information itself can support carers as part of the care package, contributing to early help-seeking as problems occur so improving quality of life and enabling early intervention to prevent crises.

5.24 Buchbinder (2001) notes that provision of information through booklets or face-to-face advice can be beneficial in improving low back pain. Bekker et al review information provision and are more circumspect: 'studies were no more likely to report an effect than report no or mixed effects' (p31). Their wide-ranging HTA-funded review included eight studies of education interventions for people with mental health problems, in only one of which was information the sole additional intervention (most included increased face-to-face contact) and this resulted in increased service uptake. Another HTA review looked

at the role of written information alongside medication. Patients first wanted information to help them decide whether to take the medication, then information to help ongoing decisions about its management. The authors note that spoken information remained the priority but should it should link closely with written information (Raynor et al, 2007).

- 5.25 Baxter et al (2008) review research findings on information needs and availability for adult social care. They note the importance to making an informed choice of building up a picture of available options and comparing their advantages and disadvantages. Fotaki and colleagues in their review of links between greater consumer choice in health and quality of care found most patients believe they are given too little information about treatment options to make a choice (SDO 2007). Many patients prefer to collaborate in decision-making but value information on care options. Unfortunately, the review showed that leaflets are often considered to be of poor quality giving out-of-date and inappropriate information but their quality improved with patient involvement in the design.
- 5.26 NHS Health Scotland do not have the costs of developing or redesigning the publication 'Coping with Dementia', which was initially produced in 1995 and updated in 2006, but they would be happy to share their publication with us - text, design, photography etc – resulting in us not having to cover these costs. Since the start of the financial year in 2006 they have distributed 88,100 copies. The current unit cost is £1.92. The team is planning to develop a DVD based version and have estimated a cost of £98,000 to develop it, including pre-testing.
- 5.27 'Worried about our memory' another more recent publication has cost approximately £30,000 to develop excluding design and editing costs. This has included pre-testing costs of £12,000 for focus groups and telephone interviews, contracted out to a research company. Photography is usually estimated to cost £15,000 per publication. The DH produced a leaflet 'Questions to ask' in 2006 to raise patient awareness. The leaflet cost approximately £15,000 to develop and a further £67,000 to design and pre-test. The design, printing and distribution were contracted out to COI. Two million copies were printed, including an easy-read version.
- 5.28 Taking these data together the costs for preparing a comprehensive set of information covering all types of dementia and all stages of dementia as well as the diverse groups affected nationally and locally that would cost **£1.5 million over the first two years. Full roll-out beyond this would be subject to review of the early evidence.**

04: Easy access to care, support and advice following diagnosis

- 5.29 Current practice across health and social care is to 'discharge' the patient once they are stable and a care package is in place. The result is that care consists of a number of quite expensive individual episodes, separated in time, provided by different people who do not necessarily have an ongoing relationship (and, therefore, some familiarity with the person and their condition), and often triggered as a result of a crisis.

Policy option: dementia advisor

- 5.30 A consistent message from our consultations is that the nature of dementia – specifically the inevitable long-term decline and increasing dependency – requires ongoing support, albeit at a low level, so that a person is 'discharge' to the supervision of a care co-ordinator.
- 5.31 This is a new idea unconsidered by the NICE-SCIE guideline. We therefore lack quantitative evidence as to the effectiveness of such extra advisors in changing the

quality of life of people with dementia (and their carers) or use of services. However the desire for continuity is very strong and doing so without using expensive front line specialist teams is attractive. The evidence base is empty; it is not that such approaches have been proven to be ineffective, it is just that they are unevaluated. Generating demonstration sites and evaluation would help to address this evidence deficiency.

- 5.32 We will assess the appropriate research required and have budgeted for £4.5m over the first two years, beyond which evidence from the research will be considered before full roll-out.
- 5.33 The benefits will be of improved knowledge for providers and commissioners with which to implement the policy. During the pilot those using the service will also hopefully benefit from improved access to services.

05: Structured peer support and learning networks

- 5.34 **Problem:** lack of sources of practical advice and emotional support.
- 5.35 **Results:** poor quality of life, inappropriate use of services.
- 5.36 **Policy option:** develop third sector led peer support.
- 5.37 One of the strongest messages from people with dementia and their carers is that they draw significant benefit from being able to talk to other people living with dementia and carers to exchange practical advice and emotional support.
- 5.38 One relevant paper, a systematic review of peer-support programs for people with cancer²³, has informed our judgement as to how an evaluation of peer support for people with dementia may be conducted. The reviewers identify models of peer support for cancer patients and systematically review evidence of their effectiveness in improving psychosocial adjustment. A range of databases was used to identify relevant literature published from 1980 to April 2007. Data on characteristics of the peer-support program, sample size, design, measures, and findings were extracted and papers were also rated with respect to research quality (categories 'poor', 'fair' or 'good'). Forty-three research papers that included data from at least one group were reviewed in detail, including 26 descriptive papers, 8 non-randomized comparative papers, and 10 papers reporting eight randomized controlled trials (RCTs). Five models of peer support were identified: one-on-one face-to-face, one-on-one telephone, group face-to-face, group telephone, and group Internet. The reviewers' conclusions were that the papers indicated a high level of satisfaction with peer-support programs; but that evidence for direct psychosocial benefit was mixed.
- 5.39 This is not directly generalisable to dementia. Internet groups are not likely to work with people with dementia and there is a dementia specific literature describing the value of group and well as individual interventions. We are suggesting groups that are facilitated, organised and supported by the local third sector, but are funded as part of the range of help available locally. These groups will not run themselves but run with people with dementia and their carers. Again, it is the issue of volume that is important here with as many as 800 newly diagnosed people per year in an average sized PCT.
- 5.40 The working group has suggested a two-year phase of setting up demonstration projects and evaluating them similar to the process for the dementia advisor role to build-up the evidence base for wider dissemination. We will assess the scale of research required and have budgeted for £3m.

O6: Improved community personal support services

- 5.41 The majority of people with dementia (including the, as yet, undiagnosed) live in their own homes (Dementia UK estimate that 63 per cent of people with dementia – over 400,000 people – live in private households);
- domiciliary care services are largely focussed on people living alone who require help with the activities of daily life, but not 24-supervision, which is estimated to be about 12,500²⁴ of the 400,000
 - the remainder are living in their own homes and dependent on support from family carers with variable input from home care services.
- 5.42 **Problem:** For those people with dementia who live in their own homes the experience is of home care delivered by a rota of non-specialists who are therefore less able to observe and appreciate the significance of small changes in behaviour and cognition that are the markers for the progression of disease that a smaller, more specialised team are able to do. An additional consideration is that succession of different people presents challenges in terms of communication for someone who is increasingly confused and so a barrier to efficient and effective communication – and care. Finally, the lack of insight in dementia may mean services are refused but this is less likely when there is a coherent focussed approach from a single known individual or group of people. We therefore wish to make the current generic home care resource work as well as it can for people with dementia, augmented by the training and information and the accurate diagnoses generated by other elements of the strategy. This is relatively simple and requires no extra investment above that already planned. We also identify the need to enhance this with a resource to establish or enhance local specialist home care services for people with dementia with the highest and most complex needs.
- 5.43 A qualitative study²⁵, using semi-structured interviews, focus groups and small group interviews used ‘soft systems’ methodology to identify features which were important to stakeholders (older people with dementia, family carers, care workers and other professionals), the constraints on delivering quality care, and perceived differences between the specialist and standard service.
- 5.44 Specialist service care workers were given additional training in dementia care. The specialist service focused on clients’ overall needs, requirements and preferences, rather than specific physical care tasks. Continuing multi-disciplinary review of provision enabled care workers to monitor clients’ needs closely, adjusting care plans as necessary. When capacity was reached a waiting list operated. The specialist service demonstrated greater flexibility and responsiveness to individual circumstances.
- 5.45 Standard service provision invites a variety of undesirable consequences. The client can become a passive recipient and such depersonalized care undermines individuality and ‘personhood’²⁶. In existing generic services productive relationships between people with dementia and service providers are often not encouraged, due to lack of knowledge and skills, shortage of time, and inconsistency in staff attending. So people with dementia are often devalued and marginalised. As a consequence caregivers may detach themselves emotionally as a psychological coping strategy²⁷.
- 5.46 Venables et al²⁸ during 2002/03 as part of a cross sectional postal survey of dementia care services in the North West of England assessed services against the following

quality indicators presented in Table I below.

