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COMPTROLLER AND
AUDITOR GENERAL

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Improving Dementia Services in England – an Interim Report

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Improving Dementia Services in England – an Interim Report

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Amyas Morse
Comptroller and
Auditor General

National Audit Office

8 January 2010

The number of people with dementia in England is expected to double within 30 years. Estimated costs of care will rise from £15.9 billion in 2009 to £34.8 billion by 2026.

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Contents

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Summary

Scope and rationale for this report

1 “Dementia” describes a range of progressive, terminal brain diseases, affecting an estimated 600,000 people in England. Age is the main risk factor, and people with dementia need a complex mix of health and social care services. In many cases unpaid family carers deliver the bulk of care, affecting their own physical and mental health. The number of people with dementia in England is expected to double within 30 years[1], and estimated costs are expected to increase from £15.9 billion in 2009 (of which around £8.2 billion are direct health and social care costs[a]) to £34.8 billion by 2026.[2]

2 In 2007 we concluded that dementia services in England were not providing value for money to taxpayers or people with dementia and their families.[3] The Committee of Public Accounts (the Committee) reported in January 2008 that the Department of Health (the Department) had not given dementia the same priority as cancer and coronary heart disease, and dementia had not therefore had the same focus for improvement. The Department agreed that it had not previously identified dementia as a priority, but said it would do so through the development of a National Dementia Strategy (the Strategy). The Committee asked for an update on progress by the end of 2008[4]. The Department’s Strategy, *Living Well with Dementia*, was published in February 2009, with a brief Implementation Plan that lacked a timetable or milestones for delivery. A more detailed Implementation Plan was published in July 2009. **Figure 1** on pages 6 and 7 details the timeline of developments since our 2007 report.

3 This report assesses the Department’s response to the Committee’s recommendations and the robustness of its Strategy and Implementation Plan, and evaluates the machinery in place to implement the Strategy, including the levers for change[5]. We used the Cabinet Office’s Capability Review framework[6], which covers Strategy, Leadership and Delivery, as the basis for our examination and to identify the risks that need to be addressed if the Strategy is to be implemented successfully. Given the short period since publication of the Strategy, we did not expect to see changes at the frontline and did not audit services themselves. Appendix 1 summarises our methodology.

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[a] Care home costs of £1.93 billion are borne by private individuals. When this cost is added to the health and social care costs, the total direct cost of dementia is £10.1 billion.

The development of the Strategy, its costs and benefits

4 The Capability Review framework specifies three criteria for an effective strategy: a focus on outcomes; building common purpose; and evidence-based choices.

5 The National Dementia Strategy is ambitious and comprehensive, setting out a vision in which people with dementia and their carers are enabled to live as well as possible. It focuses on outcomes: public and professionals' awareness of dementia; earlier specialist diagnosis and intervention through Memory Services; and higher quality health and social care for people with dementia. The Department obtained buy-in through a comprehensive consultation, which included people with dementia and carers. The Strategy's 17 objectives address the majority of the Committee's recommendations[4] (Appendix 2).

6 The Strategy is evidence-based, drawing together published data on cost-effective commissioning and care provision, and estimates on current and future costs (from the 2007 *Dementia UK* report). There are, however, still no comprehensive local data on the current costs of dementia services. Psychiatric services for dementia often fall within block contracts with mental health trusts, and there is no national "payment-by-results" tariff for costing mental health activities. The Department is in the process of commissioning a baseline audit of dementia, which will include data on costs.

7 The Department's Impact Assessment, published alongside the Strategy, estimated the additional cost of implementing it at £1.889 billion over ten years, although this does not yet include all potential costs. Seven of the objectives are being piloted and cost estimates for these will be included when they are available in 2011. There was no estimate of the cost of training NHS and social care staff. Moreover, the 2009 *National Framework for Continuing Care* and recent legal judgements are likely to mean more people with dementia receiving NHS-funded care. The Department will produce an updated Impact Assessment in 2010.

8 The Department is clear that the Strategy's implementation is to be funded largely through efficiency savings (reducing unnecessary use of acute hospital beds) re-directed to other areas (early diagnosis and intervention in people's own homes). The Impact Assessment identified annual savings of £130 million from 2013-14 (a net saving of £533 million over ten years), based on delaying entry to care homes through early diagnosis and intervention. Over the ten years, therefore, implementation costs of around £1.356 billion will need to be met from other efficiency savings. Our case studies suggest further efficiency savings of at least £284 million a year could be identified now. This is, however, dependent on widespread adoption of good practice and being able to release funding from the acute sector to other health and social care settings, which have historically been difficult to achieve.

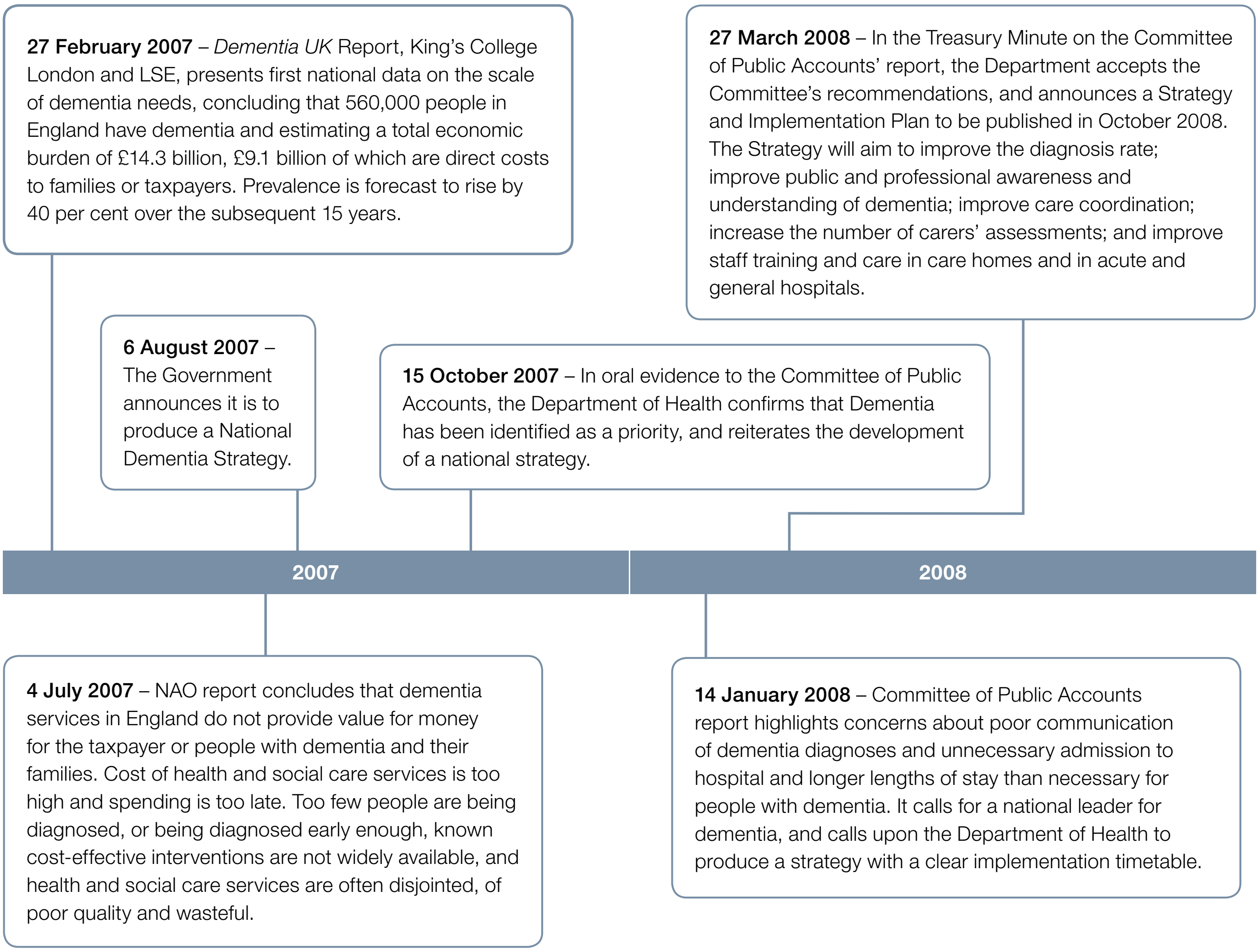
Leadership: roles, responsibilities, direction and drive

9 The Capability Model's criteria for effective leadership are to: set direction; ignite passion, pace and drive; and take responsibility for delivery and change.

10 We found strong direction and national leadership for the Strategy provided by the Director General for Social Care. The Department attempted to recruit a National Clinical Director for Older People and Dementia in June 2009, but without success. In October it commenced recruitment for separate directors for older people and dementia, and expects to make an appointment in January 2010. Regional leadership rests with nine newly appointed Deputy Regional Directors of Social Care. The appointees have strong health and social care experience, but have no performance management role and must drive improvements through leadership and influence.

Figure 1

Timetable of the development and implementation of the National Dementia Strategy



27 February 2007 – *Dementia UK* Report, King's College London and LSE, presents first national data on the scale of dementia needs, concluding that 560,000 people in England have dementia and estimating a total economic burden of £14.3 billion, £9.1 billion of which are direct costs to families or taxpayers. Prevalence is forecast to rise by 40 per cent over the subsequent 15 years.

4 July 2007 – NAO report concludes that dementia services in England do not provide value for money for the taxpayer or people with dementia and their families. Cost of health and social care services is too high and spending is too late. Too few people are being diagnosed, or being diagnosed early enough, known cost-effective interventions are not widely available, and health and social care services are often disjointed, of poor quality and wasteful.

6 August 2007 – The Government announces it is to produce a National Dementia Strategy.

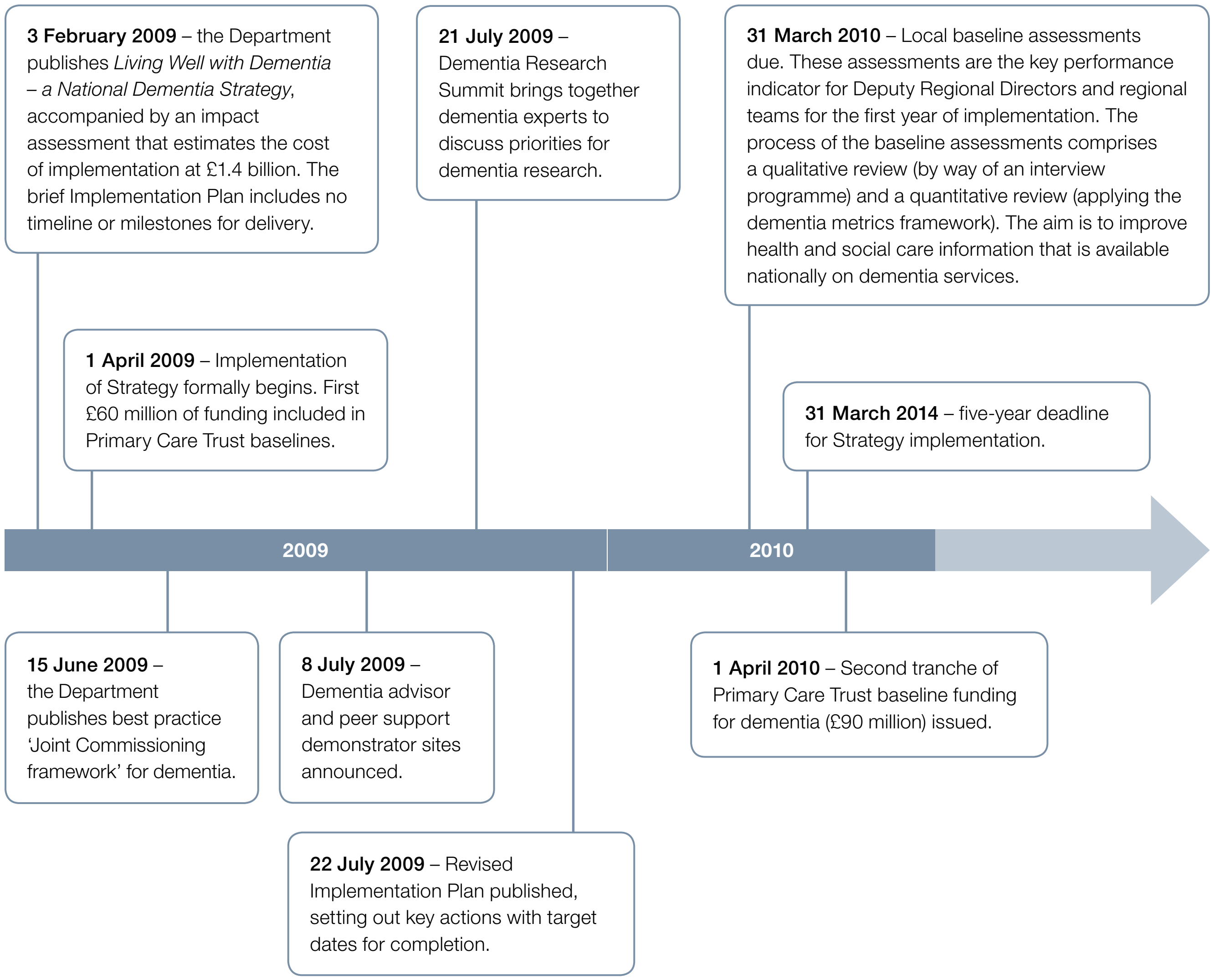
15 October 2007 – In oral evidence to the Committee of Public Accounts, the Department of Health confirms that Dementia has been identified as a priority, and reiterates the development of a national strategy.

