

DEM / 20 / 10



# **Quality outcomes for people with dementia: building on the work of the National Dementia Strategy**

Quality outcomes for people with dementia: building on the work of the National Dementia Strategy

**DH INFORMATION READER BOX**

Policy	Estates
HR / Workforce	Commissioning
Management	IM & T
Planning /	Finance
Clinical	<b>Social Care / Partnership Working</b>

<b>Document Purpose</b>	Best Practice Guidance
<b>Gateway Reference</b>	14700
<b>Title</b>	Quality outcomes for people with dementia: building on the work of the National Dementia Strategy
<b>Author</b>	DH/SCLGCP/SCP/OP&D
<b>Publication Date</b>	08 Sep 2010
<b>Target Audience</b>	PCT CEs, NHS Trust CEs, SHA CEs, Care Trust CEs, Foundation Trust CEs, Medical Directors, Directors of PH, Directors of Nursing, Local Authority CEs, Directors of Adult SSs, PCT Chairs, NHS Trust Board Chairs, Special HA CEs, Directors of HR, Directors of Finance, Allied Health Professionals, GPs, Communications Leads, Emergency Care Leads
<b>Circulation List</b>	Voluntary Organisations/NDPBs
<b>Description</b>	This document presents the Department of Health's revised, outcomes focused implementation plan for 'Living well with dementia: a National Dementia Strategy', which was published in February 2009.
<b>Cross Ref</b>	Living well with dementia: a National Dementia Strategy
<b>Superseded Docs</b>	Living well with dementia: a National Dementia Strategy - Implementation Plan
<b>Action Required</b>	N/A
<b>Timing</b>	N/A
<b>Contact Details</b>	The National Dementia Strategy Implementation Team Older People & Dementia Branch Department of Health Room 8E25 Quarry House Quarry Hill Leeds LS2 7UE <a href="mailto:dementia.strategy@dh.gsi.gov.uk">dementia.strategy@dh.gsi.gov.uk</a>
<b>For Recipient's Use</b>	

# Quality outcomes for people with dementia: building on the work of the National Dementia Strategy

First published: September 2010

# Contents

Executive Summary .....	5
Introduction .....	7
Section 1: Setting the scene.....	8
Section 2: Improving outcomes .....	11
Section 3: Enablers for change .....	14
Conclusion .....	19
Annex 1: Draft synthesis of outcomes desired by people with dementia and their carers .....	20

# Executive Summary

## Introduction

This document presents the Department of Health's revised, outcomes focused implementation plan for '*Living Well with Dementia – A National Dementia Strategy*'<sup>1</sup>, which is an England only strategy, published in February 2009. It updates the previous implementation plan for the Strategy<sup>2</sup>, which was published in July 2009.

## Purpose

The key purpose of this revised implementation plan is to set out for health and social care localities and their delivery partners:

- the Department of Health's role and its priorities during 2010/11 for supporting local delivery of and local accountability for the implementation of '*Living Well with Dementia – A National Dementia Strategy*' ;
- the Strategy's fit with the new vision for the future of health and social care as set out in the White Paper *Equity and Excellence: Liberating the NHS*<sup>3</sup>; and
- the fit with the consultation document *Liberating the NHS: Transparency in outcomes – a framework for the NHS*<sup>4</sup>.

At the heart of this vision is the Government's commitment to putting patients and the public first; improving health and social care outcomes; ensuring autonomy, accountability, democratic legitimacy and improving efficiency.

In keeping with *Revision to the Operating Framework 2010/11*<sup>5</sup> this implementation plan is not prescriptive. As highlighted in the National Dementia Strategy (the Strategy), the pace of implementation will vary depending on local circumstances and the level and development of services within each NHS and Local Authority area.

## Structure of this document

**Section 1** describes the nature of the challenge, the context and the Department of Health's priorities for securing improvements in dementia care. These priority objectives are integral to the National Dementia Strategy and the report into the over-prescribing of antipsychotic medication<sup>6</sup>. They have been identified as priority objectives because they are likely to result in immediate benefits for people with dementia and their carers if improvements are made and have good prospects for long term viability.