Table I. Standards and quality indicators assessed.

Standard/indicator	
<p>Service delivery and care process</p> <ul style="list-style-type: none"> • <i>Systematic assessment</i> Risk assessment for user is conducted; health and safety for staff is assessed; users abilities and needs assessed; planned reviews undertaken; briefing documents kept in user's home; service operates within Care Programme Approach policies; review undertaken at least every two months; care co-ordinator is given written report of review. • <i>Flexibility</i> A 24-hour service provided if necessary; live-in service provided if necessary; day and night care, seven days a week. <p>Service content</p> <ul style="list-style-type: none"> • <i>Individuality</i> Memory/life story wallets; no uniform policy for staff. • <i>Culturally appropriate care</i> Personal care; language (e.g. translated leaflets); food (e.g., specific dietary requirements); religion (e.g. providing services at appropriate times). • <i>Management practices</i> Minimum hours contract; sick pay; holiday entitlement; loyalty reward; frequent contact between hands on staff and supervisors. 	<p>Service quality</p> <ul style="list-style-type: none"> • <i>Integration</i> <i>Service shares with other services:</i> accommodation; management; <i>Service has:</i> single telephone number; single point of referral; shared assessment forms; shared care plan forms; shared client record databases system; shared case files/filing system. • <i>Care worker good practice</i> New staff receive an induction; service provides training for staff qualifications; service provides dementia-specific training to staff; supervisor contact weekly or more often; more than 60% of staff have formal qualifications. • <i>Carer involvement</i> Formal arrangements for providing support to friends/relatives. • <i>Staff training</i> Induction includes component on caring for people with dementia; more than 50% of hands on staff have specific training for caring for people with dementia; more than 60% of staff have formal qualifications; local authority assists with training. • <i>Contents of Briefing Documents</i> <i>Space on form for:</i> client need; client preferences; history; profile of client's ability in ADL; goals; changes to watch for; changes in user/carer circumstances; time log; staff names; tasks undertaken; observations; messages to other workers.

5.47 Clearly this self-report methodology is a weak one and it depends on the ad hoc development of small services in a single region but the results are encouraging for the model proposed. Table III shows the key results and the statistically significant differences between generic and specialist services detected by the study. Of the sixteen indicators tested statistically there was evidence of increased quality in the specialist service in those relating to carer involvement, integration with other services and personalisation of care, all of central importance in dementia care. Unsurprisingly the far larger generic services with unified protocols were more able to provide 24 hour and live in care and to have their documents in client's homes. Clearly both sorts of services are needed for people with dementia and it is a matter of there being task clarity between them. In any system there will be many more people with dementia and their carers supported by generic home care rather than specialist services.

Table III. Key results and areas of difference between generic and specialist home care services.

Standard/Item	Generic home care service (n = 65)	Specialist home care service for people with dementia (n = 10)	Test statistic	All services (n = 113)
<i>Systematic assessment</i>				
Briefing documents kept in user's home	56 (86.2%)	1 (10%)	$\chi^2 = 27.56, p < 0.0001$	79 (69.9%)
Service operates within CPA policies	38 (58.5%)	8 (80%)	ns	68 (60.2%)
Review undertaken at least every two months	8 (12.3%)	3 (30%)	ns	38 (33.6%)
Systematic assessment mean score (SD)	5.40 (1.27%)	4.90 (1.19)	ns	3.75 (2.96)
<i>Flexibility</i>				
24-hour service provided if necessary	48 (73.8%)	2 (20.0%)	$\chi^2 = 10.47, p < 0.01$	71 (62.8%)
Live-in service provided if necessary	22 (33.8%)	0 (0%)	$\chi^2 = 4.79, p = 0.055$	25 (22.1%)
Day and night care, seven days a week	43 (66.2%)	2 (20.0%)	$\chi^2 = 7.69, p < 0.05$	65 (57.5%)
Service flexibility mean score (SD)	1.7 (1.1)	0.4 (0.7)	$U = 118.0, p < 0.001$	1.4 (1.1)
<i>Integration</i>				
<i>Service shares with other services:</i>				
Accommodation	7 (10.8%)	4 (40%)	$\chi^2 = 5.92, p < 0.05$	27 (23.9%)
Management	6 (9.2%)	4 (40%)	$\chi^2 = 7.10, p < 0.05$	18 (15.9%)
Integration mean score (SD)	1.36 (1.86)	2.4 (2.91)	ns	1.48 (1.92)
<i>Carer involvement</i>				
Formal arrangements for providing support to friends/relatives	8 (14.5%)	8 (80.0%)	$\chi^2 = 23.66, p < 0.0001$	31 (27.4%)
<i>Individuality</i>				
Memory/Life story wallets	8 (12.3%)	5 (50.0%)	$\chi^2 = 8.59, p < 0.05$	25 (22.1%)
User-centred practice composite variable mean score (SD)	0.18 (0.46)	0.70 (0.67)	$U = 202.5, p < 0.01$	0.28 (0.53)
<i>Culturally appropriate care</i>				
Culturally appropriate care mean score (SD)	1.62 (1.46)	2.25 (1.75)	ns	1.73 (1.49)
<i>Staff training</i>				
Staff training mean score (SD)	1.28 (0.99)	1.50 (0.71)	ns	1.42 (0.97)

- 5.48 Studies considering user perspectives have identified flexibility as one of the essential dimensions of a good quality service (Francis & Netten, 2004; Godfrey et al., 2000), and evidence suggests that services for people with dementia particularly require an element of flexibility (Challis, 1993; Challis et al., 2002). Social Services Inspectorate findings of 1997 noted that generic community services for people with dementia were not always tailored towards individual need, and that specialist services were noticeably better than non-specialist equivalents.
- 5.49 Outcomes relating to specialist home care services are uncertain. There are opportunities to improve our knowledge of current practice and disseminate the learning from that more widely. We will use the evidence from the demonstration sites to model costs and benefits before making any decision about implementation.
- 5.50 We lack quantitative evidence as to the effectiveness of such extra teams in changing the quality of life of people with dementia (and their carers) or use of services. However, we are aware that there are a large number of specialist services up and down the country that are funded and functioning. These data have not been collated and evaluated; neither do we know the extent and current financing of such services. It would be of high value to do so to inform the detail of local commissioning decisions. We therefore propose a one-year project gathering, collating and analysing data on the provision of specialist dementia home care services across the country. This will require site visits across the country and given the time scale and the need to impose minimal burden on services we estimate that this project could be commissioned for approximately **£0.5 million** and completed in one year. The benefits that arise from this include both the benefits to those participating and the information derived. Our assessment is that the information we would derive would be invaluable in informing local commissioning decisions in this area.

07: Implementing the New Deal for Carers

- 5.51 The New Deal is a generic approach to the needs of carers of all kinds, but also makes specific references to the needs of people caring for a person with dementia. Our consultees, however, forcefully argued that the National Dementia Strategy itself should reinforce that message.