14 January 2008 – Committee of Public Accounts report highlights concerns about poor communication of dementia diagnoses and unnecessary admission to hospital and longer lengths of stay than necessary for people with dementia. It calls for a national leader for dementia, and calls upon the Department of Health to produce a strategy with a clear implementation timetable.

27 March 2008 – In the Treasury Minute on the Committee of Public Accounts' report, the Department accepts the Committee's recommendations, and announces a Strategy and Implementation Plan to be published in October 2008. The Strategy will aim to improve the diagnosis rate; improve public and professional awareness and understanding of dementia; improve care coordination; increase the number of carers' assessments; and improve staff training and care in care homes and in acute and general hospitals.

Source: National Audit Office analysis

11 Empowered local leadership is important for delivering transformational change[7] and is a fundamental element of the Department's performance management model[8]. We found local leadership for improving dementia has still to be put in place. By Summer 2009, only 21 per cent of consultant old-age psychiatrists said a senior clinician had taken the lead on dementia in their acute hospital; few frontline health or social care staff in our forums could identify leaders who were championing dementia. GPs are becoming more positive about diagnosing early, but there is still much for local leaders to do to "ignite passion, pace and drive" for transforming dementia care.



3 February 2009 – the Department publishes *Living Well with Dementia – a National Dementia Strategy*, accompanied by an impact assessment that estimates the cost of implementation at £1.4 billion. The brief Implementation Plan includes no timeline or milestones for delivery.

1 April 2009 – Implementation of Strategy formally begins. First £60 million of funding included in Primary Care Trust baselines.

15 June 2009 – the Department publishes best practice 'Joint Commissioning framework' for dementia.

8 July 2009 – Dementia advisor and peer support demonstrator sites announced.

21 July 2009 – Dementia Research Summit brings together dementia experts to discuss priorities for dementia research.

22 July 2009 – Revised Implementation Plan published, setting out key actions with target dates for completion.

31 March 2010 – Local baseline assessments due. These assessments are the key performance indicator for Deputy Regional Directors and regional teams for the first year of implementation. The process of the baseline assessments comprises a qualitative review (by way of an interview programme) and a quantitative review (applying the dementia metrics framework). The aim is to improve health and social care information that is available nationally on dementia services.

1 April 2010 – Second tranche of Primary Care Trust baseline funding for dementia (£90 million) issued.

31 March 2014 – five-year deadline for Strategy implementation.

Leadership: building workforce capacity

12 The fourth criterion for effective leadership is building workforce capacity and capability. In 2007 the Committee expressed concern at the lack of dementia training in social care, high staff turnover and vacancies; the All Party Parliamentary Group on dementia identified the same problems in 2009[9]. However, the programme of social care staff registration has been delayed, which will impact on the identification of training needs. Almost every health professional comes into contact with patients who have dementia, yet there is no required basic training in how to understand and support them. Addressing this training gap will require concerted action over several years by a large number of training and education bodies, most of which are independent of the Department and the NHS. The Department expects to publish a Workforce Development Action Plan during 2010, following delivery in March of the results of a mapping exercise.

Delivery: the effectiveness of the implementation plans

13 The Capability Model's criteria for effective delivery emphasise the need to: plan, resource and prioritise; develop clear responsibilities and delivery models; and manage performance.

14 The detailed Implementation Plan published in July 2009 sets out specific actions, indicative dates. The Department has put in place some of the groundwork to help organisations improve services – it announced demonstrator sites for piloting the dementia adviser role and peer support networks and produced guidance for local commissioners (Figure 1). At local level, most primary care trusts and local authorities were awaiting guidance from the Department before beginning their baseline reviews of dementia needs and services and began work in late summer 2009. The Department expects the baseline service reviews to be available in March 2010, and is also commissioning a baseline audit of dementia, which will include data on costs. Both will be important in finalising local implementation plans.

15 The Department included an additional £60 million for 2009-10 and £90 million for 2010-11 in the revenue allocations for the 152 primary care trusts, to support implementation of the Strategy. In line with the Department's devolved NHS management model, primary care trusts must decide locally how to spend these allocations. In the absence of any monitoring, and with the baseline reviews not done until March 2010 and the audit of costs in the process of being commissioned by the Department, the level of funding that primary care trusts have allocated dementia is unclear.

16 In 2007, we identified the lack of joined-up health and social care planning and delivery as a barrier to improvements in dementia. Joined-up working or "co-production" between health and social care, commissioners and providers, is also a core principle of the Department's management model. Joined-up working remains very patchy and as a result people with dementia are still being unnecessarily admitted to hospital, have longer lengths of stay and enter residential care prematurely. Whilst we found examples of good practice, these are not being adopted widely.

17 Many people with dementia spend some time in a care home and many end their life in one. Indeed, demand for "dementia care beds" is growing. Although the Strategy identifies the need for improved quality of care in care homes, the care home sector is large and diverse, and smaller providers lack the management and leadership skills to respond. We found local care home managers lacked awareness of the Strategy and did not have a "co-production" relationship with local commissioners. Only two Strategic Health Authorities were actively working with the care homes sector.

Delivery: managing and leveraging performance

18 The Government's October 2007 Comprehensive Spending Review established national requirements and funding for the Department for the three years 2008/09 – 2010/11. In December 2007, as part of its 2008-09 NHS Operating Framework[b], the Department introduced "Vital Signs", a set of fixed national and local priorities. The Department had told the Committee in November 2007 that the Government had identified dementia as a "national priority", and confirmed this in its formal Treasury Minute response (March 2008); but the timing of the Strategy (February 2009) meant that it was too late for inclusion in Vital Signs. In December 2008, the 2009-10 Operating Framework noted that there would be no new national priorities until the next Spending Review but that, in anticipation of the Strategy, "Primary Care Trusts will want to work with local authorities to consider how they could improve dementia services". Local Authorities have no specific performance requirement on improving dementia care.

19 In July 2008, the NHS Next Stage Review – *High Quality Care for All*, set out a new NHS management model, with leverage for improving services expected to come from: the use of contractual quality drivers by primary care trusts who commission services; publication of comprehensive performance information; regulation; and a drive for innovation. The first phase of the Strategy's implementation comes at a time when the system-based levers envisaged in *High Quality Care for All* are not yet mature. In particular:

- commissioning for quality is at a very early stage of development;
- the Quality and Outcomes Framework (a voluntary incentive scheme rewarding GP Practices for specific aspects of patient care) includes two indicators for dementia. However, these focus on inputs (the number of people on a dementia register and the frequency of case reviews) rather than outcomes;
- the self-assessment metrics for measuring progress on dementia are expected to be finalised in early 2010. It is unclear whether they will be mandatory or how long it will take to establish quality data;

[b] These are split into three tiers: Tier 1 Vital Signs set out five "must-dos" decided and managed at national level. Tier 2 set out national priorities where decisions about delivery are to be made locally and performance managed by Strategic Health Authorities; Tier 3 provides a range of indicators from which primary care trusts should select, based upon local joined-up assessment of need and priority.

- the new Care Quality Commission is in the process of reorganising and consulting on its regulation and inspection regime, including its guidance to providers on meeting the new quality standards; initially it is expected to focus on monitoring against the “Vital Signs” national priorities; and
- there is some evidence of innovation being used to transform dementia care, but this is very localised and has not been evaluated, disseminated, or widely adopted.

Conclusion on value for money

20 Providing care for people with dementia costs the NHS and social care services around £8.2 billion a year and rising, but, as we reported in 2007, services do not currently provide value for money. The Department told the Committee at that time that dementia would be a national priority. This and the commitments in the five-year National Dementia Strategy, launched in February 2009, were welcomed as an overdue recognition of the size and scale of the challenge presented by dementia. However, the Department has not yet matched this commitment with a robust approach to implementation, which aligns leadership, funding, incentives and information.

21 Dementia does not feature in the set of “national priorities” against which local organisations’ performance is monitored and managed by the Department. As a result, primary care trusts, who are responsible for prioritising funding under the devolved delivery system, do not see it as a “must do”. In the absence of this steer, improvements could still be driven by effective local leadership, joined-up commissioning with quality incentives, and comprehensive performance information, but these are not yet in place. It will not be clear how the first £60 million of additional baseline funding has been spent, or whether it has actually been spent on dementia, until the baseline audit is completed.

22 Delivering the Strategy is dependent on releasing some £1.8 billion of savings from the acute hospital and long-term care sectors, to fund earlier intervention and care in the community and help people live well with dementia. But without leverage provided by the factors described above, and in a time of financial constraint, actually releasing or re-directing resources from secondary to primary care, or from NHS to social care, is likely to be difficult to achieve in the short to medium term. Overall we conclude that improving services and support for people with dementia lacks the urgency and priority that the Committee had been led to expect, and there is a strong risk that value for money will not be significantly improved within the Strategy’s five-year implementation timetable.

Recommendations

23 We have identified the key risk areas where we consider action is urgently needed to increase the pace and completeness of the transformational change set out in the Strategy. We make the following recommendations to help address these risks.

Risk A: On the Strategy

Although the Strategy focuses on outcomes and was developed with strong consultation and consensus, the information on current and future costs and benefits, and sources of savings, remains inadequate and there is a risk that decisions made locally on prioritisation and service design will not be sufficiently well-evidenced or informed.

1 **The Department** should improve the completeness and robustness of its impact assessment, building in more evidence on expected efficiency savings. It should publish the results, including results from modelling the impact of different scenarios for demand and eligibility criteria, in 2010.

2 **The Department** should evaluate and promulgate examples of good practice in achieving cost-effective improvements in delivery of dementia services, including the case examples outlined in paragraphs 1.14-1.15 of this report.

RisK B: On Leadership

National and regional leadership is strong and should be strengthened further with the appointment of a national clinical lead, but at the local commissioning and provider level much more needs to be done to identify and support leaders who have the skills to ignite passion, pace and drive. Workforce capacity and capability was a serious concern in 2007 and continues to be a weakness in the implementation planning. Unless significant progress is made on leading this at the national level, the implementation of the Strategy is likely to be compromised.

3 **Every acute hospital** should identify a clinical leader for dementia by 31 March 2010. **Primary Care Trusts** should likewise appoint a lead commissioner for dementia care and, through contracts, should require evidence that acute hospitals and other providers of care have a lead person with responsibility for improving dementia care.

4 **The Department** should include in the Workforce Development Action Plan a timetable for incorporating dementia awareness and care into pre-registration medical and nursing training.

5 **The Department** should put in place by the end of 2010 an accreditation scheme for dementia training for healthcare professionals, which will allow accredited training to count towards their professional development.

Risk C: On Delivery

The lack of strong levers for improving dementia care means there is a risk that NHS and social care delivery organisations will not give it the priority status expected by the Committee and the general public, and service improvements will lag well behind the desired pace.

6 **The Department** should identify ways to provide greater leverage for improvement in dementia services between now and the next Spending Review. As a minimum, they should find a way of ensuring that Primary Care Trusts commission sufficient memory services, which are based on best practice and accredited by the Memory Service National Accreditation Programme.

7 Following completion of the baseline review exercise in March 2010, **the Department** should ensure that the next key performance indicator for Deputy Regional Directors of Social Care focuses on outcomes (such as, for example, reducing the diagnosis gap in their region).

8 **The Department's Dementia Strategy Implementation Team** should assess the potential of new quality levers such as Patient Reported Outcome Measures to apply to NHS dementia care. It should also work with the **Care Quality Commission** to ensure that the system for assessing care homes includes evidence about user experience such as direct measures of the quality of life of people with dementia.

9 **Primary Care Trusts** should use their commissioning framework and contracts with Acute and Foundation Trusts to ensure full participation in the National Clinical Audit of Dementia Services from 2010.

10 **The Department** should, by 30 April 2010, provide an open online database of local performance information by publishing the agreed dementia metrics on the Dementia Portal, and allowing localities to upload their data, benchmark their performance and provide accountability to the public and partners.

Part One

The development of the Strategy

1.1 In 2007 we concluded that dementia services in England were not providing value for money to taxpayers or people with dementia and their families.[3] The cost of service provision was high in both health and social care but spending was often late, with too few people being diagnosed or diagnosed early enough (the "diagnosis gap"); known cost effective interventions were not widely available; and health and social care services were often disjointed, of poor quality and wasteful.[3]

1.2 In 2008, the Committee of Public Accounts reported that, despite the human and financial impact of dementia, the Department had not given it the same priority as cancer and coronary heart disease and therefore it had not had the same focus for improvement. The Committee highlighted poor communication of dementia diagnoses, unnecessary admissions to hospital, and unnecessarily long lengths of stay, for people with dementia. The Department agreed it had not previously identified dementia as a priority, but said it would do so through the development of a National Dementia Strategy. The Committee asked for an update on progress by the end of 2008[4]. The Strategy, *Living Well with Dementia*, was published in February 2009.