<sup>1</sup> Living well with dementia: A National Dementia Strategy, Department of Health, 3 February 2009

<sup>2</sup> Living well with dementia: A National Dementia Strategy Implementation Plan, Department of Health, 22 July 2009

<sup>3</sup> The NHS White Paper: Equity and Excellence: Liberating the NHS, Department of Health, 12 July 2010

<sup>4</sup> Liberating the NHS: Transparency in outcomes – a framework for the NHS

<sup>5</sup> Revision to the Operating Framework for the NHS in England 2010/11 Department of Health 2010

<sup>6</sup> The use of antipsychotic medication for people with dementia: Time for action - A report for the Minister of State for Care Services by Professor Sube Banerjee, 12 November 2009

These priority objectives are:

- good-quality early diagnosis and intervention for all;
- improved quality of care in general hospitals;
- living well with dementia in care homes; and
- reduced use of antipsychotic medication.

More generally, the improvement of community personal support services is integral to and underpins the four priorities as it supports early intervention, prevents premature admission to care homes and impacts on inappropriate admission to hospital and length of stay.

**Section 2** describes the Department of Health's work in consultation with partner organisations to:

- identify key outcomes, which people with dementia and their carers expect; and,
- to develop specific, measurable indicators across health and social care, which underpin these outcomes.

The work to develop these outcomes and supporting indicators will feed into the consultation on *'Liberating the NHS: Transparency in outcomes'* and the Department of Health's zero-based review of social care data collection.

**Section 3** describes key enablers for change to support local delivery and local accountability for improving quality outcomes for people with dementia and their carers. This includes the revised Operating Framework 2010-11 and work to develop a National Dementia Declaration.

# Introduction

This document presents the Department's revised, outcomes focused implementation plan for *'Living Well with Dementia – A National Dementia Strategy'*, which was published in February 2009. It updates the previous implementation plan for the Strategy, which was published in July 2009.

The key purpose of this revised implementation plan is to set out for health and social care localities and their delivery partners:

- the Department of Health's role and its priorities during 2010/11 for supporting local delivery of and local accountability for the implementation of *'Living Well with Dementia – A National Dementia Strategy'*;
- the Strategy's fit with the new vision for the future of health and care as set out in the White Paper *'Equity and Excellence: Liberating the NHS'*; and
- its fit with the consultation document *'Liberating the NHS: Transparency in outcomes – a framework for the NHS'*.

At the heart of this vision is the Government's commitment to putting patients and the public first; improving health and social care outcomes; ensuring autonomy, accountability and democratic legitimacy and improving efficiency.

This document is not setting priorities for delivery by the NHS, social care or its delivery partners. It does not state what services should be planned, commissioned, provided and delivered. As highlighted in the National Dementia Strategy, the pace of implementation will vary depending on local circumstances and the level and development of services within each NHS and Local Authority area. It describes what the Department of Health considers as its priorities for policy development in its role of enabler for continued progress in improving outcomes for people with dementia and their carers.

# Section 1: Setting the scene

## The issue

Dementia is one of the most important issues we face as the population ages. There are estimated to be over 750,000 people in the UK with dementia and numbers are expected to double in the next thirty years. The term 'dementia' is used to describe a syndrome which may be caused by a number of illnesses in which there is progressive decline in multiple areas of function. Although dementia is primarily a condition associated with older people, there are also a significant number of people (currently around 15,000) who develop dementia earlier in life. Direct costs of dementia to the NHS and Social Care are in the region of £8.2bn annually.

## The context

'*Living well with Dementia – A National Dementia Strategy*' was published in February 2009. It set out a vision for transforming dementia services with the aim of achieving better awareness of dementia, early diagnosis and high quality treatment at whatever stage of the illness and in whatever setting. The Strategy was followed in November 2009 by the publication of a report addressing the over-prescription of antipsychotic medication for people with dementia. Implementation of the 11 recommendations contained within that report is an integral part of improving the care and experience of people with dementia and their carers.