- 5.52 We were active contributors to the development of the carers' strategy to ensure that it, and the IA, reflected the needs of people with dementia and their carers. To avoid the impression of double-counting the costs and benefits we have therefore not attached an extra cost – or claimed benefits – to this in this strategy since the costs as far as they relate to the carers of people with dementia are accounted for in the carers' strategy.

O8: Improved quality of care in general hospitals

- 5.53 Who Cares Wins²⁹ estimates that a typical district general hospital with 500 beds will admit 5,000 older people each year and 3,000 will suffer a mental disorder. On average, older people will occupy 330 of these beds at any time and 220 of these will have a mental disorder (102 with dementia). Equally, the National Service Framework for Older People estimates that up to 70 per cent of acute hospital beds are currently occupied by older people³⁰ and up to a half of them may be people with cognitive impairment, including those with dementia and delirium³¹. The majority of these are not known to specialist health services, and are undiagnosed. General hospitals are particularly challenging environments for people with memory and communication problems, with cluttered ward layouts, poor signage and other hazards. People with dementia in general hospitals have worse outcomes in terms of length of stay, mortality and institutionalisation³². This impact is not widely appreciated by clinicians, managers and commissioners. In terms of excess cost, the NAO estimated there to be in excess of £6 million per year in an average general hospital³³.
- 5.54 There is a lack of leadership and ownership of dementia in most general hospitals. There are also marked deficits in the knowledge and skills of general hospital staff that care for people with dementia. Often, insufficient information is sought from relatives and carers. This means that person-centred care is not delivered and it can lead to under-recognition of delirium and dementia. Currently, families are often excluded from discharge planning, so false assumptions may be made about whether it is possible for people with dementia to be cared for at home. The National Audit Office found that some general hospital services worked hard not to make the diagnosis of dementia, for fear it would delay discharge³⁴.
- 5.55 The NAO³⁵ case study in Lincolnshire found that 68 per cent of people with dementia in acute beds had no further need to be there and that the average length of stay for orthopaedic patients with dementia was 44 per cent longer than for those without. Henderson et al³⁶ reported that under base case estimates, patients with fractured neck of femur and dementia had an average length of stay of 43 days, while those judged on admission to be psychiatrically well stayed 26 days. Huusko et al (2000)³⁷ in an RCT of intensive specialist multidisciplinary rehabilitation of older people with hip fracture achieved the median length of hospital stay of patients with hip fracture who had moderate dementia was 47 days in the intervention group and 147 days in the control group (P=0.04). The corresponding values for patients with mild dementia were 29 days in the intervention group and 46.5 days in the control group (P=0.002).
- 5.56 Poor care can lead to malnutrition and dehydration for people with dementia, an outcome highlighted in the Age Concern England report³⁸ *Hungry to be Heard*. Many examples were cited during the consultation on the dementia strategy of people with dementia being left without assistance to eat or drink. As part of the Dignity in Care campaign, the Department of Health has produced a Nutrition Action Plan to which the key national organisations have signed up and which addresses issues of raising awareness, guidance, screening, training and inspection and regulation. The action plan and supporting materials are available at www.dignityincare.otg.uk.

5.57 There is often a lack of co-ordination between hospitals and care providers at the point of discharge, with delay in access to care packages such as home care and intermediate care that might enable successful discharge. There is a clear need therefore to improve the quality of care provided for people with dementia in general hospitals. Three ways suggested as having the potential to deliver further improvements are:

- the identification of a senior clinician within the general hospital to take the lead for quality improvement in dementia in the hospital
- the development of an explicit care pathway for the management and care of people with dementia in hospital, led by that senior clinician; and
- commissioning specialist liaison older people's mental health teams to work in general hospitals

Policy options - psychiatric consultation-liaison intervention:

5.58 Strain et al³⁹ reported that an input of 2.39 hours per patient on average of psychiatrist's time can lead to a reduction in average length of stay of 2.2 days and that psychiatric liaison screening of elderly patients with hip fractures would shorten the average length of hospital stay. The mean length of stay was reduced from 20.7 to 18.5 days at Mount Sinai hospital and from 15.5 to 13.8 days at Northwestern.

5.59 The provision of such services is already accepted as best evidence-based policy and practice as set out in the policy guide Everybody's Business and the NICE/SCIE guideline on dementia services⁴⁰. They can provide rapid high quality specialist assessment and input into care planning for those admitted to general hospitals, including input into ongoing care and discharge planning. They will generally consist of a multidisciplinary team of three to four full time members of staff (part time consultant, staff grade doctor, nurse and psychologist/therapist) with administrative support and a base in the general hospital. These teams can then work closely with the designated general hospital lead to build skills and improve care through the hospital. They need to have good links with the social work assessment teams based in or linked to the hospital. They are already provided in some but by no means all hospitals. Mental health care in Accident and Emergency departments is often focused on self-harm and acute psychosis in adults of working age. There is a clear need for services to be commissioned with skills in the diagnosis and management of dementia as well to work on the wards.

5.60 There is no doubt that such services are of value and should be provided. There is however currently considerable diversity in the models adopted and the nature and scope of the work completed by such liaison services in general hospitals. We are aware that there are a number of specialist services up and down the country that are funded and functioning. These data have not been collated and evaluated; neither do we know the extent and current financing of such services. It would be of high value to do so to inform the detail of local commissioning decisions. We therefore propose a one-year project gathering, collating and analysing data on the provision of specialist older people's mental health liaison services across the country. This will require site visits across the country and given the time scale and the need to impose minimal burden on services we estimate that this project could be commissioned for approximately **£0.7 million** and completed in one year.

5.61 We have therefore profiled into the implementation of the strategy a one-year period for the collation and synthesis of the evaluative data available on the services that currently exist in order to inform future commissioning decisions as to the precise content of any

services that should be commissioned locally, Following the outcome of this exercise, we will make detailed estimates of the costs and benefits of any widespread implementation.

Care pathway development

5.62 The care pathway for the better management of people with dementia should be developed in consultation with local social services and user and carer organizations including pathways out of hospital. It could specify the arrangements for local leadership and accountability for dementia in general hospitals and core competencies for all general hospital staff in contact with people with dementia (including Patient Advice and Liaison Services (PALS) and Local Involvement Networks (LINks) could be included, and training around these competencies. There is no extra cost for this other than that described below.

Building leadership in acute hospitals

5.63 To respond to the observed weaknesses in the response to people with dementia in the general hospital setting we envisage that a senior clinician would take responsibility for developing a dementia care pathway, appropriate to the circumstances of the hospital, and provide the leadership within the hospital to ensure that the care pathway is implemented and kept under review so that it remains fit for purpose as circumstances change. We have assumed that a senior clinician in each of 300 hospitals would need to devote one programmed activity of their time to leading the development and delivery of a specific care pathway.

5.64 The total cost of this time is estimated at around **£3 million a year**. This excludes any additional costs that would be incurred for the delivery of such a care pathway over and above the costs currently associated with treating patients. The cost will be 1/10th a consultant a week in 300 hospitals, or 30 FTEs (England) for one year this comes to £3 million (30 x £95,400), plus some on-costs related to the collation/analysis of the data. Assuming that this would be £200k then the costs for this would be **£3 million**.

O9: Improved intermediate care for older people

5.65 The Commission for Social Care Inspection (CSCI) reported that people with dementia who are admitted to hospital when home care breaks down are more likely to experience delays in discharge from hospital and are often discharged from hospital to a care home⁴¹, in part because of an assumption that this is the best – or only – safe option (especially where capacity and capability to deliver good quality home care is also lacking) but also to relieve pressures on acute beds.

