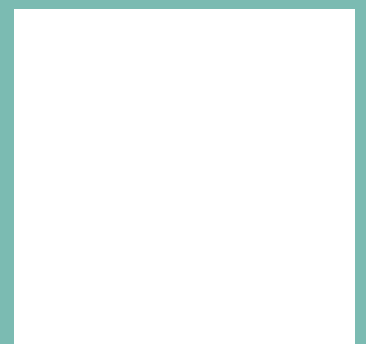


# Follow-up Research on Dementia Services

Research report prepared for the  
National Audit Office

November 2009



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## Publication of data

Any press release or publication of the findings of this survey requires the advance approval of Ipsos MORI. Such approval will only be refused on the grounds of inaccuracy or misrepresentation.

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## Presentation and interpretation of the data

It is important to note that findings of this report are not *statistically representative* of the views of social housing tenants. **Qualitative research** is designed to be *illustrative, detailed* and *exploratory*. It is designed to provide insight into the perceptions, feelings and behaviour of people rather than conclusions from a robust, quantifiable valid sample. It is also important to bear in mind that we are dealing with people's perceptions, rather than facts – how things appear and not necessarily as they actually are.

Throughout the report, use is made of verbatim comments from participants from across the discussion groups and in-depth interviews. Where this is the case, it is important to remember that the views expressed do not always represent the views of the group as a whole. However, in each case the verbatim is reflective of, at least, a small number of participants.



# **1. Background & introduction**

# 1. Introduction

## 1.1 Background

Dementia, in a range of forms, presents a huge challenge to the UK's health and social care sector – so much so that some third sector organisations and academics foresee a 'dementia crisis' looming.<sup>1</sup> There are currently 700,000 people in the UK with dementia, and this number is set to double over the next 30 years as the proportion of 'older' old people in the population grows.<sup>2</sup> The costs of supporting these people are considerable. According to the Department of Health, dementia now costs the UK economy £17 billion a year, with the amount likely to treble to over £50 billion over the next three decades.<sup>3</sup>

The size of this challenge has led to appraisals of existing dementia services from both third sector organisations and those that scrutinise public spending. Cost, however, is not the only important issue in evaluating dementia services. The quality of care available to people with dementia is also vital, and has come under considerable scrutiny, as have the delivery and implementation of dementia services. Issues such as poor diagnosis of dementia, lack of early intervention and a paucity of relevant services and support in the community have all been raised by both the voluntary sector and the NAO as key weaknesses in current provision.

In 2007, the NAO published an important VFM study on this subject, *Improving services and support for people with dementia*, which made a case for the review and reform of dementia services in light of the increasing urgency of the problems facing them. This report made a number of key recommendations. These included improving GPs' diagnosis rate of dementia, the wider provision of Memory Services, improving hospital medical responses to dementia, and improving the management of dementia services and support in the community<sup>4</sup>. These recommendations, among others, were incorporated by the Department of Health into the NHS's National Dementia Strategy (the Strategy). This was launched in February 2009, aiming to address the concerns raised by the NAO by improving awareness and earlier diagnosis of dementia, increasing earlier intervention and ensuring a higher quality of care for people with dementia.

Yet the nature of dementia care means that the far-reaching proposals of the Strategy face many barriers. People with dementia are largely supported and serviced by what Professor Sube Banerjee, an architect of the Strategy, has called a 'web of care'<sup>5</sup>. Dementia services are delivered through a range of providers, with diagnosis and medical support handled primarily by health services, and longer-term care delivered by the social care and third sectors, as well as private companies such as those managing care homes and domiciliary care. The Strategy must, therefore, bring coherent direction and objectives in dementia medicine and care across a huge range of services: General Medical Practice, social care, residential care, hospital services, community nursing and other intermediate services. It is this particular overarching challenge that means that understanding the experiences of frontline staff in health and social care will be vital to your review of the efficacy of the Strategy. It also gives a strong impetus to the undertaking of this research study.

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<sup>1</sup> Knapp, M, and Prince, M., *Dementia UK: A report into the prevalence and cost of dementia*, 2007, LSE/ The Alzheimer's Society

<sup>2</sup> *Living Well with Dementia: A National Dementia Strategy*, 2008, Department of Health

<sup>3</sup> *Living Well with Dementia: A National Dementia Strategy*, 2008, Department of Health

<sup>4</sup> National Audit Office, *Improving services and support for people with dementia*, 2007, London: The Stationery Office

<sup>5</sup> Sixth Report by the Committee of Public Accounts: Evidence, *Improving Services and Support for People with Dementia*, October 2007, HC 604



## 1.2 Research objectives

Against the background outlined above, this research project aimed to speak with a range of frontline health and social care practitioners and meet the following objectives:

- to investigate readiness of the system to deliver against the recommendations of the NAO's 2007 VFM study through the National Dementia Strategy;
- to learn what structural, cultural and procedural changes are coming through / are needed from the frontline perspective to implement and deliver the new Strategy; and
- to uncover participants' views and experiences of leadership in dementia services, and the extent of planning taking place.

## 1.3 Structure of the report

In this report we present findings on dementia services and the National Dementia Strategy, focusing on strengths and weaknesses of the Strategy, as well as possible areas for improvement. Chapter 2 will outline the methodology for the research project, and the following chapters address broad themes raised in the research.

- Chapter 3 will present some key contextual issues and findings on participants' views on existing services.
- Chapter 4 will examine participants' views and awareness of the National Dementia Strategy ("the Strategy").
- Chapter 5 will present findings on participants' views on leadership, management and implementation of the Strategy.
- Chapter 6 will look at issues around joint-working.
- Chapter 7 will present participants' views on funding and resources available for the Strategy.
- Chapter 8 will describe profiles of service providers in relation to their attitudes to the Strategy.
- Chapter 9 will present findings on participants' perceptions of an 'ideal' dementia service.

## 2. Methodology

## 2. Methodology

We conducted eight online bulletin boards with a range of health and social care professionals over two weeks between 12<sup>th</sup> and 29<sup>th</sup> July 2009. The following table shows the range of audiences we spoke to in the course of the research.

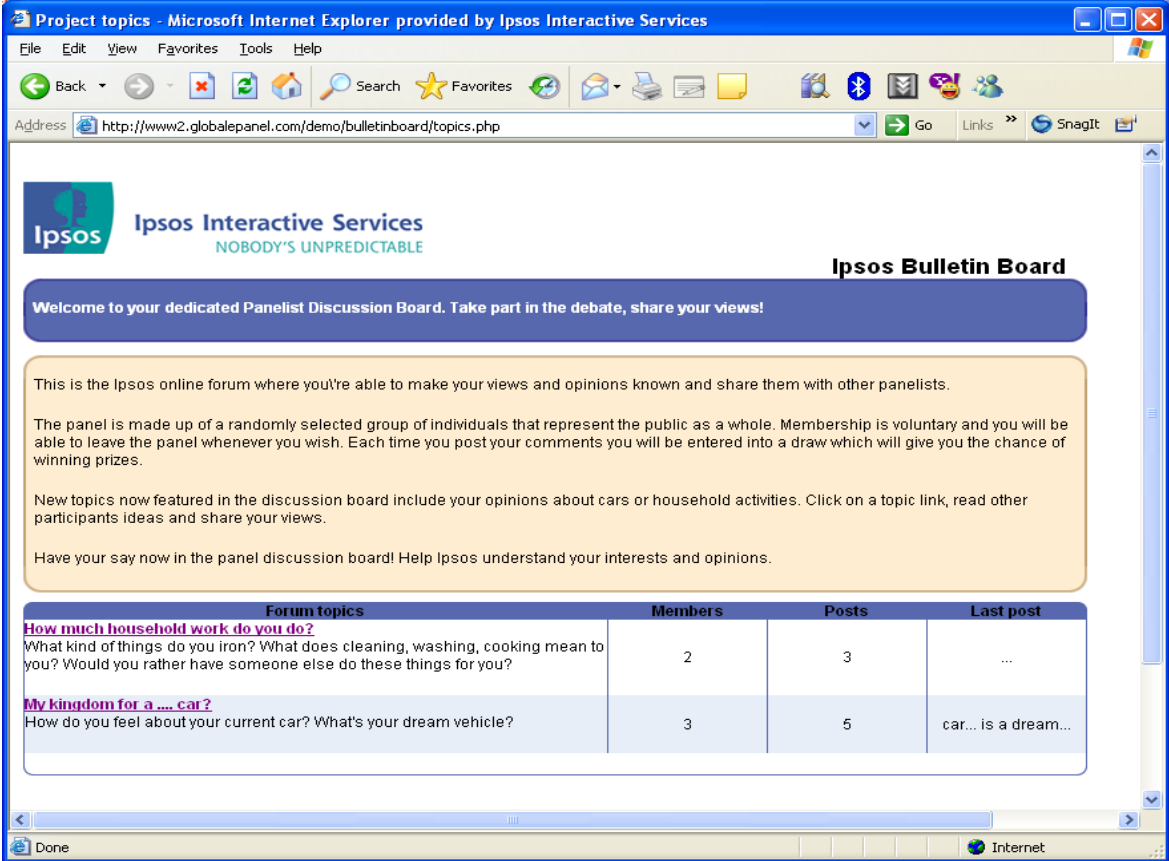
**Table 1: Sample frame of online bulletin boards**

	<b>Audience</b>	<b>Composition of group</b>	<b>Other quotas</b>	<b>Number of participants</b>
<b>Board 1</b>	<i>PCT and Local Authority commissioners</i>	Mix of lead commissioners for elderly care, mental health and long term conditions.	Mix of Local Authorities and PCTs.	11
<b>Board 2</b>	<i>General nursing staff</i>	Mix of nurses working in accident and emergency, medical, surgical and orthopaedic wards.	Fairly senior, with at least 5 years experience.	11
<b>Board 3</b>	<i>Mental health liaison staff</i>	Mainly psychiatric nurses, and some Consultant Old Age Psychiatrists.	Fairly senior, with some responsibility for Strategy work.	12
<b>Board 4</b>	<i>Memory clinic leads</i>	A mix of Old Age Psychiatrists, social workers, psychiatric nurses etc.		6
<b>Board 5</b>	<i>Community staff delivering range of services for people with dementia and carers</i>	Mix of homecare staff, occupational therapists, community nurses, health visitors, day centre staff.		12
<b>Board 6</b>	<i>Dementia trainers (People who deliver training to staff at nursing/ care homes)</i>			16
<b>Board 7</b>	<i>Nursing and residential care home managers</i>	Mix of managers from residential care homes with specialist dementia beds and those without.		9
<b>Board 8</b>	<i>Social workers</i>	Specialising in older people's mental health.		10

Participants were recruited using telephone recruitment from a sample and from contacts provided by the NAO, as well as desk research conducted by Ipsos MORI. 'Snowballing' methods were also used to attain sufficient numbers for some of the discussion boards. Between fifteen and twenty participants were recruited per board, and participation levels varied between the groups. This was because some audiences experienced barriers to taking part which included problems with ICT and unfamiliarity with the method, as well as, importantly, time constraints.

The online bulletin boards were conducted over two weeks, and during this time questions were posted on a dedicated website. The discussion guides for these bulletin boards are included in the Appendix to this report. Participants logged on with a unique username and password to post their replies during the research period. This approach worked well for participants who were both widely dispersed and faced considerable time pressures in their working lives – the boards allowed them to contribute to the discussion around shift work if necessary.

**Figure 1: The discussion area**



The online approach also offered other distinct advantages. Bulletin boards allowed participants time to reflect on and ask questions about a subject, and we were able to track reaction in real time to understand the evolution of attitudes and ideas towards particular issues. Participants had time to carry on in-depth discussions and have the possibility to change their mind, and we were able to add stimulus to the discussion, including the objectives of the Strategy, for participants to respond to. Participants were also reassured by the anonymity the method afforded them, and, as a result, the method generated very candid comments on dementia services. However, the fact that participants logged on when convenient did have an impact on the flow of the discussion, particularly for those audiences who were less forthcoming with details, and this could be considered a potential weakness of the method when consulting health and social care practitioners.

At the end of the research period, automatic transcripts of the bulletin board were generated. These were analysed by our team of researchers through a number of team analysis sessions and then through thematic analysis of the data. This process has formed the basis of the analysis in this report.

# **3. Perceptions of existing services**

## 3. Perceptions of existing services

### Summary

In this chapter we will examine the range of views on existing services for dementia patients, focusing our discussion on a number of key themes which participants felt could be areas for improvement that the Strategy needed to address.

However, perceptions of existing services, and indeed issues pertaining to the Strategy more broadly, must be understood in the context of key characteristics of the audiences in the research, and also in some larger social contexts for this research. The participants in this research were from a range of backgrounds in dementia services, including frontline and management roles, and from a variety of services incorporating both medical and social care, and 'bridging' services such as dementia training and memory clinics. Importantly, these characteristics shape their responses to dementia services.

Regarding broader contexts for the research, this study has been carried out in the context of the very recent launch of and ongoing implementation of the Strategy, meaning that for many participants, the Strategy was an extremely recent phenomenon. Furthermore, the research has been conducted in a climate of looming cuts in public spending, and considerable public debate around end-of-life care and, to some extent, dementia.

In this chapter we will first set out these 'key contexts' for the study, which are important touchpoints we will return to throughout the report. We will then look in detail at perceptions of:

- consistency of service provision;
- diagnosis of dementia;
- quality of care;
- service gaps; and
- training.

### 3.1 Key contexts

Across all the themes examined in this report, it is important to bear in mind two key cleavages in the characteristics of the audiences, and three contextual issues which relate to the climate in which the Strategy is being implemented and have had a powerful impact on the views of participants. In this section we will describe these contexts in detail, and would recommend that this report is read with these issues in mind, as they are important factors shaping participants' perceptions throughout.

#### 3.1.1. Frontline or management staff?

First of all, with regard to the characteristics of the audiences we have spoken to in this research, there are many differences between perceptions and experiences in relation to those practitioners who have a *frontline* or a *management* position.

*Frontline staff*, for whom we take the broad description of those who have direct contact with people with dementia and their carers, included general, community and psychiatric nurses,

social workers and memory clinic leads in the research. These participants were *less likely to have been consulted in the development of the Strategy* than management-level staff, and also, generally, felt they had *less power* to make changes around the implementation of the Strategy, or influence the leadership around it.

*Management staff*, who, in this project included health care commissioners and care home managers, were, along with dementia trainers, more likely to have been involved in the early stages of the consultation, and were hence more aware of many of the issues relating to the Strategy than frontline staff.

### 3.1.2. A medical or social model of dementia care?

A second important cleavage among the audience researched in this study was that of **where their views fell in relation to the *medical or social model of dementia care***, and, hence, where they fell in relation to the position taken on this model by the Strategy.

The 'medical model' of disability takes physical impairments to be of primary interest and concern, and, more broadly, considers physical impairments to be barriers to participation in society. The 'social model', however, considers the social context of barriers to participation, and is primarily concerned with the individual's perceptions of their disability and attendant needs. These models are relevant because they embody very different positions with regard to disability – in this case dementia – and in some cases, these positions are in conflict. They are also relevant because, to some extent, they epitomise the attitudes or practise of the audiences in this study: whereas those trained and practising in medicine are more likely to take the 'medical' position on dementia care, many social workers and community practitioners such as domiciliary care workers would consider their approach to be closer to the 'social model'.

This distinction is important because of the position taken by the Strategy, and the importance that all stakeholders and practitioners buy into the vision of the Strategy. The Strategy's approach brings a vision of dementia services closer to the 'social model', though perhaps not close enough for some practitioners.

Nonetheless, the emphasis on 'person-centred care' is a departure from the medical approach previously taken with dementia care, and as much as practitioners support this new vision of dementia services (see Chapter 4.1), there is a legacy of the medical model of practice to overcome. This is relevant not only to how care is delivered, but to the planning and implementation of services, especially when joint-working is considered, as the following comment illustrates.

**“We will have to work hard to ensure that dementia is not seen as a ‘mental health’ issue alone. I work in area where three PCTs have become one and so there are different patterns of service arising from different priorities and investment in the past”**

**Mental health commissioner**

Frontline practitioners, too, find themselves considering whether they should be prioritising the physical needs of their patients, or their social and emotional needs. For many practitioners, a lack of resources that relate to supporting the social model may jeopardise their ability to reinforce that model through their own practise.

**“Dementia is, to date, a medical diagnosis. We know it is under-diagnosed. So we are struggling to develop information sets that would help us make sure that individual budgets, telecare, acute hospital care, supported to live at home, are inclusive and appropriate for those with dementia. The Long Term Care strategy has a lot to offer to the development of services for those with dementia, but locally has addressed physical health needs only”**

Mental health commissioner

### 3.1.3. Public perceptions of dementia

Many participants in this research study have noted that public attitudes to dementia are a hugely important context for their work. They feel that the **general public's lack of knowledge about dementia and the social stigma that is still attached to the illness contribute to neglect and under-diagnosis of the condition.**

**"The change that would make the most difference to patients and practitioners alike would probably be reducing the stigma associated with dementia and making services user-friendly and accessible"**

Psychiatric nurse

At management level, changing public attitudes towards dementia were also considered to be vital, and although some commissioners and dementia trainers felt that public awareness of dementia was growing, they also noted that this did not necessarily equate to the public knowing *how to support* people with dementia. Commissioners identified this as a key challenge for the Strategy.

**“I feel that we have not fully addressed as yet communication re dementia. There is still some stigma attached to this area but we will continue to work on improving people’s attitudes through education, communication and working with people with dementia and their carers”**

Mental health commissioner

### 3.1.4 Timing of the research study

This research study has been conducted only five months after the launch of the Strategy. For *frontline practitioners*, especially those who do not work primarily in mental health, this has meant that they feel it is simply **too early to see changes happening** as a result of the Strategy, as many of these changes have only just been implemented. It also means that frontline staff in this study have been less likely to be aware of the Strategy, as information may not, as yet, have been cascaded down to them. Management-level staff were more



informed - many of the health commissioners and dementia trainers in this study, as well as some of the memory clinic leads, had been involved in the consultation, so they were more able to comment on the 'vision' behind the Strategy.

The timing of the research was, however, also an issue for management level staff, who, despite a higher level of awareness more generally about the Strategy, felt that they were ill-informed about some aspects of its implementation. The details of financing and joint-working were not clear to many, and this may be due to the fact that the revised implementation plan for the Strategy was published in the middle of the fieldwork period. Managers and practitioners *had not as yet seen the details of the Strategy's implementation when the research began* and were, therefore, largely unaware of these details.

**"I also think the strategy has some good aims and implementation could greatly benefit services, but the bits that's missing is detail on exactly what to do next and just what money will come from where and on what basis and what will be used to judge its cost effectiveness."**

Psychiatric nurse

### 3.1.5. Cuts in public spending

The research was also conducted in the context of the economic downturn, in a climate of widespread concern about budgets available for health and social care, and cuts in public spending. Participants at both frontline and management levels expressed strong concern about the ramifications of these cuts for the Strategy. As such, **the economic context of the study engendered some scepticism about the future of the initiative**, particularly from frontline staff, while management level staff expressed concern over resources.

**"In this current market of cutbacks and streamlining services to save money within the NHS I find it difficult to believe that the Strategy will be introduced smoothly"**

Accident and Emergency nurse

**"Much more capacity is required, at every level, to drive this enormous agenda in the midst of so much else going on, both in NHS and LAs, and in the context of the downturn in the economy"**

Mental health commissioner

Nonetheless, the economic context also meant that frontline staff were more conscious of efficiency with regard to the implementation of the Strategy. There was also some sense that if dementia were not a priority – not just for the Department of Health, but also where public opinion was concerned – services associated it would be more likely to face cuts. Participants felt that without public support for the services and wider acknowledgement of the issues facing people with dementia, it would be harder for the services to win funding and support from the central government. Furthermore, **in the context of a downturn, such services would be more vulnerable to cuts without public support**. As the following comment illustrates, some practitioners felt that the solution to this would be to protect resources aimed at dementia services by ring-fencing them specifically for dementia. We will explore this issue in greater detail in our later chapter on the funding of the Strategy, in

section 7.1.

**“My view has always been that people with dementia and their carers receive a disparate Cinderella service. I am heartened by recent media attention and heightened awareness of the condition but disappointed that the ... Strategy does not specifically ring-fence funds for dementia services, rather it allows PCTs to make the decision whether to make dementia a priority”**

Memory clinic lead

Nonetheless, one positive consequence of the current economic context was that many participants had a stronger sense of the importance of using resources efficiently and ensuring that services added value. Several participants, especially those in managerial roles, were very conscious of the imperatives for ensuring cost effectiveness when delivering services.

**“I think the recession/ national debt will impact on services ... over the coming years and finding the most efficient / cost effective way to implement is important.”**

Psychiatric nurse

Changing public perceptions towards dementia were considered important here with regard to pushing dementia treatment up the government agenda, as were issues of implementation, such as the level of funding allocated to dementia services and how this was managed. We provide more details on such aspects of views on dementia services in Chapter 5 on management, leadership and implementation of the Strategy.

### 3.2 Consistency of service provision

Against the background of the contextual issues outlined in the previous sections, we have identified a number of themes regarding participants' views on existing services. This first theme related to consistency of dementia service provision. Many participants, notably those working on the frontline of health and social care suggested that the **service was highly inconsistent within local areas**. These views were held strongly by nurses, especially those working in the community, and frontline social workers.

**“I feel that there has been little or no progress in providing seamless service in our area and it does continue to be a postcode lottery”**

Psychiatric nurse

Commissioners agreed that services were inconsistent across Local Authorities, and viewed the situation as a problem. They did propose a number of reasons why this may have come about, notably a legacy of dementia services being provided by health services alone, rather than drawing together services provided through social care and other providers, including private and third sector organisations.

**“I do not think that it has helped that dementia has been subsumed in general mental health services previously and that much of the**

**previous funding for mental health services has excluded older people”**

Mental health commissioner

For these reasons, as we will see in Chapters 4 and 6, the Strategy was very much welcomed by frontline and management health and social care staff. Participants stated that the Strategy has provided an opportunity to develop more consistent provision across health and social care, as well as address issues around the quality of care in the private sector.

**“Dementia care is often left to the private sector and is difficult to regulate to ensure that people with dementia and their carers are provided with the health services they need”**

Psychiatric nurse

### 3.3 Diagnosis of dementia

Both frontline and management practitioners were in agreement that improving early diagnosis of dementia was an important challenge for services, particularly those provided by General Medical Practitioners. Many also agreed that the existing level of early diagnosis of dementia was an area which urgently needed to be improved.

**“I still think generally we are poor at early diagnosis and assistance”**

Mental health commissioner

However, as much as participants were keen to see early diagnosis rates improving, many frontline practitioners put forward strong arguments that services and resources needed to be in place for post-diagnosis support. Mental health commissioners, memory clinic leads, and care home managers observed that **early diagnosis placed a strain on resources**, particularly as public expectations are not always managed appropriately, and there may be restrictions on the medication prescribed and the care available to support those diagnosed with dementia.

**“I find the services which support people with dementia are generally fragmented. Early diagnosis seems to have romped ahead leaving post-diagnosis void”**

Care home manager

Psychiatric nurses told us that people with dementia, carers and relatives expect both memory support services as well as medication at the point of diagnosis, and that many health and social care services may struggle to provide these. Negative attitudes to early diagnosis from the medical profession – perhaps due to a lack of resources available to support people with dementia and carers once a diagnosis has been made – were also considered an important barrier to improving rates of early diagnosis.