Raising the quality of care for people with dementia and their carers is a major priority under the new Coalition Government. It is necessary to respond to the challenge in the context of a changed political and economic landscape, where the Department's role is more enabling and less directive. The Government has a clear vision about the future. In his speech on "The Big Society" on 19 July 2010 the Prime Minister, David Cameron, described this as:

*'...a huge culture change...where people, in their everyday lives, in their homes, in their neighbourhoods, in their workplace...don't always turn to officials, local authorities or central government for answers to the problems they face ...but instead feel both free and powerful enough to help themselves and their own communities. This means a whole new approach to Government and governing. We've got to get rid of the centralised bureaucracy that wastes money and undermines morale. And in its place we've got to give professionals much more freedom. There are three strands... First, social action.... Second, public service reform. And third, community empowerment... there are three techniques we must use to galvanise them. First, decentralisation. Second, transparency. Third, providing finance...'*<sup>7</sup>

In line with this, the Government is committed to ensuring there is a greater focus on accelerating the pace of improvement in dementia care, through local delivery of quality outcomes and local accountability for achieving them.

<sup>7</sup> <http://www.number10.gov.uk/news/speeches-and-transcripts/2010/07/big-society-speech-53572>



This is a new outcomes-focused approach, a key element of which is ensuring greater transparency and provision of information to individuals. This enables people to have a good understanding of their local services, how these compare to other services, and the level of quality that they can expect.

Local organisations are expected to publish how they are delivering quality outcomes so that local people can hold them to account. This new approach is signalled in 'Revisions to the Operating Framework 2010/11' which states:

*'NHS organisations should be working with partners on implementing the National Dementia Strategy. People with dementia and their families need information that helps them understand their local services, and the level of quality and outcomes that they can expect. PCTs and their partners should publish how they are implementing the National Dementia Strategy to increase local accountability for prioritisation. This is to support a move away from central command to local determination and as such PCTs will not be subject to requirements on how or what they publish, neither will there be any national performance requirements put on them.'*

### **The Department of Health's priorities for policy development**

Since the publication of the National Dementia Strategy and the report into the over-prescription of antipsychotic medicines to people with dementia, the imperative to focus on local accountability and local delivery has been underscored by reports published by the National Audit Office (NAO – January 2010)<sup>8</sup> and the Public Accounts Committee (PAC – March 2010)<sup>9</sup>. In the light of these reports and the new political and economic landscape for delivering for National Dementia Strategy, there is a greater need for the Department of Health to focus on those activities, which will deliver sustainable outcomes, which are likely to have most impact at local level to the lives of people with dementia and carers.

There are four priority areas for the Department of Health's policy development work during 2010/11 to support local delivery of the Strategy. These areas provide a real focus on activities that are likely to have the greatest impact on improving quality outcomes for people with dementia and their carers. It is important to emphasise however that the priorities are enablers for local delivery of the Strategy in full, across all 17 objectives, as well as the work to implement the recommendations of the report in to the over-prescribing of antipsychotic medicines to people with dementia.

---

<sup>8</sup> Improving Dementia Services in England - an Interim Report Report by the Comptroller and Auditor General, National Audit Office, 14 January 2010

<sup>9</sup> Improving Dementia Services in England - An Interim Report, House of Commons: Committee of Public Accounts, 8 March 2010

The four priority areas are:

**Good quality early diagnosis and intervention for all** - Two thirds of people with dementia never receive a diagnosis; the UK is in the bottom third of countries in Europe for diagnosis and treatment of people with dementia; only a third of GPs feel they have adequate training in diagnosis of dementia.

**Improved quality of care in general hospitals** - 40% of people in hospital have dementia; the excess cost is estimated to be £6m per annum in the average General Hospital; co-morbidity with general medical conditions is high, people with dementia stay longer in hospital.