1.3 Based on the Cabinet Office's Capability Review framework[6] this part of the report details the scale of the challenge for dementia services and assesses the Strategy in terms of its focus on outcomes, evidence base and the building of common purpose.

The scale of the challenge

1.4 Dementia (**Figure 2** overleaf) affects an estimated 600,000 people in England. Unpaid family carers deliver a large proportion of day to day care, which affects their own physical and mental health (the Department has a separate published Carers' Strategy[c]). Although some 21 million people in England know someone with dementia, public awareness remains poor.[d] A May 2009 survey found 28 per cent of people still thought (wrongly) that dementia was a 'natural part of ageing'; and 22 per cent thought (again wrongly) there was no way to reduce the risk of dementia[10]. This lack of awareness and stigma, among health and social care staff as well as the public, contributes to a negativity about dementia resembling the attitude to cancer in the 1950s[3]. The estimated number of people with dementia, and overall costs of services and support, based on current models, will more than double in 30 years[1] (**Figure 3** overleaf and **Figures 4** and **5** on page 15).

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[c] In June 2008, the Government launched a £255 million Carers' Strategy, including the piloting of annual health checks for carers and training for GPs to recognise and support carers.

[d] Alzheimer's Research Trust, YouGov Poll, May 2008 suggests 25 million people in the UK; applying the Dementia UK estimate of 84 per cent of UK people with dementia residing in England gives a figure of 21 million.

Figure 2
What is dementia?

There are many different types of dementia, of which Alzheimer's disease is the most common, all caused by structural and chemical changes in the brain. Symptoms include a decline in memory, reasoning and communication skills, leading to an inability to perform everyday tasks and eventually a need for 24-hour care. There is no cure for dementia, and drugs that slow its progress do not benefit everyone. Promising scientific research is under way, and much can be done to promote quality of life for people with dementia, even in the very late stages, but this is not widely understood even by health and social care professionals.[1] The average time from diagnosis to death is 7-11 years. Age is the main risk factor, but 12,000[2] people aged less than 65 years in England have young-onset dementia. Other factors, including genetic background, medical history and lifestyle can also increase the risk of dementia.

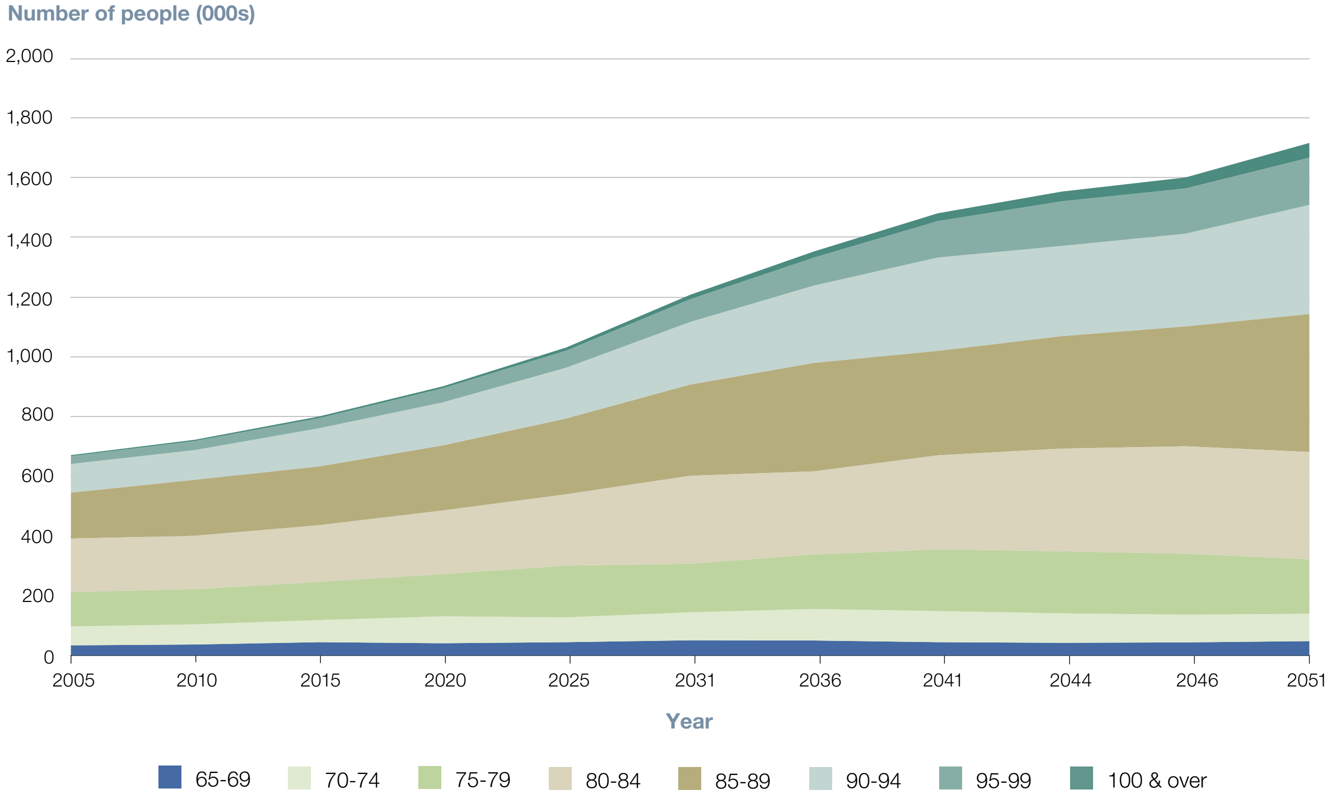
Source: National Audit Office analysis

NOTES

1 Marshall, M. (2001) The challenge of looking after people with dementia, *British Medical Journal* 323: 410-411.

2 Knapp, M. et al. (2007) *Dementia UK: Report to the Alzheimer's Society,* Kings College London and London School of Economics and Political Science.

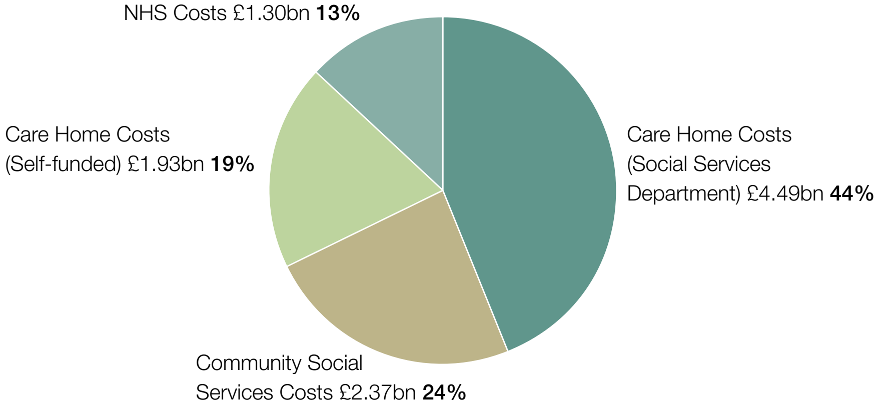
Figure 3
Projected increase in the number of people with late-onset dementia in the UK by age group



Source: Knapp, M et al. (2007) Dementia UK: Report to the Alzheimer's Society, Kings College London and London School of Economics and Political Science

Figure 4

The total estimated direct cost of dementia in 2009 is £10.1 billion, the bulk of which relates to the cost of care home provision



Source: Adapted from Knapp et al (2007) Dementia UK and the King's Fund (2008) Paying the Price

NOTE

1 Direct costs of dementia exclude informal care costs of £5.8 billion borne by families. Two-thirds of the direct costs, £6.42 billion, relate to the provision of care home places for people with dementia and are split between families, the NHS and social services. NHS and social services provision outside care homes (costing £3.68 billion) accounts for the remaining one third of direct costs.

Figure 5

Costs of dementia are predicted to more than double by 2026

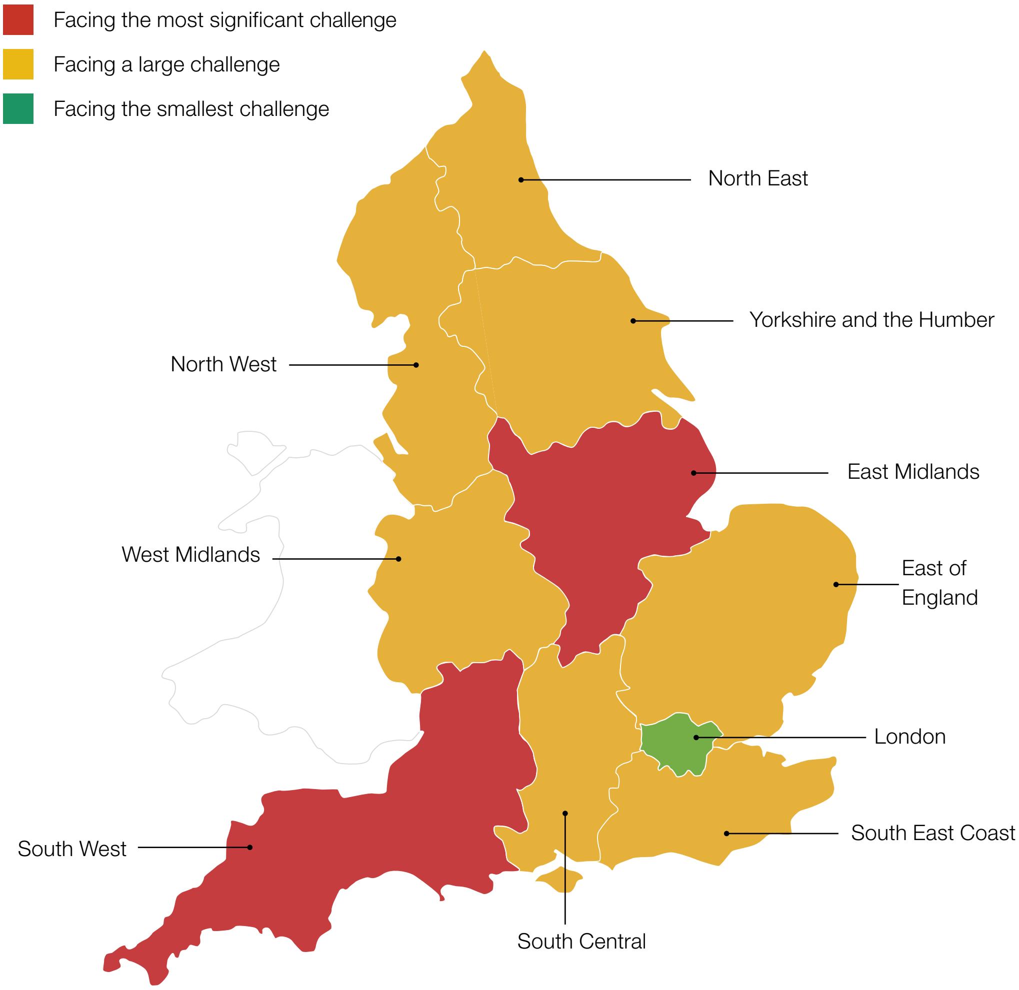
Type of cost	2009 estimated (£bn)	2026 estimated (£bn)
Residential care cost shared between families (30 per cent) and public spending (70 per cent)	6.42	14.3
Informal care costs (to families)	5.80	12.6
Health and social care costs	3.68	8.0
Overall economic burden of dementia	15.9	34.8

Source: Knapp et al (2007) Dementia UK and The King's Fund (2008) Paying the Price

1.5 Only around a third of people with dementia are formally diagnosed[3,11]. The majority of people with dementia therefore miss out on early intervention and specialist care. Social care, funded privately or through councils, provides help with daily living but not psychiatric and psychological needs. The "diagnosis gap" varies across Strategic Health Authority regions – South Central has the smallest gap at 57.7 per cent and South West the highest at 66.5 per cent.[e] Using an indicator that combines regional diagnosis gap, current prevalence and its expected rate of increase, we found the South West and East Midlands facing the biggest challenge (**Figure 6** overleaf). London is best placed, with a more slowly ageing population.

[e] Diagnosis gap by region (per cent): South Central 57.7, London 58.6, North West 59.1, North East 59.7, Yorkshire & the Humber 60.2, East of England 61.0, West Midlands 62.0, East Midlands 62.3, South East Coast 65.4, South West 66.5.