**“There is still a negative attitude to early diagnosis especially as the access to medication has been restricted. This has given a contradictory message and confuses people as well as causing frustration and anxiety”**

Psychiatric nurse

From the perspective of participants, early diagnosis, therefore, seems to be an admired objective, but one which may prove problematic without the resources required to support people with dementia and carers leading up to and at the point of diagnosis, as well as after diagnosis has been made.

### 3.4 Quality of care

Participants in the discussion had a strong and coherent view of what good quality care for people with dementia should look like. Interestingly, the view that social and emotional needs of people with dementia and carers should be prioritised cut across health and social care professionals, suggesting that many in the ‘medical’ camp aspired to a ‘social model’ perspective on dementia. Participants felt strongly that good quality care for people with dementia should be:

- **home-based if that was in the best interests of the person with dementia;**
- **supported by trained professionals who were experienced in dealing with people with dementia; and**
- **managed in a way that replicated the best aspects of familial care, with time taken to consider the needs of the person with dementia.**

However, this model was perceived to be an ideal which current services need to go some way to attaining, particularly with regard to support for carers. Participants were also aware of the cost of delivering such a service, and once again returned to the key barrier of the *resources* available to deliver the strategy (which we will explore in more detail in Chapter 7). There was a strong consensus that excellent care requires *time*, and for many professionals in the dementia field, an emphasis was placed on completing tasks quickly. Frontline participants stated that was due to heavy caseloads, both in hospital and in community dementia care, and a wider lack of resources in staffing.

**“Domiciliary services are often time-limited and task-focused which does not recognise the emotional and supportive needs of the person with dementia and their carers”**

Domiciliary care worker

**“I have found that residents who have had to go into hospital ... are cared for on a physical side very well but are usually lost, confused and left to fend for themselves with eating and drinking. This is not the case for the local small cottage hospitals that have been brilliant, I think size of the ward and the amount of time the nurses have is important”**

Care home manager

Participants from a range of roles in health and social care spoke of the importance of ‘person-centred care’, to mean both ensuring a tailoring of services to the needs of the people with dementia and carers, and also encompassing support for the *personalisation agenda* in social care. Local Authority commissioners were among the most articulate on this subject, putting forward strong arguments for using existing systems to develop personalised care, as the following comment illustrates.

**“We urgently need the ability to draw up care plans which are individual in nature and offer personalised services. The law need to be changed to allow us ... give individual budgets”**

Mental health commissioner

### 3.5 Service gaps: resources

Participants in the research had strong views on the current state of resources for dementia care. One issue on which both managerial and frontline staff felt very strongly was the **need for improved late-stage dementia care**. Frontline nursing staff noted the lack of dementia beds available in care homes and other follow-up services for those people at advanced stages of dementia, and this was an issue noted also by social workers and mental health commissioners.

**“There are not enough care homes with nurses in the area catering for people with dementia, the majority seem to be residential homes who often struggle”**

Community psychiatric nurse

Participants also felt strongly about having the autonomy over funding to support services in their areas of expertise. Some frontline staff felt that devolving these decisions to senior management at commissioning level was responsible for unsuitable decisions regarding the provision of dementia services. This was because, in their view, such managers were too removed from the realities of frontline work, and from the practical problems faced by people with dementia and their carers.

**“Previously our line managers could make the decisions on funding, at a local area team level, but now our assessments are passed through to a team of senior managers ... The hoops we now have to jump through simply to get someone a few hours extra home care, day care or whatever are way beyond what were necessary previously”**

Social worker

Participants also observed the **need to support the diversity of people with dementia**, for example, addressing the access needs of rural communities and understanding the perceived different cultural responses to dementia of black and minority ethnic communities. Frontline participants also noted the impact of fragmented services on quality of care, which in many cases made them advocates of joint-working (see Chapter 6 for more discussion on this). Participants from social work in particular felt strongly that dementia services were not holistic, to the detriment of patient care and carer support.

**“Whilst there is evidence of good practice and integrated working, on the whole this isn't done very well, resulting in fragmented services across many areas, often leaving the person with dementia and their carers confused about the services they receive and where to go when in need of support and help”**

Social worker

### 3.6 Service gaps: training

In terms of training around dementia, many participants saw **the training and formal assessments of carers** as being a key gap in services. Frontline participants, particularly in community psychiatric nursing and social care, saw training and support for carers as being a key element in improving patient care in dementia treatment.

Dementia training was conducted in different ways in the different sectors. Whereas medical practitioners were more likely to have had face-to-face training sessions, care home managers reported that they used long-distance learning courses to train their staff instead. Of the two types of training, long-distances courses were seen very favourably, as those being trained were able to consider the issues and return to training modules in more detail. Face-to-face training was not always dementia-specific, but sometimes directed instead at assessing older people's needs. As the following comment illustrates, frontline psychiatric staff who had had training in this area felt that often other types of training took precedence, as supporting people with dementia was not high on the agenda.

**"Our service doesn't often deal with service users with dementia ... so when a case arises staff don't feel skilled to deal with it. [Dementia] training would be beneficial but there is so much demand for mandatory training ... that is more essential to our service that it is difficult to free up capacity for staff to attend"**

Psychiatric nurse

There was also a sense that existing training for frontline staff was not sufficiently in-depth. Participants recognised the need for more training in order to meet the objectives of the Strategy, and often felt that the resources were not there to support their desire to learn more. We will explore this issue in greater depth in Chapter 7. Some staff attributed this to a legacy where dementia awareness had been neglected, and to perceptions that dementia awareness is not a management priority in allocating resources. For instance, participants noted that the opportunities for attending conferences, and for taking time off for courses to keep them updated on learning in the field, were often restricted to them on these grounds.

**"Staff are still unsure and don't always have positive role models to watch and learn from. They generally leave the Dementia Awareness training wanting to know more"**

Domiciliary care worker

## **4. Views and awareness of the Strategy**

## 4. Views and awareness of the Strategy

### Summary

Frontline and management awareness and understanding of the Strategy is highly important to achieving the anticipated aims in dementia service improvement. As the evidence of this chapter and Chapter 6 on joint-working will illustrate, understanding, good communications and buy-in from social and health care staff will mean stronger implementation of the Strategy.

We will then look at the following aspects of participants' awareness of the Strategy:

- their views on the Strategy;
- their existing knowledge of the Strategy; and
- the information they have received about it since the launch of the Strategy.

### 4.1 Reception of the Strategy

Overall responses to the Strategy were **highly positive**, from the frontline to management level. **Many commented that the initiative was a step in the right direction and that it was both timely and important.**

**“I have been impressed at the approach taken by the Department of Health. The strategy is very ambitious but consistent with other messages from DH and does seem to reflect the needs of the population it is trying to address”**

**Mental health commissioner**

The level of support for the Strategy's vision is an important strength – it seems unlikely from the evidence of this study that the Department of Health will face challenges in winning over the hearts and minds of health and social care workers, particularly frontline staff. This, nonetheless, places the onus on the Department to deliver the resources to support the implementation of the Strategy, or face disappointment from staff who are ready and willing to contribute to improving dementia services.

The Strategy was particularly praised by social care staff for being holistic, addressing the needs of people with dementia from early to advanced cases with strong emphasis on community care. It was seen as a huge opportunity to address the perceived historical neglect of services for people with dementia.

**“This is really the first time that older people's services have been the focus for significant service development. There is more discussion about the needs of the younger person with dementia too. This in itself is seen by our team as a positive change”**

**Community psychiatric nurse**

However, the strong sense of optimism about the core vision of the Strategy was tempered by concern from some participants about some aspects of what was proposed. For some



participants, at both frontline and management levels, the most difficult aspects of dementia care were not addressed directly enough in the Strategy. **Some frontline staff also felt that the objectives were perhaps too far-reaching and thus hard to achieve.**

**“There is a glossing over of the fact that a good number of people with dementia have extremely challenging behaviour ... It's a distressing presentation that requires high levels of nursing but the Strategy really doesn't acknowledge that very much in my view”**

Mental health commissioner

Finally, the **financing and implementation of the Strategy raised concerns** from participants from across health and social care. Participants did not feel well informed about the funding available from the Strategy, and many commissioners were unsure of how the Strategy was to be implemented. We will explore these issues in more detail in later chapters, but to some extent these issues may be related to the timing of the study, as explored in Chapter 3.1.4 above.

## 4.2 Existing knowledge

For **frontline staff**, especially those in general nursing, there was very low awareness of the Strategy, and very few were able to name direct changes brought about as a result. Community and hospital psychiatric nurses, and social workers specialising in elderly care had meetings about the Strategy with their team or had been informed about it by their manager, but very few had detailed knowledge of the policy. To these staff, changes in services that have been and were being made were perceived to be the consequence of pre-existing initiatives. There was mention of discussion and review but little action taken as a follow-up to the launch of the Strategy. General nurses in particular were very unaware of planned changes, the broader implication being that the Strategy has to date had a fairly limited impact on non-specialised services at a front-line level.

Where **management staff and those involved with dementia training and memory clinics** were concerned, there was a much stronger awareness of the Strategy and its impact was beginning to be felt. Commissioners had taken part in regional events and stakeholder forums, and had also been responsible for organising working groups around the subject of dementia services as a result of the Strategy. Commissioners also perceived an increased awareness among frontline staff around dementia, which was not necessarily reflected by the experiences of the frontline participants in this research.

**“There is increased awareness and interest and more community-based support emerging for people with dementia and their carers”**

Mental health commissioner

Awareness levels were also low among **care home managers**. Although some had been informed by their employer, and others had set up meetings with staff to discuss the issues raised, they nonetheless felt that information about the Strategy needed to be disseminated more widely, as the following comment illustrates.

**“Our company has set up conferences to discuss this or I would not have heard about it”**

Care home manager

The disparity between management perceptions of frontline awareness of the Strategy and actual frontline experiences suggests that **communicating the objectives of the Strategy to frontline staff may be an important area of risk for the Strategy**. However, as with other aspects of this research, it may be too early to comment on whether frontline awareness of the Strategy is satisfactory, and it is important to consider this. The differences between frontline and management experiences may also be accounted for by the regional differences discussed in Chapter 3. Some Local Authorities were clear examples of good practice in information-sharing, involving third sector organisations and carers in their discussions and developing local strategies from a Strategy framework.

**“Each locality has a senior officer group, which includes both Mental Health and acute provider Trusts and Alzheimer’s Society and Age Concern, also carers”**

Mental Health Commissioner

However, some participants noted that in their area very little information-sharing regarding the Strategy had been undertaken.

### 4.3 Information received and shared since launch of the Strategy

Frontline general nursing staff felt they had received very little information on the Strategy since it was launched, and this research study in fact proved a welcome opportunity for them to learn about it in more depth. Some participants told us that they had experienced objections from managers with regard to sharing information about the Strategy, and there was a strong perception from some frontline participants that **managers did not take the initiative seriously because it was not a priority** in comparison to other areas of health.

**“I feel this will take a long time to filter down to the relevant carers, as having had to research it for myself and understand the objectives, I approached my direct manager and was told ‘it’s not something you need to know about yet.’ Also, no meetings are in place to discuss it!”**

Community psychiatric nurse

Those frontline staff who were more closely linked with older people’s care and mental health were better informed, and had received information through attending events held by Trusts and conferences, as well as through discussions within teams. They also commented that they had read about the Strategy in journals. On probing, some psychiatric nurses and other practitioners working in mental health liaison did note that dementia services in their locality were being set out in a more systematic way, which they attributed to the Strategy changing the way these were organised.

Others felt there was **still a need to ‘cascade’ the vision down to those on the front line**, and felt that bridging the gap between those who manage services and those who have to deliver them was imperative to the Strategy’s success. Care home managers also reported that they lacked information on the Strategy, suggesting that this information could be integrated into the long-distance learning schemes on the subject that many such organisations used.

These frontline participants also noted a number of ways in which information about the Strategy was being disseminated well: **dementia training and dementia care cafes** were

**both cited as convenient and accessible sources of information for the general public** and also potential avenues for de-stigmatising the condition. We will discuss these initiatives in greater detail in the following chapter. **Frontline participants also felt they would benefit from an information leaflet** about the Strategy, as many felt they would have little time in their working lives to look at a screen and read a whole policy document.

**Managers and dementia trainers, however, were much clearer about the objectives of the Strategy**, having been involved with the initiative at consultation stage. Many commissioners told us that they had taken part in regional group meetings and read summaries of key information, which meant they felt informed about the new objectives and, to some extent, how to achieve them.

**“The regional meetings have been useful in keeping us up to date both regionally and nationally and have initiated some good work around benchmarking current services, also useful in gaining information about the national demonstrator pilots”**

**Mental health commissioner**

# **5. Management and implementation**

# 5. Management and implementation

## Summary

In this chapter we will present our findings on participants' experiences of the management, leadership and general implementation of the Strategy. First of all, we will outline general perceptions of the management, leadership and implementation of the Strategy, and follow this by presenting findings on the following themes:

- service redesign;
- the need for milestones; and
- developing care pathways.

## 5.1 General perceptions

From the **frontline** perspective there was a strong feeling that joint-working would be hugely important to the success of the strategy. 'Patchworking' care and support for people with dementia from the health, social care, third and private sectors was a common experience of most frontline workers dealing with people with dementia, and participants were keen to see improvements to services that addressed this issue, and others, such as improving end-of-life care, and addressing the needs of carers.

However, as we have seen, many frontline participants were not very aware of the Strategy, and many were not sure who was in charge of which aspect of the implementation – or indeed who should be. There was some awareness, though, among frontline staff that PCTs and mental health trusts will be responsible for implementing the Strategy. However, community and hospital-based nurses differed in their views on where funds and leadership should lie, with the former feeling that social services should have more power. There was also a range of views on how inspired people felt about the leadership of the Strategy, with regional differences coming into play.

For **commissioners**, the Strategy was proving to be a chance to map existing services, identify gaps, prioritise, plan and finally evaluate current services. They noted a number of changes which had been initiated in their local areas: the planning and commissioning of new services; accountability for dementia services to local councillors; incorporating dementia into joint-commissioning frameworks and bidding to be dementia care advisor demonstrator sites. However, they also commented that it was too early to see the full impact of these changes.

## 5.2 Service redesign

Considering the implementation of the Strategy, participants in the research felt strongly that it was **important to recognise good practice** and make the most of strategies that are already working. For those at management level, the Strategy provided an opportunity to support initiatives that were working well. Many participants were able to cite **examples of new services which they considered to be highly effective**, and which they perceived to have emerged from the Strategy. Participants in psychiatric nursing from a range of localities cited the establishment of '**dementia care cafes**', which provided informal forums for relatives and carers to share information about different types of dementia and how future

changes may manifest themselves. There was also evidence that good practice was being shared, with a number of memory service liaison professionals speaking about how 'Memory Cafes' were about to be established in their area, with support from the county council. Community nurses also saw the benefits of dementia services initiatives, and were advocates, as the following comment illustrates. Other initiatives that were considered effective were co-ordinated Memory Services and changing the delivery of nursing facilities to ensure they are more flexible. The following comments illustrate some of the ways in which the Strategy is being used to support existing good practice:

**"I started work within the new Memory Service in December. I am really enjoying being part of something new and the response from GPs and service users has been very positive. We are really busy so it shows that the strategy is working in the right direction"**

Community psychiatric nurse

**"The PCT is going ahead with re-commissioning our block contracted nursing home for people with dementia and making it more flexible and better able to respond to the changing needs of people as they go in and out of the Continuing Care Criteria"**

Mental health commissioner

**"There are some pockets of excellence, e.g. specialist services providing a service for people who are in the end stages of dementia, network forums for carers, development of training materials / resources all helping to improve dementia care"**

Domiciliary care worker

Participants also perceived **systemic changes** as a result of the Strategy. Commissioners were reconsidering the allocation of budgets and management strategies, and for some frontline practitioners, these changes were evident in their working lives. Some nurses working in mental health liaison reported seeing changes in managerial structures which meant resources for dementia were being co-ordinated more effectively, as the following comment illustrates:

**"We are now working in a more systematic way... It has led to some changes. Organisationally we now have in post a Dementia Care Manager with overarching responsibilities for both the Residential and Nursing Units (EMI)"**

Psychiatric nurse

However, the redesign of services, particularly the emphasis on early diagnosis, did raise concerns from some quarters, and these concerns were mainly related to resources. Some social workers and dementia trainers felt that the reframing of services around detecting early cognitive impairment could lead to unfairly raising expectations of both people with dementia and the general public due to the lack of available support post-diagnosis. The following comment illustrates how this aspect of the Strategy was potentially inappropriate, should additional resources not be allocated:

**“I am concerned about the Strategy. Without any suitable medication to treat and with the current NICE guidance blocking early prescription of cholinesterase inhibitors, shouldn't we be targeting the very limited resources on supporting people when dementia is having a negative impact on sufferers' lives, rather than letting lots of people know they have a mild cognitive impairment?”**  
Social worker

### 5.3 The need for milestones

There was a clear message from frontline staff – particularly from those in general nursing – that **they need targets and milestones to help them prioritise dementia services and have a sense of what they are aiming for**. This suggestion was also raised by participants in community nursing, and suggests that for health professionals, who are now accustomed to working in a climate of meeting targets on delivery of services, milestones and targets would be hugely constructive.

**“The treatment of cancer patients and joint replacements has a high priority, as failure to achieve these results in financial penalty. Thus, an incentive to meet these goals exists. What incentive is there for trust to ensure that they introduce specialist care for dementia patients? They may [otherwise] be perceived as a drain of resources”**  
Acute Nurse

Participants at management level also agreed with the idea of targets, citing the importance of clarity of objectives in the research. Commissioners suggested that PCTs should be obliged to submit agreed action plans in response to the Strategy, which would set out the way forward. Other participants suggested that given the original funds were not ring-fenced, this approach would be vital to ensure a thorough evaluation of dementia spending, as well as appropriate planning and resourcing of services.

**“Money ... should be monitored that it is being spent on actual services for people with dementia and should be a national target – this is a vital sign!”**  
Mental health commissioner

### 5.4 Developing care pathways

The **development of care pathways for dementia was considered to be an important aspect of effective implementation of the Strategy**. Many practitioners felt that some aspects of service provision were far more comprehensive than others, and care pathways would be an important aspect of reducing this unevenness.

**“The needs of people with dementia at the early and middle stage are better met. It is at the later stage that we find current**

**accommodation is unsuitable and this is proving an unmet social care need”**

Domiciliary care worker

Furthermore, participants felt that it was vital to involve a range of stakeholders in the development of these pathways, and that they would be a useful tool in evaluating services and assessing gaps.

**“The service I work in is developing care pathways at present and it should influence services. Four of us went on a conference and the work developed from there. It has been very useful for developing clearer thinking about services”**

Psychiatric nurse

Frontline and commissioning staff were in agreement on the importance of developing pathways, and in areas where they were being developed, there was also a greater awareness of the Strategy among frontline staff. Developing care pathways was considered to **enhance the clarity of the system for both patient and practitioner**, especially given the range of services required to meet the needs of people with dementia. A number of frontline practitioners reported that they thought their PCTs were aware of the importance of planning such pathways for dementia, and that the Strategy had been useful in driving this initiative.

However, some participants from health commissioning and dementia training suggested that developing local care pathways alone was not the only important aspect of planning. There was the strong sense from some that despite the Strategy, dementia was still a ‘Cinderella’ service, and needed to be prioritised even more highly in the NHS. As we will see in Chapter 7, funding was seen to be key to the success of the Strategy, and there was agreement among commissioners that still more support from the Department of Health, such as the conferring of Darzi workstream status, may be important to this funding.

**“If dementia was a Darzi workstream it would have a greater profile within the commissioning of services and increase the chances of additional funding”**

Mental health commissioner

Finally, one care home manager pointed out the importance of incorporating patients’ explicit wishes into the pathway, especially with regard to end-of-life care. This viewpoint illustrates the potential sensitivities around designing care pathways in dementia, illustrated in the following comment.

**“What residents would have wanted in the way of end-of-life care is usually disregarded ... paramedics complain that [care] homes try CPR even when it's stated that the resident does not want it ... They ought to acknowledge the situation and give the resident the dignity they would want for themselves.”**

Care home manager



## **6. Working as a whole system**

## 6. Working as a whole system

### Summary

In this chapter we address the key issue of how well the range of dementia services work together to meet the needs of patients. This matter is crucial to the efficacy of the National Dementia Strategy, as dementia care is a 'web' - as we have seen from our introduction to this report - with individual care often pieced together from a range of service providers.

In this section we first examine general perceptions of existing joint-working practices, and what might be needed to make systems more effective. We then go on to examine the following aspects of joint-working:

- frontline views on joint-working;
- management views on joint working;
- the role of GPs; and
- the role of actors outside health and social care

### 6.1 General perceptions

Participants in this research affirmed the importance of working as a whole system for efficient dementia care services. They also felt that the Strategy had an important part to play in improving this aspect of dementia services.

Management staff felt that current **inconsistencies in service provision** where joint-working was concerned were a key challenge, and this related to inconsistencies across both areas and between services. For example, while some areas had good working relationships with non-government providers, others had further to go in developing good relationships with voluntary providers in all services. Other struggled to develop and maintain a co-ordinated approach between health and social care providers.

**“[The Strategy] certainly has highlighted the inconsistencies in our services across the health and social care communities where we commission services [...] We have already good working relationships established with the Alzheimer's Society in some areas but not all”**

**Mental health commissioner**

Participants at both frontline and management levels were highly aware of the **diversity of services** that supported people with dementia and their carers, from GPs, to hospital services, to care homes. Some areas were making strong efforts to bring these services together through the employment of specialised dementia care managers in PCTS, or cross-cutting initiatives such as Memory Services. Nonetheless, the different approaches to dementia care discussed in chapter 3 did present challenges to joint-working and developing a service that designs care on an individual basis. We will discuss this in detail in the section on frontline experiences of joint-working below, but this was more of an issue for some participants than for others.

**“I think we can become too embroiled in the detail of whether it should be health or social care rather than looking at the person and their family as a person on a pathway of care and responding according to need”**

Community Psychiatric Nurse

Many participants recognised the divisions between different services, but did not know how to address this issue. In this context, the Strategy was seen as vital to bringing together a range of attitudes and acting as a bridge. Some management staff felt it is well-placed to inform a way forward, because it provides a **single template for patient- and carer-centred dementia**.

**“Has been helpful to have the Strategy to both profile dementia and also prioritise the way forward for all stakeholders and partners. SO useful to have the one template for all of our interventions and also to inform commissioning and decommissioning”**

Mental health commissioner

At management level, the **joint-commissioning approach** was considered vital to making services more inclusive, as it was thought to address the accessibility issue of universal care services. The North East was mentioned by one commissioner as an example of good practice, where engaging agencies and providers proved a good way to get Local Authorities on board.

**“Dementia care services in the North East are being mapped across agencies and providers, which is proving a useful means of engaging with Local Authorities ... The opportunity offered by the Strategy is that it requires a joint commissioning approach, which should enable much more coherent commissioning across communities and agencies”**

Mental health commissioner

## 6.2. Management perspective

Attitudes of management towards joint-working reflected their heightened awareness compared to frontline staff. Because of their exposure to the Strategy and their high-ranking positions, they were aware of the leadership at least at a *regional* level, which they considered appropriate. This, in conjunction with the identifying of funding through PCTs, was felt to create the opportunity for proper local commissioning in the future.