**Living well with dementia in care homes** - Two thirds of people in care homes have dementia; dependency is increasing; over half are poorly occupied; behavioural disturbances are highly prevalent and are often treated with antipsychotic drugs.

**Reduced use of antipsychotic medication** - There are an estimated 180,000 people with dementia on antipsychotic drugs. In only about one third of these cases are the drugs having a beneficial effect and there are 1800 excess deaths per year as a result of their prescription.

More generally the improvement of community personal support services is integral to and underpins each of the four priorities as it supports early intervention; prevents premature admission to care homes and impacts on inappropriate admission to hospital and length of stay.

These priorities do not deflect from work that is underway and continuing in parallel on key aspects of the Strategy such as workforce development, support for carers and provision of information following diagnosis.

## Section 2: Improving outcomes

The White Paper 'Equity and Excellence: Liberating the NHS' states that the current performance regime will be replaced with separate frameworks for outcomes that set direction for the NHS, for public health and social care. These outcomes frameworks will provide for clear and unambiguous accountability, and enable better joint working.

For the NHS, a focused but balanced set of national outcome indicators spanning effectiveness, patient experience and safety will be included in the NHS Outcomes Framework<sup>10</sup>. The primary purpose of the framework will be to focus on the outcomes that the NHS can deliver through the provision of treatment and healthcare. These outcome goals will be determined by the Secretary of State for Health, and used to hold the new NHS Commissioning Board to account for securing improved health outcomes through the commissioning process. The NHS Commissioning Board will be free to determine how these outcomes will be translated into a broader framework covering all NHS funded care, which it will use to hold GP Consortia to account. This will not only provide the public with meaningful information on which to base choices about their healthcare, but enable greater transparency about the quality of health care services.

The first publication of NHS Outcomes Framework for 2011/12 will use, as a starting point, existing outcome indicators for which data is already collected. It will evolve over time and be reviewed annually so that it can accommodate new and better outcome indicators as they become available. There will, of course, be outcomes that can only be delivered for patients and carers if the NHS works in partnership with social care services and the proposed new public health service that will be created. The latter will have an important role in addressing the needs of people with dementia and their carers, within the wider health and wellbeing context in communities. The Department will be constructing and consulting on outcomes frameworks for these sectors in coming months as part of an integrated cross-service approach in the Spending Review.

### **Developing an outcome focused approach for dementia**

The Department of Health is working in consultation with partner organisations to identify key outcomes, which people with dementia and their carers expect. The Department will also be developing specific, measurable indicators across health and social care, which underpin these outcomes, building on existing work such as the 2006 NICE/SCIE guideline, the NICE Quality Standard published in June 2010 and work undertaken by Alzheimer's Society.