5.66 The NAO have found that

- people with dementia are estimated to make up half of people who remain in hospital unnecessarily
- only 58 per cent of community mental health teams work closely with acute trusts to manage discharge
- in one area, 68 per cent of people with dementia in acute beds did not need to be there, and the average length of stay [in hospital] for people with dementia was 44 per cent longer than for older people without dementia.⁴²

5.67 Another source⁴³ reports that over 13 per cent of functional mental illness beds and over 28 per cent of organic assessment beds were occupied by people whose discharge had been delayed.

- 5.68 Intermediate care has a twofold role in tackling this problem as it can be used as an alternative to
- hospital admission (so-called 'step-up' care) for people who need a short period of care to address a health problem before it become so serious that admission to an expensive acute bed is necessary, and
 - time-limited care and support in a non-acute setting on discharge from an acute bed (so-called 'step-down' care), including allowing the individual and their family a 'breathing space' so that they are not rushed into premature admission to residential care when – with appropriate support – a return to their own home is both possible and safe.
- 5.69 The research evidence on the effectiveness of intermediate care for other groups points to success at reducing unnecessary in-patient episodes, reducing lengths of stay and enabling people to return safely to their own homes rather than being diverted into residential care. Henderson et al (2007) found evidence to suggest that a Hospital at Home package leads to a reduction in length of stay of 6.9 days per patient. While it is true that it is sometimes necessary to admit people with dementia to hospital because of their dementia (perhaps to stabilise behaviour that cannot be managed safely or effectively in any other setting), people with dementia have all the same health problems as other older people (if not more) and so experience disorders and injuries that require hospital care. So, for example, a person suffering injury because of a fall may be admitted to an orthopaedic ward where all necessary and appropriate care for the injury will be delivered by appropriate specialists. What is sometimes absent is an appreciation that there may be a causal relationship between the fall and undiagnosed dementia or that – even where there is no causal relationship between the individual's dementia and the immediate reason for the admission – there is the possibility of rehabilitation for people with dementia enabling them to return home, if properly supported. This often results in reflexive and unnecessary care home use and extending hospital stay length.
- 5.70 Up to 70 per cent of acute hospital beds are occupied by older people⁴⁴ and up to half of those may have a cognitive impairment (including dementia and delirium)⁴⁵. The Royal College report Who Cares Wins also identified the fact that people with dementia in general hospitals have worse outcomes in terms of mortality and institutionalisation⁴⁶, but that this is not widely recognised by clinicians, managers of commissioners.
- 5.71 Most evaluations of intermediate care exclude people with dementia and there is a wide range of services included in this category. For those with acute health problems such services facilitate earlier discharge. They are likely to result in more patients returning home (rather than long-term care) by maintaining personal independence through rehabilitation, and through provision of tailored support packages. There is very little literature specifically on intermediate care for people with dementia (Patterson, 2004). One evaluation of intermediate care after an acute health problem in five areas found no impact on high-level performance indicators and long lead-in times (Godfrey et al, 2005). However, once set up the service generated substantive changes in the service delivery structure and high levels of commitment among operational staff, making a significant difference to people's lives. More than two-thirds of the patients studied returned home after discharge from the intermediate care service.
- 5.72 Godfrey and colleagues suggest a move away from thinking about the location of an intermediate service towards considering a local service configuration that would allow people to flow through appropriate service routes. This study identified 50 intermediate care services in five sites that were used in various combinations for various lengths of

time (see also Patel et al, 2003; Martin et al, 2004). Six vignettes were developed to describe the typical pathways. Costs (at 2002 prices) varied from £722 for a 12-day use of a rehabilitation-at-home service to a pathway that included 85 days (exceeding policy recommendations of a period not normally exceeding six weeks) residence at a community rehabilitation unit costing a total of £10,785. Costs for the other vignettes were £881, £2544, £6377, £6585. These totals excluded the considerable input from informal carers. Intermediate care was followed by increased service use (GP, day centres, district nurse, home care, outpatients, physiotherapy) up to 12 months post-admission to Intermediate Care. Episode costs for an admission to an intermediate care nursing home were £2216, and £4553 for an episode of care at an intermediate care residential home (2003 prices). Non-residential services were considerably cheaper to the public purse at £304-£447 per episode. Curtis and Netten (2007) suggest the average cost per episode for a local authority intermediate care service based in a residential home is £3780 [54 days * £70 per day].

- 5.73 Compared to routine care, a joint NHS/Social Services intermediate care unit found costs over 12 months to be similar for the two groups (around £8500; 2000 prices) as were the outcomes, measured as days survival in the community, quality of life, coping ability, although the unit did appear to facilitate earlier discharge from hospital (Ellis et al, 2006; Trappes-Lomax et al 2006). Costs to social services were higher for those using the unit but higher to the NHS for those using routine care. In their review of services for older people with dementia, Godfrey and colleagues (2005b) cite a UK study that compared nursing home 'intermediate care' (aimed at rehabilitation and discharge back home) with 'home for life' nursing home care (permanent institutional care) for people with dementia. They found that the behaviour of those admitted to both types of care deteriorated over 12 months but those in the intermediate care group deteriorate more. Neuroleptic medication prescription was significantly higher in intermediate care, as was mortality. Residents' quality of life and well-being were not assessed.
- 5.74 In this element of the strategy we have two aims. First to make existing intermediate care work for people with enabling access to existing resources. Pathways out of hospital and avoiding hospital, such as intermediate care, often exclude people with dementia, meaning that they cannot access rehabilitation services that could enable them to return home or prevent their admission to hospital. Specialist intermediate dementia or mental health care services that enable discharge from the general hospital setting are rare. Both factors appear to stem from a misunderstanding of the Department of Health guidance in this area. Staff working in intermediate care are often reluctant to offer people with dementia the opportunity to benefit from the service because they feel they are likely to need longer than the usual six weeks, and therefore are perceived to not meet the criteria. This is an erroneous interpretation of the Department's guidance. Also problematic is the false assumption that people with dementia cannot benefit from rehabilitation. Criteria for services have therefore often specifically excluded people with dementia. Pressures to reduce lengths of stay in acute care, combined with risk-averse discharge planning, can mean that people with dementia are rushed into long-term residential care prematurely.
- 5.75 The Department is already reviewing and updating its 2001 guidance to reflect the new policy landscape and to correct misconceptions. We will take the opportunity to ensure that the revised guidance gives proper emphasis to the needs of people with dementia and their carers. It will make explicit the need to enable people with dementia to access intermediate care, whether through support to mainstream services for people with physical rehabilitation needs or by developing specialist intermediate care for people with more advanced or complex mental health needs. It will take account of the acute care pathways developed through the Next Stage Review and the prevention and early intervention agenda of Putting People First. The new guidance is scheduled to be

available in the spring of 2009. No extra funds are required for this since the services and the policy support needed are available via existing intermediate care structures.

- 5.76 Secondly, there will however be a need to increase slightly the capacity of intermediate care services to allow for dementia specific services. We are suggesting that Intermediate Care could and should be used for a small group of people with dementia, including some needing specialist dementia intermediate care, equivalent to about 2.5 per cent of current capacity. An intermediate care episode costs about £3,780 and we have estimated that the unmet need for intermediate care for people with dementia (those who remain in hospital longer than they need to for lack of such services) is about 10,100 (about 2.5 per cent of the number of episodes of Intermediate Care in 2006/07⁴⁷) and so the total cost is around **£38 million a year**. This does not include any offsetting savings from reduced use of acute services.