Joint-working within PCTs and across LAs was beginning, and local steering groups were being set up. However, although commissioners were clear on the purpose and vision of the Strategy, they were unsure about many details relating to the implementation. This, they commented, hindered planning, and this problem was reflected in the experiences of dementia trainers and memory clinic leads, some of whom suggested that they were not seeing the resources to support their work.

**“Regionally there is appropriate leadership, and the dynamic created by identifying funding through PCTs combined with leadership from Government Office could create sufficient drive to bind together commissioning for the very first time at local level”**

Mental health commissioner

For those outside core health and social care services, joint-working across sectors was not currently happening, and strong leadership was key. Participants did not feel that this was in place at the time of the research, but, as mentioned previously, this may have been related to the timing of the study.

**“Leadership is not clearly defined to me. Hopefully local roles will be allocated, as leaders are the main drivers in moving this strategy forward”**

Care home manager

### 6.3 Frontline perspective

Frontline staff had a very different point of view on this issue. This reflects both a lower level of communication and a higher concern with the practicalities of service delivery. Some frontline participants also noted that allocating the time required to liaise with other teams and follow up cases appropriately was not a priority among managers, and that this may jeopardise the Strategy’s objectives in this area. For them, *local* leadership was pivotal, but there was a lack of clarity about where responsibilities lay.

**“I feel it is still not clear who will take the lead locally ... As far as I am aware very little engaging has happened between partners. Within my workplace I feel we have good role models trying to implement better services for dementia care, but we are only a small area within the trust”**

Occupational therapist

Some frontline staff also felt there were attitudinal barriers to overcome related to the division between mental health and social care roles. This may reflect the fact that responsibilities used to be split in line with the medical model and now struggle to adjust to joint-working with a patient-centred approach, as the following comment illustrates:

**“Although there is great emphasis on joint-working, personal experience would suggest that there is resentment between services. I feel that mental health services are very precious about looking after those with dementia and don’t relinquish ‘control’ of their patients to other services such as community nurses lightly”**

General Nurse

Furthermore, some participants suggested the challenge of finding funds to support care frequently placed a strain on joint-working. Those in managerial positions in the private and social care sectors felt most strongly about this, as their services were picking up the burden

of health sector referrals. As the following comment illustrates, participants felt that clearer communications could improve joint working:

**“Quite often the relevant services do not communicate with each other, or pass the responsibility. I know they all have to work within budgets, but it seems that cases or referrals are passed around until someone finally finds spare funds.”**

Care home manager

Finally, bureaucracy and an excess of processes were felt to be a final barrier to successful joint working, which compounded the problems of traditional silo working in health and social care. For many front line participants, these aspects of joint-working presented a huge problem, and many suggested that this would be an important challenge for meeting the Strategy’s aims in delivering a comprehensive service that met the needs of individual patients.

**“Red tape and territorial behaviour have always been a barrier to successful interagency relationships.”**

General Nurse

Nonetheless, there were strong examples of best practice. A number of frontline staff were able to point to examples of successful joint-working, where specialist and community services were strongly integrated into the patient journey. The following comment gives an example of such best practice.

**“I work in a Community Mental Health Trust with home helps integrated into the team for specialist dementia care. This makes a huge difference as we talk to each other very quickly and easily. The key, I agree, is joint team working with hopefully shared protocols”**

Community psychiatric nurse

## 6.4. The role of GPs

GPs were perceived as distant from a lot of implementation plans. This may be because their interaction with patients takes place in a very different and more isolated realm, compared with the hospital environment.

**“Clients and carers have to fit into the structure of services available, which in many cases moves us away from a client-centred approach. [...] We still struggle with the attitudes of some General Practitioners and Primary Care staff”**

Domiciliary care worker

Community nurses and memory clinics thought that GPs were referring more people after the launch of the Strategy, which suggests that they have started implementing the joint approach. However, there were some concerns about the GPs’ willingness to take on more work as part of the Strategy on top of their existing workload. For instance, community nurses felt that GPs were not always willing to carry out health and blood tests

recommended by memory clinics. Participants also felt that GPs may be reluctant to step up early diagnosis due to patient demand for prescriptions.

**“The impact of early diagnosis might mean an increase in drug regimes and this might impact on the cost and time for GPs to prescribe and monitor”**

Domiciliary care worker

Overall, there was a strong sense that lack of funding and specialist services to refer into meant reluctance by GPs and community practitioners to follow up on early diagnosis.

## 6.5 The role of actors outside health and social care

Frontline participants recognised that the role of the Third Sector is providing support services and filling gaps that health and social care services struggle to provide. The *Alzheimer's Society* and *Age Concern* were particularly mentioned as partners with whom cooperation on support services is working well. However, many frontline participants noted that there was considerable distance to go in supporting, training and informing *carers*, particularly if the Strategy were to achieve the aim of helping more people with dementia to live in their own homes if they chose.

**“I think that we still have a lot of work to do with supporting carers in a meaningful way; there are still many people who really do not see themselves as a carer and, as such, are 'hidden'”**

Mental health commissioner

Participants also noted the importance of *housing providers* in supporting the aim of allowing people with dementia to live independently. Commissioners told us that as a result of the Strategy, they were able to drive forward work with specialist providers, and frontline staff were able to see these initiatives at work too, which they viewed very positively.

**“The Strategy is also helping the local service lobby the commissioning team for better provision of suitable accommodation”**

Domiciliary care worker

# **7. Funding and resources**

## 7. Funding and resources

### Summary

In this chapter we address participants' perceptions of the major challenge of resourcing the National Dementia Strategy. In the following sections we look more closely at the perceptions of financial, staff and training resources available to deliver the Strategy. Finally, we present findings on a final theme: that of the provision of beds for dementia patients.

### 7.1 Funding

There was concern across all stakeholder groups about the availability of funding for the implementation of the Strategy. Generally, the stakeholders were unclear as to where finance for this would come from, and were sceptical of their Trust's ability to implement the Strategy using existing budgets, especially in a time of recession and public sector cutbacks. This concern over finance does not look likely to diminish as time goes on, with many commissioners conscious of the impact that increasing numbers of elderly will have on the ability of the NHS to cope.

**Commissioners** in particular had extremely strong views about funding – most were not aware of the additional £150 million per PCT that has been made available by the Strategy over two years. Even where they were aware of this, many were unhappy that it had not been ring fenced specifically for dementia. Commissioners expected this to delay local level planning and implementation as they stated that they would have to reallocate existing resources, and frontline dementia specialists felt that this diminished the control they had over their ability to deliver the service they were striving for.

**“It would have been helpful if the additional funding had been ring-fenced rather than put in our bottom line. Our finance people were not even aware of the money until we told them, which was about 6 months after we supposedly were given the money. This means we have been given no real new money with which to implement the Strategy”**

Mental health commissioner

**“We have been informed that there will be no money to support necessary changes ... and it is not yet clear who is taking the lead at local level”**

Domiciliary care worker

Commissioners also suggested that the way in which the Strategy fits into broader processes of NHS reform restricted their ability to leverage funding themselves. The perceived lack of new funding was considered to present particular challenges in areas where management had seen restructuring. Commissioners felt faced with inequalities across the local area regarding service availability but were unsure how to rectify these problems.



**“In our experience here, if funds are not ring-fenced and/or there isn't a "point-scoring" target set for the commissioning agency, it makes it that much harder to secure the funds locally to support your commissioning intentions”**

Mental health commissioner

As we have seen, **frontline staff** in both the NHS and social care demonstrated tremendous goodwill regarding the overall objectives of the Strategy. Nonetheless, many were frustrated by the lack of practical changes they had seen, and lack of funding was perceived as the main issue.

**“I think there is a genuine wish to try and improve dementia care and control the future expense of care. It could be a really exciting time of innovation and service improvement but unfortunately I don't come across that much and so far have only heard of small changes within restricted budgets because of the current financial constraints”**

Psychiatric nurse

Many of the frontline staff, particularly general nurses and social workers, were sceptical about how funding was allocated within the NHS more broadly. They were concerned that budgets did not necessarily follow the patients with the most pressing needs, especially where the patients did not have a strong public profile and the attendant social pressure to push for change.

**“Dementia is not something that is currently curable and thus once a sufferer is taken on by the NHS this is for life. As the disease progresses they cost the NHS more money ... However within the existing climate of internal markets and value for money, who is seriously going to want to use their budget to introduce services that are exponentially expanding?”**

General nurse

Staff were clear that adequate funding is the key to achieving many crucial aspects of the Strategy's objectives – in particular delivering on joint-working, care homes and carers' concerns. Participants working in these fields were particularly explicit on the importance of receiving specific funding for dementia, as the following comment illustrates:

**“We at present do not intend to change the care we give to our residents. The staff are dedicated to the wellbeing of all our residents, so this will not change. Perhaps we will receive more assistance, advice and funds to extend the services we offer. We can only wait and hope.”**

Care home manager

A lack of funding was also considered a significant barrier to the implementation of joint working. Whilst most participants acknowledged the need, and have the desire to work together, they felt that budgetary constraints in their own organisations led to a reluctance to absorb any additional costs which were 'imposed' by other services.

**“Issues around who funds what is always a sticking point, as, from my experience, unless a patient is cared for by a speciality that has the funding to access the appropriate professionals, it doesn’t happen”**

General nurse

Dementia specialists were also concerned that the *research element* of the Strategy will be difficult to deliver as a result of funding limitations. They suggested that more research which is nurse-led and focused on social models of care, rather than on medication and clinical approaches, would be the most effective, but that is currently not happening because of a dearth of funds. Participants also noted a particular lack of research around the experience of carers, which they felt was vital to the field.

**“Dementia research lags well behind other areas, such as cancer. Projects are often not funded because funding bodies and reviewers do not understand the complexities and the challenges faced by research, we also need to grow and considerably expand the next generation of academics in dementia research, i.e. old age psychiatry. There are too few and those that are [around] are over-committed”**

Old Age Psychiatrist

However, some stakeholders were applying innovative approaches to addressing their dementia funding deficit. Some commissioners and memory clinic leads told us that a range of additional funding sources were being approached to fill the gap: from the regional SHA, central Department of Health grants such as Skills for Care, or funding from private organisations such as pharmaceutical companies.

## 7.2 Staff resources

Many participants, especially frontline workers, expressed strong concerns about the knock-on effect for staff resources of increased early diagnosis of dementia. There was a strong sense from participants in both health and social care that pressure on resources was already acute, especially regarding following cases up. As noted earlier, participants felt that pressure to diagnose would increase pressure on GPs to prescribe and monitor early-stage patients, and that resources were already stretched.

**“We have commissioned a widely-known community memory service, which is working well, but even this does not have sufficient capacity to fully meet the levels of need in our area”**

Mental health commissioner

Nurses and social workers were keen to note that their case loads were already heavy, and that the Strategy would continue to overburden them – even if they supported the aims in principle. Social workers felt particularly strongly on this point. Nurses also felt strongly that the economic climate was a barrier, and that recruitment freezes in the profession should be lifted.

**“Am I alone in being confused how a bigger, better, more focussed service for a burgeoning client population is going to be delivered for less money? Everybody in my team is working flat out trying to support and enable our patients with half the staff we had a year ago”**

Social worker

Finally, participants noted the difficulty of recruiting enough enthusiastic and well-trained staff to meet the needs of the Strategy. Staff turnover in care homes was noted to be high and wages low, and participants observed that dementia care was not glamorous and, in fact, frightening to many young applicants to the caring professions. Furthermore, one care home manager also suggested that poor links between the elder care sector and schools/ colleges were to some extent responsible for the low entry of recruits into the field. It was also felt that because carers have to be over the age of 18, many school leavers are choosing other career paths instead.

**“It is no secret that that elderly care specialities struggle to attract and maintain its workforce. I wonder if existing nurses and other healthcare workers will end up burdened with this role of implementing this strategy”**

Orthopaedic nurse

**“Salary is definitely an issue as it is one of the lower paid career paths, but until the funding gap in care is addressed this will not change ... There are currently no good links between colleges and homes, which is where good ground could be made in teaching good practice and understanding to the new carers coming into the field”**

Care home manager

### 7.3 Resources for training

Dementia trainers felt, and care home managers agreed, that a lack of funding for training would also limit the ability of the NHS and care homes to deliver the strategy – many staff did not have the skills and knowledge that they will need to deliver the person-centred care which the strategy is striving for. Dementia trainers in our study had already noticed that many organisations would only give their staff the bare minimum of training, often by distance learning; and trainers themselves asserted that this was inadequate to be able to provide an appropriate level of care.

**“Many organisations have to supply so much mandatory training that any additional may not be seen as a priority. Private organisations such as care homes, particularly smaller ones may not even have a training budget”**

Dementia trainer

Community nurses also felt that there was definitely a need for more training. Furthermore, they felt that this training should go beyond simply raising general awareness and, instead, should be more practical and hands-on to enable them to support patients appropriately.

They also suggested that they faced problems with getting access to training, time for training and also funding for training from their managers.

**"I have been booked onto a full day dementia course twice and both times my managers have stopped me going as I had to cover my own shift!" This time I have asked the course tutor to let me know when it will run so I can go off my own back and book it as a day's holiday!"**

Community psychiatric nurse

## 7.4 Supply of dementia beds

Concern was expressed by frontline staff in terms of the wide capacity of the NHS to provide quality care to people with dementia, especially in the acute sector where beds were at a premium and there were competing demands on staff attention. Staff also felt that the way services were incentivised in a differential manner meant that services which did not yet attract an incentive would receive lower prioritisation.

**"Dementia patients often have complex health and social issues and thus are seen as bed blockers if they are admitted to hospital"**

General nurse

In addition, dementia specialists pointed out that shifting of patients between wards due to bed shortages can be especially detrimental to those with dementia, as it increases their already high levels of confusion.

**"Patients can be transferred from ward to ward in quick succession due to pressure of beds adding to their level of confusion"**

Old age psychiatrist

The need for beds was raised by care home managers too, who noted that people placed in care home settings had to wait for funding from the social services, and without these funds people are often forced to go home with inadequate care packages in place, often placing them at high risk. The strength of feeling around this issue across many of the audiences we spoke to suggests that the supply of dementia beds is a key issue for resources in support of the Strategy.

## **8. Service provider profiles**

## 8. Service provider profiles

### Summary

This section of the report will provide an analysis of the range of experiences within each audience type, assessing their views in terms of the specific risks presented to/by each group to the implementation of the Strategy. We will aim to compare these profiles to each other where appropriate. These risks will be assessed along the following criteria:

- their awareness of the Strategy;
- level of training in relation to dementia care;
- philosophy of care according to the medical or social model; and
- their position in the hierarchy of the NHS and care services (frontline or management).

In this chapter we provide a rich picture of the differences between the range of frontline and management service providers affected by the Strategy. The following chart sets out our findings on the characteristics of different service providers in this study, and the sections which follow it give more detail on each provider's 'profile' in relation to the Strategy.

**Table 2: Service provider profiles**

<b>Audience</b>	<b>Philosophy of care</b>	<b>Management or frontline</b>	<b>Approach (generalist or specialist)</b>	<b>Awareness of the Strategy</b>	<b>Level of training</b>
<b>Mental health and elderly commissioners</b>	Medical, but aiming towards a social model	Management	Generalist approach	High	Medium
<b>General nurses</b>	Medical	Frontline	Generalist approach	Low	Low
<b>Mental health liaison staff</b>	Medical	Management and frontline	Specialist approach	Medium	Medium
<b>Memory clinic leads</b>	Medical / Social mix	Management and frontline	Specialist approach	High	High
<b>Community Staff</b>	Medical / Social mix	Frontline	Generalist approach	Medium	Medium
<b>Dementia trainers</b>	Medical / Social mix	Frontline	Specialist approach	High	High
<b>Care home managers</b>	Social	Management	Generalist and specialist	Medium	Medium

<b>Social workers</b>	Social	Frontline	Specialist	Medium	Medium
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## 8.1 Commissioners of services for the elderly

Commissioners were highly aware of the Strategy but were confused as to how to implement it locally. Whilst the Strategy had allowed them to lead local reviews of dementia care, they were very concerned about the lack of ring-fenced funding, which means they had to develop complex work-arounds and efficiency savings in other areas in order to develop dementia services in their area. Commissioners felt there was good leadership on the Strategy, but a lack of money and staffing capacity to deliver on the implementation.

## 8.2 General nurses

Those nurses who do not specialise in dementia or mental health are generally unaware of the Strategy. None of the general nurses who participated in this study had detailed knowledge of the Strategy for the following reasons:

- **people living with dementia make up a small number of their patients**, so it is not clear yet how the Strategy will impact on their workplace;
- even when there is a patient with dementia, their **physical needs tend to take priority** over any dementia-related care (for instance, in the ICU); and
- the Strategy has **not set out any specific targets**. As it is competing with other target-driven policies, these will take priority in a high-pressure environment such as a hospital.

Having read the Strategy, most nurses felt that it was clear and concise, but they did not understand fully what was expected of them. They were also concerned about resources and fear that, in the future, implementation targets for the Strategy will be added to their already overburdened schedule, feeling there are not enough nursing staff willing to specialise in geriatric medicine, let alone dementia care itself. Other mental health staff, including those working in care homes, commented that this was due to the challenges faced in working in this field, as well as other factors such as pay.

Nurses would like to see clearer information on where staff and financial resources will come from for a successful implementation, and where the responsibility for delivering on Strategy objectives will lie. They would also welcome training on the Strategy and in skills for dealing with patients with dementia.

## 8.3 Mental health liaison staff

Mental health liaison staff were concerned about the inconsistency of service provision across local areas, and a continuing public image problem which does not encourage people with dementia or carers to confront dementia, and discourages staff from specialising in this area.

They felt that pressure on hospital beds, the slow speed of referrals to old age psychiatrists, and a lack of clear intermediate or community care options after a stay in hospital mean that many people with dementia are unnecessarily placed in residential care. They also felt that

their advice may be overridden by generalist consultants who wish to compartmentalise mental health to a separate service. However, they praised the memory clinic and café systems, and are pleased to see a movement towards an explicit care pathway in many areas.

## 8.4 Memory clinic leads

Memory clinic leads felt that (partly due to the commissioning of their service), care for those with dementia is improving through a focus on nurse-led, person-centred services, joint-working and a clearer care pathway. However, they felt that improved awareness and training of 'physical health' professionals and the public will be key to creating real change. They stated that there needs to be a greater emphasis on skills and training within the Strategy to deliver on its objectives, as well as improved access by people with dementia, carers and professionals to social care services.

They were concerned that provision is not uniform across the country and felt that a lack of ring-fenced funding would not help to resolve this. They were concerned that an emphasis on early diagnosis without appropriate resourcing of relevant services is fast becoming a problem. They also wanted to be involved in funding and implementation decisions rather than being told by senior management at the PCT level what they were expected to conform to. They would like to see wider sharing of information, research and good practice across the country.

## 8.5 Community staff

Community mental health staff and care workers were relatively well-informed about the Strategy, and the person-centred care model which it espouses resonates with their approach.

They related a range of experiences in terms of the provision in the community; some feel that services for early diagnosis are very good, but fall away for those who have recently received diagnosis at a later stage. Others felt that the important gaps were in provision for people with late-stage dementia and their carers.

A number were, however, concerned about a lack of skills and awareness on the part of other staff based in primary care, especially GPs, and, as with other practitioners, a lack of ring-fenced funding to implement changes as a result of the Strategy. They felt that while managers were well informed, this information was not filtering down to the frontline (especially for home care and care home workers). The community team was very concerned about the level of skills and care in care homes especially.

Their experience was similar to that of social workers, particularly in the sense that where joint working had been implemented, it meant good leadership and services, but that paperwork could get in the way of focus on the patient. Community staff are strong supporters of the memory clinic and memory café services, and feel there is a need for a clear care pathway for people with dementia. They do, however, feel that end-of-life care and care for those with learning disabilities and offenders with dementia require additional support and reform.

## 8.6 Dementia trainers



Dementia trainers were extremely well informed about the Strategy, as well as about advances in dementia care more holistically, and seem to have been more heavily involved in the consultation and launch of the Strategy than most frontline staff. They delivered courses to social and medical staff about dementia, but felt that budget constraints and a lack of management commitment to appropriate training within the NHS, as well in care homes, were limiting their ability to share their knowledge with the frontline workforce delivering day-to-day dementia care.

They were strong advocates of a 'person-centred' approach to care, and supported the parts of the Strategy which aimed to deliver this. However, they were unsure that the Strategy was clear enough in its implementation plans to deliver this change in dementia services overall. They would like more resources to deliver training to carers.

They were somewhat frustrated by their limited ability to influence changes in dementia care in a practical manner, as many of them worked as freelance consultants or in the workforce-planning areas of local authorities, rather than being 'embedded' in geriatric medicine or older people's mental health teams.

## 8.7 Care home managers

A few care home managers were involved in local conferences about the Strategy but, other than this, awareness amongst these participants was surprisingly low. Care home managers generally said they support the Strategy, although dementia trainers were not convinced that this was backed up in practice, feeling that care home managers could be doing more to inform staff about the Strategy and invest in dementia-related training. Care home managers, however, wanted more resources to support training and implement the Strategy fully. They welcomed the inclusion of dementia-specific skills and care quality assessments in the inspection of care homes, and hoped that this kind of progress will go some way towards fixing the negative public perception of care homes as places which are about 'beds and meds'.

They were unclear as to what their responsibilities would be when implementing the Strategy and felt there was a lack of local leadership on this issue. They welcomed new ideas on how to deal with people with dementia but feel training is expensive. They felt that they were understaffed and overworked (especially those in voluntary sector homes) which limited their capacity to deliver on Strategy objectives.

They did not feel well-supported by Community Psychiatric Nurses and social workers in dealing with individual cases and did not feel that acute hospital staff deal adequately with their residents when they have to go into hospital. Community staff in this research also told us they felt unwelcome in some care homes. However, care home managers recognised that these professionals also had staffing shortages and would like this to be addressed to reduce the number of inappropriate admissions to residential care due to a lack of support for people with dementia and carers in the community.

There was a feeling among care home managers that PCTs and social services may be trying to pass their financial problems on to care homes, and they were concerned that the introduction of individual budgets would only make this worse. They were, therefore, also nervous about the implications of early diagnosis on admission requests, as they felt there were already too many people with dementia with specialist needs placed in generalist care homes, where they could be very disruptive.

## 8.8 Social workers

Most social workers had relatively low awareness of the Strategy and had not been provided with training on it – what they know they have found out for themselves. A few have had the information cascaded from managers or received it by attending consultation events – these tended to be in areas with stronger joint-working in Community Mental Health Teams.

They felt stressed and overloaded with cases and paperwork, and worried that early diagnosis would make this worse unless extra staff were recruited. They feel that money would be better spent on services to help those already diagnosed with dementia rather than increasing the number with a formal diagnosis. They were concerned about the quality of care given to people with dementia in residential homes, especially those that are privately or charitably funded (and therefore cannot afford the specialist staff and training needed).

Social workers, like care home managers, felt that individual budgets were not a good solution to financing elderly care, especially for those with more advanced dementia who are isolated from friends and family or may live in a rural area where community-based care is hard to deliver. They also felt that bureaucracy was slowing down access to care, as quality control staff were rejecting assessments or taking a long time to process them. They felt frustrated that their professional opinion was not enough to give someone access to the care they needed.

They did, however, welcome new approaches to managing individual cases in the community which allowed them to work jointly with community mental health teams to deliver appropriate services and deal with crises swiftly. Where these were in place, social workers were very positive; where they were yet to be developed, social workers felt frustrated. This was because while some health teams were improving, social workers were still facing many NHS staff who operated within a medical model of care which they felt was not wholly constructive when dealing with people with dementia.