Figure 6
Regional breakdown of the diagnosis gap challenge in England



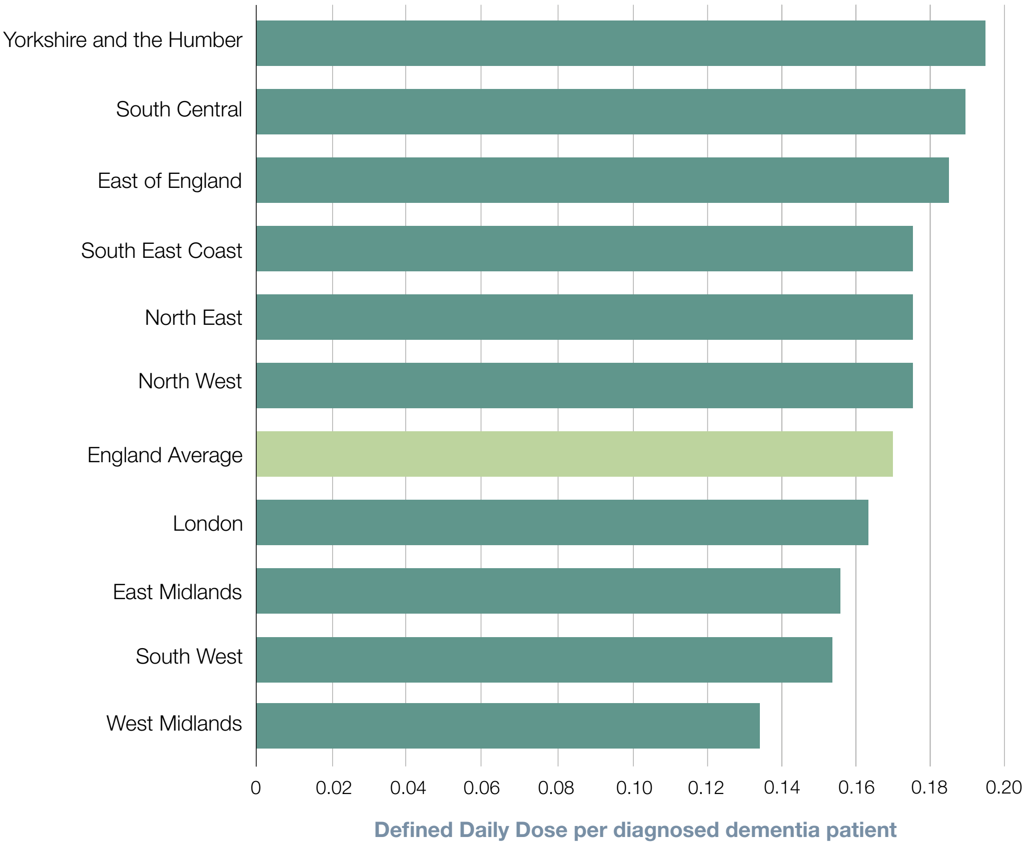
Strategic Health Authority	Number of PCTs	Estimated prevalence in 2007	Expected rise in prevalence by 2021 (%)
East of England	14	50,169	45.6
East Midlands	9	60,444	45.4
South Central	9	41,897	40.9
South West	14	72,811	40.1
West Midlands	17	59,859	37.1
North East	12	30,821	36.4
Yorkshire & the Humber	14	59,230	35.9
North West	24	79,720	32.1
South East Coast	8	58,803	32.0
London	31	57,715	14.2

Source: National Audit Office analysis of QOF data presented in the 2009 Alzheimer's Society report Dementia: What Every Commissioner Needs to Know. An index has been created reflecting the current and future (2021) prevalence of dementia and the dementia diagnosis gap in each SHA. The higher the index, the greater the challenge for that SHA to reduce the diagnosis gap in their region.

1.6 The prescription of cholinesterase inhibitors – drugs that can slow the progress of dementia – has increased by 28 per cent over three years to 31 March 2009. But there are regional variations, suggesting that people in some parts of the country who might benefit from the drugs are not receiving them[12] (**Figure 7**).

Figure 7

Prescription of anti-dementia drugs in England



Source: NHS Information Centre 2008/09 Quality and Outcomes Framework Data

NOTE

The figures exclude prescriptions from unidentified doctors and deputising services totalling 21,322 defined daily doses.

1.7 Around 208,000 people with dementia live in care homes,[f] of whom 91,000 are in dedicated dementia care beds, but the quality of care varies. In 2008 the Commission for Social Care Inspection (now part of the Care Quality Commission) rated as poor to adequate over a quarter of care homes in Eastern and West Midlands regions, and 15 per cent in the North East and London.[13] Around 59,000 people with dementia receive domiciliary care[g] – quality inspectors rated between ten (North West region) and 18 per cent (West Midlands) of providers as poor to adequate.[13] Recent research[14] reveals that 70 per cent of care home residents experience drug errors caused by poor staff training. And an independent review[15], which had been commissioned by the Department reported in November 2009 that up to 150,000 people with dementia are inappropriately prescribed anti-psychotic drugs, contrary to clinical guidelines. This may contribute to 1,800 additional deaths each year. The Department set out an action plan to reduce the use of these drugs, including an audit to establish definitive prescribing figures.

The Development of the Strategy, its costs and benefits

1.8 The Capability Model has three criteria for assessing the effectiveness of a strategy – it should focus on outcomes, build common purpose, and be based on robust evidence. Against the background of a costly and growing problem, ineffectively addressed by current services, the Department's five-year Strategy[1], sets out three aims (earlier diagnosis and intervention, improved awareness, and higher quality care) and 17 objectives for improved dementia care, with seven priority areas – see Appendix 2. We consider that it effectively targets those outcomes identified in our 2007 report, and addresses most of the Committee's recommendations.

1.9 The development of the Strategy was led jointly by an NHS clinical expert and the then Vice-President of the Association of Directors of Adult Social Services, supported by an expert reference group. The consultation involved over 50 public and stakeholder events and received 600 submissions. Stakeholders welcomed the aims and objectives of the Strategy and the thoroughness of the consultation. One per cent of GPs we surveyed were involved in the consultation, and 36 per cent of consultant old age psychiatrists (consultant psychiatrists). The Department involved patients and carers in the consultation and in implementation. The Alzheimer's Society has also played a pivotal role. At national level, there is a clear common purpose.

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[f] Laing & Buisson, Dementia Care Services Market Briefing 2009 suggests 248,000 people with dementia live in care homes in the UK in 2009. Applying 2007 Dementia UK estimates of 84 per cent residing in England gives 208,000 people.

[g] Laing & Buisson, Dementia Care Services Market Briefing 2009 p12 suggests 70,000 people with dementia receive home care in the UK in 2009. Applying 2007 Dementia UK estimates of 84 per cent residing in England gives 59,000 people.

1.10 The current figures for overall direct NHS and social care costs of dementia care in England (£10.1 billion) rely on 2007 national estimates[16] and no accurate local-level figures exist. Many memory services, and psychiatric support in acute general hospitals, are provided by mental health trusts through generic block contracts so there is little information on these costs. Moreover, 64 per cent of surveyed consultant psychiatrists said they undertake work with care homes without a contract. Whilst most hospital services (e.g. surgery, outpatient appointments) are costed using a national tariff, there is no tariff for mental health services. The ten London Mental Health Trusts, supported by the SHA, have set up a project to look at the development of 'currencies'[h] for mental health services, by grouping patients into clinical clusters based on their care needs, rather than diagnosis. Outputs from the project are expected to be available to inform 2010-11 Mental Health Contracts. A baseline audit of costs, to be commissioned shortly by the Department, should provide gradually improving cost data from mid-2010.

1.11 The Department's Impact Assessment[17] estimated the cost to the taxpayer of implementing the Strategy at £1.889 billion over ten years (**Figure 8** overleaf),[i] but this does not include all potential costs. Of the 17 objectives, six are considered to be cost neutral or covered by other strategies/programmes. Of the remaining 11, four were fully costed, while seven are being piloted to determine the cost-effectiveness of full implementation.

1.12 The data used take into account estimates of the increase in prevalence of dementia, and inflation, but include only limited consideration of the effect on future costs of: changing family structures (increase in divorce rates and single person households); differences in the use of services by ethnic groups including varying attitudes to dementia; and increasing expectations of the generations now approaching older age from services. The costs of staff training have not yet been included. Moreover, recent legal rulings requiring the state to meet families' liabilities for care home fees in certain cases, including for late-stage dementia, combined with the new *National Framework for Continuing Care* (August 2009) and *Continuing Care Directions*[j], suggest primary care trusts could face increasing costs, as more people are recognised as eligible for NHS-funded nursing care. While means-tested social care costs to the taxpayer will see a decrease, it will not match the increase in NHS-funded nursing care as this is free at the point of need. The Department plan to produce a revised impact assessment in 2010.

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[h] Currency means a common set of units for contracting for mental health services.

[i] Present value of future cash flows over ten years.

[j] NHS Continuing healthcare and NHS-funded nursing care is intended to meet the physical or mental health needs that have arisen as a result of disability, accident or illness (as provided in a hospital, nursing home, hospice or patient's own home).

Figure 8
Analysis of the Department's impact assessment

Objectives in the National Dementia Strategy (See Appendix 2 for details)	Explicit Commitment to implement	Evaluation Only (Rollout depending on review outcome)	Covered by other existing strategies or programmes	Time period (Years)	Departmental Costs[1] (£m)		Savings[1] Identified in the Impact Analysis (£m)
					10-year ongoing cost	One-off costs	
O1 (Increased awareness of dementia)	✓			10	33.9		
O2 (Memory clinic – net public cost)	✓			10	1,348.1		–533.6[2]
O3 (Information – provision)		✓		2		1.0	
O4 (Access to support & advice)		✓		2		4.5	
O5 (Peer support)		✓		2		3.0	
O6 (Personal support – rollout)		✓		1		0.5	
O7 Implementing the new deal for carers			✓				
O8 (Hospital – leadership)	✓			10	28.1		
O8 (Hospital – liaison)		✓		1		0.3	
O9 (Intermediate care)	✓			10	162.0		
O10 (Telecare – Running)		✓	✓				
O10 (Housing)		✓	✓				
O11 (Care home – leadership)		✓					
O11 (Care home – in-reach service)	✓			10	285.9		
O11 (Improved end of life care with dementia)			✓	2		1.5	
O13 (Workforce – complex CPD)		✓					
O13 (Workforce – simple CPD)		✓		2		2.0	
O14 (Joint commissioning)	✓		✓				
O15 (Inspection and monitoring)	✓		✓				
O16 (Research)			✓				
O17 (National and regional support)	✓			10	18.4		
Total					**1,876.4**	**12.8**	**–533.6**
Net funding gap							**1,355.6**[3]

Source: National Audit Office analysis of Department of Health's Impact Assessment

NOTES

1 Costs and savings shown are at net present value (NPV) over the time period shown.

2 The only savings identified so far by the Department arise mainly from the avoidance of entry into residential care following improvements in diagnosis resulting from memory clinics.

3 The funding gap of £1.36 billion could be much larger in reality, since the full costs of implementation are not yet known (the Department is still gathering this information).

1.13 The Department is clear that the Strategy is to be funded largely from efficiency savings. The impact assessment identifies savings of £130 million a year from 2013-14, based on delaying entry into care homes through early diagnosis and intervention. Over the ten years of the impact assessment, the net present value of these savings is £533.6 million, which leaves a net cost of the Strategy of £1.356 billion (not including any additional costs of rolling out pilots). Therefore more efficiency savings will need to be identified quickly and widely adopted, if there is to be a transformational change in dementia care within five years.

1.14 We identified other examples of cost-effective innovations which could improve care and release savings, if the good practice could be adopted across England **(Case examples 1, 2** and **3** overleaf). Our 2007 report also highlighted how effective interventions for hip surgery patients with dementia could generate annual savings of between £110 and £182 million.[3] The Department already has a Falls and Fractures Toolkit that primary care trusts could draw on to set up commissioned hip fracture services and make these savings. And the Department's own plans to shift care of people with dementia out of acute beds and into intermediate care beds where possible could provide a further £21 million a year[18]. The Alzheimer's Society's November 2009 report *Counting the cost: caring for people with dementia on hospital wards*, underlined the importance of reducing the time a person with dementia spends in acute hospital, wherever possible, because of the detrimental effect of hospital stays on their independence, and the costs involved.

1.15 In total these additional sources of savings could contribute £1.1 billion towards the £1.356 billion costs (net present values over ten years). However, there remain difficulties around:

- achieving nationwide take-up of these or equivalent improvements;
- ensuring the savings are actually redirected from one part of the health and social care system (acute hospitals) to another (social or intermediate care), something which has historically been very difficult to achieve. The Audit Commission[19] recently reported that primary care trusts have so far failed to shift resources from hospital care to community care; either in terms of investment or activity; and
- funding the additional costs of training and other objectives not included in the impact assessment.

Case example 1
Leeds dementia care pathway

In Leeds, a 2008 review of the dementia care pathway led local health bodies to introduce:

- Psychiatric Liaison Service in the acute hospital;
- rapid response community mental health team;
- specialist short term mental health home care; and
- dementia-specific intermediate care beds.

Initial funding of £4.2 million from the national Partnerships for Older People's Project led to an average reduction in hospital length of stay of four days per admission, for people with dementia over three years. This released beds to achieve other targets, such as the 18-week wait. The absence of a national tariff for mental health services has made it difficult so far to estimate the savings.

Case example 2
Lincolnshire whole-system approach to dementia care

In 2007 the National Audit Office commissioned the Balance of Care Group to undertake a bed usage survey in Lincolnshire NHS and social care settings. They found people with dementia most commonly in acute beds, but most no longer needed to be there. If those people with dementia who did not need acute care were cared for in an alternative setting, this would save £500,000 per annum. Similarly, if length of stay for people with dementia were reduced, around £400,000 would be saved, generating total savings of £900,000 for one primary care trust, or £135 milion across England. Since 2007, Lincolnshire believes it has made more cost effective use of resources that were previously tied up in the acute setting.