O10: Housing and telecare for people with dementia

- 5.77 There are substantial programmes of work across Government on the development of housing services for older people including those with dementia and also in investigating the potential value of telecare, telemedicine and other assistive technologies. These are generic approaches that address the needs of people with all health and social care needs, but they also make specific references to the needs of people with dementia. Our consultees strongly argued that the National Dementia Strategy itself should reinforce positive messages in this area so we have done by including as an outcome message that the needs of people with dementia and their carers should be included in the development of housing options, assistive technology and telecare. As evidence emerges commissioners should consider the provision of options to prolong independent living and delay reliance on more intensive services.
- 5.78 There has been little research conducted into the role of supported housing in dementia care. Nevertheless, those studies that have been conducted demonstrate that, overall, people with dementia can benefit from the support offered in sheltered and extra-care housing. They are not always offered this opportunity. A study in 1995⁴⁸ found that sheltered housing could offer a positive environment to people with dementia, if appropriate opportunities for social interaction are available. The role of housing staff was identified as critical in the integration of tenants with dementia.
- 5.79 More recently⁴⁹ the importance of flexible care packages in meeting the needs of people with dementia in extra care housing has been demonstrated. Many areas are now offering this sort of flexible, responsive care package through floating support services. Many residents with dementia in sheltered or extra care housing have complex health and care needs. The Housing Corporation/Housing 21 study found that these needs could be met where health, social care and housing worked together to provide a whole system strategy, although the researchers acknowledged that this remains a key challenge in supported housing.
- 5.80 The evidence base on design principles is sparse, but there is consensus on key principles and a number of good practice checklists are available. There is a more substantial evidence base to show the opportunities offered by assistive technology and telecare to support people with dementia to remain independent for longer and in particular to help the management of risk. However, the data on newer approaches is still sparse and inconclusive. An evaluation of one scheme demonstrated cost-effectiveness and reports of improved quality of life⁵⁰. Large-scale DH field trials of such technology are underway.

5.81 This is an evolving field but one that is of potentially high and central importance in enabling people with dementia to live well with dementia. Much that is being done currently is positive in terms of housing options and assistive technologies that are part of mainstream care for people with dementia and that contribute to their independence and safety. However, with respect to more recent innovation this is not an area where the strategy is able at this time to make specific recommendations. Instead central, regional and local teams should keep in touch with initiatives in the areas of housing and telecare and make appropriate commissioning decisions as data becomes available, for example when the Department publishes the findings of its large-scale field trials of telecare and assistive technology. Consequently, there is no extra cost attached to this element of the strategy at this time.

O11: Living well with dementia in care homes

5.82 A third of people with dementia live in care homes and at least two thirds of all people living in care homes have a form of dementia. This state of affairs has not been planned for, either through commissioning services or through workforce planning. The need for workforce development is profound, and training in this area is covered elsewhere. This objective focuses on: making dementia an explicit owned priority within care homes; enabling a minimum standard level of input into care homes from specialist mental health services for older people; and using the inspection regimes to drive up care quality.

5.83 For all its problems, residential care may be the most appropriate and effective way of meeting someone's needs and a service of choice. There are care homes that provide excellent care for people with dementia. Such homes generally pay close attention to leadership and staff management; staff training and development; and provide physical environments that enable people with dementia to move around the home safely. They provide purposeful activities that relate to individual preferences rather than mass entertainment; actively involving relatives and friends in the care of residents; and develop strong links with and involvement in local communities. They do so at the same unit cost of those that do poorly.

5.84 However, evidence from the Alzheimer's Society Home from Home report⁵¹ suggests that:

- 54 per cent of carers reported their relative did not have enough to do in care homes
- the typical person in a care home spent just two minutes interacting with staff or other residents over a 6 hour period of observation (excluding time spent on care tasks)
- the availability of activities and opportunities for occupation is a major determinant of quality of life affecting mortality, depression, physical function and behavioural symptoms, but that these are seldom available; and
- staff enjoy providing opportunities of activity and occupation and would like to be able to do more of this within their work but do not feel they have the time.

5.85 The report found that maintaining good relationships between the relatives and the home and supporting the ongoing relationship between relatives and the person with dementia have important benefits for both parties, including carers' degree of stress, residents' quality of life and engagement in activity. A study by CSCI in care homes has shown the quality of staff communication with people with dementia has a major impact on their quality of life. Leadership, ethos of the care home, staff training and support and development are the crucial factors in supporting good practice⁵². Commissioners can

develop service specifications with providers that include these key factors, and identify how performance will be assessed in contract monitoring and evaluation.

Policy option: leadership in care homes

- 5.86 There is a lack of leadership and ownership of dementia in care homes. There are also marked deficits in the knowledge and skills of staff that care for people with dementia. Often, insufficient information is sought from relatives and carers. This means that person-centred care is not delivered and it can lead to under-recognition of needs. Currently, families are often excluded from care planning. To respond to the observed weaknesses in the response to people with dementia in care homes we envisage that a senior clinician would take responsibility for dementia care within each home, and provide the leadership within the home to ensure that the good quality care is implemented.
- 5.87 However, prior to instituting this there is a need to develop materials with which to help these people take on this role. We have therefore profiled into the implementation a one-year project to assess implementation and to develop leadership and quality care aids for care homes costed at **£1.5 million over two years**. Costs and benefits of rolling this out will be assessed at this stage.

Dementia care in care homes

- 5.88 The mental health needs of people living in care homes are extensive and generally not well met. Up to 75 per cent of residents in non-specialist care homes for older people have dementia⁵³ and the prevalence rises to between 90 and 95 per cent in homes for the elderly mentally infirm⁵⁴. In addition, an estimated half of all care home residents has depressive disorders that would warrant intervention⁵⁵. Behavioural disturbance in dementia in these settings is both very common and a cause of stress to residents and staff. It is striking that there is very little in the way of active non-pharmacological management of these problems in these settings, despite accumulating evidence of the effectiveness of old age psychiatric intervention⁵⁶. Current input from mental health services is generally on an ad hoc basis or reactive with referrals at times of crisis.
- 5.89 One issue that is of particular concern is the use of anti-psychotic medication in care homes for the management of behavioural and psychological symptoms in those residents with dementia. Those criticising current practice include the Parliamentary Accounts Committee⁵⁷, the Alzheimer's Society⁵⁸ and the All Party Parliamentary Group on Dementia⁵⁹. It appears that there are particular risks that are serious and negative in the use of anti-psychotic medications with people with dementia. These include increased mortality and stroke. There is accumulating evidence that in care homes they are initiated too freely, that they are not reviewed appropriately following initiation, and that they are not withdrawn as quickly as they could be. However, it is also the case that behavioural problems in the dementia can be dangerous and disruptive and in some cases medication is the least worst option. Improving the quality of care in care homes requires this issue to be addressed effectively.
- 5.90 In response to the widespread concern at inappropriate use of anti-psychotic drugs for people with dementia, the Minister for Care Services, announced a review on the issue of the use of antipsychotic medication for people with dementia in June 2008. This review is underway and it is expected to complete its work and issue a full public report early in 2009.
- 5.91 In the course of developing the strategy one means of addressing these problems suggested could be a system of regular specialist mental health assessment following

admission and regular review for this vulnerable population. This would enhance the quality of care by providing a regular forum for discussion between nursing staff, GPs and mental health teams to identify and manage the mental health problems of care home residents. Any intervention would need to be in partnership with the GPs responsible for care within care homes. In this system, the quality of mental health care for residents in care homes could be improved by:

- detailed specialist assessment of mental health needs following admission
- regular 6 monthly mental health reviews of residents in conjunction with the GP and nursing home staff
- providing access to specialist advice for problems arising between reviews to prevent problems by means of a regular pattern of visiting
- formulation and deployment of non-pharmacological management strategies for behavioural disorder in dementia, so avoiding the initiation of anti-psychotic medication
- specialist input into decision making concerning the initiation, review and cessation of anti-psychotic medication for people with dementia
- rapid specialist review of all those with dementia initiated on anti-psychotic medication
- rapid specialist response to problems as they occur within homes; and
- assessment of the residential care provided and the potential for improvement to create a more therapeutic environment.