---

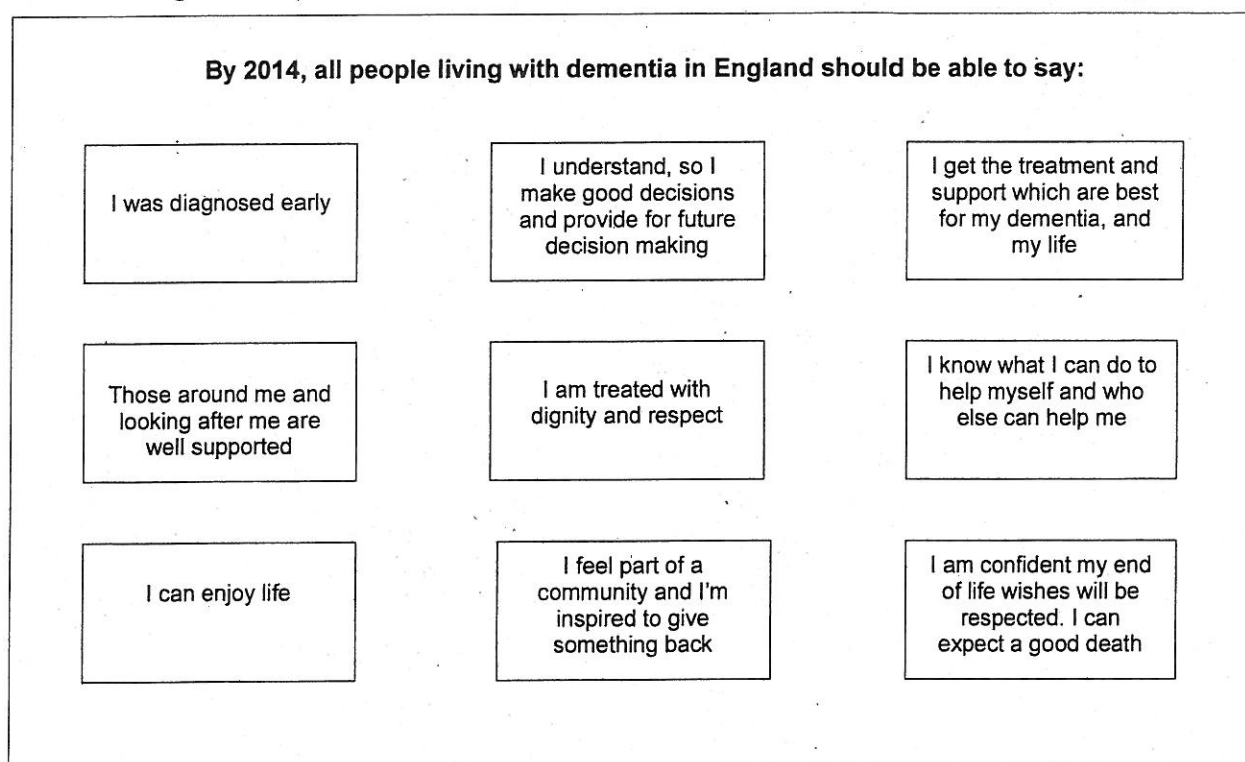
<sup>10</sup> Available at [http://www.dh.gov.uk/en/Consultations/Liveconsultations/DH\\_117583](http://www.dh.gov.uk/en/Consultations/Liveconsultations/DH_117583)

The work to develop these outcomes and supporting indicators will feed in to the consultation on '*Liberating the NHS: Transparency in outcomes-a framework for the NHS*' and the Department of Health's "zero-based review" of social care data collection.

In the context of '*Liberating the NHS: Transparency in outcomes – a framework for the NHS*', health and social care localities and their delivery partners may find the approach signalled in this implementation plan helpful for local planning purposes.

In line with established work in relation to cancer, the following nine statements have been proposed which capture what people with dementia tell us they aspire to in terms of their expectations of health and social care systems.