# **9. The ideal dementia service**

## 9. The ideal dementia service

Overall, participants felt the Strategy is a step in the right direction towards their ideal dementia service. Many hoped that the Strategy would be the long-awaited step towards a **joined-up service** for dementia patients with **adequate resources to provide a good quality of care**. These two issues, of bringing together discrete services into a joined-up experience for the patient and providing sufficient funds to support care, were the two dominant themes regarding an ideal service among participants on the research.

This chapter addresses detailed suggestions for improvement and an ideal dementia service.

### 9.1 Consistent service provision

Participants felt strongly that dementia services need to be consistent across different local areas and across the different stages of the condition. This ensures service-users receive the same support across the board. Perceived 'postcode lottery', care for young people with dementia, and end-of-life care were seen as areas that needed particular improvement on the way to the ideal dementia service.

To achieve this aim, participants thought that **predictable inputs** were necessary, such as **ring-fenced** financial and staff **resources**. **Joint-commissioning** and **joint-working** would help ensure all the different stakeholders are on the same page. Finally, **targets** (which they were used to from other areas of their work) would make progress and consistency measurable.

### 9.2 Early diagnosis and a clear care pathway

**Early diagnosis** of dementia was considered key to effective care by most practitioners, as long as it is supported by sufficient resources. Many also noted the importance of a **care pathway** to follow diagnosis. Participants felt that this pathway should include immediate **post-diagnosis support** for people living with dementia and their carers, including medication.

Many participants felt that this element of an ideal service again was dependent on the availability of sufficient resources and effective joint-working. Should this not be present, participants felt that a good service would manage expectations as to what support and care pathways are available.

### 9.3 An excellent quality of care

Quality of care was felt to be at the core of first-class dementia support. Ideally, participants felt it should **centre on patient and carer**. While there was some tension between adherents to the social and the medical model as to how good quality care should look in practice, the consensus was that the **emotional and social needs of patients** should not fall behind when taking care of their medical needs. The Strategy has the potential to act as a bridge here and bring the different parties involved together.

Quality **pathways** should incorporate the **patient's** explicit **wishes**, including with regard to end-of-life care, to be able to comply with the patient's wishes around dignity. Where possible, care provision should be **home-based**, supported by **trained** and experienced professionals, and managed in a way that replicates **familial care**.

Frontline staff felt that quality of care linked back to certainty of **resources** as good care is time- and thus resource-intensive. It also requires effective **joint-working** to ensure consistent care is provided all along the pathway, led **locally** to make sure local priorities are met.

Finally, boosting frontline **staff morale** would help improve the care experience. More public recognition of the importance of dementia care and improved career opportunities (including remuneration) can contribute to making staff feel more valued.

## 9.4 Improved training and information sharing

Training was seen as a key component of good management and implementation of dementia care. In the ideal dementia service, it would play a crucial role in **skill acquisition** and maintenance, **information-sharing**, and cross-specialism team-building. It could also be an element that has the ability to bring together managerial and frontline staff and bridge the divide between the social and medical models by sharing **best practice**.

There was a sense that frontline staff feel they need more training in **how to best care** for people living with dementia. This was especially the case for those who do not deal with people with dementia on a daily basis. There was also a feeling among frontline staff that **carers** tend to get left behind and that this is a stakeholder group that may need more support, training and information.

Training should include updates on **details of the Strategy**, such as who is responsible for what at what level, targets and milestones, and the implications for staff in their workplaces. Dementia-related training should be given to all staff along the pathway. This was thought to be important because selective or staggered training sends mixed signals and is thought to imply that the Strategy is not a priority and that staff are not important to the success of the Strategy.

## 9.5 Bridging key service gaps

At present, gaps were seen in the service provision for **young people living with dementia**, **end-of-life** care, and a lack of **consistency** across different local areas (see 9.1), especially **rural areas**. These are points the ideal dementia service would address. Moreover, the ideal service needs to take into account the diversity of people with dementia, including **different cultural attitudes and needs** in relation to care. Other service gaps which needed addressing were **post-diagnosis follow-up**, including **memory support**. **More places at care homes and day centres** were also seen to be an important area of need, especially in the context of an ageing population of carers, as well as patients.

At present, frustrations arise because expectations are higher than the service provided in these areas. Where an ideal service is unable to address this gap, it **manages expectations** of people with dementia and their carers. Inviting stakeholders, including people with dementia and their carers, to evaluate services and assess gaps will show openness to dialogue and improvement.

# Appendices

# Appendix A: Discussion guides

## TOPIC GUIDE FOR BOARD 1 – PCT and Local Authority Commissioners

### Objectives:

The key objectives of the research are to investigate the experiences of PCT and Local Authority Commissioners, in order to:

- investigate readiness of the system to deliver against the recommendations of the NAO's 2007 VFM study through the Strategy;
- learn what structural, cultural and procedural changes are coming through / are needed from the frontline perspective to implement and deliver the new Strategy; and
- uncover participants' views and experiences of leadership in dementia services, and the extent of planning taking place.

Moderators are advised to phrase online prompts simply, informally and **succinctly**.

### Welcome text

- Welcome to the NAO and Ipsos MORI bulletin board on dementia services and the Strategy.
- **What is the Strategy (the Strategy)?**

In 2007, the National Audit Office (NAO) published an important Value for Money study, [Improving services and support for people with dementia](#) [link] which made a powerful case for the review and reform of dementia services in light of the increasing urgency of the problems facing them. This report made a number of key recommendations. These included improving GPs' diagnosis rate of dementia, the wider provision of Memory Services, improving hospital medical responses to dementia, and improving the management of dementia services and support in the community. This report was followed by a report by the Public Accounts Committee (PAC) which also made recommendations.

The recommendations of both these reports were incorporated by the Department of Health into the [National Dementia Strategy](#) [link]. This was launched in February 2009, aiming to address the concerns raised by the NAO and PAC by improving awareness and earlier diagnosis of dementia, increasing earlier intervention and ensuring a higher quality of care for people with dementia and support for their carers.



- **Why are we researching the Strategy?**

The Strategy must bring coherent direction and objectives in dementia care across a huge range of services: General Medical Practice, social care, residential care, hospital services, community nursing and other intermediate services. It must also improve services for people with dementia and their carers.

We are aiming to understand your views on the Strategy, and on whether staff in the health and social care systems are in a position to be able to deliver the expected improvements for people with dementia.

- **Who are we?**

The National Audit Office scrutinises public spending on behalf of Parliament. The NAO is working with Ipsos MORI to understand what you think about dementia services, the impact of the Strategy, and how to take the Strategy forward.

Ipsos MORI is an independent social research organisation. Ipsos MORI is talking to health and social service practitioners and would like to know your experiences, views and ideas.

There are no right or wrong answers – all opinions are equally valid, but we do need to know your honest opinions.

**All comments posted here will be completely anonymous.**

**Instructions:**

Please click on a forum topic and add your comments.

NOTE: We would like to learn about **your personal and local experiences**, to capture what the Strategy means for frontline staff at a local level. We do not expect participants to make comments about services and the Strategy at the national level.

Date of upload	Description	Notes
13 July 2009	<p><b>First thoughts on dementia services</b></p> <p><b>What do you think of dementia services at present?</b></p> <hr/> <p><b>TOPIC: How well do you think dementia services meet the needs of people with dementia and their carers in your area?</b></p> <p>DESCRIPTION: Have your views on this changed over the last few months? Why is this? Which services are working? And which ones aren't? Do you think attitudes are moving in the right direction?</p> <p><b>TOPIC: What do you know about the National Dementia Strategy?</b></p> <p>DESCRIPTION: Were you aware of the Strategy before this research? If so, how did you hear about it? Were you involved in the consultation? What do you think the Strategy aims to do?</p> <p><b>TOPIC: What does the National Dementia Strategy mean, in practice, for you?</b></p> <p>DESCRIPTION: Has the Strategy already led to any changes in the way you think about your work, behave or plan? What kind of changes? What about for your organisation and team?</p>	<p>This section warms up participants and opens the discussion forum, aiming to elicit general views on the National Dementia Strategy and dementia services. This will provide useful context that frames their views of the Strategy.</p>
15 July 2009	<p><b>Understanding the National Dementia Strategy</b></p> <hr/> <p><b>TOPIC: What information have you received to date about the Strategy?</b></p> <p>DESCRIPTION: Do you know what is expected of you as part of the Strategy? What were you told about this? Where did the information come from? What did you think of it?</p> <p><b>TOPIC: Have you discussed the implications of the Strategy internally or with any of your partner organisations?</b></p>	<p>In this section we examine participants' understanding of the Strategy and the changes it brings about, exploring any unmet needs.</p>

	<p>DESCRIPTION: Have you discussed the implications of the Strategy in your organisation? What was the reaction? Have you spoken about it with other commissioners or stakeholders from health and care services or providers?</p> <p><b>TOPIC: How clear is the Strategy's vision?</b></p> <p>DESCRIPTION: Do you think the Strategy's vision is clear? Are the Strategy's objectives appropriate? Are the aims clear? Which aims are particularly relevant to your role? From your experience, is anything missing?</p> <p><b>TOPIC: Which initiatives help or hinder the deliver of the Strategy?</b></p> <p>DESCRIPTION: Do you think there are certain initiatives which support change? Are there initiatives which are a barrier to implementing changes to deliver the Strategy? What works well and what doesn't? What about World Class Commissioning, Practice Based Commissioning, Local Area Agreements, or similar initiatives?</p>	<p><b>Download stimulus: Strategy objectives</b></p>
16 July 2009	<p><b>Managing the National Dementia Strategy implementation</b></p> <p><b>TOPIC: What do you think of the leadership of the Strategy implementation?</b></p> <p>DESCRIPTION: Is it clear who is responsible for what? Do you think there is strong national leadership for the Strategy? What about regional and local leadership? Is there enough money to support the necessary changes in dementia services? Has money been released? Do leaders communicate about the priority of dementia effectively? How important are these factors for the Strategy to succeed?</p> <p><b>TOPIC: Do you think that leaders of the Strategy implementation lead by example?</b></p> <p>DESCRIPTION: Do you think there are visible role models at the national, regional and local level for the Strategy? Do leaders of the Strategy implementation support the changes that the Strategy requires? Does their communication and commitment inspire the confidence of staff and stakeholders? Has the leadership managed to engage partners in the delivery chain to work together as a team to deliver the Strategy, for example local NHS services, carer</p>	<p>This section explores if participants' views on how the Strategy is managed, and if they have noticed any changes as part of the Strategy. We also interrogate issues around leadership and support offered to participants in delivering the Strategy.</p> <p>For this topic area, we would aim to use examples and comments from other boards as stimulus for the discussion.</p>

support groups, respite services etc?

**TOPIC: Do you know of any planned changes in the way local dementia services are managed and/or commissioned due to the Strategy?**

DESCRIPTION: Can you give details? Are you aware of the leadership talking about changes? Are there any structural changes planned? Or changes in procedures or processes? What about changes in the culture of your organisation and its management? What impact do you think these changes will have - on you and on others?

**TOPIC: If you know of any planned changes, what contribution do you think these will make to patient and carer support?**

DESCRIPTION: Can you give examples? Are there any barriers that could limit the effect these changes may have? If so, how can the barriers be overcome?

**TOPIC: If there is little evidence of change, why do you think this has been the case?**

DESCRIPTION: What is preventing change from happening? What changes are needed/would you like to see? Can you give me some examples? What difference would this make?

**TOPIC: Do you need any additional support or information to fulfil what is expected of you under the Strategy?**

DESCRIPTION: What support, if any, have you received so far to help you play your part in implementing the Strategy? What has been most useful? Is there any other help or support that you need? How would this help you in your role? Who should provide this help and support? How should they provide it? Are you aware of others getting support which would also be helpful for you?

	<p><b>TOPIC: Can you tell us about any examples of good practice in delivering services that are linked to the Strategy?</b></p> <p>DESCRIPTION: Do you know of any examples of good practice in commissioning? How are these being shared? Are there any positive changes that have happened in the last few months? What elements of the Strategy have already had an impact? Why?</p>	
20 July 2009	<p><b>A better quality service?</b></p> <p>“The aim of the National Dementia Strategy is to ensure that significant improvements are made to dementia services across three key areas: improved awareness, earlier diagnosis and intervention, and a higher quality of care.” <i>(DH: Living well with dementia: A National Dementia Strategy)</i></p> <p><b>Are services / the system ready to address these aims?</b></p> <hr/> <p><b>TOPIC: From your personal experience, do you think the launch of the Strategy is improving awareness of dementia amongst (a) PCT or Local Authority commissioners (b) their partner organisations?</b></p> <p>DESCRIPTION: Are commissioners now more aware of dementia? Are Strategy objectives filtering down effectively to frontline staff? How can commissioners help achieve better awareness? What about their partner organisations? What works and what does not? Can you give details and examples? What helps in achieving improved awareness? What hinders its achievement?</p> <p><b>TOPIC: What about achieving earlier diagnosis and intervention?</b></p> <p>DESCRIPTION: Are partners agreed on a way forward on this? Is there now a ‘pathway of care that delivers’? Or is one being developed? What works and what does not? Can you give details and examples? What would help achieve earlier diagnosis and intervention? What hinders its achievement?</p> <p><b>TOPIC: And is the system ready to deliver better quality of care for people with dementia?</b></p>	<p>This section elicits participants’ opinions on how well the system is performing in three key cross-cutting areas, in line with the NAO’s 2007 recommendations for change.</p> <p>For this topic area, we would aim to use examples and comments from other boards as stimulus for the discussion.</p> <p><b>Download Stimulus: Strategy objectives</b></p> <p><b>Objective 1, 13</b></p> <p><b>Objectives 2, 4</b></p> <p><b>Objectives 4, 5, 6, 8, 9, 10, 11</b></p>

	<p>DESCRIPTION: What works and what does not? Can you give details and examples? What about care in hospitals? And care homes? What about housing support? What new services are to be / could be commissioned? What would help improve care for people with dementia? What hinders its achievement? Are providers ready to respond? What can be done to help them get ready?</p> <p><b>TOPIC: And what about the service for carers?</b></p> <p>DESCRIPTION: Does the Strategy set out plans which would support carers sufficiently? Would you say the Carers' Strategy is being implemented locally? What else might carers need?</p>	<p><b>Objectives 7, 10</b></p>
<p>22 July 2009</p>	<p><b>Managing joint working</b></p> <p><b>How adequate are current joint working arrangements to drive improved care for people with dementia and support for their carers?</b></p> <p><b>TOPIC: How adequate are current joint working arrangements to drive improved care for people with dementia and support for their carers?</b></p> <p>DESCRIPTION: How successful is co-operation between different services at present? Has it improved over the last few months? Has development of the Strategy built common purpose? What role can commissioners play here? Are learning and examples of good practice shared? Are there barriers to effective joint working? Why do these act as barriers? How can these be overcome?</p> <p><b>TOPIC: How realistic are the Strategy's objectives?</b></p> <p>DESCRIPTION: Which objectives are you aware of? Which objectives are particularly relevant to your job role? Can you give examples of realistic objectives and also examples of those which you think will be more challenging? Do you think the Strategy's objectives can be fulfilled within the specified timeframe of five years? If not, how long do you think it will take? How can you measure whether the Strategy achieves its objectives?</p>	<p>This section explores how well mental health services, local social services, user organisations, carer organisations, and other services appear to work together.</p> <p>For this topic area, we would aim to use examples and comments from other boards as stimulus for the discussion.</p> <p><b>Download Stimulus: Strategy objectives</b></p>

	<p><b>TOPIC: Do you have sufficient good quality data upon which to rely when commissioning health and social care services?</b></p> <p>DESCRIPTION: Tell us about your data / knowledge management. What data would you need to need to be able to make the ideal commissioning decisions for dementia services? What data do you actually have? Is there help available to get the data you need? What additional data would you like to be collected?</p> <p><b>TOPIC: Is an explicit care pathway for the management and care of people with dementia being developed in your area?</b></p> <p>DESCRIPTION: Are you aware of a care pathway? Is this in its planning stage or already developed? What prompted this? Who is involved in its development? How well is it working at present?</p> <p><b>TOPIC: What do you think would make the joint working process easier?</b></p> <p>DESCRIPTION: Can you give examples? Have you had personal experience of barriers to joint working when trying to implement the Strategy?</p>	
24 <sup>th</sup> July	<p><b>TOPIC: Have you had any specific training at any point in your career that covers dementia?</b></p> <p>DESCRIPTION: Do you think <b>you</b> need any specific training? If not, why not? What would this training cover?</p>	
	<p><b>TOPIC: Do you think members of your team need further training on dementia?</b></p> <p>DESCRIPTION: Is anything stopping you from accessing dementia training for you or your staff? If so, what?</p>	

	<p><b>TOPIC: We have heard from dementia trainers (on another forum) that they believe dementia training is treated as a 'tick box' exercise by managers and staff. Do you agree with them?</b></p>	
	<p><b>TOPIC: The dementia strategy was accompanied by £150m unring-fenced money allocated to PCTs over two years. Is this enough?</b></p> <p>DESCRIPTION: What do you know about how this money has been spent in your locality (please answer whether you are from health or social care)?</p>	
	<p><b>TOPIC: Are you looking to find money for dementia improvements from elsewhere?</b></p> <p>DESCRIPTION: What other sources of funding might be used? Which, if any, of these are you using currently? What about examples such as Efficiency money, Personalisation money, Carers' Strategy money, CQUIN, POPPs, intermediate care funding, "spend to save" budgets etc.</p>	
	<p><b>TOPIC: How can you commission for better quality of dementia care?</b></p> <p>DESCRIPTION: what, if anything, is stopping you doing so now?</p>	
	<p><b>TOPIC: How does dementia feature on your organisation's Board agenda now (you could look at the latest minutes if you do not attend)?</b></p> <p>DESCRIPTION: Is it there at all? is it a separate agenda item? does it get wrapped up in older people, mental health or some other item?</p>	
	<p><b>TOPIC: Is leadership coming from within PCTs, LA commissioners or elected members?</b></p> <p>DESCRIPTION: Or are social care and health care providers (for example mental health trusts) providing more of the leadership?</p>	



	<p><b>Areas for change</b></p> <p><b>What needs to change to make progress in dementia services?</b></p> <hr/> <p><b>TOPIC: What do you think will be the impact of the strategy focusing on early diagnosis of dementia?</b></p> <p>TOPIC: What you would like to see as the model for dementia diagnosis and care in 5, 10 and 20 years' time? Can you tell us what services you would like to see in place should you become a user of these services? What do you think success of this strategy will look like?</p> <hr/> <p><b>TOPIC: What should a good dementia service provide?</b></p> <p>DESCRIPTION: What should dementia services that provide good care for people with dementia and support for their carers look like? Does the Strategy have enough levers to help achieve this goal? What are the requirements for the Strategy to be successful? What difference will they make?</p> <p><b>TOPIC: Are there any barriers to improvement in care for people with dementia or carer support?</b></p> <p>DESCRIPTION: Can you give details? How should they be addressed? What will happen if they are not addressed? What role can you as commissioners play in addressing these?</p> <p><b>TOPIC: Is there anything else you would like to add about dementia services or the Dementia Strategy in general?</b></p> <p>DESCRIPTION: Have your thoughts about the provision of dementia services changed since you began taking part in this project?</p>	<p>This section concludes the discussion by looking at improvements and refinements that could be made to the Strategy from the frontline perspective. This will enable us to make detailed suggestions for improvement.</p> <p>For this topic area, we would aim to use examples and comments from other boards as stimulus for the discussion.</p>
27 <sup>th</sup> July 2009	<p><b>Thank you for your help.</b></p> <p>All the information you have given us will remain entirely anonymous. Ipsos MORI will use it to write an independent report for the National Audit Office. The NAO, in turn, will use this report to inform their national follow-up study on dementia services. Both reports will be available for</p>	<p>Offer to email participants a link to the published report on the NAO website and the separate report on the online forums and their findings.</p>

	you to read on the NAO website in Winter 2009. We will email you a link to the reports once they are published.	
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## TOPIC GUIDE FOR BOARD 2 – General Nursing Staff

### Objectives:

The key objectives of the research are to investigate the experiences of general nursing staff, in order to:

- investigate readiness of the system to deliver against the recommendations of the NAO's 2007 VFM study through the National Dementia Strategy;
- learn what structural, cultural and procedural changes are coming through / are needed from the frontline perspective to implement and deliver the new Strategy; and
- uncover participants' views and experiences of leadership in dementia services, and the extent of planning taking place.

Moderators are advised to phrase online prompts simply, informally and **succinctly**.

### Welcome text

- Welcome to the NAO and Ipsos MORI bulletin board on dementia services and the National Dementia Strategy.
- **What is the National Dementia Strategy (the Strategy)?**

In 2007, the National Audit Office (NAO) published an important Value for Money study, [Improving services and support for people with dementia](#) [link] which made a powerful case for the review and reform of dementia services in light of the increasing urgency of the problems facing them. This report made a number of key recommendations. These included improving GPs' diagnosis rate of dementia, the wider provision of Memory Services, improving hospital medical responses to dementia, and improving the management of dementia services and support in the community. This report was followed by a report by the Public Accounts Committee (PAC) which also made recommendations.

The recommendations of both these reports were incorporated by the Department of Health into the [National Dementia Strategy](#) . This was launched in February 2009, aiming to address the concerns raised by the NAO and PAC by improving awareness and earlier diagnosis of dementia, increasing earlier intervention and ensuring a higher quality of care for people with dementia and support for their carers.

- **Why are we researching the Strategy?**

The Strategy must bring coherent direction and objectives in dementia care across a huge range of services: General Medical Practice, social care, residential care, hospital services, community nursing and other intermediate services. It must also improve services for people with dementia and their carers.

We are aiming to understand your views on the National Dementia Strategy, and on whether staff in the health and social care systems are in a position to be able to deliver the expected improvements for people with dementia.

- **Who are we?**

The National Audit Office scrutinises public spending on behalf of Parliament. The NAO is working with Ipsos MORI to understand what you think about dementia services, the impact of the National Dementia Strategy, and how to take the Strategy forward.

Ipsos MORI is an independent social research organisation. Ipsos MORI is talking to health and social service practitioners and would like to know your experiences, views and ideas.

There are no right or wrong answers – all opinions are equally valid, but we do need to know your honest opinions.

**All comments posted here will be completely anonymous.**

**Instructions:**

Please click on a forum topic and add your comments.

NOTE: We would like to learn about **your personal and local experiences**, to capture what the Strategy means for frontline staff at a local level. We do not expect participants to make comments about services and the Strategy at the national level.