Case example 3
The Enriched Opportunities Programme for people living in extra-care housing

Over half of people with dementia living in "extra care" housing are transferred elsewhere during the first two years due to challenging behaviour, distress and conflicts with staff and other residents.[1]

The Enriched Opportunities Programme employs a staff member with specialist mental health training and expert support to provide leadership and engage with residents and relatives, and health and social care teams, to support residents.

Our analysis of the Programme data[2] indicates that if it were rolled out to all existing extra care settings in England, over a two-year period, the net savings to the public through reduced hospital stays and reduced use of nursing homes could be £21 million, shared between Local Authorities and the NHS, or a net present value of £89 million over 10 years).[3]

NOTES

1 Bradford Dementia Group (2009) *The Enriched Opportunities Programme*.

2 Data used with permission of Professor Dawn Brooker.

3 These savings figures apply across residents with mental health problems including dementia or depression. The total figure is 40,000 people, of which 25 per cent are assumed to have dementia. For further details about this analysis, please refer to the technical paper on the NAO website www.nao.org.uk.

1.16 As well as measuring costs and savings there is a need to evaluate the benefits (value added) of services, to monitor improvement. Currently, monitoring of dementia services is based largely on input and output measures such as: inclusion on GP registers; hours worked; or number of tasks of daily living completed by care workers in clients' homes. As a result commissioners have limited data on the effectiveness of services to increase quality of life (i.e. outcomes-based data). Frontline clinical and management staff in our forums agreed that lack of robust information makes it difficult to make a case for new services or changes to existing ones. More could be made of proven methods for measuring quality of life such as scoring by service users or carers[20], or 'dementia care mapping'[21].

Part Two

The role of leadership in developing and implementing the Strategy

2.1 The Capability Model defines effective leadership as: setting clear direction and clear responsibilities for delivery; igniting passion, pace and drive; and building workforce capacity and capability. This part of the report examines the effectiveness of leadership. It draws on experience from developing and implementing previous national strategies such as cancer, stroke and learning disabilities, and on management science.

Clarity of direction and responsibility for delivery and change

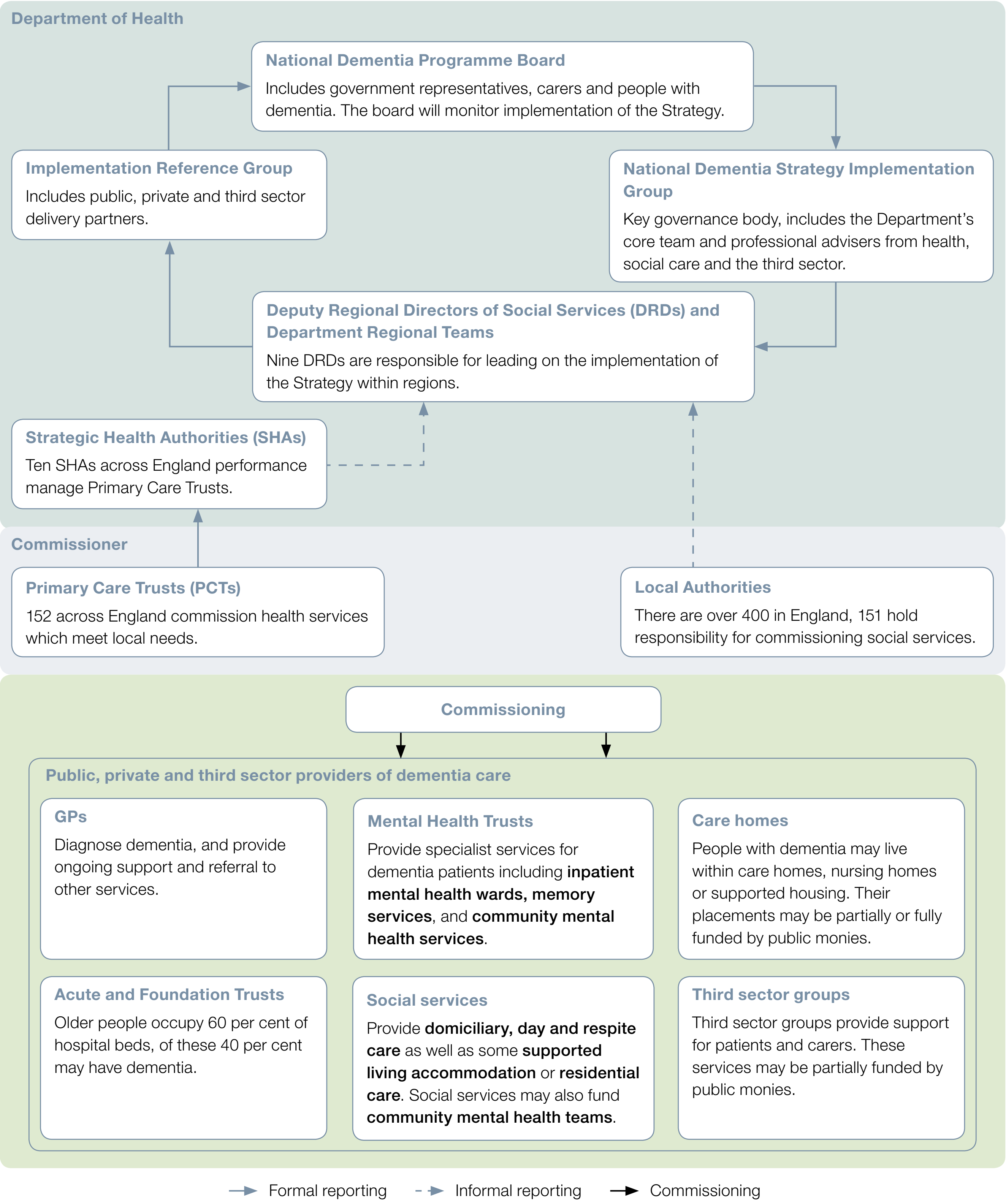
2.2 Leadership from the local authority, NHS management and clinical fields worked closely together on developing the Strategy. The Department established a National Dementia Programme Board, under the leadership of the Director General for Social Care. The Board is supported by an Implementation Reference Group and an Implementation Group, which includes representatives of the third sector, within the Department (**Figure 9**). Departmental leadership throughout development of the Strategy was judged as excellent by most stakeholders.

2.3 In response to the recommendation of the Committee and evidence from stroke, cancer and learning disabilities' strategies that the existence of a National Clinical Director is a key factor in driving change, the Department attempted to recruit a National Clinical Director for older People and Dementia in June 2009, but without success. In October it commenced recruitment for separate directors for older people and dementia. The Department expects to make appointments in January 2010.

2.4 The Department has made nine Deputy Regional Directors of Social Care (Deputy Regional Directors) responsible for building the "necessary linkages between health, social care and other local stakeholders, and obtaining the engagement and ownership necessary for delivery"[22]. The Deputy Regional Directors' role is new and they were not all in place until January 2009. We interviewed all nine and found they were highly experienced with strong health and/or social care backgrounds and influencing skills; nine out of ten SHAs rated their leadership as strong. They were also committed to delivering the Strategy as one of their four objectives. Whilst they have a personal key performance indicator related to implementation of the Strategy, they have no direct performance management role and are expected to achieve change through influence.

Figure 9

Accountability and delivery structures in place



Department of Health

National Dementia Programme Board
Includes government representatives, carers and people with dementia. The board will monitor implementation of the Strategy.

Implementation Reference Group
Includes public, private and third sector delivery partners.

National Dementia Strategy Implementation Group
Key governance body, includes the Department's core team and professional advisers from health, social care and the third sector.

Deputy Regional Directors of Social Services (DRDs) and Department Regional Teams
Nine DRDs are responsible for leading on the implementation of the Strategy within regions.

Strategic Health Authorities (SHAs)
Ten SHAs across England performance manage Primary Care Trusts.

Commissioner

Primary Care Trusts (PCTs)
152 across England commission health services which meet local needs.

Local Authorities
There are over 400 in England, 151 hold responsibility for commissioning social services.

Commissioning

Public, private and third sector providers of dementia care

GPs
Diagnose dementia, and provide ongoing support and referral to other services.

Mental Health Trusts
Provide specialist services for dementia patients including **inpatient mental health wards, memory services**, and **community mental health services**.

Care homes
People with dementia may live within care homes, nursing homes or supported housing. Their placements may be partially or fully funded by public monies.

Acute and Foundation Trusts
Older people occupy 60 per cent of hospital beds, of these 40 per cent may have dementia.

Social services
Provide **domiciliary, day and respite care** as well as some **supported living accommodation** or **residential care**. Social services may also fund **community mental health teams**.

Third sector groups
Third sector groups provide support for patients and carers. These services may be partially funded by public monies.

Source: National Audit Office analysis

2.5 SHAs can drive changes through their performance management of primary care trusts. All ten SHAs said dementia was a priority for them prior to the Strategy, but only seven considered their role as one of leadership and only six have a budget for implementing the Strategy. Six reported having a specific decision-making forum for dementia. The Department has since recognised the need for SHA leadership on dementia, and in October 2009 appointed Sir Ian Carruthers, Chief Executive of South West SHA, as SHA dementia lead.

The extent to which leaders have ignited passion, pace and drive

2.6 Deputy Regional Directors are establishing Regional Dementia Boards and using existing Joint Improvement Partnerships (JIPs)[k] to bring together council and health leaders and encourage sharing of information and, where possible, budgets. One key task is to develop the synergies between the Strategy and other initiatives such as Dignity in Care[23] and Personalisation[24].

2.7 Research highlights the importance of empowered local leadership for delivering transformational change[7]; the Department itself considers local clinical ownership and leadership a fundamental element of its devolved management model[8]. We found that visible leadership and ownership for improving dementia in local NHS and social care delivery organisations was not yet in place. Few frontline staff could identify leaders who were championing dementia, and few could give examples where the profile and priority of dementia at local level had increased. Only 21 per cent of consultant psychiatrists said a senior clinician had taken the lead for improving dementia care in their general hospital; 44 per cent were unsure. Frontline nurses participating in our forum had received no information or leadership about the Strategy. **Figure 10** illustrates the degree of familiarity and buy-in by staff.

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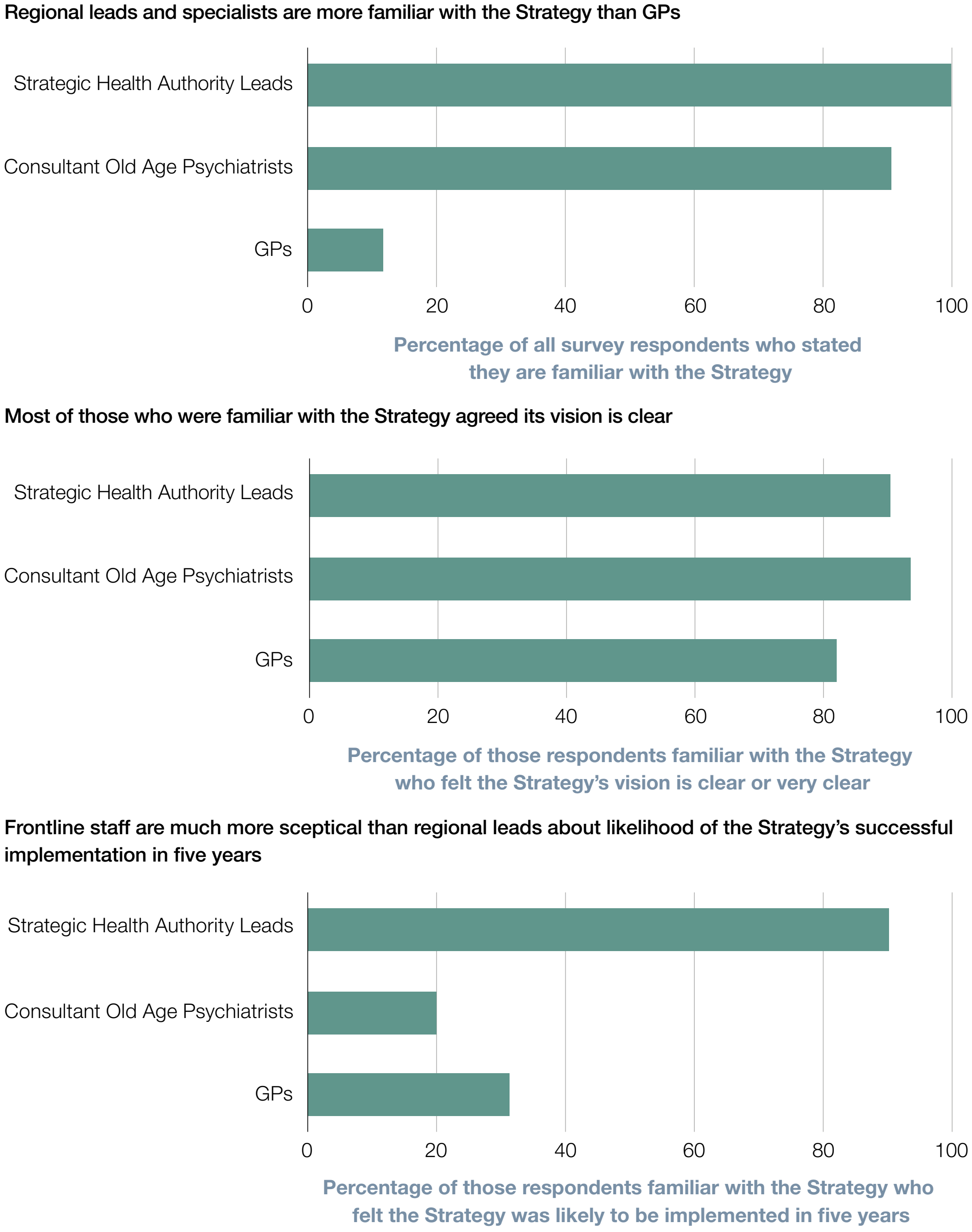
[k] A JIP is a partnership of organisations involved in improving services within social care. It is charged with: accelerating the pace of improvement and targeting it where capacity to improve is lacking; and promoting and coordinating the range of high quality support available to organisations from existing agencies.