**Fig 1 Draft synthesis of outcomes desired by people with dementia and their carers**

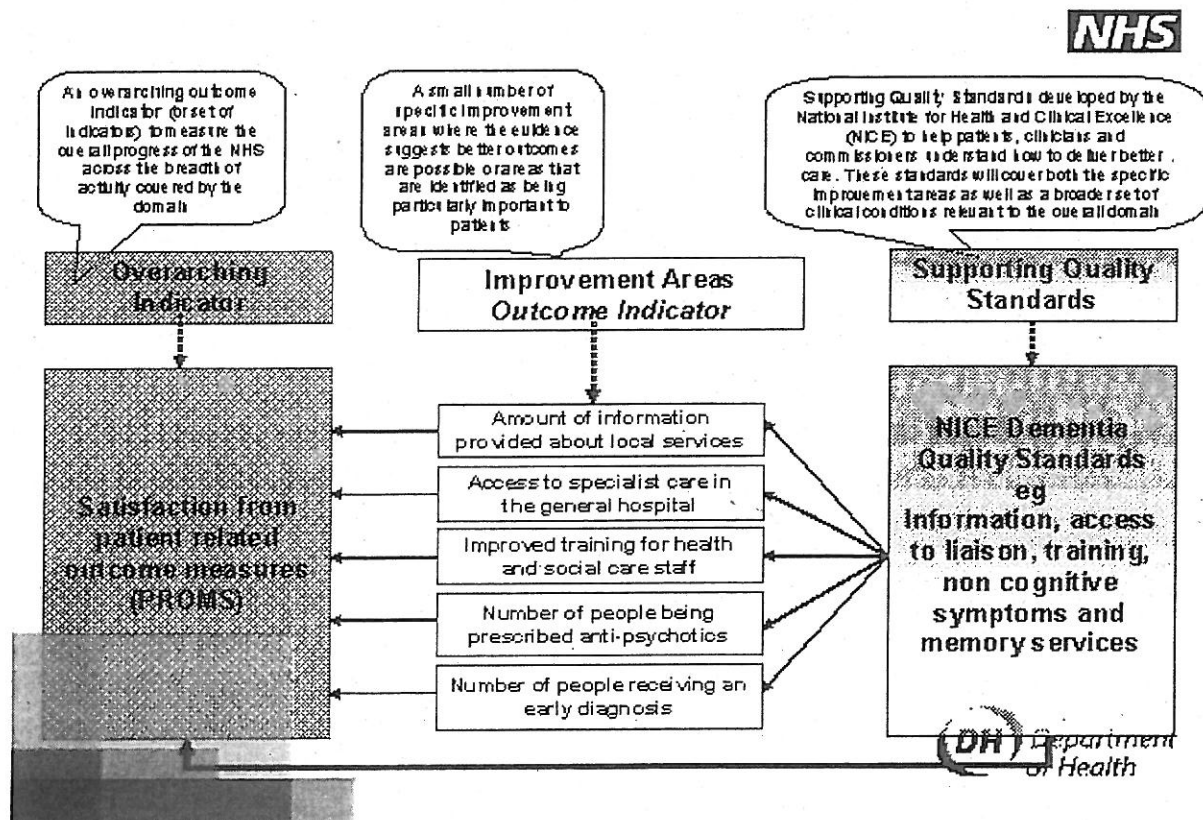


These outcomes will be supplemented by a similar series of specific evidence based statements being developed in partnership with Alzheimer's Society and with people with dementia and their carers. This will include a statement about the importance of research in dementia care, which will provide the necessary incentives to the life sciences industry so that they continuously invest in the research and development of medicines and technologies, and work with the NHS and its partners to improve outcomes in this area.

Annex 1 shows how these statements map onto the National Institute for Health and Clinical Excellence (NICE) Quality Standard for Dementia<sup>11</sup> and to the objectives of the Strategy using an illustrative example, based on the template provided in the consultation for the NHS Outcomes Framework.

(Domain 2 – enhancing quality of life for people with long term conditions) shown in figure 2 below).

**Figure 2: NHS Outcomes Framework: Illustrative example for Dementia in Domain 2 - supporting you (and your carer) managing your long term condition**



<sup>11</sup> The National Institute for Health and Clinical Excellence  
<http://www.nice.org.uk/aboutnice/qualitystandards/dementia/dementiaqualitystandard.jsp>



## Section 3: Enablers for change

In line with the Department of Health's new role, which is more enabling and less directive, this section sets out the key enablers for change. These are aimed at supporting local delivery of and local accountability for achieving quality outcomes in dementia care.