Date of upload	Description	Notes
13 July 2009	<p data-bbox="506 292 965 316"><b>First thoughts on dementia services</b></p> <hr/> <p data-bbox="506 384 1597 440"><b>TOPIC: How well do you think health services meet the needs of people with dementia and their carers?</b></p> <p data-bbox="506 477 1574 533">DESCRIPTION: Have your views on this changed over the last few months? Why is this? Which is working? And what isn't? Do you think attitudes are moving in the right direction?</p> <p data-bbox="506 601 1335 625"><b>TOPIC: What do you know about the National Dementia Strategy?</b></p> <p data-bbox="506 662 1615 718">DESCRIPTION: Were you aware of the Strategy before this research? If so, how did you hear about it? Were you involved in the consultation? What do you think the Strategy aims to do?</p> <p data-bbox="506 786 1485 810"><b>TOPIC: What does the National Dementia Strategy mean, in practice, for you?</b></p> <p data-bbox="506 847 1556 903">DESCRIPTION: Has the Strategy already led to any changes in your work? What kind of changes? What about for your organisation and team?</p>	<p data-bbox="1653 292 2047 533">This section warms up participants and opens the discussion forum, aiming to elicit general views on the National Dementia Strategy and dementia services. This will provide useful context that frames their views of the Strategy.</p>
15 July 2009	<p data-bbox="506 946 1095 970"><b>Understanding the National Dementia Strategy</b></p> <hr/> <p data-bbox="506 1050 1413 1074"><b>TOPIC: What information have you received to date about the Strategy?</b></p> <p data-bbox="506 1110 1619 1230">DESCRIPTION: Do you know what is expected of you as part of the Strategy? What were you told about this? Where did the information come from? What did you think of it? Have you discussed the Strategy with your colleagues? Which aspects did you consider apply most closely to you?</p>	<p data-bbox="1653 946 2047 1094">In this section we examine participants' understanding of the Strategy and the changes its implementation brings about, exploring any unmet needs.</p>

	<p><b>TOPIC: How clear is the Strategy's vision?</b></p> <p>DESCRIPTION: Do you think the Strategy's vision is clear? Are the Strategy's objectives appropriate? Are the aims clear? From your experience, is anything missing?</p>	<p><b>Download stimulus: Strategy objectives</b></p>
<p>16 July 2009</p>	<p><b>Managing the National Dementia Strategy Implementation</b></p> <p><b>TOPIC: What do you think of the leadership of the Strategy's implementation?</b></p> <p>DESCRIPTION: Is it clear who is responsible for what? Do you think there is strong national leadership for the Strategy? What about local leadership? Is there enough money to support the necessary changes to improve dementia care? Has money been released? Do leaders communicate the priority of dementia /of the Strategy effectively? How important are these factors for the Strategy to succeed?</p> <p><b>TOPIC: Do you think that leaders of the Strategy lead by example?</b></p> <p>DESCRIPTION: Do you think there are visible role models driving improvement in dementia care? Are leaders in the local NHS/social care clearly behind the changes that the Strategy requires? Does their communication and commitment inspire the confidence of staff and stakeholders? Has the leadership engaged with partners in the delivery chain (e.g. councils, other trusts) to work together as a team to deliver the Strategy?</p> <p><b>TOPIC: Do you know of any planned changes in your service due to the Strategy?</b></p> <p>DESCRIPTION: Can you give details? Is there anything that you now do differently? Are you aware of the leadership talking about changes? Are there any structural changes? Or changes in procedures or processes? What about changes in the culture of your organisation and its management? What impact do you think these changes will have - on you and on others?</p>	<p>This section explores if participants' views on how the Strategy is managed, and if they have noticed any changes as part of the Strategy. We also interrogate issues around leadership and support offered to participants in delivering the Strategy.</p> <p>For this topic area, we would aim to use examples and comments from other boards as stimulus for the discussion.</p>

	<p><b>TOPIC: If you know of any planned changes, what contribution do you think these will make to support for people with dementia?</b></p> <p>DESCRIPTION: Can you give examples? Are there any barriers that could limit the effect these changes may have? If so, how can the barriers be overcome?</p> <p><b>TOPIC: If there are no planned changes, why do you think this is the case?</b></p> <p>DESCRIPTION: What is preventing change from happening? What changes are needed/would you like to see? Can you give some examples? What difference would this make?</p> <p><b>TOPIC: Do you need any additional support or information to fulfil what is expected of you under the Strategy?</b></p> <p>DESCRIPTION: What support, if any, have you received so far to help you play your part in implementing the Strategy? What has been most useful? Is there any other help or support that you need? How would this help you in your role? Who should provide this help and support? How should they provide it? Are you aware of others getting support which would also be helpful for you? Do you think health and social care staff have the right skills and level of awareness across the system to deliver the Strategy's vision? Is more training required?</p> <p><b>TOPIC: Can you tell us about any examples of good practice in delivering services that are linked to the Strategy?</b></p> <p>DESCRIPTION: Are there any positive changes that have happened in the last few months? What elements of the Strategy have already had an impact? Why?</p>	
20 July 2009	<p><b>A better quality service?</b></p> <p>“The aim of the National Dementia Strategy is to ensure that significant improvements are made to dementia services across three key areas: improved awareness, earlier diagnosis and intervention, and a higher quality of care.” (DH: <i>Living well with dementia: A National Dementia Strategy</i>)</p>	This section elicits participants' opinions on how well the system is performing in three key cross-cutting areas, in line with the NAO's 2007 recommendations for change.

	<p><b>Are services / the system ready to address these aims?</b></p> <p><b>TOPIC: From your personal experience, do you think the launch of the Strategy is improving awareness of dementia amongst (a) health professionals (b) the general public?</b></p> <p>DESCRIPTION: Are the messages on dementia filtering down effectively to all staff? What works and what does not? Can you give details and examples? What helps in achieving improved awareness? What hinders its achievement?</p> <p><b>TOPIC: What about achieving earlier diagnosis and intervention?</b></p> <p>DESCRIPTION: Are you are colleagues agreed that early diagnosis is desirable? How can your part of the system help achieve this? Can you give details and examples? What would help achieve earlier diagnosis and intervention? What hinders its achievement?</p> <p><b>TOPIC: Is it clear what needs to be done to improve quality of care for people with dementia in accordance with the Strategy?</b></p> <p>DESCRIPTION: Can you see how things could improve? What works and what does not? Is your service ready to make those changes? Can you give details and examples? How will you know that outcomes are improving? What hinders its achievement? What would help improve care for people with dementia?</p> <p><b>TOPIC: And what about the service for carers?</b></p> <p>DESCRIPTION: Is it clear what needs to be done to support carers better? Is the service ready to do this? How will you know outcomes are improved?</p>	<p>For this topic area, we would aim to use examples and comments from other boards as stimulus for the discussion.</p> <p><b>Download Stimulus: Strategy objectives</b></p>
22 July 2009	<p><b>Working as a whole system</b></p> <p><b>TOPIC: How effectively do services work together for better care for people with</b></p>	<p>This section explores how well mental health services, local social services, user organisations, carer organisations, and other services</p>



	<p><b>dementia and support for their carers?</b></p> <p>DESCRIPTION: How successful is co-operation between different services at present? Has it improved over the last few months? Has development of the Strategy built common purpose? Are learning and examples of good practice shared? Are there barriers to effective joint working? Why do these act as barriers? How can these be overcome?</p> <p><b>TOPIC: How realistic are the Strategy's objectives?</b></p> <p>DESCRIPTION: Which objectives are you aware of? Can you give examples of realistic objectives and also examples of those which you think will be more challenging? Do you think the Strategy's objectives can be fulfilled within the specified timeframe of five years? If not, how long do you think it will take? How will you judge whether the Strategy is making a difference?</p> <p><b>TOPIC: Is an explicit care pathway for the management and care of people with dementia being developed in your area?</b></p> <p>DESCRIPTION: Are you aware of a care pathway? Is this in its planning stage or already developed? How was this developed? What prompted this? Who was or is involved in its development? How well is it working at present? If none has been developed, is an explicit care pathway planned?</p>	<p>appear to work together.</p> <p>For this topic area, we would aim to use examples and comments from other boards as stimulus for the discussion.</p> <p><b>Download Stimulus: Strategy objectives</b></p>
24 July 2009	<p><b>TOPIC: Have you had any specific training at any point in your career that covers dementia?</b></p> <p>DESCRIPTION: Do you think <b>you</b> need any specific training? If not, why not? What would this training cover?</p> <p><b>TOPIC: Do you think members of your team need further training on dementia?</b></p> <p>DESCRIPTION: Is anything stopping you from accessing dementia training for you or your staff? If so, what?</p>	

	<p><b>TOPIC: We have heard from dementia trainers (on another forum) that they believe dementia training is treated as a 'tick box' exercise by managers and staff. Do you agree with them?</b></p> <p><b>TOPIC: How would you currently describe your aims when you have a patient with dementia under your care?</b></p> <p>DESCRIPTION: Do you prioritise making them physically well over and making arrangements to tackle their cognitive difficulties? How important is it to get them home? What would you aim to do in an ideal world?</p> <p><b>TOPIC: What is the relationship between NHS nursing staff and care home staff in providing effective care for people with dementia?</b></p> <p><b>TOPIC: What stops people in health and social care specialising in working with people with dementia?</b></p>	
	<p><b>Areas for change</b></p> <p><b>What needs to change to make progress in services for people with dementia?</b></p> <p><b>TOPIC: What do you think will be the impact of the strategy focusing on early diagnosis of dementia?</b></p> <p><b>TOPIC: What you would like to see as the model for dementia diagnosis and care in 5, 10 and 20 years' time?</b></p> <p>DESCRIPTION: Can you tell us what services you would like to see in place should you become a user of these services? What do you think success of this strategy will look like?</p>	<p>This section concludes the discussion by looking at improvements and refinements that could be made to the Strategy from the frontline perspective. This will enable us to make detailed suggestions for improvement.</p> <p>For this topic area, we would aim to use examples and comments from other boards as stimulus for the discussion.</p>

	<p><b>TOPIC: What should a good dementia service provide?</b></p> <p>DESCRIPTION: What should dementia services that provide good care for people with dementia and support for their carers look like? Does the Strategy help achieve this goal? What are the requirements for the Strategy to be successful? What difference will they make?</p> <p><b>TOPIC: Are there any areas of care for people with dementia or carer support that the Strategy is not addressing at the moment?</b></p> <p>DESCRIPTION: Can you give details? Why are these areas important? How should they be addressed? What will happen if they are not addressed?</p> <p><b>TOPIC: Is there anything else you would like to add about dementia services and the Strategy of dementia services in general?</b></p> <p>DESCRIPTION: Have your thoughts about the provision of dementia services changed since you began taking part in this project?</p>	
27 <sup>th</sup> July 2009	<p><b>Thank you for your help.</b></p> <p>All the information you have given us will remain entirely anonymous. Ipsos MORI will use it to write an independent report for the National Audit Office. The NAO, in turn, will use this report to inform their national follow-up study on dementia services. Both reports will be available for you to read on the NAO website in Winter 2009. We will email you a link to the reports once they are published.</p>	Offer to email participants a link to the published report on the NAO website and the separate report on the online forums and their findings.

## TOPIC GUIDE FOR BOARD 3 – Mental Health Liaison Staff

### Objectives:

The key objectives of the research are to investigate the experiences of mental health liaison staff, in order to:

- investigate readiness of the system to deliver against the recommendations of the NAO's 2007 VFM study through the National Dementia Strategy;
- learn what structural, cultural and procedural changes are coming through / are needed from the frontline perspective to implement and deliver the new Strategy; and
- uncover participants' views and experiences of leadership in dementia services, and the extent of planning taking place.

Moderators are advised to phrase online prompts simply, informally and **succinctly**.

### Welcome text

- Welcome to the NAO and Ipsos MORI bulletin board on dementia services and the National Dementia Strategy.
- **What is the National Dementia Strategy (the Strategy)?**

In 2007, the National Audit Office (NAO) published an important Value for Money study, [Improving services and support for people with dementia](#) [link] which made a powerful case for the review and reform of dementia services in light of the increasing urgency of the problems facing them. This report made a number of key recommendations. These included improving GPs' diagnosis rate of dementia, the wider provision of Memory Services, improving hospital medical responses to dementia, and improving the management of dementia services and support in the community. This report was followed by a report by the Public Accounts Committee (PAC) which also made recommendations.

The recommendations of both these reports were incorporated by the Department of Health into the [National Dementia Strategy](#). This was launched in February 2009, aiming to address the concerns raised by the NAO and PAC by improving awareness and earlier diagnosis of dementia, increasing earlier intervention and ensuring a higher quality of care for people with dementia and support for their carers.

- **Why are we researching the Strategy?**

The Strategy must bring coherent direction and objectives in dementia care across a huge range of services: General Medical Practice, social care, residential care, hospital services, community nursing and other intermediate services. It must also improve services for people with dementia and their carers.

We are aiming to understand your views on the National Dementia Strategy, and on whether staff in the health and social care systems are in a position to be able to deliver the expected improvements for people with dementia.

- **Who are we?**

The National Audit Office scrutinises public spending on behalf of Parliament. The NAO is working with Ipsos MORI to understand what you think about dementia services, the impact of the National Dementia Strategy, and how to take the Strategy forward.

Ipsos MORI is an independent social research organisation. Ipsos MORI is talking to health and social service practitioners and would like to know your experiences, views and ideas.

There are no right or wrong answers – all opinions are equally valid, but we do need to know your honest opinions.

**All comments posted here will be completely anonymous.**

**Instructions:**

Please click on a forum topic and add your comments.

NOTE: We would like to learn about **your personal and local experiences**, to capture what the Strategy means for frontline staff at a local level. We do not expect participants to make comments about services and the Strategy at the national level.

Date of upload	Description	Notes
13 July 2009	<p data-bbox="506 292 965 320"><b>First thoughts on dementia services</b></p> <hr/> <p data-bbox="506 384 1599 443"><b>TOPIC: How well do you think health services meet the needs of people with dementia and their carers?</b></p> <p data-bbox="506 475 1554 534">DESCRIPTION: Have your views on this changed over the last few months? Why is this? What is working? What is not? Do you think attitudes are moving in the right direction?</p> <p data-bbox="506 598 1335 627"><b>TOPIC: What do you know about the National Dementia Strategy?</b></p> <p data-bbox="506 659 1615 718">DESCRIPTION: Were you aware of the Strategy before this research? If so, how did you hear about it? Were you involved in the consultation? What do you think the Strategy aims to do?</p> <p data-bbox="506 782 1485 810"><b>TOPIC: What does the National Dementia Strategy mean, in practice, for you?</b></p> <p data-bbox="506 842 1592 938">DESCRIPTION: Has the Strategy led to any changes in your work? What kind of changes? Has there been an increase in demand for your services? Have you been involved in the rolling-out similar services elsewhere? What about changes for your organisation and team?</p>	<p data-bbox="1653 292 2047 531">This section warms up participants and opens the discussion forum, aiming to elicit general views on the National Dementia Strategy and dementia services. This will provide useful context that frames their views of the Strategy.</p>
15 July 2009	<p data-bbox="506 978 1095 1007"><b>Understanding the National Dementia Strategy</b></p> <hr/> <p data-bbox="506 1070 1413 1099"><b>TOPIC: What information have you received to date about the Strategy?</b></p> <p data-bbox="506 1131 1621 1259">DESCRIPTION: Do you know what is expected of you as part of the Strategy? What were you told about this? Where did the information come from? What did you think of it? Have you discussed the Strategy with your colleagues? Which aspects did you consider apply most closely to you?</p>	<p data-bbox="1653 978 2047 1121">In this section we examine participants' understanding of the Strategy and the changes its implementation brings about, exploring any unmet needs.</p>

	<p><b>TOPIC: How clear is the Strategy's vision?</b></p> <p>DESCRIPTION: Do you think the Strategy's vision is clear? Are the Strategy's objectives appropriate? Are the aims clear? Is this filtering down to staff? From your experience, is anything missing?</p>	<p><b>Download stimulus: Strategy objectives</b></p>
<p>16 July 2009</p>	<p><b>Managing the National Dementia Strategy implementation</b></p>	<p>This section explores if participants' views on how the Strategy is managed, and if they have noticed any changes as part of the Strategy. We also interrogate issues around leadership and support offered to participants in delivering the Strategy.</p> <p>For this topic area, we would aim to use examples and comments from other boards as stimulus for the discussion.</p>
	<p><b>TOPIC: What do you think of the leadership of the Strategy's implementation?</b></p> <p>DESCRIPTION: Is it clear who is responsible for what? Do you think there is strong national leadership for the Strategy? What about local leadership? Is there enough money to support the necessary changes in services for people with dementia? Has money been released? Do leaders communicate the priority of dementia and the role of mental health liaison effectively? How important are these factors for the Strategy to succeed?</p> <p><b>TOPIC: Do you think that leaders of the Strategy lead by example?</b></p> <p>DESCRIPTION: Do you think there are visible and effective role models driving improvement in dementia care? Are leaders in the local NHS and social care clearly behind changes that the Strategy requires? Does their communication and commitment inspire the confidence of staff and stakeholders? Has the leadership engaged with partners in the delivery chain to work together as a team to deliver the Strategy?</p> <p><b>TOPIC: Do you know of any planned changes in your service due to the Strategy in the places where you work? Have any already happened?</b></p> <p>DESCRIPTION: Can you give details? Is there anything that you now do differently? Are you aware of the leadership talking about changes? Are there any structural changes? Or changes in procedures or processes? What about changes in the culture of your organisation and its management? What impact do you think these changes will have - on you and on others?</p>	

	<p><b>TOPIC: If you know of any planned changes, what contribution do you think these will make to patient care?</b></p> <p>DESCRIPTION: Can you give examples? Are there any barriers that could limit the effect these changes may have? If so, how can the barriers be overcome?</p> <p><b>TOPIC: If there are no planned changes, why do you think this is the case?</b></p> <p>DESCRIPTION: What has prevented change from happening? What changes are needed/would you like to see? Can you give me some examples? What difference would this make?</p> <p><b>TOPIC: Do you need any additional support or information to fulfil what is expected of you under the Strategy?</b></p> <p>DESCRIPTION: What support, if any, have you received so far to help you play your part in implementing the Strategy? Is there any other help or support that you need? How would this help you in your role? Who should provide this help and support? How should they provide it? Are you aware of others getting support which would also be helpful for you? Do you think health and social care staff have the right skills and level of awareness across the system to deliver the Strategy's vision? Is more training required?</p> <p><b>TOPIC: Can you tell us about any examples of good practice in delivering services that are linked to the Strategy?</b></p> <p>DESCRIPTION: Are there any positive changes that have happened in the last few months? What elements of the Strategy have already had an impact? Why?</p>	
20 July 2009	<p><b>A better quality service?</b></p> <p>“The aim of the National Dementia Strategy is to ensure that significant improvements are made to dementia services across three key areas: improved awareness, earlier diagnosis and intervention, and a higher quality of care.”</p>	This section elicits participants' opinions on how well the system is performing in three key cross-cutting areas, in line with the NAO's 2007 recommendations for



	<p><i>(DH: Living well with dementia: A National Dementia Strategy)</i></p> <p><b>Are services / the system ready to address these aims?</b></p>	<p>change.</p> <p>For this topic area, we would aim to use examples and comments from other boards as stimulus for the discussion.</p> <p><b>Download Stimulus: STRATEGY objectives</b></p>
	<p><b>TOPIC: From your personal experience, do you think the launch of the Strategy is improving awareness of dementia amongst (a) health professionals (b) the general public?</b></p> <p>DESCRIPTION: Are the messages on dementia filtering down effectively to all staff? What works for improving awareness and what does not? Can you give details and examples? What hinders its achievement?</p> <p><b>TOPIC: What about achieving earlier diagnosis and intervention?</b></p> <p>DESCRIPTION: Are local partners agreed on a way forward on this? Is there now a 'pathway of care that delivers? If not, is one being developed? 'What works and what does not? Can you give details and examples? What would help achieve earlier diagnosis and intervention? What hinders its achievement?</p> <p><b>TOPIC: And has quality of care for people with dementia begun to change as a result of the Strategy's implementation?</b></p> <p>DESCRIPTION: How well does the system deliver on care for people with dementia? What works and what does not? Can you give details and examples? Can you see how things could improve? What would help improve care for people with dementia? Is your service ready to make changes to improve care? What hinders improvement in care? How will you know that outcomes are improving?</p> <p><b>TOPIC: Do you feel you know enough about emerging research and evidence in the field of dementia treatment?</b></p> <p>DESCRIPTION: Are you involved in any research on dementia? Has the Strategy improved the sharing of this information? Is there anything the Department of Health should be doing to</p>	<p><b>Objective 16</b></p>

	support research needs in dementia?	
22 July 2009	<p><b>Working as a whole system</b></p> <p><b>How adequate are current joint working arrangements to drive improved care for people with dementia?</b></p> <hr/> <p><b>TOPIC: How adequate are current joint working arrangements to drive care for people with dementia?</b></p> <p>DESCRIPTION: How successful is co-operation between different services at present? Has it improved recently? Has development of the Strategy begun to build common purpose? How can strong joint working benefit mental health liaison? Are learning and examples of good practice shared? Are there barriers to effective joint working? Why do these act as barriers? How can these be overcome?</p> <p><b>TOPIC: What do you think would make the joint working process easier?</b></p> <p>DESCRIPTION: Can you give examples? Have you had personal experience of barriers to joint working?</p> <p><b>TOPIC: How realistic are the Strategy's objectives?</b></p> <p>DESCRIPTION: Which objectives are you aware of? Can you give examples of realistic objectives and also examples of those which you think will be more challenging? Do you think the Strategy's objectives can be fulfilled within the specified timeframe of five years? If not, how long do you think it will take? How will you judge whether the Strategy is making a difference?</p> <p><b>TOPIC: Have you seen examples of an explicit care pathway for the management and care of people with dementia being developed?</b></p> <p>DESCRIPTION: Are you aware of care pathways? Is this in its planning stage or already developed? How was this developed? What prompted this? Who was or is involved in its</p>	<p>This section explores how well mental health services, local social services, user organisations, carer organisations, and other services appear to work together.</p> <p>For this topic area, we would aim to use examples and comments from other boards as stimulus for the discussion.</p> <p><b>Download Stimulus: Strategy objectives</b></p>

	development? How well is it working at present? If none has been developed, is an explicit care pathway planned?	
24 July 2009	<p><b>TOPIC: Have you had any specific training at any point in your career that covers dementia?</b></p> <p>DESCRIPTION: Do you think <b>you</b> need any specific training? If not, why not? What would this training cover?</p> <p><b>TOPIC: Do you think <u>members of your team</u> need further training on dementia?</b></p> <p>DESCRIPTION: Is anything stopping you from accessing dementia training for you or your staff? If so, what?</p> <p><b>TOPIC: We have heard from dementia trainers (on another forum) that they believe dementia training is treated as a 'tick box' exercise by managers and staff. Do you agree with them?</b></p> <p><b>TOPIC: Can you characterise your relationships with the hospital or other staff with whom you provide liaison?</b></p> <p>DESCRIPTION: Is it that of customer and provider, or a partnership? Is it "just-in-time" call out or day-to-day shared care? Where does the balance of power and seniority in the relationship lie? Are you/your staff empowered to make decisions about patients in their care?</p>	
	<p><b>Areas for change</b></p> <p><b>What needs to change to make progress in dementia services?</b></p> <p><b>TOPIC: What do you think will be the impact of the strategy focusing on early diagnosis of dementia?</b></p> <p>TOPIC: What you would like to see as the model for dementia diagnosis and care in 5, 10 and 20 years' time? Can you tell us what services you would like to see in place should you become a user of these services? What do you think success of this strategy will look like?</p>	<p>This section concludes the discussion by looking at improvements and refinements that could be made to the Strategy implementation from the frontline perspective. This will enable us to make detailed suggestions for improvement.</p> <p>For this topic area, we would aim to use examples and comments</p>

	<p><b>TOPIC: What should a good dementia service provide?</b></p> <p>DESCRIPTION: What should dementia services that provide good care for people with dementia and support for their carers look like? Does the Strategy have enough levers to help achieve this goal? What are the requirements for the Strategy's implementation to be successful? What difference will they make?</p> <p><b>TOPIC: Are there any areas of care for people with dementia or carer support that the Strategy is not addressing at the moment?</b></p> <p>DESCRIPTION: Can you give details? Why are these areas important? How should they be addressed? What will happen if they are not addressed?</p> <p><b>TOPIC: Is there anything else you would like to add about dementia services and the Strategy in general?</b></p> <p>DESCRIPTION: Have your thoughts about the provision of dementia services changed since you began taking part in this project?</p>	<p>from other boards as stimulus for the discussion.</p>
27 <sup>th</sup> July 2009	<p><b>Thank you for your help.</b></p> <p>All the information you have given us will remain entirely anonymous. Ipsos MORI will use it to write an independent report for the National Audit Office. The NAO, in turn, will use this report to inform their national follow-up study on dementia services. Both reports will be available for you to read on the NAO website in Winter 2009. We will email you a link to the reports once they are published.</p>	<p>Offer to email participants a link to the published report on the NAO website and the separate report on the online forums and their findings.</p>

## TOPIC GUIDE FOR BOARD 4 – Memory Clinic Leads

### Objectives:

The key objectives of the research are to investigate the experiences of memory clinic staff, in order to:

- investigate readiness of the system to deliver against the recommendations of the NAO's 2007 VFM study through the National Dementia Strategy;
- learn what structural, cultural and procedural changes are coming through / are needed from the frontline perspective to implement and deliver the new Strategy; and
- uncover participants' views and experiences of leadership in dementia services, and the extent of planning taking place.

