



National Audit Office

**REPORT BY THE
COMPTROLLER AND
AUDITOR GENERAL**

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Improving Dementia Services in England – an Interim Report

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 years¹, 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 2008⁴. 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 change⁵. We used the Cabinet Office’s Capability Review framework⁶, 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.

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 recommendations⁴ (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.

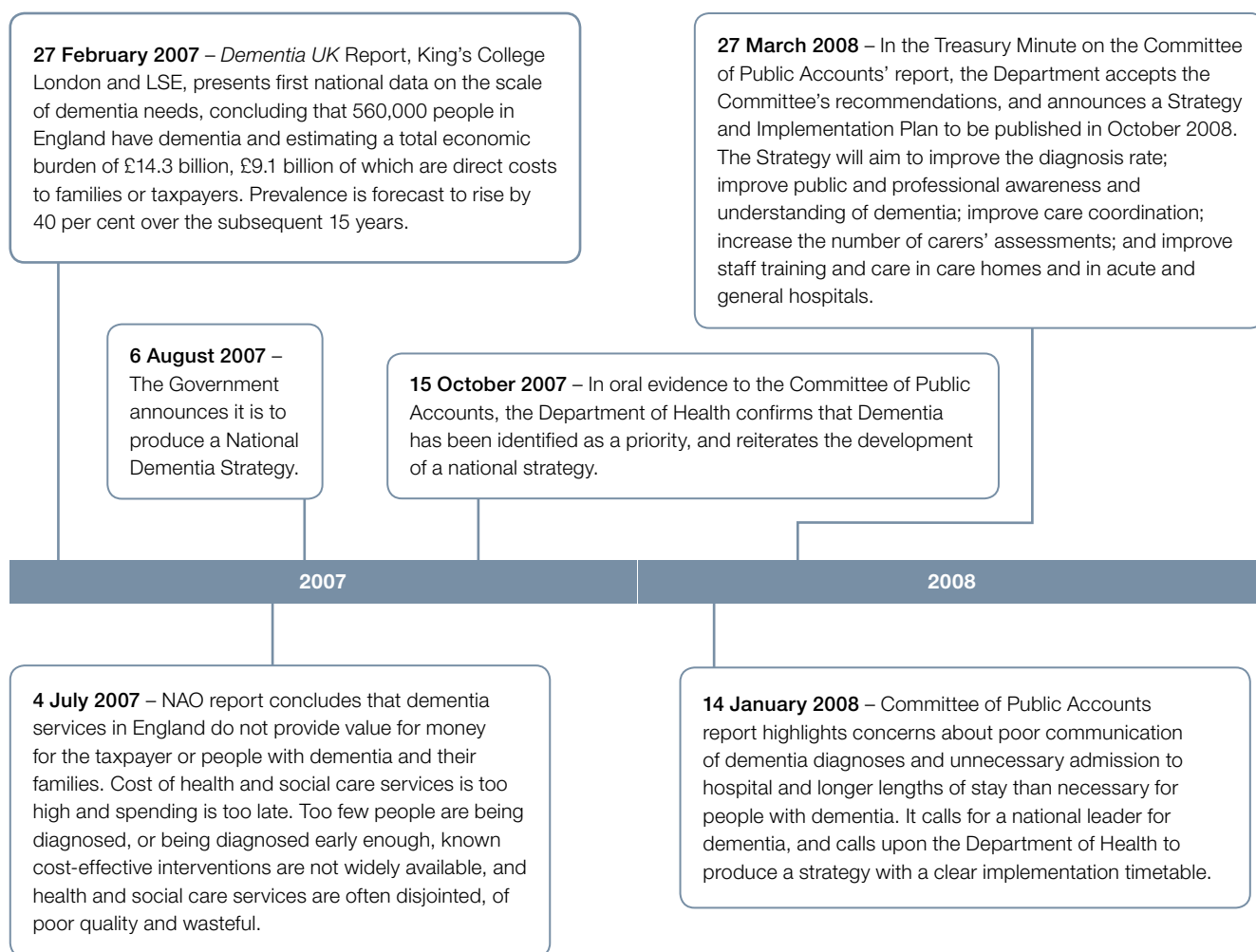
Leadership: roles, responsibilities, direction and drive

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.