5.92 All the above would act to minimize the use of such medication and improve the quality of dementia care more generally. Commissioners could achieve this by commissioning an extension of the existing role of the old age community mental health teams building on existing capacity, rather than by setting up a separate service.

Policy option: in-reach specialist mental health services

5.93 In-reach services delivered by a Community Psychiatric Nurse (CPN) or other multidisciplinary team member could visit each care home once a month (or more or less pro rata based on size). The service could provide support for the care home staff and assist with the preparation of care plans that are appropriate to the needs of the individual as detailed above. One recent randomised controlled trial (RCT) explored the impact of an in-reach service on people with dementia living in residential homes⁶⁰. The intervention group of homes received a very limited liaison input of 1 hour per week to deliver a personalised intervention package over 20 weeks (approximately 5 minutes per resident/week).

5.94 While the reduction in unmet needs was not statistically significant, unmet needs decreased considerably in the intervention homes, they also reduced to a lesser extent in the control homes. Reviewing this study, it was small and statistically underpowered to identify a clinically significant change. Despite this, the authors reported a decrease in case level depression and anxiety fell in the intervention group, both priority targets for intervention. Other unmet needs such as sensory problems, mobility and drugs were also especially reduced in the intervention group at follow up.

- 5.95 Ballard et al (2002)⁶¹ reported on the effectiveness of a psychiatric liaison service delivered by a full time psychiatric nurse who undertook weekly visits to a number of care homes. On quality of care, there was a significant reduction in the magnitude of decline of expressive language function in the people receiving the liaison service.
- 5.96 **Costs:** modelling on the basis that each care home will receive one visit per month by a grade 6/7 CPN (or more or less pro rata based on size of home). It is assumed that an extra four CPNs per PCT will be needed at an annual cost of around £59,000 each, including on-costs. This in-reach service costs around £60 per care home visit. Overall, the long run annual cost of improving specialist in-reach services for all care homes on this basis is therefore around **£35 million per year**.
- 5.97 **Benefits:** The in-reach service will enhance the quality of care in care homes by providing a regular forum for discussion between nursing staff, GPs and mental health teams to identify and manage the mental health problems of residents. Most care homes have a contract with a GP who visits once or twice a week to provide medical care for the residents. Such intervention would enhance their ability to deliver good quality dementia care. Other benefits from the recommendation are likely to include:
- decrease in the use of anti-psychotic medication in people with dementia
 - a reduction in common unmet needs in older people: memory, eyesight/hearing, continence, mobility and psychological distress
 - a decrease in the number of people in care homes with case level depression and/or anxiety
 - earlier detection of illness, which may enhance the effectiveness of treatment. This may impact positively on residents health and quality of life and also reduce the number of avoidable emergency hospital admissions
 - residents requiring fewer GP contacts, and a reduction in the number of days in psychiatric inpatient facilities. This may produce a cost saving for the NHS.

O12: Improved end of life care for people with dementia

- 5.98 The End of Life Care strategy is a generic approach to the needs of all people at the end of life, but also makes specific references to the needs of people with dementia. The need for quality improvement in the end of life care of people with dementia is clear. Our consultees strongly argued that the National Dementia Strategy itself should reinforce that message.
- 5.99 We were active contributors to the development of the End of Life Care strategy to ensure that it, and its IA, reflected the needs of people with dementia and their carers. To avoid the impression of double-counting we have therefore not attached an extra cost to this in this strategy since the costs as far as they relate to the carers of people with dementia are accounted for in the carers' strategy.

O13: An informed and effective workforce

- 5.100 The need for improved training is a priority that runs across all the themes in the strategy. It is its own objective here to emphasise its central importance. Two major criticisms

were made by people with dementia and their carers during the consultation process. First, those professionals who should have been there to help them get a diagnosis did not seem to have the skills and knowledge needed to do so. Second, that professionals often seemed unable to understand that what works for people without dementia may well not work for people with dementia, and that professionals are often unable or unwilling to adapt their practice to make it work for people with dementia.

- 5.101 Two thirds of people with dementia live in their own homes or those of carers, and a third live in care homes. People with dementia access all services and so need informed understanding and support from all the services they come into contact with, not only from specialist dementia services. Awareness and skills are therefore needed in all sections of the workforce and society (eg housing, emergency services, employers, utilities, benefits agency staff, public sector services, GP receptionists, criminal justice system staff) not just those involved with dementia care. A lack of understanding of dementia in the workforce, whether in mainstream or specialist services, can lead to care practices that can make the situation worse for both the person with dementia and their carers. Providing adequate training and support is likely to improve staff morale and ease recruitment and retention problems in dementia care. The top challenges to providing good dementia care from a care home manager's point of view are developing a staff team with the right attributes and skills and keeping them motivated⁶².

Commissioning a trained and competent workforce

- 5.102 People with dementia and their carers need to be supported and cared for by a trained workforce, with the right knowledge, skills and understanding of dementia to offer the best quality care and support. The challenge is for professional colleges and bodies, commissioners and learning consortia to take action to ensure that we have a workforce able and supported to deliver the changes over the five-year life of this strategy. For social care workers the Department of Health Adult Social Care Workforce Strategy will be a force for change. Skills for Care, the General Social Care Council, the Social Care Institute for Excellence and the new Skills Academy all have a role to play in developing the standards and skills of the social care workforce, and can be commissioned to drive forward improvement.
- 5.103 Action can also be taken in the short term. PCTs and local authorities need to commission a trained and competent workforce using regional and local workforce development resources. Core competencies could be developed to train staff that are not professionally qualified or registered. This would also help care organisations identify learning and development needs; focus learning providers on producing courses that have content the sector needs; and assist regulators and commissioners in identifying quality in dementia care.
- 5.104 In the medium and longer-term curricula for undergraduate professional qualifications, and continuing professional development, for health staff, doctors, nurses and therapists, and social care staff should all contain modules on dementia care. Training should enable an understanding of the diversity in dementia including younger people with dementia, those that have dementia and a learning disability, and those that are from black and minority ethnic backgrounds. There is currently a range of training and education providers in dementia care but there is no nationally recognised system of quality assurance. Some form of 'kite-marking' of good practice would assist commissioners and care providers in selecting effective training.
- 5.105 Here we consider the nature and cause of the problem, and review the evidence on possible interventions. There is evidence of GPs and clinicians lacking knowledge of dementia but evidence is limited on the effectiveness of providing training. Dementia training in care homes is low, partly due to high staff turnover. However, the evidence

appears to support dementia training as an intervention, through better care and reduced use of antipsychotic drugs.