Moderators are advised to phrase online prompts simply, informally and **succinctly**.

### Welcome text

- Welcome to the NAO and Ipsos MORI bulletin board on dementia services and the National Dementia Strategy.
- **What is the National Dementia Strategy (the Strategy)?**

In 2007, the National Audit Office (NAO) published an important Value for Money study, [Improving services and support for people with dementia](#) [link] which made a powerful case for the review and reform of dementia services in light of the increasing urgency of the problems facing them. This report made a number of key recommendations. These included improving GPs' diagnosis rate of dementia, the wider provision of Memory Services, improving hospital medical responses to dementia, and improving the management of dementia services and support in the community. This report was followed by a report by the Public Accounts Committee (PAC) which also made recommendations.

The recommendations of both these reports were incorporated by the Department of Health into the [National Dementia Strategy](#). This was launched in February 2009, aiming to address the concerns raised by the NAO and PAC by improving awareness and earlier diagnosis of dementia, increasing earlier intervention and ensuring a higher quality of care for people with dementia and support for their carers.

- **Why are we researching the Strategy?**

The Strategy must bring coherent direction and objectives in dementia care across a huge range of services: General Medical Practice, social care, residential care, hospital services, community nursing and other intermediate services. It must also improve services for people with dementia and their carers.

We are aiming to understand your views on the National Dementia Strategy, and on whether staff in the health and social care systems are in a position to be able to deliver the expected improvements for people with dementia.

- **Who are we?**

The National Audit Office scrutinises public spending on behalf of Parliament. The NAO is working with Ipsos MORI to understand what you think about dementia services, the impact of the National Dementia Strategy, and how to take the Strategy forward.

Ipsos MORI is an independent social research organisation. Ipsos MORI is talking to health and social service practitioners and would like to know your experiences, views and ideas.

There are no right or wrong answers – all opinions are equally valid, but we do need to know your honest opinions.

**All comments posted here will be completely anonymous.**

**Instructions:**

Please click on a forum topic and add your comments.

NOTE: We would like to learn about **your personal and local experiences**, to capture what the Strategy means for frontline staff at a local level. We do not expect participants to make comments about services and the Strategy at the national level.

Date of upload	Description	Notes
13 July 2009	<p><b>First thoughts on dementia services</b></p> <p><b>What do you think of dementia services at present?</b></p>	<p>This section warms up participants and opens the discussion forum, aiming to elicit general views on the National Dementia Strategy and dementia services. This will provide useful context that frames their views of the Strategy.</p>
	<p><b>TOPIC: How well do you think dementia services meet the needs of people with dementia and their carers?</b></p> <p>DESCRIPTION: Have your views on this changed over the last few months? Why is this? What is working? What is not? Do you think attitudes are moving in the right direction?</p> <p><b>TOPIC: What do you know about the National Dementia Strategy?</b></p> <p>DESCRIPTION: Were you aware of the Strategy before this research? If so, how did you hear about it? Were you involved in the consultation? What do you think the Strategy aims to do?</p> <p><b>TOPIC: What does the National Dementia Strategy mean, in practice, for you?</b></p> <p>DESCRIPTION: Has the Strategy led to any changes in your work? What kind of changes? Has there been an increase in demand for your services? Have you been involved in the rolling-out of similar services elsewhere? What about changes for your organisation and team?</p>	
15 July 2009	<p><b>Understanding the National Dementia Strategy</b></p> <p><b>How informed are you about the Strategy?</b></p>	<p>In this section we examine participants' understanding of the Strategy and the changes its implementation brings about, exploring any unmet needs.</p>
	<p><b>TOPIC: What information have you received to date about the Strategy?</b></p> <p>DESCRIPTION: Do you know what is expected of you as part of the Strategy? What were you told about this? Where did the information come from? What did you think of it? Have you discussed the Strategy with your colleagues? Which aspects did you consider apply most closely to you?</p>	

	<p><b>TOPIC: How clear is the Strategy's vision?</b></p> <p>DESCRIPTION: Do you think the Strategy's vision is clear? Are the Strategy's objectives appropriate? Are the aims clear? Is this filtering down to staff? From your experience, is anything missing?</p>	<p><b>Download stimulus: Strategy objectives</b></p>
<p>16 July 2009</p>	<p><b>Managing the National Dementia Strategy implementation</b></p> <p><b>TOPIC: What do you think of the leadership of the Strategy implementation?</b></p> <p>DESCRIPTION: Is it clear who is responsible for what? Do you think there is strong national leadership for the Strategy's implementation? What about local leadership? Is there enough money to support the necessary changes in services for people with dementia? Has money been released? Do leaders communicate the priority of dementia and the role of memory clinics effectively? How important are these factors for the Strategy to succeed?</p> <p><b>TOPIC: Do you think that leaders of the Strategy implementation lead by example?</b></p> <p>DESCRIPTION: Do you think there are visible and effective role models driving improvements in dementia care? Are leaders supporting the local NHS and social care clearly behind the changes that the Strategy requires? Does their communication and commitment inspire the confidence of staff and stakeholders? Has the leadership engaged with partners in the delivery chain to work together as a team to deliver the Strategy?</p> <p><b>TOPIC: Do you know of any planned changes in your service due to the Strategy? Have any changes already happened?</b></p> <p>DESCRIPTION: Can you give details? Is there anything that you now do differently? Are you aware of the leadership at the clinic or commissioners talking about changes? Are there any structural changes planned? Or changes in procedures or processes? What about changes in the culture of your organisation and its management? What impact do you think these changes will have - on you and on others?</p>	<p>This section explores if participants' views on how the Strategy is managed, and if they have noticed any changes as part of the Strategy. We also interrogate issues around leadership and support offered to participants in delivering the Strategy.</p> <p>For this topic area, we would aim to use examples and comments from other boards as stimulus for the discussion.</p>



	<p><b>TOPIC: If you know of any planned changes, what contribution do you think these will make to care of people with dementia and support for carers?</b></p> <p>DESCRIPTION: Can you give examples? Are there any barriers that could limit the effect these changes may have? If so, how can the barriers be overcome?</p> <p><b>TOPIC: If there are no planned changes, why do you think this is the case?</b></p> <p>DESCRIPTION: What has prevented change from happening? What changes are needed/would you like to see? Can you give some examples? What difference would this make?</p> <p><b>TOPIC: Do you need any additional support or information to fulfil what is expected of you under the Strategy?</b></p> <p>DESCRIPTION: What support, if any, have you received so far to help you play your part in implementing the Strategy? Is there any other help or support that you need? How would this help you in your role? Who should provide this help and support? How should they provide it? Are you aware of others getting support which would also be helpful for you? Do you think health and social care staff have the right skills and level of awareness across the system to deliver the Strategy's vision? Is more training required?</p> <p><b>TOPIC: Can you tell us about any examples of good practice in delivering services that are linked to the Strategy?</b></p> <p>DESCRIPTION: Are there any positive changes that have happened in the last few months? What elements of the Strategy have already had an impact? Why?</p>	
20 July 2009	<p><b>A better quality service?</b></p> <p>“The aim of the National Dementia Strategy is to ensure that significant improvements are made to dementia services across three key areas: improved awareness, earlier diagnosis and intervention, and a higher quality of care.”  (DH: <i>Living well with dementia: A National Dementia Strategy</i>)</p>	This section elicits participants' opinions on how well the system is performing in three key cross-cutting areas, in line with the NAO's 2007 recommendations for change.

	<p><b>Are services/system ready to address these aims?</b></p>	<p>For this topic area, we would aim to use examples and comments from other boards as stimulus for the discussion.</p> <p><b>Download Stimulus: Strategy objectives</b></p>
	<p><b>TOPIC: From your personal experience, do you think the launch of the Strategy is improving awareness of dementia amongst (a) health and social care professionals (b) the general public?</b></p> <p>DESCRIPTION: Are the messages on dementia filtering down effectively to all staff? What works for improving awareness and what does not? Can you give details and examples? What hinders its achievement?</p> <p><b>TOPIC: What about achieving earlier diagnosis and intervention?</b></p> <p>DESCRIPTION: Are local partners agreed on a way forward on this? Is there now a 'pathway of care' that delivers? If not, is one being developed? What works and what does not? Can you give details and examples? What would help achieve earlier diagnosis and intervention? What hinders its achievement?</p> <p><b>TOPIC: And has quality of care for people with dementia begun to change as a result of the Strategy's implementation?</b></p> <p>DESCRIPTION: How well does the system deliver on care for people with dementia? What works and what does not? Can you give details and examples? Can you see how things could improve? What would help improve care for people with dementia? Is your service ready to make changes to improve care? What hinders improvement in care? How will you know that outcomes are improving?</p> <p><b>TOPIC: And what about the service for carers?</b></p> <p>DESCRIPTION: How well does the system deliver on carer support? Does the Strategy set out plans which would support carers sufficiently? Would you say the Carers' Strategy is being implemented locally? What else might carers need?</p> <p><b>TOPIC: Do you feel you know enough about emerging research and evidence in the field</b></p>	

	<p><b>of dementia treatment?</b></p> <p>DESCRIPTION: Are you involved in any research on dementia? Has the Strategy improved the sharing of this information? Is there anything the Department of Health should be doing to support research needs in dementia?</p>	
<p>22 July 2009</p>	<p><b>Working as a whole system</b></p> <p><b>How adequate are current joint working arrangements to drive improved care for people with dementia?</b></p>	<p>This section explores how well mental health services, local social services, user organisations, carer organisations, and other services appear to work together.</p> <p>For this topic area, we would aim to use examples and comments from other boards as stimulus for the discussion.</p> <p><b>Download Stimulus: Strategy objectives</b></p>
	<p><b>TOPIC: How adequate are current joint working arrangements to drive improved care for people with dementia?</b></p> <p>DESCRIPTION: How successful is co-operation between different services at present? Has it improved recently? Has development of the Strategy begun to build common purpose? How can strong joint working benefit memory clinics? Are learning and examples of good practice shared? Are there barriers to effective joint working? Why do these act as barriers? How can these be overcome?</p> <p><b>TOPIC: What do you think would make joint working easier?</b></p> <p>DESCRIPTION: Can you give examples? Have you had personal experience of barriers to joint working?</p> <p><b>TOPIC: How realistic are the Strategy's objectives?</b></p> <p>DESCRIPTION: Which objectives are you aware of? Can you give examples of realistic objectives and also examples of those which you think will be more challenging? Do you think the Strategy's objectives can be fulfilled within the specified timeframe of five years? If not, how long do you think it will take? How will you judge whether the Strategy is making a difference?</p>	

	<p><b>TOPIC: Have you seen examples of an explicit care pathway for the management and care of people with dementia being developed?</b></p> <p>DESCRIPTION: Are you aware of care pathways? Is this in its planning stage or already developed? How was this developed? What prompted this? Who was or is involved in its development? How well is it working at present? If none has been developed, is an explicit care pathway planned?</p>	
	<p><b>TOPIC: Do you think you need any further training on dementia? If not, why not? Do you think members of your team need further training on dementia?</b></p> <p>DESCRIPTION: What would this training cover? Is anything stopping you from accessing further training for you or your staff? If so, what?</p> <p><b>TOPIC: We have heard from dementia trainers (on another forum) that they believe dementia training is treated as a 'tick box' exercise by some managers and healthcare staff. Do you agree with them?</b></p>	
24 July 2009	<p><b>Areas for change</b></p> <p><b>What needs to change to make progress in dementia services?</b></p> <p><b>TOPIC: What do you think will be the impact of the strategy focusing on early diagnosis of dementia?</b></p> <p><b>TOPIC: What you would like to see as the model for dementia diagnosis and care in 5, 10 and 20 years' time? Can you tell us what services you would like to see in place should you become a user of these services? What do you think success of this strategy will look like?</b></p>	<p>This section concludes the discussion by looking at improvements and refinements that could be made to the Strategy from the frontline perspective. This will enable us to make detailed suggestions for improvement.</p> <p>For this topic area, we would aim to use examples and comments from other boards as stimulus for the discussion.</p>

	<p><b>TOPIC: What should a good dementia service provide?</b></p> <p>DESCRIPTION: What should dementia services that provide good care for people with dementia and support for their carers look like? Does the Strategy have enough levers to help achieve this goal? What are the requirements for the Strategy's implementation to be successful? What difference will they make?</p> <p><b>TOPIC: Are there any areas of care for people with dementia or carer support that the Strategy is not addressing at the moment?</b></p> <p>DESCRIPTION: Can you give details? Why are these areas important? How should they be addressed? What will happen if they are not addressed?</p> <p><b>TOPIC: Is there anything else you would like to add about dementia services and the Strategy in general?</b></p> <p>DESCRIPTION: Have your thoughts about the provision of dementia services changed since you began taking part in this project?</p>	
27 <sup>th</sup> July 2009	<p><b>Thank you for your help.</b></p> <p>All the information you have given us will remain entirely anonymous. Ipsos MORI will use it to write an independent report for the National Audit Office. The NAO, in turn, will use this report to inform their national follow-up study on dementia services. Both reports will be available for you to read on the NAO website in Winter 2009. We will email you a link to the reports once they are published.</p>	Offer to email participants a link to the published report on the NAO website and the separate report on the online forums and their findings.

## TOPIC GUIDE FOR BOARD 5 – Community mental health staff

### Objectives:

The key objectives of the research are to investigate the experiences of social care staff, in order to:

- investigate readiness of the system to deliver against the recommendations of the NAO's 2007 VFM study through the National Dementia Strategy;
- learn what structural, cultural and procedural changes are coming through / are needed from the frontline perspective to implement and deliver the new Strategy; and
- uncover participants' views and experiences of leadership in dementia services, and the extent of planning taking place.

Moderators are advised to phrase online prompts simply, informally and **succinctly**.

### Welcome text

Welcome to the NAO and Ipsos MORI bulletin board on dementia services and the National Dementia Strategy.

#### ○ **What is the National Dementia Strategy (the Strategy)?**

In 2007, the National Audit Office (NAO) published an important Value for Money study, [Improving services and support for people with dementia](#) which made a powerful case for the review and reform of dementia services in light of the increasing urgency of the problems facing them. This report made a number of key recommendations. These included improving GPs' diagnosis rate of dementia, the wider provision of Memory Services, improving hospital responses to dementia, improving the management of dementia services and support in the community, and improving the skills and awareness of health and social care professionals about dementia and how to deal with those suffering from it. This report was followed by a report by the Public Accounts Committee (PAC) which also made recommendations.

The recommendations of both these reports were incorporated by the Department of Health into the [National Dementia Strategy](#). This was launched in February 2009, aiming to address the concerns raised by the NAO and PAC by improving awareness and earlier diagnosis of dementia, increasing early intervention and ensuring a higher quality of care for people with dementia and support for their carers.

- **Why are we researching the Strategy?**

The Strategy must bring coherent direction and objectives in dementia care across a huge range of services: General Medical Practice, social care, residential care, hospital services, community nursing and other intermediate services. It must also improve services for people with dementia and their carers.

We are aiming to understand your views on the National Dementia Strategy, and on whether staff in the health and social care systems are in a position to be able to deliver the expected improvements for people with dementia.

- **Who are we?**

The National Audit Office scrutinises public spending on behalf of Parliament. The NAO is working with Ipsos MORI to understand what you think about dementia services, the impact of the National Dementia Strategy, and how to take the Strategy forward.

Ipsos MORI is an independent social research organisation. Ipsos MORI is talking to health and social service practitioners and would like to know your experiences, views and ideas.

There are no right or wrong answers – all opinions are equally valid, but we do need to know your honest opinions.

**All comments posted here will be completely anonymous.**

**Instructions:**

Please click on a forum topic and add your comments.

NOTE: We would like to learn about **your personal and local experiences**, to capture what the Strategy means for frontline staff at a local level. We do not expect participants to make comments about services and the Strategy at the national level.

Date of upload	Description	Notes
13 July 2009	<p><b>First thoughts on dementia services</b></p> <p><b>TOPIC: How well do you think health and social care services meet the needs of people with dementia and their carers?</b></p> <p>DESCRIPTION: Have your views on this changed recently? Why is this? What is working? What is not? Do you think attitudes are moving in the right direction?</p> <p><b>TOPIC: What do you know about the National Dementia Strategy?</b></p> <p>DESCRIPTION: Were you aware of the Strategy before this research? If so, how did you hear about it? Were you involved in the consultation? What do you think the Strategy aims to do?</p> <p><b>TOPIC: What does the National Dementia Strategy mean, in practice, for you?</b></p> <p>DESCRIPTION: Has the Strategy already led to any changes in your work? What kind of changes? What about for your organisation and team?</p>	<p>This section warms up participants and opens the discussion forum, aiming to elicit general views on the National Dementia Strategy and dementia services. This will provide useful context that frames their views of the Strategy.</p>
15 July 2009	<p><b>Understanding the National Dementia Strategy</b></p> <p><b>TOPIC: What information have you received to date about the Strategy?</b></p> <p>DESCRIPTION: Do you know what is expected of you as part of the Strategy? What were you told about this? Where did the information come from? What did you think of it? Which aspects did you consider applied most closely to you? Have you discussed the Strategy with your staff or colleagues? What did you discuss? What was their reaction?</p>	<p>In this section we examine participants' understanding of the Strategy and the changes its implementation brings about, exploring any unmet needs.</p>



	<p><b>TOPIC: How clear is the Strategy's vision?</b></p> <p>DESCRIPTION: Do you think the Strategy's vision is clear? Are the Strategy's objectives appropriate? Are the aims clear? Is this filtering down to other frontline staff you meet? Which aims are particularly relevant to your role? From your experience, is anything missing?</p>	<p><b>Download stimulus: Strategy objectives</b></p>
<p>16 July 2009</p>	<p><b>Managing the National Dementia Strategy implementation</b></p> <p><b>TOPIC: What do you think of the leadership of the Strategy implementation?</b></p> <p>DESCRIPTION: Is it clear who is responsible for what? Do you think there is strong national leadership for the Strategy? What about regional and local leadership? Is there enough money to support the necessary changes in dementia services? Has money been released? Do leaders communicate about the priority of dementia effectively? How important are these factors for the Strategy to succeed?</p> <p><b>TOPIC: Do you think that leaders of the Strategy implementation lead by example?</b></p> <p>DESCRIPTION: Do you think there are visible and effective role models driving improvement in dementia care? Are leaders supporting the local NHS/social care clearly behind the changes that the Strategy requires? Does their communication and commitment inspire the confidence of staff and stakeholders? Has the leadership engaged with partners in the delivery chain to work together as a team to deliver the Strategy?</p> <p><b>TOPIC: Do you know of any changes in the procedures in your health and/or social care services for people with dementia and their carers that have happened recently? Do you know of any planned for the near future as a result of the Strategy?</b></p> <p>DESCRIPTION: Can you give details? Is there anything that you now do differently? Are you aware of your management/leadership talking about changes? Are there any structural changes in the way health and/or social care is delivered and managed? Or changes in procedures or processes? What about changes in the culture, attitudes, training or performance management of staff? What impact do you think these changes will have?</p>	<p>This section explores if participants' views on how the Strategy is managed, and if they have noticed any changes as part of the Strategy. We also interrogate issues around leadership and support offered to participants in delivering the Strategy.</p> <p>For this topic area, we would aim to use examples and comments from other boards as stimulus for the discussion.</p>

	<p><b>TOPIC: If you know of any planned changes, what contribution do you think these will make to health and social care support for those with dementia and their carers?</b></p> <p>DESCRIPTION: Can you give examples? Are there any barriers that could limit the effect these changes may have? If so how can the barriers be overcome?</p> <p><b>TOPIC: If there are no planned changes, why do you think this is the case?</b></p> <p>DESCRIPTION: What has prevented change from happening? What changes are needed/would you like to see? Can you give some examples? What difference would this make?</p> <p><b>TOPIC: Do you need any additional support or information to fulfil what is expected of you under the Strategy?</b></p> <p>DESCRIPTION: What support, if any, have you received so far to help you play your part in implementing the Strategy? What has been most useful? Is there any other help or support that you need? How would this help you in your role? Who should provide this help and support? How should they provide it? Are you aware of others getting support which would also be helpful for you?</p> <p>Are there any particular areas of the Strategy you're not clear about? Which ones? What would help to bridge these gaps in your understanding?</p> <p><b>TOPIC: Can you tell us about any examples of good practice in delivering services that are linked to the Strategy?</b></p> <p>DESCRIPTION: Are there any positive changes that have happened in the last few months? What elements of the Strategy have already had an impact? Why?</p>	
20 July 2009	<p><b>A better quality service?</b></p> <p>“The aim of the National Dementia Strategy is to ensure that significant improvements are made to dementia services across three key areas: improved awareness, earlier diagnosis and</p>	<p>This section elicits participants' opinions on how well the system is performing in three key cross-cutting areas, in line with the</p>

	<p>intervention, and a higher quality of care.” (DH: <i>Living well with dementia: A National Dementia Strategy</i>)</p> <p><b>Are services / the system ready to address these aims?</b></p>	<p>NAO’s 2007 recommendations for change.</p> <p>For this topic area, we would aim to use examples and comments from other boards as stimulus for the discussion.</p> <p><b>Download Stimulus: Strategy objectives</b></p> <p><b>Objective 1, 11</b></p>
	<p><b>TOPIC: From your personal experience, do you think the launch of the Strategy is improving awareness of dementia across (a) health and social care (b) the general public?</b></p> <p>DESCRIPTION: Are leadership filtering down messages/priorities on dementia effectively to all staff? Are health and social care staff now more aware of dementia? Are there differences between managerial staff and frontline workers? What works and what does not? Can you give details and examples? What helps in achieving improved awareness? What hinders its achievement?</p>	<p><b>Objective 13</b></p>
	<p><b>TOPIC: Do you feel that there is currently an ‘informed and effective workforce’ in place to care for people with dementia and support their carers?</b></p> <p>DESCRIPTION: Do staff in health and social care have the skills they need? Are they able to access appropriate training? What is the attitude of staff to dementia training? What is effective in the current training provision and what is not? Can you give details and examples? What hinders the provision or effectiveness of training?</p> <p><b>TOPIC: And has quality of health and social care for people with dementia begun to change as a result of the Strategy implementation?</b></p> <p>DESCRIPTION: How well does the system deliver on care for people with dementia? What works and what does not? Can you give details and examples? What would help improve care for people with dementia? What hinders its achievement? Have you seen examples of improved outcomes of care? Are you seeing/do you expect to see a change in the care arrangements chosen for people with dementia, for instance assisted living? What about telecare services?</p>	<p><b>Objectives 4, 5, 9, 10, 11, 12, 15, 17</b></p>