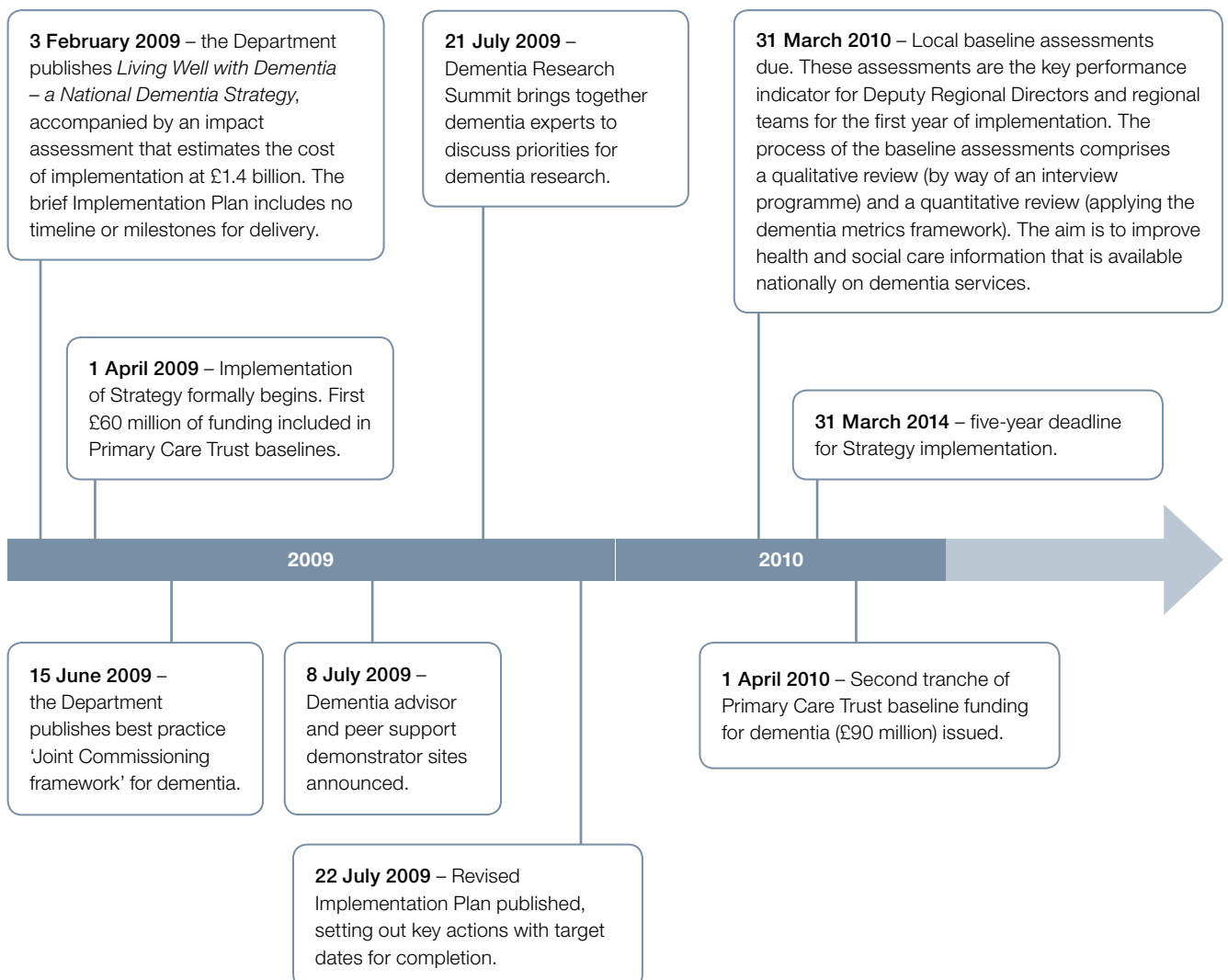
10 We found strong direction and national leadership for the Strategy provided by the Director General for Social Care. The Department attempted to recruit a National Clinical Director for Older People and Dementia in June 2009, but without success. In October it commenced recruitment for separate directors 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



11 Empowered local leadership is important for delivering transformational change⁷ and is a fundamental element of the Department’s performance management model⁸. 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.



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 2009⁹. 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.