Figure 10
Familiarity of survey respondents with the Strategy and their opinions on its clarity and likelihood of successful implementation in five years



Source: National Audit Office census of Strategic Health Authorities, National Audit Office survey of Consultant Old Age Psychiatrists, and National Audit Office survey of GPs

NOTE

There are ten Strategic Health Authorities and our SHA survey had a 100 per cent response rate. The online forum participants' views (depending on whether they were managers, frontline staff, generalists or specialists) supported these findings.

2.8 Care homes reported in interviews and on our forum that they had had no communication about the Strategy and saw no sector leadership, reflecting the fact that the care home sector is still underdeveloped, and lacking in strong leadership[9,25]. The Chief Executive of the English Community Care Association was appointed in July 2009 to act as a sector champion for dementia.

2.9 Early diagnosis and intervention provide the key to implementing the Strategy, and buy-in from all staff is needed. We noted a positive shift in the attitude of GPs to this (**Figure 11**), but GPs remain unsure about the level of specialist support and services available to their patients after diagnosis. The same concerns surfaced in our online forums, with both frontline and managerial staff and respondents from memory clinics expressed concern about their capacity to see more patients. Lessons could be learned from other long term conditions like diabetes, where patients are referred to specialist care for diagnosis and treatment and then discharged back to primary care for regular monitoring, allowing specialist services to focus on new and more challenging cases.

Building workforce capability

2.10 In 2007 the Committee expressed concern at the lack of dementia training in social care, high staff turnover and vacancies. The All Party Parliamentary Group on dementia identified the same problems in June 2009[9]. The creation of an informed and effective workforce for people with dementia is included as one of the objectives of the Strategy. The stigma attached to dementia is reflected in the low status society gives to this work, which reduces morale and motivation. Staff turnover rates (23.2 per cent in nursing homes, 20.5 per cent in residential homes and 22 per cent in domiciliary care[26]) are around twice the 2004-05 NHS rate of 11.8 per cent, and the 2006 private sector rate of 12 per cent[I]. Care homes told us changes in employment rules, and increasing NHS pay, have made recruitment and retention of care staff even more difficult.

Figure 11

There has been a positive shift in GP attitudes towards early diagnosis

	Percentage of GPs agreeing in 2006	Percentage of GPs agreeing in 2009
It is beneficial to make an early diagnosis of dementia.	68	77
Families would rather be told about their relative's dementia as early as possible.	68	73
Providing a patient with a diagnosis is usually more helpful than harmful.	51	58

Source: National Audit Office survey of GPs (2006 and 2009)

[I] Calculated by employment researchers IRS.

2.11 Dementia training is currently not part of the Common Induction Standards for staff in adult social care. Fundamental changes are occurring in the architecture surrounding social care registration, training and workforce development, but the programme of registration has been delayed and will take several years to have an effect on training and development (**Figure 12**). However, there are some examples of good practice (**Case Example 4**).

Figure 12

Social care bodies involved in reforming training

Social Care Bodies	Role
Department of Health	Issues guidance and support for workforce education, training and development in health and social care.
Social Care Institute for Excellence (SCIE)	To identify, produce and communicate good practice, evidence and innovation. It is developing streamed training webcasts for Social Care Television aimed at domiciliary and residential care workers.
Skills for Care	The employer-led authority on the training standards and development needs of social care staff in England. It works with social care employers and training providers regionally and nationally to establish standards and qualifications for social care workers. It is developing a dementia-specific qualification as part of the new Qualification and Credit Framework.
General Social Care Council (GSCC)	Registers social care workers and regulates their conduct and training.
National Skills Academy (not yet set up)	Will be part of the new National Skills Academy network. One of its aims will be to drive excellence among learning providers, trainers and those developing learning materials. It will accredit social care training providers from January 2010.

Source: National Audit Office

Case Example 4

The Old Vicarage, Dorset

This care home has no dementia registered beds, yet it has a workforce trained and equipped to meet the special needs of its 33 residents, many of whom have dementia. Staff turnover is four per cent and the home believes the key to retaining staff is training. It spends eight per cent of its turnover on staff training, which includes mandatory induction and NVQs and additional units of training at staff's request. The home also runs its own apprenticeship scheme to recruit new staff. Staff are offered additional training on dementia and provided with books and videos on dementia, whilst the care manager has completed Marie Curie training. This, combined with close liaison with community staff, enables the home to deliver good quality care to patients from admission to end of life, rather than moving them to a hospital in their final days or hours.

2.12 Most healthcare workers come into contact with people with dementia regularly, but there is no required dementia training for generalist healthcare professionals. Only 47 per cent of GPs we surveyed said they had had sufficient training in dementia management, and almost a third were not very confident in diagnosing dementia. There has been no improvement in GP knowledge and awareness of dementia over five years (**Figure 13**). Dementia is not included in the core requirements for nursing degrees.

2.13 On-the-job training in dementia for healthcare staff is difficult to access, and dementia trainers in our forum noted that employers usually opt for the minimum (often distance learning) packages which they consider inadequate for transforming practice. There is as yet no accreditation scheme and our online forum called for a set of mandatory competencies to standardise dementia training. We found little progress on bringing together the independent medical schools, universities, training and education bodies needed to progress generalist dementia training.

2.14 The Department has commissioned Skills for Care and Skills for Health to map the training needs of the workforce and the training currently available across all sectors, identifying the gaps. The mapping exerecise will conclude in March 2010 and make recommendations to inform the Department's workforce action plan.

Figure 13

GP knowledge quiz scores between 2004 and 2009 have remained below 50 per cent

Year	Average GP Knowledge Quiz Score (%)
2004	49
2006	47
2007	49
2009	49

Source: 2006-2009 results from National Audit Office online survey of GPs – answers to dementia knowledge quiz comprising a set of eight questions which were common to all four years. 2004 results taken from results of the same quiz in Turner S, Iliffe S, Downs M, Wilcock J, Bryans M, Levin E, Keady J and O'Carroll R (2004) General practitioners' knowledge, confidence and attitudes on the diagnosis and management of dementia Age and Ageing; 33: 461-467

Part Three

Cost-effective delivery of the Strategy

3.1 The Capability Model's criteria for assessing delivery are the need: to plan, prioritise and resource appropriately; for strong performance management; and for clear roles, responsibilities and delivery models. This part examines the Department's implementation arrangements against these criteria including the various sources of leverage for change.

3.2 Over the last ten years the Department has moved through three stages of reform of its management model. The first stage used national targets as levers to address serious problems; the second used bottom-up incentives – choice and competition, payment-by-results and commissioning (splitting up purchasers and providers). In December 2007, following agreements made in the 2007 Comprehensive Spending Review about national requirements and funding, the Department introduced the "Vital Signs" set of national and local priorities for 2008-09 – 2010-11, as part of its 2008-09 NHS Operating Framework.

3.3 In July 2008, the NHS Next Stage Review, *High Quality Care for All*, set out the third stage of reform for the NHS management model, with four guiding principles (**Figure 14**). Leverage for improving services is expected to come from: the use of contractual quality drivers by primary care trusts who commission services; publication of comprehensive performance information; regulation; and a drive for innovation.

Figure 14

Guiding principles for the Department's devolved approach to implementing the Strategy

Co-production: implementation should be discussed and decided in partnership with the NHS, local authorities and key stakeholders.

Clinical ownership and leadership: clinical staff will continue to be active participants and leaders as the Strategy is implemented and changes are made.

Subsidiarity: where necessary, the Department will play an enabling role, but wherever possible the details of implementation will be decided locally.

System alignment: the wider system needs to be aligned round the same goals, enabling combined leverage to drive up quality across the system.

Source: Department of Health

3.4 Potential levers for improving dementia services examined below include:

- Stated priorities in the NHS Operating Framework – the "Vital Signs" set of national indicators performance managed by the Department[27] (paragraphs 3.6-3.7);
- the allocation of additional funding (paragraphs 3.8-3.9);
- joined-up, informed and outcome-focused commissioning of services, rewarding quality and innovation (paragraphs 3.10-3.16);
- contracts with GPs – incorporating the Quality and Outcomes Framework performance indicators (paragraph 3.18);
- accurate and detailed performance information including clinical audit (paragraphs 3.19-3.20); and
- regulation and inspection (paragraphs 3.21-3.22).

Planning, resourcing and prioritising

3.5 In February 2009 the Department issued a short initial implementation plan alongside the Strategy which lacked detail on specific actions and on measures of success. Since June 2009, the Department has published guidance for local primary care trust and council commissioners of dementia services, and a more detailed Implementation Plan (Figure 1). The Department has delivered some key actions, including the announcement of pilot sites and a guide for commissioners of services (Figure 1). However, the Department has stated that it does not expect all localities to have achieved full implementation of the Strategy's objectives in five years, without specifying what level of implementation it does expect.

3.6 Transforming services for people with dementia requires leveraging change in the 152 primary care trusts and 151 councils who commission services, and thousands of public, private and third sector providers who deliver them. Prior to the publication of the Strategy, seven out of ten SHAs reported that primary care trusts in their regions had mentioned dementia within their five-year plans, although few localities had begun to gather data on dementia needs and services. There are some exceptions, such as Kent and Medway, where the primary care trusts and councils completed an initial dementia needs assessment in 2008. Work is now under way across the country, as all localities aim to complete Baseline Reviews and Local Action Plans by 31 March 2010. The results will be subject to formal "challenge" by a panel including the Third Sector and service users.

3.7 The Department told the Committee in November 2007 that the Government had identified dementia as a "national priority", and confirmed this in their formal Treasury Minute response (March 2008). Dementia was not included in the December 2007 Vital Signs, and the timing of the Strategy (February 2009) meant that it was too late for inclusion in the December 2008 edition (**Figure 15**). In fact the December 2008 Operating Framework for 2009-10 noted that there would be *no* new national targets; Vital Signs will be revised again only at the next Spending Review. Instead the Operating Framework stated that "Primary Care Trusts will want to work with local authorities to consider how they could improve dementia services". In the 2010-11 Operating Framework published in December 2009 there is a brief reference to the improved outcomes and efficiencies to be gained by "early and accurate diagnosis of dementia".

Figure 15
The NHS Vital Signs Indicator Set

Tier 1: A small number of "must-dos", which apply to all PCTs

These are subject to performance management from the Department centrally. SHAs hold PCTs and NHS Trusts to account for these performance indicators and the Care Quality Commission assesses performance annually. Five Tier One indicators relate to cancer; two to hospital acquired infection; and one to stroke. **Dementia is not mentioned**.

Tier 2: National priorities for local delivery

The Department considers that concerted effort on these is required across the board but allows local organisations flexibility on how they deliver. SHAs hold PCTs and NHS Trusts to account for these performance indicators and the Care Quality Commission assesses performance annually. **Dementia is not mentioned**.

Tier 3: Priorities determined and set locally

These are a set of indicators from which PCTs can choose a small number to target local action and improvement effort. The Department does not performance manage these indicators, and the Care Quality Commission is not expected to include them in its annual assessments. SHAs need to be satisfied that PCTs have identified and are acting on a group of Tier Three indicators. Learning disabilities has three specific Tier Three indicators.

There are Tier Three indicators relating to the timeliness of social care assessments and the proportion of carers receiving a "carer's break" or other carer's service which link to dementia care, but **dementia is not mentioned specifically**.

Source: National Audit Office analysis

3.8 Based on its estimate of the costs of the Strategy, the Department included an additional £150 million in baseline revenue funding, allocated across the 152 English primary care trusts (£60 million in 2009-10 and £90 million in 2010-11 **(Figure 16**). In line with the devolved NHS management model, ring-fencing is not used and primary care trusts must decide how to spend their allocations and, within there, how to fund dementia care locally. The Department did not require primary care trusts to report on how they had spent the dementia allocation (as it did in 2008 when publishing the End of Life Care Strategy, where the Department committed to monitor the use of the additional funding as end of life care had been treated as such a low priority area). The detailed baseline audit of dementia costs is being commissioned by the Department and baseline reviews of services are due in March 2010 – until then the level of funding that primary care trusts have allocated to dementia is unclear. Of the consultant psychiatrists we surveyed, 15 per cent reported that their primary care trust had invested extra funds into their service, and commissioners in our forums found difficulties trying to access the funding. There is no extra funding for councils: no additional financial provision has been made for dementia in local government expenditure plans for 2009-10 and 2010-11, and there are no ringfenced grants from the Department for dementia services, in contrast to those for the stroke strategy in 2007.