22 July 2009	<p><b>Working as a whole system</b></p> <p><b>How adequate are current joint working arrangements to drive improved dementia care?</b></p> <hr/> <p><b>TOPIC: How adequate are current joint working arrangements to drive improved dementia care?</b></p> <p>DESCRIPTION: How successful is co-operation between social care and health services at present? Has it improved recently? Has development of the Strategy begun to build common purpose? Are learning and examples of good practice shared? Are there barriers to effective joint working? Why do these act as barriers? How can these be overcome?</p> <p><b>TOPIC: What do you think would make the joint working process easier?</b></p> <p>DESCRIPTION: Can you give examples? Have you had personal experience of barriers to joint working?</p> <p><b>TOPIC: How realistic are the Strategy's objectives?</b></p> <p>DESCRIPTION: Which objectives are you aware of? Which objectives are particularly relevant to your job/role? Can you give examples of realistic objectives and also examples of those which you think will be more challenging? Do you think the Strategy's objectives can be fulfilled within the specified timeframe of five years? If not, how long do you think it will take? How will you judge whether the Strategy is achieving its objectives?</p>	<p>This section explores how well mental health services, local social services, user organisations, carer organisations, and other services appear to work together.</p> <p>For this topic area, we would aim to use examples and comments from other boards as stimulus for the discussion.</p> <p><b>Download Stimulus: Strategy objectives</b></p>
24 July 2009	<p><b>TOPIC: Have you had any specific training at any point in your career that covers dementia?</b></p> <p>DESCRIPTION: Do you think <b>you</b> need any specific training? If not, why not? What would this training cover?</p> <p><b>TOPIC: Do you think you or members of your team need further training on dementia?</b></p> <p>DESCRIPTION: Is anything stopping you from accessing dementia training for you or your</p>	

	<p>staff? If so, what?</p> <p><b>TOPIC: We have heard from dementia trainers (on another forum) that they believe dementia training is treated as a 'tick box' exercise by managers and staff. Do you agree with them?</b></p>	
	<p><b>Areas for change</b></p> <p><b>What needs to change to make progress in dementia services?</b></p>	<p>This section concludes the discussion by looking at improvements and refinements that could be made to the Strategy from the frontline perspective. This will enable us to make detailed suggestions for improvement.</p>
	<p><b>TOPIC: What do you think will be the impact of the strategy focusing on early diagnosis of dementia?</b></p> <p><b>TOPIC: What you would like to see as the model for dementia diagnosis and care in 5, 10 and 20 years' time?</b></p> <p>DESCRIPTION: Can you tell us what services you would like to see in place should you become a user of these services? What do you think success of this strategy will look like?</p> <p><b>TOPIC: What should a good dementia service provide?</b></p> <p>DESCRIPTION: What should dementia services that provide good care for people with dementia and support for their carers look like? Is activity being generated by the Strategy contributing effectively to this goal? What are the requirements for the Strategy to be successful? What difference will they make?</p> <p><b>TOPIC: Are there any areas of care for people with dementia or carer support that the Strategy is not addressing at the moment?</b></p> <p>DESCRIPTION: Can you give details? Why are these areas important? How should they be addressed? What will happen if they are not addressed?</p>	<p>For this topic area, we would aim to use examples and comments from other boards as stimulus for the discussion.</p>

	<p><b>TOPIC: Is there anything else you would like to add about dementia services and the Strategy of dementia services in general?</b></p> <p>DESCRIPTION: Have your thoughts about the provision of dementia services changed since you began taking part in this project?</p>	
27 <sup>th</sup> July	<p><b>Thank you for your help.</b></p> <p>All the information you have given us will remain entirely anonymous. Ipsos MORI will use it to write an independent report for the National Audit Office. The NAO, in turn, will use this report to inform their national follow-up study on dementia services. Both reports will be available for you to read on the NAO website in Winter 2009. We will email you a link to the reports once they are published.</p>	Offer to email participants a link to the published report on the NAO website and the separate report on the online forums and their findings.

## TOPIC GUIDE FOR BOARD 6 – Dementia Trainers

### Objectives:

The key objectives of the research are to investigate the experiences of dementia trainers, in order to:

- investigate readiness of the system to deliver against the recommendations of the NAO's 2007 VFM study through the National Dementia Strategy;
- learn what structural, cultural and procedural changes are coming through / are needed from the frontline perspective to implement and deliver the new Strategy; and
- uncover participants' views and experiences of leadership in dementia services, and the extent of planning taking place.

Moderators are advised to phrase online prompts simply, informally and **succinctly**.

### Welcome text

Welcome to the NAO and Ipsos MORI bulletin board on dementia services and the National Dementia Strategy.

#### ○ **What is the National Dementia Strategy (the Strategy)?**

In 2007, the National Audit Office (NAO) published an important Value for Money study, [Improving services and support for people with dementia](#) which made a powerful case for the review and reform of dementia services in light of the increasing urgency of the problems facing them. This report made a number of key recommendations. These included improving GPs' diagnosis rate of dementia, the wider provision of Memory Services, improving hospital medical responses to dementia, improving the management of dementia services and support in the community, and improving the skills and awareness of health and social care professionals about dementia and how to deal with those suffering from it. This report was followed by a report by the Public Accounts Committee (PAC) which also made recommendations.

The recommendations of both these reports were incorporated by the Department of Health into the [National Dementia Strategy](#). This was launched in February 2009, aiming to address the concerns raised by the NAO and PAC by improving awareness and earlier diagnosis of dementia, increasing earlier intervention and ensuring a higher quality of care for people with dementia and support for their carers.

- **Why are we researching the Strategy?**

The Strategy must bring coherent direction and objectives in dementia care across a huge range of services: General Medical Practice, social care, residential care, hospital services, community nursing and other intermediate services. It must also improve services for people with dementia and their carers.

We are aiming to understand your views on the National Dementia Strategy, and on whether staff in the health and social care systems are in a position to be able to deliver the expected improvements for people with dementia.

- **Who are we?**

The National Audit Office scrutinises public spending on behalf of Parliament. The NAO is working with Ipsos MORI to understand what you think about dementia services, the impact of the National Dementia Strategy, and how to take the Strategy forward.

Ipsos MORI is an independent social research organisation. Ipsos MORI is talking to health and social service practitioners and would like to know your experiences, views and ideas.

There are no right or wrong answers – all opinions are equally valid, but we do need to know your honest opinions.

**All comments posted here will be completely anonymous.**

**Instructions:**

Please click on a forum topic and add your comments.

NOTE: We would like to learn about **your personal and local experiences**, to capture what the Strategy means for frontline staff at a local level. We do not expect participants to make comments about services and the Strategy at the national level.



Date of upload	Description	Notes
13 July 2009	<p data-bbox="506 292 965 320"><b>First thoughts on dementia services</b></p> <p data-bbox="506 384 1509 443"><b>TOPIC: How well do you think dementia services meet the needs of people with dementia and their carers?</b></p> <p data-bbox="506 475 1626 534">DESCRIPTION: Have your views on this changed recently? Why is this? What is working? And what isn't? Do you think attitudes are moving in the right direction?</p> <p data-bbox="506 598 1335 627"><b>TOPIC: What do you know about the National Dementia Strategy?</b></p> <p data-bbox="506 659 1615 718">DESCRIPTION: Were you aware of the Strategy before this research? If so, how did you hear about it? Were you involved in the consultation? What do you think the Strategy aims to do?</p> <p data-bbox="506 782 1485 810"><b>TOPIC: What does the National Dementia Strategy mean, in practice, for you?</b></p> <p data-bbox="506 842 1608 938">DESCRIPTION: Has the Strategy led to any changes in the content of courses you deliver? How about levels of demand for your training courses? The way in which you deliver training? Who you deliver training to? Or who delivers the courses?</p>	<p data-bbox="1653 292 2047 531">This section warms up participants and opens the discussion forum, aiming to elicit general views on the National Dementia Strategy and dementia services. This will provide useful context that frames their views of the Strategy.</p>
14 July 2009	<p data-bbox="506 978 1095 1007"><b>Understanding the National Dementia Strategy</b></p> <p data-bbox="506 1070 1413 1099"><b>TOPIC: What information have you received to date about the Strategy?</b></p> <p data-bbox="506 1131 1626 1259">DESCRIPTION: Have you attended any events where information about the Strategy has been disseminated? How about with those you train? How do they feel about the Strategy? Have you yourself been involved in any dissemination events? What was the reaction of those attending?</p>	<p data-bbox="1653 978 2047 1121">In this section we examine participants' understanding of the Strategy and the changes its implementation brings about, exploring any unmet needs.</p>

	<p><b>TOPIC: How clear is the Strategy's vision?</b></p> <p>DESCRIPTION: Do you think the Strategy's vision is clear? Are the Strategy's objectives appropriate? Are the aims clear? Is this filtering down to staff or leaders you meet? Which aims are particularly relevant to your role? From your experience, is anything missing?</p>	<p><b>Download stimulus: Strategy objectives</b></p>
<p>16 July 2009</p>	<p><b>Managing the National Dementia Strategy implementation</b></p> <p><b>TOPIC: What do you think of the leadership of the Strategy implementation?</b></p> <p>DESCRIPTION: Is it clear who is responsible for what? Do you think there is strong national leadership for the Strategy? What about regional and local leadership? Is there enough money to support the necessary changes in dementia services? Has money been released? Do leaders communicate about the priority of dementia effectively? How important are these factors for the Strategy to succeed?</p> <p><b>TOPIC: Do you think that leaders of the Strategy implementation lead by example?</b></p> <p>DESCRIPTION: Do you think there are visible role models at the national, regional and local level for the Strategy? Do leaders of the Strategy implementation support the changes that the Strategy requires? Does their communication and commitment inspire the confidence of staff and stakeholders? Has the leadership managed to engage partners in the delivery chain to work together as a team to deliver the Strategy, for example local NHS services, carer support groups, respite services etc?</p> <p><b>TOPIC: Do you know of any changes in dementia services that have happened recently, or are planned for the near future as a result of the Strategy?</b></p> <p>DESCRIPTION: Can you give details? Is there anything that you now do differently? Are you aware of those who commission your training courses talking about changes? Are there any changes in the way services in nursing and care homes are delivered and managed? In the delivery of training? What about changes in the culture of nursing and care home staff to whom you deliver training? What impact do you think these changes will have?</p>	<p>This section explores if participants' views on how the Strategy is managed, and if they have noticed any changes as part of the Strategy. We also interrogate issues around leadership and support offered to participants in delivering the Strategy.</p> <p>For this topic area, we would aim to use examples and comments from other boards as stimulus for the discussion.</p>

	<p><b>TOPIC: What are the particular difficulties in your sector in making changes to improve services for people with dementia?</b></p> <p>DESCRIPTION: What are the barriers to improving dementia care in care homes? Please discuss within the context of staff skills, retention &amp; attitudes, incentives (for staff and management), performance management and management attitudes. Do you think changes in training are being complemented by appropriate changes in leadership style, staff training &amp; retention policies, culture, commissioning approach and funding? Which of these is most important for services for people with dementia to improve? What levers are there on care homes to encourage them to improve training of staff?</p> <p><b>TOPIC: If you know of any planned changes, what contribution do you think these will make to patient support?</b></p> <p>DESCRIPTION: Can you give examples? What about the effect of changes on carers of people with dementia?</p> <p><b>TOPIC: If there have not been any changes or planning activity, why do you think this has been the case?</b></p> <p>DESCRIPTION: What has prevented change from happening? What changes are needed/would you like to see? Can you give me some examples? What difference would this make?</p> <p><b>TOPIC: Can you tell us about any examples of good practice in delivering services that are linked to the Strategy?</b></p> <p>DESCRIPTION: Are there any positive changes that have happened in the last few months? What elements of the Strategy have clients and staff been talking about? Why?</p>	
20 July 2009	<p><b>A better quality service?</b></p> <p>“The aim of the National Dementia Strategy is to ensure that significant improvements are made to dementia services across three key areas: improved awareness, earlier diagnosis and intervention, and a higher quality of care.”</p>	This section elicits participants’ opinions on how well the system is performing in three key cross-cutting areas, in line with the NAO’s 2007 recommendations for

	<p><i>(DH: Living well with dementia: A National Dementia Strategy)</i></p> <p><b>Are services / systems ready to address these aims?</b></p>	<p>change.</p> <p>For this topic area, we would aim to use examples and comments from other boards as stimulus for the discussion.</p> <p><b>Download Stimulus: Strategy objectives</b></p> <p><b>Objective 1, 11</b></p> <p><b>Objective 13</b></p>
	<p><b>TOPIC: From your personal experience, do you think the push of the Strategy is improving awareness of dementia across health and social care settings?</b></p> <p>DESCRIPTION: Are leaders filtering down dementia as a priority to frontline staff? Are nursing and care home staff becoming more aware of dementia? Are there differences between managerial staff and frontline carers? What works and what does not? Can you give details and examples? What helps in achieving improved awareness? What hinders its achievement?</p> <p><b>TOPIC: Do you feel that there is currently an ‘informed and effective workforce’ in place to care for people with dementia?</b></p> <p>DESCRIPTION: Do staff in health and social care have the skills they need? Are they able to access appropriate training? What is the attitude of staff to dementia training? What is effective in the current training provision and what is not? Can you give details and examples? What hinders the provision or effectiveness of training?</p>	
	<p><b>TOPIC: What about achieving improved end of life care for people with dementia?</b></p> <p>DESCRIPTION: Have you noticed changes? Are people with dementia and their carers getting more involved in planning end of life care? Are you beginning to see ‘pathways of care that deliver’? What works and what does not? Can you give details and examples? What would help achieve better care? What hinders its achievement?</p> <p><b>TOPIC: And has quality of care for people with dementia begun to change as a result of the Strategy?</b></p> <p>DESCRIPTION: How well is the system delivering on care for people with dementia? What works and what does not? Can you give details and examples? Have you seen improved outcomes of care? What would help improve care for people with dementia? What hinders its achievement?</p>	<p><b>Objectives 12, 4</b></p> <p><b>Objectives 4, 5, 9, 10, 11, 12, 15, 17</b></p>

22 July 2009	<p><b>Working as a whole system</b></p> <p><b>How well does the Strategy support joint working across organisations to deliver care for people with dementia and support for their carers?</b></p> <hr/> <p><b>TOPIC: How effectively do services work together for better care for people with dementia and support for their carers?</b></p> <p>DESCRIPTION: How successful is co-operation between different services at present? Has it improved over the last few months? Has development of the Strategy begun to build common purpose? Are learning and examples of good practice shared across organisational boundaries e.g. PCTs, care homes, acute hospitals etc? Are there barriers to effective joint working? Why do these act as barriers? How can these be overcome?</p> <p><b>TOPIC: How realistic are the Strategy's objectives?</b></p> <p>DESCRIPTION: Which objectives are you aware of? Which objectives are particularly relevant to your job role? Can you give examples of realistic objectives and also examples of those which you think will be more challenging? Do you think the Strategy's objectives can be fulfilled within the specified timeframe of five years? If not, how long do you think it will take? How would you judge whether the Strategy is achieving its objectives?</p> <p><b>TOPIC: Have you seen examples of explicit care pathways for the management and care of people with dementia being developed?</b></p> <p>DESCRIPTION: Are you aware of care pathways? How do nursing and residential care homes fit into the pathways? Were you involved in the development of the care pathway? How well is it working at present? If none has been developed, do you know if an explicit care pathway is planned?</p>	<p>This section explores how well mental health services, local social services, user organisations, carer organisations, and other services appear to work together.</p> <p>For this topic area, we would aim to use examples and comments from other boards as stimulus for the discussion.</p> <p><b>Download Stimulus: Strategy objectives</b></p>
24 July 2009	<p><b>Areas for change</b></p> <p><b>What needs to change to make progress in dementia services?</b></p>	<p>This section concludes the discussion by looking at improvements and refinements that could be made to the Strategy's implementation from</p>

	<p><b>TOPIC: What do you think will be the impact of the strategy focusing on early diagnosis of dementia?</b></p>	<p>the frontline perspective. This will enable us to make detailed suggestions for improvement.</p> <p>For this topic area, we would aim to use examples and comments from other boards as stimulus for the discussion.</p>
<p><b>TOPIC: What you would like to see as the model for dementia diagnosis and care in 5, 10 and 20 years' time?</b></p> <p>DESCRIPTION: Can you tell us what services you would like to see in place should you become a user of these services? What do you think success of this strategy will look like?</p>		
<p><b>TOPIC: What should a good dementia service provide?</b></p> <p>DESCRIPTION: What should dementia services that provide good care for people with dementia and support for their carers look like? Is activity being generated by the Strategy contributing effectively to this goal?</p>		
<p><b>TOPIC: Are there any areas of care for people with dementia or carer support that the Strategy is not addressing at the moment?</b></p> <p>DESCRIPTION: Can you give details? Why are these areas important? How should they be addressed? What will happen if they are not addressed?</p> <p><b>TOPIC: Is there anything else you would like to add about dementia services and the Dementia Strategy in general?</b></p> <p>DESCRIPTION: Have your thoughts about the provision of dementia services changed since you began taking part in this project?</p>		
<p>27<sup>th</sup> July</p>	<p><b>Thank you for your help.</b></p> <p>All the information you have given us will remain entirely anonymous. Ipsos MORI will use it to write an independent report for the National Audit Office. The NAO, in turn, will use this report to inform their national follow-up study on dementia services. Both reports will be available for you to read on the NAO website in Winter 2009. We will email you a link to the reports once they are published.</p>	<p>Offer to email participants a link to the published report on the NAO website and the separate report on the online forums and their findings.</p>

## TOPIC GUIDE FOR BOARD 7 – Nursing and residential care home managers

### Objectives:

The key objectives of the research are to investigate the experiences of nursing and residential care home managers, in order to:

- investigate readiness of the system to deliver against the recommendations of the NAO's 2007 VFM study through the National Dementia Strategy;
- learn what structural, cultural and procedural changes are coming through / are needed from the frontline perspective to implement and deliver the new Strategy; and
- uncover participants' views and experiences of leadership in dementia services, and the extent of planning taking place.

Moderators are advised to phrase online prompts simply, informally and **succinctly**.

### Welcome text

- Welcome to the NAO and Ipsos MORI bulletin board on dementia services and the National Dementia Strategy.
- **What is the National Dementia Strategy (the Strategy)?**

In 2007, the National Audit Office (NAO) published an important Value for Money study, [Improving services and support for people with dementia](#) [link] which made a powerful case for the review and reform of dementia services in light of the increasing urgency of the problems facing them. This report made a number of key recommendations. These included improving GPs' diagnosis rate of dementia, the wider provision of Memory Services, improving hospital medical responses to dementia, and improving the management of dementia services and support in the community. This report was followed by a report by the Public Accounts Committee (PAC) which also made recommendations.

The recommendations of both these reports were incorporated by the Department of Health into the [National Dementia Strategy](#). This was launched in February 2009, aiming to address the concerns raised by the NAO and PAC by improving awareness and earlier diagnosis of dementia, increasing earlier intervention and ensuring a higher quality of care for people with dementia and support for their carers.

- **Why are we researching the Strategy?**

The Strategy must bring coherent direction and objectives in dementia care across a huge range of services: General Medical Practice, social care, residential care, hospital services, community nursing and other intermediate services. It must also improve services for people with dementia and their carers.

We are aiming to understand your views on the National Dementia Strategy, and on whether staff in the health and social care systems are in a position to be able to deliver the expected improvements for people with dementia.

- **Who are we?**

The National Audit Office scrutinises public spending on behalf of Parliament. The NAO is working with Ipsos MORI to understand what you think about dementia services, the impact of the National Dementia Strategy, and how to take the Strategy forward.

Ipsos MORI is an independent social research organisation. Ipsos MORI is talking to health and social service practitioners and would like to know your experiences, views and ideas.

There are no right or wrong answers – all opinions are equally valid, but we do need to know your honest opinions.

**All comments posted here will be completely anonymous.**

**Instructions:**

Please click on a forum topic and add your comments.

NOTE: We would like to learn about **your personal and local experiences**, to capture what the Strategy means for frontline staff at a local level. We do not expect participants to make comments about services and the Strategy at the national level.