- 5.106 Rationale: All professional and vocational staff working with older people should have an understanding of dementia that allows them to meet the needs of all people with dementia and their carers effectively. Skills should be developed and sustained through their core training.
- 5.107 After qualification, GPs are required to complete a certain number of hours CPD each year, but there is no requirement to spend any of these on older people's mental health. Evidence suggests only a few GPs may have undertaken additional training in dementia. There is no official figure on the number of GPwSI (GPs with special interest) in dementia, however it is thought to be very small⁶³. There is evidence to show GPs lack skills and knowledge in supporting people with dementia. In one study, only 31 per cent of GPs believe they have received sufficient basic and post-qualification training to diagnose and manage dementia⁶⁴. Where professionals working in acute or geriatric services do not have sufficient knowledge of mental health care, they may choose to transfer people to care homes at the first indication of a mental health problem.
- 5.108 Despite the fact that the majority of care home residents have dementia, there are yet no clear standards of the required level of dementia care training⁶⁵. Dementia is associated by care home staff with challenging behaviours. Although training is widely available in the UK care homes may have difficulty in releasing staff for training in non-pharmacological approaches that are not required as mandatory training. Likewise, dementia training is currently not a requirement for care home staff, so is not a priority for care homes.

Summary

- 5.109 There would be three elements to the costs of this workforce development objective. First, in developing the strategy we have become aware of the complexity in making change to undergraduate and vocational curricula and in terms of securing the ability to deliver training in social care settings, especially those that are outsourced or provided by private companies. We have therefore made such change a longer-term goal that needs to follow a period of at least two years detailed consultation and joint development work co-ordinated by the Department but including all training providers. We have costed this work on analysis and training development at **£1 million per annum for two years**. Following this work a specific Impact Assessment will be prepared on this subject. Any subsequent spend would also need to take into account the one-off costs associated with updating the core medical curricula and National Vocational Qualifications (for non-medical care staff). and costs associated with the ongoing costs for Continuing Professional Development (CPD) for home care staff, care home staff and staff on hospital wards.

O14: Joint local commissioning and World Class Commissioning

- 5.110 This is more a process than an objective. As people with dementia will live with their condition for a number of years, and their care needs will change over time, their need for health and social services will change. It is important therefore for PCTs and local authorities to consider the need for the commissioning of coherent joint services. The joint commissioning strategy for dementia should be based on a Joint Strategic Needs Assessment. This needs to specify the quality outcomes required and should be developed in consultation with people with dementia and their carers.

- 5.111 It should feed into the operational plans and budget cycles of PCTs and local authorities, and demonstrate how they plan to improve services for people with dementia. It should be informed by guidance in the World Class Commissioning Framework and specific guidance on world class commissioning for dementia developed to support this Strategy Putting People First guidance. As a local priority, local authority, PCT, and practice-based commissioners should lead the development of an integrated pathway of care, specifying the elements of the pathway against which services will be procured and performance managed.
- 5.112 Joint local commission and aspiring to World Class Commissioning – in the context of Joint Strategic Needs Assessment and Local Area Agreements – are essential parts of the day-to-day business of local commissioning arrangements. In cost terms, given that such work is a core function of commissioners, the funds needed are available are part of commissioners' existing resources. This therefore attracts no extra cost.

O15: Performance monitoring and evaluation, including inspection

- 5.113 Following the establishment of the Care Quality Commission, a new independent assessment and inspectorate regime "Comprehensive Area Assessment", will be introduced from April 2009. This will put a greater focus on public experiences and perspectives than has hitherto been the case. The Care Quality Commission will be able to inspect across health and social care services, and primary and secondary care, and will therefore have a crucial role in driving up standards, particularly in conditions such as dementia that span health and social care.
- 5.114 Respondents to the consultation consistently represented a need to align the inspection and monitoring arrangements of the Care Quality Commission with the National Dementia Strategy and we are working with them to do so.
- 5.115 All funds necessary for the inspection regimes are included in their current budgetary arrangements and the NDS will impose no new burdens. Therefore, to avoid double-counting no extra cost has been attached here.

O16: A clear picture of research evidence and needs

- 5.116 This is an action rather than a funding commitment. There has been a clear and consistent message from the consultation of the need to build the research base in dementia. There has been a growth in public, industrial, and charity funding of dementia research but it appears that the level of funding lags behind other major priorities such as cancer and heart disease. The need for further research has been identified across a wide range of disciplines; including medicine and biology, assistive technology to support care giving and non-clinical support, and the design of the built environment for people with dementia . The potential and the importance of research in this area have been clearly articulated by the Department for Innovation Universities and Skills Foresight Programme.
- 5.117 In February 2008, the MRC conducted a strategic review of neurodegeneration research. The aim of the review was to formulate strategic advice to the MRC Neurosciences and Mental Health Board on the changes in health need, new scientific opportunities and the most important research and training questions that the MRC/UK could address. Following on from this, at the beginning of October 2008, the MRC and the Wellcome Trust launched a £30 million joint call for collaborative and innovative interdisciplinary

proposals in neurodegeneration. The focus of the call is on advancing understanding of biological processes underpinning neurodegenerative diseases. The aims of call are to: create consortia comprising leading UK research groups wherever base; facilitate interdisciplinary approaches to address key gaps in our knowledge of the biological basis of neurodegenerative diseases; and catalyse development of new approaches for diagnosis and interventions.

- 5.118 The Dementias & Neurodegenerative Diseases Research Network (DeNDRoN) was established in September 2005 as part of the UK Clinical Research Network. The aim of the Network is to facilitate research by bringing about focused, effective investment to enhance NHS research infrastructure, and to increase collaborative working between academics, clinicians, patients, carers and research funders. It builds on strengths already present in the UK as well as increasing general capacity in the field of dementia and neurodegeneration and covers major diseases including the dementias, as well as Motor Neurone Disease, Parkinson's disease and Huntington's disease
<http://www.dendron.org.uk/index.html>.
- 5.119 Between 2002-2006 the MRC invested £150 million in neurodegeneration research of which 21 per cent (£32 million) was spent on the dementias. The *Biotechnology & Biological Sciences Research Council (BBSRC)* funds research relevant to understanding normal human function. Neurodegeneration related research funded by BBSRC includes neuronal damage & repair, neurogenesis; cognitive dysfunction & decline; research underpinning Alzheimer's/Parkinson's and research into transmissible spongiform encephalopathies (TSE). Their estimated spend on all the above between 2004-07 was £11 million. The Department of Health in 2006/07 spent £22.8 million on dementia research under the Departments national research programme including infrastructure support for DeNDRoN. Charitable funding includes The Wellcome Trust, the UK's largest charity funding biomedical research that in 2007 funded £23 million across research in neurodegeneration. The Alzheimer's Research Trust spends approximately £3 million per annum on Alzheimer's/dementia related research and the Alzheimer's Society approximately £1.5 million per year.
- 5.120 In recognition of the importance of this area, DH with MRC will convene a summit of all relevant organisations funding, conducting and using research into dementia to consider dementia research and the potential for further development and co-ordination. This is in recognition that dementia is now one of the most significant challenges facing our society and in support of this strategy. This would enable a focus on how research funders, charities and industry could work together to deliver the programme of dementia research needed on prevention, cause, cure and care. The costs of this conference will be bourn from existing DH/NIHR/MRC funds. There is no commitment to extra research funding. This is therefore rated at no extra cost in this IA.

O17: Effective national and regional support for implementation of the strategy

- 5.121 The Department will provide regionally based diagnostic advice and improvement support to local health and social care economies to implement the national dementia strategy. The regional teams will work with the regional tier to identify localities within the region, based on local authority areas, that require help to implement the strategy, using agreed criteria (such as absence of a designated memory service, numbers on GP QOF registers, high numbers of admissions to residential care direct from hospital, evidence of poor partnership working). They will develop effective links with PCT and SHA leads for the delivery of the Darzi regional visions, some of which include specific pathways for dementia. Similarly they will make the necessary links with local authority

leads to ensure coherence with the Putting People First agenda, working in collaboration with JIPs and REIPs.