Roles, responsibilities and delivery models

3.9 The Committee recommended in 2007 that the Royal Colleges of Psychiatrists and GPs should develop a dementia care pathway, and that a single professional contact should coordinate care between the various services and professionals. The need for more effective and informed commissioning, resulting in joined-up working and planning, is a wider issue affecting all NHS and social care services and their partners, and not just those used by people with dementia, though it may cause particular difficulties for this group. (**Figure 17** details some of the ways in which a lack of joint working and sharing of information between health and social care services can critically affect the length and quality of life for a person with dementia.) We looked at the evidence on the current extent of joint working in dementia services and the maturity of wider improvement programmes in place.

Figure 16
New funding provided for the Strategy

	2009-10 £000's	2010-11 £000's
Department's Regional Teams	1,800	2,000
Department's Core National Team	343	TBC[1]
PCT budget allocations	60,000	90,000
Dementia Advisor Demonstrator Sites	1,273	2,493
Peer Support Demonstrator Sites	724	1,426
Total	**64,140**	**95,915**

Source: Department of Health

NOTE

1 The 2010-11 budget for the Core National Team has not yet been fixed by the Department.

Figure 17

How more joined-up planning and services can improve dementia care

	What we found in 2007 and 2009	What can help?
Getting a timely diagnosis	Low public awareness may prevent people presenting at GPs. Twenty-eight per cent of GPs are not very confident in their dementia diagnosis, and 42 per cent are not confident about advising patients on dementia management (2009). Eighty-seven per cent of GPs say they can access a memory clinic, compared with 69 per cent in 2007.	Awareness-raising activities that stress the benefits of diagnoses. A clear cross-organisational pathway to specialist services and support.
Avoiding unnecessary admission to hospital e.g. after a minor fall	Dementia patients and carers do not routinely hold copies of their care plans. Without this information to hand it is difficult for ambulance services to avoid unnecessary hospital admission.	A protocol between Acute Trusts, GPs and Ambulance Trusts to avoid unnecessary admissions.
Managing patients with dementia in Acute Hospital	In 2007 we found hip fracture patients with dementia stayed in hospital on average 43 days compared to 26 days for those without dementia. Only 58 per cent of consultants psychiatrists report having an older people's mental heath liaison service in their hospital (2009).	Mental Health Liaison Teams to support acute physicians in identifying and meeting dementia care needs. This can reduce length of stay (Case Example 1).
Prompt discharge from hospital with proper support	Stays in acute general hospital affect people with dementia badly – increasing their confusion and speeding up deterioration.[1] Our 2007 work in Lincoln found 68 per cent of people in acute beds with dementia were no longer in need of acute care, and could have been discharged.	Joint working between social care staff and the hospital on effective discharge planning.
Rehabilitation and support to remain at home for longer	Forty-four per cent of GPs say there are satisfactory specialised services for people with dementia in 2009, compared with 31 per cent in 2007. Only 25 per cent of consultant psychiatrists say mental health intermediate care services are available for people with dementia, and only 13 per cent say mental health rehabilitation services are available (2009). Physical rehabilitation is open to people with dementia in only 38 per cent of consultants psychiatrists' patches.	Simple information sharing between health, social care and the third sector to help patients access services in their area, avoiding premature care home admission. Joint working between commissioners to spot shortfalls in capacity at different parts of the system and fill the gaps. Enabling access to services for people with dementia in line with Departmental guidelines.

Source: National Audit Office analysis

NOTE

1 Alzheimer's Society (2009) Counting the cost: caring for people with dementia on hospital wards.

3.10 In Summer 2009, 37 per cent of consultant psychiatrists we surveyed said a multi-agency group had been formed in their area to plan implementation of the Strategy (41 per cent were unsure). Fifty-eight per cent of consultant psychiatrists had an older people's mental health liaison team in their general hospital. Agreed joint care pathways would help with commissioning the vast array of services required to meet the needs of people with dementia, but only 11 per cent of consultant psychiatrists could point to one in their area (41 per cent were unsure). Care home providers and participants in our online forum highlighted bureaucratic behaviour and unwillingness by health and social care organisations to pool costs and savings as evidence that services are still not joined up.

3.11 Commissioning and delivering joined-up services requires a joint approach to assessing needs. Despite good examples (**Case Example 5**) the level of competency in this area is low, as shown by the recent results from the Audit Commission's World Class Commissioning evaluation (**Figure 18**). For dementia, where the measurement of costs and benefits has been poor (paragraph 1.15-1.19), specialist mental health input to commissioning and measuring services is vital. Only five per cent of GPs surveyed had discussed the implications of the Strategy with their primary care trust commissioners, and 39 per cent of consultant psychiatrists.

Case example 5

Joint working and joint commissioning

In 2007, NHS Telford and Wrekin commissioned an analysis of dementia services. This, combined with the views of 100 people with dementia and carers who were interviewed about local services, led to a report highlighting service gaps. The work captured the whole patient pathway, examining interactions between PCT, Local Authority and third sector groups and identifying shortcomings in local provision. The PCT and Council come together to find solutions. A Strategic Commissioning Group was formed, comprising social care, health, commissioners, providers and the third sector to prioritise areas for improvement and funding. Joint resource planning led to greater efficiencies, with over-capacity in some areas being balanced by under-capacity in others.

Figure 18

PCT competency in assessing local needs

Level achieved for Competency five[1]		Number of PCTs (%)
High	4	0
	3	2 (1%)
	2	109 (72%)
Low	1	41 (27%)

Source: Health Service Journal Information for Improvement Supplement 25 June 2009: Competency 5 Grasping the key to successful World Class Commissioning

NOTES

1 Competency five, one of 11 competencies in the World Class Commissioning assurance process, examines how well PCTs manage knowledge and conduct regular assessment of current and future local health needs.

2 Milton Keynes PCT and Nottingham City PCT achieved a level 3 and were the highest performing PCTs nationally.

3.12 Care homes are also a key partner in planning to meet capacity and quality challenges. There are around 18,000, mostly private sector, providers of care home places for older people; the largest ten provide 30 per cent of dementia beds.[28] Demand is set to rise even if early diagnosis delays care home entry, and quality of care in homes must also rise. However, smaller providers are ill-equipped in terms of management and leadership skills to respond.

3.13 Day-to-day contact between care homes and commissioners exists, but local care home managers we surveyed lacked awareness of the Strategy and were not involved in "co-production" relationships with local commissioners. Smaller providers assumed that larger providers were consulted on the Strategy – in fact, larger providers felt similarly uninvolved. Interviewees found the public sector reluctant to engage with them on strategic issues and felt that their contribution was undervalued by commissioners. Two Strategic Health Authorities were actively working with the care homes sector and three shared information with the sector, but four had no relationship with them.

3.14 The Department has identified commissioning for quality as the key lever for change into the future, but it is still immature:

- The Department's World Class Commissioning programme aims to transform the way health and care services are commissioned by encouraging commissioners to take a strategic long-term approach, with a focus on improved health outcomes. In its first year no primary care trust achieved the top performance level 4[29].
- World Class Commissioning is focused on health and unlikely to encompass councils, where commissioning of domiciliary care is poor at addressing the needs of people with dementia. Fifteen-minute home-care visits that focus on care tasks only, and not quality interaction with the client, are common, though this approach is known to be counter-productive for people with dementia.[9]
- "Practice-based commissioning" aims to provide primary care professionals, including GPs, with the resources and support to become more involved in commissioning decisions. The initiative has not addressed dementia services.

3.15 Some tools are emerging that could help improve the effectiveness of commisioning and may be able to be used in dementia. Commissioners are now expected to build quality into contracts using the new concept of "quality accounts", and the "Commissioning for Quality and Innovation" payment framework which ties a small proportion of contract payments to hospital trusts and other providers to quality improvements. Patient Reported Outcome Measures[30] are another new contractual tool not yet applied to dementia.

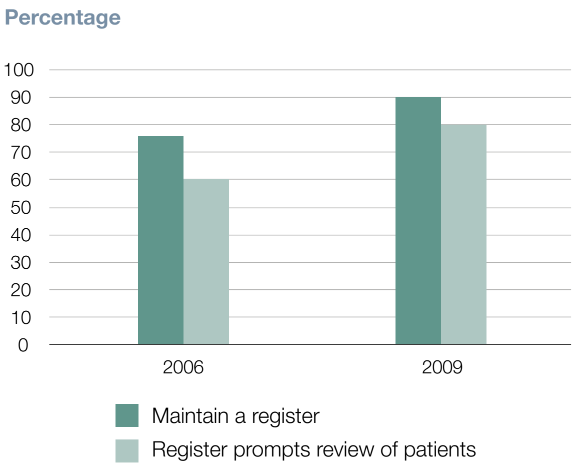
Monitoring and managing performance

3.16 The Committee recommended in 2007 that the Strategy should include criteria for evaluation, reporting progress and addressing areas of underperformance. Managing performance is also a key criterion of Capability.[6]

3.17 Since 2007 GPs receive financial rewards for two aspects of dementia care: maintaining a dementia register, and review of dementia patients every 15 months. Although performance has improved (**Figure 19**), it focuses on inputs and not outcomes. Whilst SHAs are committed to managing the performance of primary care trusts on dementia, some have told us their ability to do so is limited by the need to focus most attention on holding primary care trusts to account for those activities where there is a "Vital Sign" tier 2 indicator. Councils, who deliver or commission much dementia care, have no specific performance requirement on improving dementia care. In 2007 we reported that since primary care trusts became coterminous with Local Authorities there were opportunities for joint funding and accountability as part of Local Area Agreements, but this has yet to provide any leverage for dementia.[m]

Figure 19

Increase in the number of GPs registering and reviewing patients with dementia



Source: National Audit Office survey of GPs (2006 and 2009)

NOTE

QOF data from the NHS Information Centre states that 99 per cent of practices maintain a dementia register, whilst 96 per cent review patient care.

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[m] A Local Area Agreement is a three-year agreement that sets out the priorities for a local area in certain policy fields as agreed between the relevant Government Office, the local authority, Local Strategic Partnership and other partners. The agreement is made up of outcomes, indicators and targets aimed at delivering a better quality of life for people through improving performance on a range of national and local priorities.

3.18 Research shows that a devolved approach to management requires more robust performance monitoring information than a "command-and-control" approach[31]. Since our 2007 report, there has been some good work on developing dementia performance indicators, notably the rollout of data on our diagnosis gap indicator data at primary care trust level across England, which was initially championed by South East Coast Primary Care Trust. The Deputy Regional Director for the South East region has developed a set of 'dementia metrics', some of them outcome-based (**Figure 20**) and is trialling these. The new metrics will be accessible via the Department's Dementia Portal and the NHS Information Centre website in January 2010. The Department expects regional teams to use the metrics to inform baseline reviews (due March 2010) and to perform ongoing self-assessment.

3.19 The "Sentinel" Stroke Audit[32] has been a strong lever for improvement in stroke care, and can provide lessons for the National Clinical Audit of Dementia Care in the General Hospital, to be launched by the Royal College of Psychiatrists in January 2010. In June 2009, the College also launched an accreditation scheme for memory services based on self and peer review. Thirty-seven services have signed up so far.

Figure 20

A selection of proposed dementia performance metrics

Strategy Objective	Proposed measure of improvement
Objective 2. Early diagnosis and intervention for all	Narrowing the diagnosis gap, ie, the difference between the estimated prevalence of dementia in the population and the number of people with a diagnosis of dementia
Objective 6. Improved community personal support services	Improvement in the ratio of the number of people with dementia who receive an assessment, to the estimated prevalence of dementia in the population
Objective 8. Improved care in general hospitals	Improvement in: ● Acute admissions per actual prevalence index ● Actual excess bed days per actual prevalence

Source: Adapted from the Core National Team's Dementia Metrics Framework

NOTE

1 The framework is being developed with a set of indicators to measure improvements against each Strategy objective. The examples provided are for three of the Department's seven 'priority objectives'.

3.20 Regulation is provided by the Care Quality Commission (the Commission), established on 1 April 2009, a merger of the Healthcare Commission, Commission for Social Care Inspection and Mental Health Act Commission. The Commission regulates public, private and third sector provision of all health and adult social care services in England. It registers providers, carries out inspections and thematic reports,[33] and can impose fines or closures. The Commission is currently developing its approach and new systems of regulation; care home providers reported uncertainty about the future regulation of their dementia services and scepticism about infrequent inspection as a lever for change. The Care Quality Commission's Short Observational Framework for Inspectors (SOFI)[n] is an inspection tool that helps to assess the experiences of people with dementia in care homes, but this is time-intensive and only applied in 5-10 per cent of all inspections.