Date of upload	Description	Notes
13 July 2009	<p data-bbox="506 292 965 316"><b>First thoughts on dementia services</b></p> <p data-bbox="506 384 1509 440"><b>TOPIC: How well do you think dementia services meet the needs of people with dementia and their carers?</b></p> <p data-bbox="506 480 1592 536">DESCRIPTION: Have your views on this changed recently? Why is this? Which services are working? And which ones aren't? Do you think attitudes are moving in the right direction?</p> <p data-bbox="506 600 1335 624"><b>TOPIC: What do you know about the National Dementia Strategy?</b></p> <p data-bbox="506 663 1615 719">DESCRIPTION: Were you aware of the Strategy before this research? If so, how did you hear about it? Were you involved in the consultation? What do you think the Strategy aims to do?</p> <p data-bbox="506 791 1485 815"><b>TOPIC: What does the National Dementia Strategy mean, in practice, for you?</b></p> <p data-bbox="506 855 1603 911">DESCRIPTION: Has the Strategy already led to any changes in your work? Or are there any changes planned? What kind of changes? What about for your organisation and team?</p>	<p data-bbox="1653 292 2047 536">This section warms up participants and opens the discussion forum, aiming to elicit general views on the National Dementia Strategy and dementia services. This will provide useful context that frames their views of the Strategy.</p>
14 July 2009	<p data-bbox="506 946 1095 970"><b>Understanding the National Dementia Strategy</b></p> <p data-bbox="506 1050 1413 1074"><b>TOPIC: What information have you received to date about the Strategy?</b></p> <p data-bbox="506 1114 1626 1265">DESCRIPTION: Do you know what is expected of you as part of the Strategy? What information have you received to date about the Strategy? Where did the information come from? What did you think of it? Have you discussed the Strategy with your staff, clients, and/or other organisations you work with? What did you discuss? What was their reaction? Do you need any additional information to fulfil what is expected of you under the Strategy?</p>	<p data-bbox="1653 946 2047 1098">In this section we examine participants' understanding of the Strategy and the changes its implementation brings about, exploring any unmet needs.</p>

	<p><b>TOPIC: How clear is the Strategy's vision?</b></p> <p>DESCRIPTION: Do you think the Strategy's vision is clear? Are the Strategy's objectives appropriate? Are the aims clear? Is this filtering down to the staff delivering care? Which aims are particularly relevant to your role? From your experience, is anything missing?</p>	<p><b>Download stimulus: Strategy objectives</b></p>
<p>16 July 2009</p>	<p><b>Managing the National Dementia Strategy implementation</b></p> <p><b>TOPIC: What do you think of the leadership of the Strategy implementation?</b></p> <p>DESCRIPTION: Is it clear who is responsible for what? Do you think there is strong national leadership for the Strategy? What about regional and local leadership? Is there enough money to support the necessary changes in dementia services? Has money been released? Do leaders communicate about the priority of dementia effectively? How important are these factors for the Strategy to succeed?</p> <p><b>TOPIC: Do you think that leaders of the Strategy implementation lead by example?</b></p> <p>DESCRIPTION: Do you think there are visible role models at the national, regional and local level for the Strategy? Do leaders of the Strategy implementation support the changes that the Strategy requires? Does their communication and commitment inspire the confidence of staff and stakeholders? Has the leadership managed to engage partners in the delivery chain to work together as a team to deliver the Strategy, for example local NHS services, carer support groups, respite services etc?</p> <p><b>TOPIC: Do you know of any changes in dementia services due to the Strategy?</b></p> <p>DESCRIPTION: Can you give details and examples? Is there anything that you now do differently? Are you aware of the leadership talking about changes? Are there any structural changes in the way services in nursing and residential care homes are delivered and managed? Or changes in procedures or processes? What about changes in the culture in nursing and residential care homes? What impact do you think these changes will have - on you and on others?</p>	<p>This section explores if participants' views on how the Strategy is managed, and if they have noticed any changes as part of the Strategy. We also interrogate issues around leadership and support offered to participants in delivering the Strategy.</p> <p>For this topic area, we would aim to use examples and comments from other boards as stimulus for the discussion.</p>

	<p><b>TOPIC: What are the particular difficulties in your sector in making changes to improve services for people with dementia?</b></p> <p>DESCRIPTION: What are the barriers to improving dementia care in care homes? Please discuss within the context of staff skills, retention &amp; attitudes, incentives (for staff and management), performance management and management attitudes. Do you think changes in training are being complemented by appropriate changes in leadership style, staff training &amp; retention policies, culture, commissioning approach and funding? Which of these is most important for services for people with dementia to improve? What levers are there on care homes to encourage them to improve training of staff?</p> <p><b>TOPIC: If you know of any planned changes, what contribution do you think these will make to support of people with dementia?</b></p> <p>DESCRIPTION: Can you give examples? Are there any barriers that could limit the effect these changes may have? If so, how can the barriers be overcome? What about the wider impact of supporting families of people with dementia?</p> <p><b>TOPIC: If there have not been any planned changes, why do you think this has been the case?</b></p> <p>DESCRIPTION: What has prevented change from happening? What changes are needed/would you like to see? Can you give me some examples? What difference would this make?</p> <p><b>TOPIC: Can you tell us about any examples of good practice in delivering services that are linked to the Strategy?</b></p> <p>DESCRIPTION: Are there any positive changes that have happened in the last few months? What elements of the Strategy are being talked about by clients, staff, and colleagues in other care homes? Why?</p>	
20 July 2009	<p><b>A better quality service?</b></p> <p>“The aim of the National Dementia Strategy is to ensure that significant improvements are</p>	This section elicits participants’ opinions on how well the system is performing in three key cross-

	<p>made to dementia services across three key areas: improved awareness, earlier diagnosis and intervention, and a higher quality of care.” (DH: <i>Living well with dementia: A National Dementia Strategy</i>)</p> <p><b>Are services / systems ready to address these aims?</b></p>	<p>cutting areas, in line with the NAO’s 2007 recommendations for change.</p> <p>For this topic area, we would aim to use examples and comments from other boards as stimulus for the discussion.</p>
	<p><b>TOPIC: From your personal experience, do you think the push of the Strategy is improving awareness of dementia amongst nursing and residential care home staff?</b></p> <p>DESCRIPTION: Is leadership filtering down dementia as a priority effectively to frontline staff? Are nursing and care home staff becoming more aware of dementia? Are there differences between managerial staff and frontline care staff? What works and what does not? Can you give details and examples? Has there been /is there a planned increase in dementia training for staff? And managers? What helps in achieving improved awareness? What hinders its achievement e.g. time, funding, availability of trainers, attitudes, culture etc</p> <p><b>TOPIC: What about achieving improved end of life care for people with dementia?</b></p> <p>DESCRIPTION: Have you noticed changes? Are people with dementia and their carers getting more involved in planning end of life care? Are you beginning to see ‘pathways of care that deliver’? What works and what does not? Can you give details and examples? What would help achieve better care? What hinders its achievement?</p> <p><b>TOPIC: And has quality of care for people with dementia in nursing and care homes begun to change as a result of the Strategy?</b></p> <p>DESCRIPTION: How well does the system deliver on care for people with dementia? What works and what does not? Can you give details and examples? What would help improve care for people with dementia? What hinders its achievement? Have you seen examples of improved outcomes of care?</p>	<p><b>Download Stimulus: Strategy objectives</b></p> <p><b>Objective 1, 11, 13</b></p> <p><b>Objectives 12, 4</b></p> <p><b>Objectives 4, 5, 9, 10, 11, 12, 15, 17</b></p>
22 July 2009	<p><b>Working as a whole system</b></p> <p><b>How well does the Strategy support joint working across organisations to deliver care for people with dementia and support for their carers?</b></p>	<p>This section explores how well mental health services, local social services, user organisations, carer organisations, and other services</p>

	<p><b>TOPIC: How effectively do services work together for better care for people with dementia and support for their carers?</b></p> <p>DESCRIPTION: How successful is co-operation between different services at present? Has development of the Strategy begun to build common purpose? Are learning and examples of good practice shared? Is co-operation improving between the care home sector, PCTs, hospitals, GP services? Are there barriers to effective joint working and co-operation? Why do these act as barriers? How can these be overcome?</p> <p><b>TOPIC: How realistic are the Strategy's objectives?</b></p> <p>DESCRIPTION: Which objectives are you aware of? Which objectives are particularly relevant to your job/role? Can you give examples of realistic objectives and also examples of those which you think will be more challenging? Do you think the Strategy's objectives can be fulfilled within the specified timeframe of five years? If not, how long do you think it will take? How would you judge whether the Strategy is achieving its objectives?</p> <p><b>TOPIC: Have you seen examples of explicit care pathways for the management and care of people with dementia being developed?</b></p> <p>DESCRIPTION: Are you aware of care pathways? How do nursing and residential care homes fit into the pathway? Were you involved in the development of the care pathway? How well is it working at present? If none has been developed, do you know if an explicit care pathway is planned?</p>	<p>appear to work together.</p> <p>For this topic area, we would aim to use examples and comments from other boards as stimulus for the discussion.</p> <p><b>Download Stimulus: Strategy objectives</b></p>
24 July 2009	<p><b>TOPIC: Have you had any specific training at any point in your career that covers dementia?</b></p> <p>DESCRIPTION: Do you think <b>you</b> need any specific training? If not, why not? What would this training cover?</p> <p><b>TOPIC: Do you think members of your team need further training on dementia?</b></p> <p>DESCRIPTION: Is anything stopping you from accessing dementia training for you or your staff? If so, what?</p>	

	<p><b>TOPIC: We have heard from dementia trainers (on another forum) that they believe dementia training is treated as a 'tick box' exercise by managers and staff. Do you agree with them?</b></p> <p><b>TOPIC: What is the relationship between NHS nursing staff and care home staff in providing effective care for people with dementia?</b></p> <p><b>TOPIC: What, if any, are the factors that stop people from working in care homes/stop them staying?</b></p> <p>DESCRIPTION: How far is salary an issue and also salary compared with the NHS and other sectors? What stops people in health and social care specialising in working with people with dementia?</p> <p><b>TOPIC: What services, if any, do you provide outside your premises in the community in which you operate, e.g. respite, advice, training, outreach?</b></p> <p>DESCRIPTION: If commissioned, could/would you provide any such services?</p>	
	<p><b>Areas for change</b></p> <p><b>What needs to change to make progress in dementia services?</b></p> <p><b>TOPIC: What do you think will be the impact of the strategy focusing on early diagnosis of dementia?</b></p> <p><b>TOPIC: What you would like to see as the model for dementia diagnosis and care in 5, 10 and 20 years' time? Can you tell us what services you would like to see in place should you become a user of these services? What do you think success of this strategy will look like?</b></p>	<p>This section concludes the discussion by looking at improvements and refinements that could be made to the Strategy's implementation from the frontline perspective. This will enable us to make detailed suggestions for improvement.</p> <p>For this topic area, we would aim to use examples and comments from other boards as stimulus for the discussion.</p>

	<p><b>TOPIC: What should a good dementia service provide?</b></p> <p>DESCRIPTION: What should services that provide good care for people with dementia and support for their carers look like? Is activity being generated by the Strategy contributing to this goal?</p> <p><b>TOPIC: Are there any areas of care for people with dementia that the Strategy is not addressing at the moment?</b></p> <p>DESCRIPTION: Can you give details? Why are these areas important? How should they be addressed? What will happen if they are not addressed?</p> <p><b>TOPIC: Is there anything else you would like to add about dementia services and the Strategy in general?</b></p> <p>DESCRIPTION: Have your thoughts about the provision of dementia services changed since you began taking part in this project?</p>	
27 <sup>th</sup> July 2009	<p><b>Thank you for your help.</b></p> <p>All the information you have given us will remain entirely anonymous. Ipsos MORI will use it to write an independent report for the National Audit Office. The NAO, in turn, will use this report to inform their national follow-up study on dementia services. Both reports will be available for you to read on the NAO website in Winter 2009. We will email you a link to the reports once they are published.</p>	Offer to email participants a link to the published report on the NAO website and the separate report on the online forums and their findings.

## TOPIC GUIDE FOR BOARD 8 – Social Workers

### Objectives:

The key objectives of the research are to investigate the experiences of social care staff, in order to:

- investigate readiness of the system to deliver against the recommendations of the NAO's 2007 VFM study through the National Dementia Strategy;
- learn what structural, cultural and procedural changes are coming through / are needed from the frontline perspective to implement and deliver the new Strategy; and
- uncover participants' views and experiences of leadership in dementia services, and the extent of planning taking place.

Moderators are advised to phrase online prompts simply, informally and **succinctly**.

### Welcome text

Welcome to the NAO and Ipsos MORI bulletin board on dementia services and the National Dementia Strategy.

#### ○ **What is the National Dementia Strategy (the Strategy)?**

In 2007, the National Audit Office (NAO) published an important Value for Money study, [Improving services and support for people with dementia](#) which made a powerful case for the review and reform of dementia services in light of the increasing urgency of the problems facing them. This report made a number of key recommendations. These included improving GPs' diagnosis rate of dementia, the wider provision of Memory Services, improving hospital responses to dementia, improving the management of dementia services and support in the community, and improving the skills and awareness of health and social care professionals about dementia and how to deal with those suffering from it. This report was followed by a report by the Public Accounts Committee (PAC) which also made recommendations.

The recommendations of both these reports were incorporated by the Department of Health into the [National Dementia Strategy](#). This was launched in February 2009, aiming to address the concerns raised by the NAO and PAC by improving awareness and earlier diagnosis of dementia, increasing early intervention and ensuring a higher quality of care for people with dementia and support for their carers.



- **Why are we researching the Strategy?**

The Strategy must bring coherent direction and objectives in dementia care across a huge range of services: General Medical Practice, social care, residential care, hospital services, community nursing and other intermediate services. It must also improve services for people with dementia and their carers.

We are aiming to understand your views on the National Dementia Strategy, and on whether staff in the health and social care systems are in a position to be able to deliver the expected improvements for people with dementia.

- **Who are we?**

The National Audit Office scrutinises public spending on behalf of Parliament. The NAO is working with Ipsos MORI to understand what you think about dementia services, the impact of the National Dementia Strategy, and how to take the Strategy forward.

Ipsos MORI is an independent social research organisation. Ipsos MORI is talking to health and social service practitioners and would like to know your experiences, views and ideas.

There are no right or wrong answers – all opinions are equally valid, but we do need to know your honest opinions.

**All comments posted here will be completely anonymous.**

**Instructions:**

Please click on a forum topic and add your comments.

NOTE: We would like to learn about **your personal and local experiences**, to capture what the Strategy means for frontline staff at a local level. We do not expect participants to make comments about services and the Strategy at the national level.

Date of upload	Description	Notes
13 July 2009	<p data-bbox="506 292 965 316"><b>First thoughts on dementia services</b></p> <hr/> <p data-bbox="506 384 1532 440"><b>TOPIC: How well do you think social care services meet the needs of people with dementia and their carers?</b></p> <p data-bbox="506 477 1570 533">DESCRIPTION: Have your views on this changed recently? Why is this? What is working? What is not? Do you think attitudes are moving in the right direction?</p> <p data-bbox="506 601 1335 625"><b>TOPIC: What do you know about the National Dementia Strategy?</b></p> <p data-bbox="506 662 1615 718">DESCRIPTION: Were you aware of the Strategy before this research? If so, how did you hear about it? Were you involved in the consultation? What do you think the Strategy aims to do?</p> <p data-bbox="506 786 1485 810"><b>TOPIC: What does the National Dementia Strategy mean, in practice, for you?</b></p> <p data-bbox="506 847 1556 903">DESCRIPTION: Has the Strategy already led to any changes in your work? What kind of changes? What about for your organisation and team?</p>	<p data-bbox="1653 292 2058 533">This section warms up participants and opens the discussion forum, aiming to elicit general views on the National Dementia Strategy and dementia services. This will provide useful context that frames their views of the Strategy.</p>
14 July 2009	<p data-bbox="506 946 1095 970"><b>Understanding the National Dementia Strategy</b></p> <hr/> <p data-bbox="506 1050 1413 1074"><b>TOPIC: What information have you received to date about the Strategy?</b></p> <p data-bbox="506 1110 1621 1230">DESCRIPTION: Do you know what is expected of you as part of the Strategy? What were you told about this? Where did the information come from? What did you think of it? Which aspects did you consider apply most closely to you? Have you discussed the Strategy with your staff or colleagues? What did you discuss? What was their reaction?</p>	<p data-bbox="1653 946 2051 1094">In this section we examine participants' understanding of the Strategy and the changes its implementation brings about, exploring any unmet needs.</p>

	<p><b>TOPIC: How clear is the Strategy's vision?</b></p> <p>DESCRIPTION: Do you think the Strategy's vision is clear? Are the Strategy's objectives appropriate? Are the aims clear? Is this filtering down to frontline staff you meet? Which aims are particularly relevant to your role? From your experience, is anything missing?</p>	<p><b>Download stimulus: Strategy objectives</b></p>
<p>16 July 2009</p>	<p><b>Managing the National Dementia Strategy implementation</b></p> <p><b>TOPIC: What do you think of the leadership of the Strategy implementation?</b></p> <p>DESCRIPTION: Is it clear who is responsible for what? Do you think there is strong national leadership for the Strategy? What about regional and local leadership? Is there enough money to support the necessary changes in dementia services? Has money been released? Do leaders communicate about the priority of dementia effectively? How important are these factors for the Strategy to succeed?</p> <p><b>TOPIC: Do you think that leaders of the Strategy implementation lead by example?</b></p> <p>DESCRIPTION: Do you think there are visible role models at the national, regional and local level for the Strategy? Do leaders of the Strategy implementation support the changes that the Strategy requires? Does their communication and commitment inspire the confidence of staff and stakeholders? Has the leadership managed to engage partners in the delivery chain to work together as a team to deliver the Strategy, for example local NHS services, carer support groups, respite services etc?</p> <p><b>TOPIC: Do you know of any changes in the procedures in your social care service for people with dementia and their carers that have happened recently, or are planned for the near future as a result of the Strategy?</b></p> <p>DESCRIPTION: Can you give details? Is there anything that you now do differently? Are you aware of your management/leadership talking about changes? Are there any structural changes in the way social care is delivered and managed? Or changes in procedures or processes? What about changes in the culture, attitudes, training or performance management of social care staff? What impact do you think these changes will have?</p>	<p>This section explores if participants' views on how the Strategy is managed, and if they have noticed any changes as part of the Strategy. We also interrogate issues around leadership and support offered to participants in delivering the Strategy.</p> <p>For this topic area, we would aim to use examples and comments from other boards as stimulus for the discussion.</p>

	<p><b>TOPIC: If you know of any planned changes, what contribution do you think these will make to social care support for those with dementia and their carers?</b></p> <p>DESCRIPTION: Can you give examples? Are there any barriers that could limit the effect these changes may have? If so how can the barriers be overcome?</p> <p><b>TOPIC: If there are no planned changes, why do you think this is the case?</b></p> <p>DESCRIPTION: What has prevented change from happening? What changes are needed/would you like to see? Can you give some examples? What difference would this make?</p> <p><b>TOPIC: Do you need any additional support or information to fulfil what is expected of you under the Strategy?</b></p> <p>DESCRIPTION: What support, if any, have you received so far to help you play your part in implementing the Strategy? What has been most useful? Is there any other help or support that you need? How would this help you in your role? Who should provide this help and support? How should they provide it? Are you aware of others getting support which would also be helpful for you?</p> <p>Are there any particular areas of the Strategy you're not clear about? Which ones? What would help to bridge these gaps in your understanding?</p> <p><b>TOPIC: Can you tell us about any examples of good practice in delivering services that are linked to the Strategy?</b></p> <p>DESCRIPTION: Are there any positive changes that have happened in the last few months? What elements of the Strategy have already had an impact? Why?</p>	
20 July 2009	<p><b>A better quality service?</b></p> <p>"The aim of the National Dementia Strategy is to ensure that significant improvements are made to dementia services across three key areas: improved awareness, earlier diagnosis and</p>	This section elicits participants' opinions on how well the system is performing in three key cross-cutting areas, in line with the

	<p>intervention, and a higher quality of care.” (DH: <i>Living well with dementia: A National Dementia Strategy</i>)</p> <p><b>Are services / the system ready to address these aims?</b></p>	<p>NAO’s 2007 recommendations for change.</p> <p>For this topic area, we would aim to use examples and comments from other boards as stimulus for the discussion.</p> <p><b>Download Stimulus: STRATEGY objectives</b></p> <p><b>Objective 1, 11</b></p> <p><b>Objective 13</b></p> <p><b>Objectives 4, 5, 9, 10, 11, 12, 15, 17</b></p>
	<p><b>TOPIC: From your personal experience, do you think the launch of the Strategy is improving awareness of dementia across (a) social care (b) the general public?</b></p> <p>DESCRIPTION: Are leadership filtering down messages/priorities on dementia effectively to all staff? Are social care staff now more aware of dementia? Are there differences between managerial staff and frontline workers? What works and what does not? Can you give details and examples? What helps in achieving improved awareness? What hinders its achievement?</p> <p><b>TOPIC: Do you feel that there is currently an ‘informed and effective workforce’ in place to care for people with dementia and support their carers?</b></p> <p>DESCRIPTION: Do staff in social care have the skills they need? Are they able to access appropriate training? What is the attitude of staff to dementia training? What is effective in the current training provision and what is not? Can you give details and examples? What hinders the provision or effectiveness of training?</p> <p><b>TOPIC: And has quality of social care for people with dementia begun to change as a result of the Strategy implementation?</b></p> <p>DESCRIPTION: How well does the system deliver on care for people with dementia? What works and what does not? Can you give details and examples? What would help improve care for people with dementia? What hinders its achievement? Have you seen examples of improved outcomes of care? Are you seeing/do you expect to see a change in the care arrangements chosen for people with dementia, for instance assisted living? What about telecare services?</p>	
22 July 2009	<p><b>Working as a whole system</b></p> <p><b>How adequate are current joint working arrangements to drive improved dementia care?</b></p>	<p>This section explores how well mental health services, local social services, user organisations, carer</p>

	<p><b>TOPIC: How adequate are current joint working arrangements to drive improved dementia care?</b></p> <p>DESCRIPTION: How successful is co-operation between social care and health services at present? Has it improved recently? Has development of the Strategy begun to build common purpose? Are learning and examples of good practice shared? Are there barriers to effective joint working? Why do these act as barriers? How can these be overcome?</p> <p><b>TOPIC: How effectively do services work together for better care for people with dementia and support for their carers?</b></p> <p>DESCRIPTION: How successful is co-operation between social care and health services at present? Has it improved recently? Has development of the Strategy begun to build common purpose? Are learning and examples of good practice shared? Are there barriers to effective joint working? Why do these act as barriers? How can these be overcome?</p> <p><b>TOPIC: What do you think would make the joint working process easier?</b></p> <p>DESCRIPTION: Can you give examples? Have you had personal experience of barriers to joint working?</p> <p><b>TOPIC: How realistic are the Strategy's objectives?</b></p> <p>DESCRIPTION: Which objectives are you aware of? Which objectives are particularly relevant to your job/role? Can you give examples of realistic objectives and also examples of those which you think will be more challenging? Do you think the Strategy's objectives can be fulfilled within the specified timeframe of five years? If not, how long do you think it will take? How will you judge whether the Strategy is achieving its objectives?</p>	<p>organisations, and other services appear to work together.</p> <p>For this topic area, we would aim to use examples and comments from other boards as stimulus for the discussion.</p> <p><b>Download Stimulus: Strategy objectives</b></p>
24 July 2009	<p><b>TOPIC: Have you had any specific training at any point in your career that covers dementia?</b></p>	

	<p>DESCRIPTION: Do you think <b>you</b> need any specific training? If not, why not? What would this training cover?</p> <p><b>TOPIC: Do you think members of your team need further training on dementia?</b></p> <p>DESCRIPTION: Is anything stopping you from accessing dementia training for you or your staff? If so, what?</p> <p><b>TOPIC: We have heard from dementia trainers (on another forum) that they believe dementia training is treated as a 'tick box' exercise by managers and staff. Do you agree with them?</b></p>	
	<p><b>Areas for change</b></p> <p><b>What needs to change to make progress in dementia services?</b></p>	<p>This section concludes the discussion by looking at improvements and refinements that could be made to the Strategy from the frontline perspective. This will enable us to make detailed suggestions for improvement.</p> <p>For this topic area, we would aim to use examples and comments from other boards as stimulus for the discussion.</p>
	<p><b>TOPIC: What do you think will be the impact of the strategy focusing on early diagnosis of dementia?</b></p> <p><b>TOPIC: What you would like to see as the model for dementia diagnosis and care in 5, 10 and 20 years' time?</b></p> <p>DESCRIPTION: Can you tell us what services you would like to see in place should you become a user of these services? What do you think success of this strategy will look like?</p> <p><b>TOPIC: What should a good dementia service provide?</b></p> <p>DESCRIPTION: What should dementia services that provide good care for people with dementia and support for their carers look like? Is activity being generated by the Strategy contributing effectively to this goal? What are the requirements for the Strategy to be successful? What difference will they make?</p>	

	<p><b>TOPIC: Are there any areas of care for people with dementia or carer support that the Strategy is not addressing at the moment?</b></p> <p>DESCRIPTION: Can you give details? Why are these areas important? How should they be addressed? What will happen if they are not addressed?</p> <p><b>TOPIC: Is there anything else you would like to add about dementia services and the Strategy of dementia services in general?</b></p> <p>DESCRIPTION: Have your thoughts about the provision of dementia services changed since you began taking part in this project?</p>	
27 <sup>th</sup> July	<p><b>Thank you for your help.</b></p> <p>All the information you have given us will remain entirely anonymous. Ipsos MORI will use it to write an independent report for the National Audit Office. The NAO, in turn, will use this report to inform their national follow-up study on dementia services. Both reports will be available for you to read on the NAO website in Winter 2009. We will email you a link to the reports once they are published.</p>	Offer to email participants a link to the published report on the NAO website and the separate report on the online forums and their findings.