5.122 A national team will co-ordinate the programme and oversee production of materials to support implementation, using web based materials and networks as well as running workshops and conferences. They will provide additional assistance at a national level, based on particular themes in the strategy. For example, the Strategy emphasises the need to improve the quality of residential care for people with dementia and also addresses the issue of the use of anti-psychotic medication for people with dementia. Improvement support will need to reach commissioners, care managers, specialist mental health teams, residential care staff, home managers and medical staff. Whilst much of this will be developed and provided in the regions according to local needs, there will also be some core support materials that will be needed everywhere. Producing these nationally will avoid duplication and make best use of resources.

5.123 In addition, it is essential that a uniform set of measures are developed centrally to ensure that future arrangements for monitoring and performance management through, for example, the National Indicator Sets for Local Authorities and Local Authority partnerships and the 'Vital Signs' (used to performance manage NHS bodies). This is a key task for the central support team.

5.124 This has been costed at **£2 million per year**.

Costs of individual recommendations of the strategy

5.125 Some elements of the Strategy require no additional inputs beyond those described in other strategies for which Impact Assessments (covering the costs and benefits for whole populations, including people with dementia and their carers) or have no cost, as follows.

O7: Implementing the New Deal for Carers See the Impact Assessments for the new deal for carers
O10: Considering the potential for housing support, housing-related services and telecare to support people with dementia and their carers See the Impact Assessment for Lifetime Homes, Lifetime Neighbourhoods
O12: Improved end of life care for people with dementia See the Impact Assessment for the End of Life Care Strategy
O14: Joint local and World Class Commissioning
O15: Improved registration and inspection of care homes and other health and social care services for people with dementia and their carers.
O16: A clear picture of research evidence and needs

Summary

5.139 A summary of the National Dementia Strategy objectives is given below:

- O1 - a public information campaign seems effective/cost effective
- O2 - memory clinics may be cost-effective
- O3 - information provision – limited direct evidence but necessary activity
- O4 - dementia advisor – demonstration work to inform commissioning
- O5 - peer support – demonstration work to inform commissioning

- O6 - specialised home care – limited evidence base but high support needs collation and evaluation of current practice to inform commissioning
- O7 - implementing New Deal for carers – no new additional inputs required above those already accounted for in the Impact Assessment for that strategy
- O8 - general hospital support - collation and evaluation of current liaison practice to inform commissioning
- O9 - intermediate care – limited evidence but strong equity argument
- O10 - housing and telecare – no new additional inputs required above those already accounted for in the Impact Assessment for those strategies
- O11 - care home interventions – evidence of effectiveness for liaison services, need to develop leadership aids for care home need to be developed
- O12 - end of life care – no new additional inputs required above those already accounted for in the Impact Assessment for that strategy
- O13 - workforce training – necessary
- O14 - joint commissioning – no new additional inputs required
- O15 – inspection – no new additional inputs required
- O16 – research – no new additional inputs required
- O17 –implementation - likely to be cost-effective

Options considered

5.140 Option 1: do nothing, has, as a matter of definition, zero costs and benefits.

5.141 Option 2: implement all objectives immediately.

5.142 Option 3 start to implement those recommendations where benefits are clearer and start demonstration projects on other objectives to inform subsequent commissioning, in terms of

- Improved quality of life for people with living with dementia and their carers
- The delivery of early (relatively low-cost) interventions that will obviate the need for more expensive interventions at a later stage in the disease process.
- Beginning the diversion of some people from inappropriate, and expensive, residential care towards more appropriate and cost-effective home care.

5.143 Option 1 is in all practical and policy terms unacceptable.

5.144 Option 2, to aim to implement all of the recommendations immediately, is the costliest, and riskiest.

5.145 Option 3 is the preferred option.

Specific Impact Tests

Competition

6.1 A National Dementia Strategy will not have any measurable impact on competition.

Small Firms

6.2 If more people with dementia are provided with early diagnosis, support and interventions we expect that fewer will have recourse to institutional care, or – if they do – it will take place later in the progression of the disease than is sometimes the case now. We therefore expect there to be some reduction in the demand for residential care with an offsetting increase in the demand for home care services. This will also be offset by increasing underlying demand due to our ageing population.

Legal Aid

6.3 A National Dementia Strategy will have no effect on Legal Aid.

Sustainable Development

6.4 The National Dementia Strategy will take account of the key principles of sustainable development (living within environmental limits; ensuring a strong, healthy and just society; achieving a sustainable economy; promoting good governance; using sound science responsibly).

Carbon Assessment

6.5 A quantitative assessment is not practicable, but it could be argued that supporting people to stay longer in their own – possibly fuel-inefficient – home rather than move to a more fuel-efficient specialist institution would have a negative effect. Conversely, admission of one partner to residential care while the other remains in the family home means that two households are occupied where they might only need to occupy one. On balance we have concluded that the overall effect is likely to be negligible.

Health Impact

6.6 In screening for whether a full Health Impact Assessment is required we have to consider whether the impact is likely to be 'significant' across within at least two of the three domains. The definition of 'significant' is that it refers to the whole population, to a major sub-group of the population, or to the degree of severity of the impact.

6.6.1 Although dementia has a major impact on individuals and their families, the current population of about 570,000 is a small proportion of the total population of England. We therefore consider that the Strategy is not 'significant' in terms either of the whole population or to a major sub-group.

6.6.2 We do however have to consider whether the Strategy is 'significant' in terms of the impact on people with dementia and their carers across at least two of the domains.

6.6.3 The domains are

- wider determinants of health (Income, Crime, Environment, Transport, Housing, Education, Employment, Agriculture, Social cohesion)
- lifestyle related variables (Physical activity, Diet, Smoking, drugs, or alcohol use, Sexual behaviour, Accidents and stress at home or work)
- demand for health and social care services (Primary care, Community services, Hospital care, Need for medicines, Accident or emergency attendances, Social services, Health protection and preparedness response)

6.6.4 We expect that the Strategy will have some impact so far as the third domain is concerned. In particular, it is the case that only about one-third of all people who die with dementia receive a confirmed diagnosis or come into contact with specialist health and social care services in their lifetime. If the aims of the Strategy are achieved, the numbers receiving a diagnosis and accessing specialist services will triple (albeit there will be no impact so far as A&E attendances, Health protection & preparedness are concerned). However, we do not consider that the Strategy will have more than marginal impact within either of the first two domains and that although there are likely to be increased demand for health and social care this is itself likely to be marginal within the context of the whole system given the relatively few people involved.

Single Equality Assessment

6.7 An Equality Impact Assessment will be published.

Rural Proofing

7.8 The draft National Dementia Strategy recognises that for some people in rural areas, access to services and support is more difficult. The Strategy therefore includes the commissioning of care pathways for people with dementia that work in rural and island communities as well as cities and towns.

Specific Impact Tests: Checklist

Use the table below to demonstrate how broadly you have considered the potential impacts of your policy options.

Ensure that the results of any tests that impact on the cost-benefit analysis are contained within the main evidence base; other results may be annexed.

Type of testing undertaken	<i>Results in Evidence Base?</i>	<i>Results annexed?</i>
Competition Assessment	Yes	No
Small Firms Impact Test	Yes	No
Legal Aid	Yes	No
Sustainable Development	Yes	No
Carbon Assessment	Yes	No
Other Environment	Yes	No
Health Impact Assessment	Yes	No
Race Equality	Yes	Yes
Disability Equality	Yes	Yes
Gender Equality	Yes	Yes
Human Rights	Yes	Yes
Rural Proofing	Yes	No

Annex 1: Selected Sources/ References for costing of individual recommendations in National Dementia Strategy (Section 5)

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