3.21 The Commission will publish guidance on how it plans to monitor compliance of providers with new registration requirements in 2010, which will focus on outcomes, experiences and rights of those receiving care. These requirements could be a powerful lever if they include specifically what is expected for good dementia care. The Commission's thematic reports can also drive change by providing a national progress update on services. The Commission has begun reviews on the healthcare needs of people in care homes and the experiences of people in care homes with stroke. Both could provide evidence on dementia care practice.

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[n] SOFI is a methodology used to understand the quality of the experiences of people who use services who are unable to provide feedback due to their cognitive or communication impairments. SOFI helps inspectors to assess and understand whether people who use services are receiving good quality care that meets their individual needs.

Appendix One

Methodology

Main methods (carried out May to September 2009)	**Purpose**
The questions used in each were based on the elements of the Cabinet Office's Capability Review Framework. A more detailed description of the framework can be found at www.civilservice.gov.uk/capability reviews.	
Review of key documents including Strategy, Implementation Plan and Impact Assessment; interviews with the Department.	To assess the Strategy and the Department's implementation plans.
Interviews with external stakeholders including professional bodies, sector skills councils, third sector groups and regulators. Online survey of GPs (1,001 responses). Online survey of Consultant Old Age Psychiatrists (218 responses). Census of all 10 Strategic Health Authorities. Structured interviews with all nine Deputy Regional Directors of Social Care. Structured interviews with nine care home providers.	To identify: • views on the clarity and vision of the Strategy; • arrangements in pace to drive implementation; • perceived barriers to implementing the Strategy; • how GPs' attitude to and knowledge of dementia have changed since 2007; • what services are available to consultant psychiatrists' dementia patients; and • how SHAs and Deputy Regional Directors perceive their role in monitoring implementation.
Eight online discussion boards, hosted by IpsosMORI (87 participants). Board members included commissioners, hospital based nurses, mental health liaison staff, memory clinic leads, community staff, dementia trainers, care home managers, and social workers.	To test what level of understanding and buy-in to the Strategy exists, and hence illustrate the attitudinal and behaviour changes required.
Analysis of data including Quality and Outcomes Framework and dementia prevalence data.	To provide measures of performance.
Review of existing research and other Strategies (England and overseas).	To compare the Department's approach on dementia with other fields and countries, and inform our understanding of developments in dementia care and research.
An expert panel, including most of the members of the panel who advised us in 2007, commented on our emerging findings and conclusions.	To confirm the reasonableness of our methodology, findings and conclusions.

A more detailed description of our methodology can be found at: www.nao.org.uk/dementia2010

Appendix Two

Summary of the National Dementia Strategy

Summary of the National Dementia Strategy

2008 Committee of Public Accounts recommended (Recommendation number)

1 The Department's Strategy should have a clear timetable for implementation, criteria for evaluation and reporting progress, and a strategy to engage all stakeholders

4 The Department should commission a dementia awareness campaign

3i GPs should receive better support from Community Mental Health teams

5 Dementia patients should be assigned a coordinator/single point of contact

3ii A dementia care pathway should be developed

8i Hospitals should routinely undertake mental health assessments

8ii Carers should hold copies of care records[1]

6i The Department should emphasise the importance of assessing and meeting carers' needs

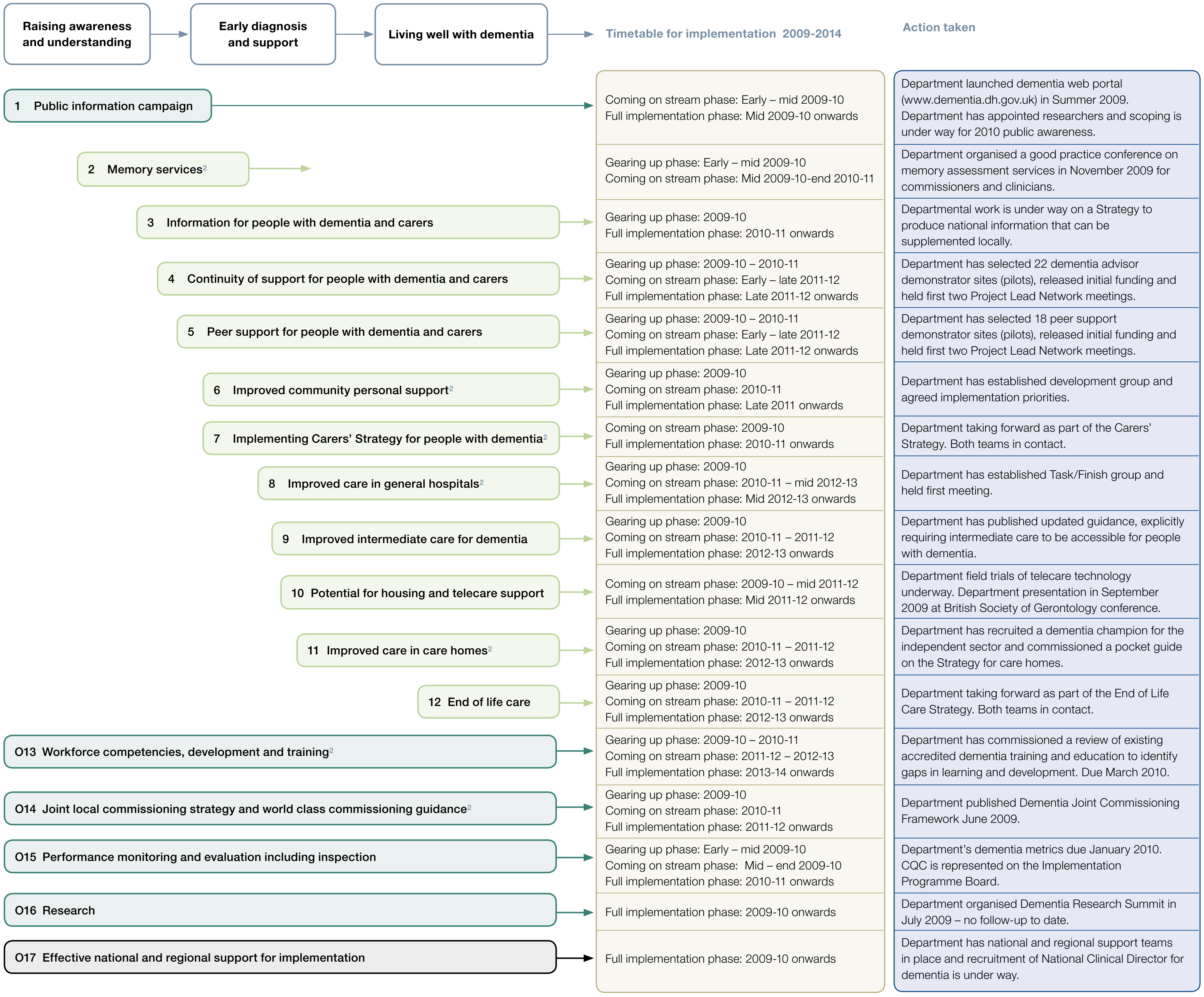
7i Community Mental Health Teams should provide out-reach to more care homes

7ii There should be improved regulation of staff qualifications

6ii The Department should commission a toolkit to demonstrate the cost benefits of care methods

2 The Department should appoint a Senior Responsible Officer

2009 National Dementia Strategy: 3 aims and 17 objectives



Raising awareness and understanding → **Early diagnosis and support** → **Living well with dementia** → **Timetable for implementation 2009-2014**

	Timetable for implementation 2009-2014	**Action taken**
1 Public information campaign	Coming on stream phase: Early – mid 2009-10 Full implementation phase: Mid 2009-10 onwards	Department launched dementia web portal (www.dementia.dh.gov.uk) in Summer 2009. Department has appointed researchers and scoping is under way for 2010 public awareness.
2 Memory services[2]	Gearing up phase: Early – mid 2009-10 Coming on stream phase: Mid 2009-10-end 2010-11	Department organised a good practice conference on memory assessment services in November 2009 for commissioners and clinicians.
3 Information for people with dementia and carers	Gearing up phase: 2009-10 Full implementation phase: 2010-11 onwards	Departmental work is under way on a Strategy to produce national information that can be supplemented locally.
4 Continuity of support for people with dementia and carers	Gearing up phase: 2009-10 – 2010-11 Coming on stream phase: Early – late 2011-12 Full implementation phase: Late 2011-12 onwards	Department has selected 22 dementia advisor demonstrator sites (pilots), released initial funding and held first two Project Lead Network meetings.
5 Peer support for people with dementia and carers	Gearing up phase: 2009-10 – 2010-11 Coming on stream phase: Early – late 2011-12 Full implementation phase: Late 2011-12 onwards	Department has selected 18 peer support demonstrator sites (pilots), released initial funding and held first two Project Lead Network meetings.
6 Improved community personal support[2]	Gearing up phase: 2009-10 Coming on stream phase: 2010-11 Full implementation phase: Late 2011 onwards	Department has established development group and agreed implementation priorities.
7 Implementing Carers' Strategy for people with dementia[2]	Coming on stream phase: 2009-10 Full implementation phase: 2010-11 onwards	Department taking forward as part of the Carers' Strategy. Both teams in contact.
8 Improved care in general hospitals[2]	Gearing up phase: 2009-10 Coming on stream phase: 2010-11 – mid 2012-13 Full implementation phase: Mid 2012-13 onwards	Department has established Task/Finish group and held first meeting.
9 Improved intermediate care for dementia	Gearing up phase: 2009-10 Coming on stream phase: 2010-11 – 2011-12 Full implementation phase: 2012-13 onwards	Department has published updated guidance, explicitly requiring intermediate care to be accessible for people with dementia.
10 Potential for housing and telecare support	Coming on stream phase: 2009-10 – mid 2011-12 Full implementation phase: Mid 2011-12 onwards	Department field trials of telecare technology underway. Department presentation in September 2009 at British Society of Gerontology conference.
11 Improved care in care homes[2]	Gearing up phase: 2009-10 Coming on stream phase: 2010-11 – 2011-12 Full implementation phase: 2012-13 onwards	Department has recruited a dementia champion for the independent sector and commissioned a pocket guide on the Strategy for care homes.
12 End of life care	Gearing up phase: 2009-10 Coming on stream phase: 2010-11 – 2011-12 Full implementation phase: 2012-13 onwards	Department taking forward as part of the End of Life Care Strategy. Both teams in contact.
O13 Workforce competencies, development and training[2]	Gearing up phase: 2009-10 – 2010-11 Coming on stream phase: 2011-12 – 2012-13 Full implementation phase: 2013-14 onwards	Department has commissioned a review of existing accredited dementia training and education to identify gaps in learning and development. Due March 2010.
O14 Joint local commissioning strategy and world class commissioning guidance[2]	Gearing up phase: 2009-10 Coming on stream phase: 2010-11 Full implementation phase: 2011-12 onwards	Department published Dementia Joint Commissioning Framework June 2009.
O15 Performance monitoring and evaluation including inspection	Gearing up phase: Early – mid 2009-10 Coming on stream phase: Mid – end 2009-10 Full implementation phase: 2010-11 onwards	Department's dementia metrics due January 2010. CQC is represented on the Implementation Programme Board.
O16 Research	Full implementation phase: 2009-10 onwards	Department organised Dementia Research Summit in July 2009 – no follow-up to date.
O17 Effective national and regional support for implementation	Full implementation phase: 2009-10 onwards	Department has national and regional support teams in place and recruitment of National Clinical Director for dementia is under way.

Main leadership responsibility lies with: ☐ National Core Team ☐ DRDs locally ☐ Both

NOTES

1 PAC recommendation not reflected within the Strategy or subsequent Department work.

2 Seven priority objectives as identified by the Department of Health

Endnotes

1 Department of Health (2009) Living Well with Dementia – a National Dementia Strategy.

2 The Kings Fund (2008) Paying the Price.

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4 House of Commons Committee of Public Accounts (2008) Improving Services and Support for People with Dementia Sixth Report of Session 2007-2008.

5 High Quality Care for All and Operating Framework 2009-2010.

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11 NHS Information Centre 2007-08 Quality Outcomes Framework data www.ic.nhs.uk/qof

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13 Care Quality Commission www.cqc.org.uk/registeredservicesdirectory/rsquicksearch.asp (September 2009 data)

14 Led by Professor Nick Barber, School of Pharmacy, Uniersity of London (October 2009).

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16 Knapp, M. et al. (2007) Dementia UK: Report to the Alzheimer's Society, Kings College London and London School of Economics and Political Science.

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27 Department of Health, Operational Plans 2008-2009 – 2010-2011.

28 Laing & Buisson (2009) Dementia Care Services UK Market Briefing 2009.

29 HSJ (2009) Competency 5 – Grasping the Key to Successful World Class Commissioning Health Service Journal Information for Improvement Supplement (25 June 2009).

30 http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_092647

31 Sir Michael Barber (2007) Three Paradigms of Public-Sector Reform McKinsey & Company.

32 See, for example, Clinical Effectiveness and Evaluation Unit, Royal College of Physicians (2008) National Sentinel Stroke Audit Report for England, Wales and Northern Ireland.

33 Commission for Social Care Inspection (2008) See Me, Not Just the Dementia: Understanding People's Experiences of Living in a Care Home.

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