Key enablers for change include:

- **Revision to the NHS Operating Framework 2010-11:** the revised NHS Operating Framework for 2010/11<sup>12</sup> set out that dementia was one of the areas that stood out as not being given sufficient emphasis during the recent sign-off of Strategic Healthcare Authority plans, and set out that NHS organisations should be working with partners on implementing the National Dementia Strategy. These changes will result in more locally relevant information about the quality of local services for use by the public, people with dementia and carers. On dementia the revised Framework states:

*'NHS organisations should be working with partners on implementing the National Dementia Strategy. People with dementia and their families need information that helps them understand their local services, and the level of quality and outcomes that they can expect. Localities should publish how they are implementing the National Dementia Strategy to increase local accountability for prioritisation'.*

- **The appointment of Professor Alistair Burns as the first National Clinical Director (NCD) for Dementia** to promote clinical and professional engagement in the design and management of services. Professor Alistair Burns will work with clinicians, professionals and managers in acute, community, mental health and primary care health services and in social care and the care home sector to support active transformation of these services and to improve health outcomes for people with dementia and their carers. The NCD will provide leadership and support for shaping implementation of the Strategy within the new architecture, working with key partners at a national, regional and local level. For example, supporting engagement with general practitioner commissioning consortia to enable local leadership and continuity of delivery of the Strategy.
- **The NHS National Quality Board (NQB)** has been established by the Department to look at ways in which quality of care can be improved. As part of this work, the NQB is looking at the dementia care pathway and ways to support improved commissioning, workforce capability and better quality data.

<sup>12</sup> Revision to the Operating Framework for the NHS in England 2010/11 Department of Health 2010  
[http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyandGuidance/DH\\_110107](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyandGuidance/DH_110107)

- **The NICE Quality Standard for Dementia** was launched in June 2010. The Quality Standard provides a significant reference point and there is close coherence with the Strategy. It provides specific, concise quality statements, measures and audience descriptors to provide patients and the public, health and social care professionals, commissioners and service providers with definitions of high-quality care. It builds on the 2006 NICE/SCIE guideline, which also has continued relevance<sup>13</sup> and links to related materials such as the memory assessment service commissioning guide. The Department is working with NICE and the Dementia Alignment Sub-group of the National Quality Board to ensure harmonisation of the standards with the Strategy.
- **The appointment of National Dementia Champions:** While overall clinical leadership at a national level is provided by the National Clinical Director for Dementia, he is supported by three high profile national dementia champions for the NHS (Sir Ian Carruthers), the independent sector (Martin Green) and social care (Jenny Owen). The Dementia Champions will focus on an organised programme of activity to:
  - provide leadership at local level;
  - encourage and embed delivery at all levels; and
  - support local accountability.
- **The development of a National Dementia Declaration:** Work to develop a National Dementia Declaration is a sector-wide initiative, which involves a wide range of national organisations. It is led by Alzheimer's Society and supported by the Department of Health. The Declaration will be launched in Autumn 2010, and will be a call to action to improve the quality of life outcomes for people with dementia and their carers. Signatories will publish what they expect to achieve in helping people to live well with dementia and what they will do over the life of the Strategy to 2014, and beyond where possible.
- **Reduction in the use of antipsychotic medication:** The National Clinical Director for dementia is leading the work to implement the recommendations contained within the report into the over-prescribing of antipsychotic medication<sup>14</sup>. The Department has established an Advisory Group including representation from across health, social care, the independent sector and relevant national organisations to inform the project. The first part of this work is to establish and communicate the current position regarding the prescribing of antipsychotic medicines for people with dementia. This work is underway via the NHS Information Centre and the initial results are expected in Autumn 2010.

---

<sup>13</sup> <http://www.nice.org.uk/>

<sup>14</sup> The use of antipsychotic medication for people with dementia: Time for action - A report for the Minister of State for Care Services by Professor Sube Banerjee, 12 November 2009

Localities should publish how they are implementing the National Dementia Strategy: this data will support localities to determine and publish the outcomes they need to deliver locally, taking into account their current position in reducing the use of antipsychotic drugs for people with dementia.

The Department is also collating examples of best practice from around the country where localities have undertaken their own local audits and delivered improved outcomes for people with dementia through reducing the use of antipsychotic medicines. These examples will be disseminated widely via the Department's Dementia Information Portal. The aim is to support local areas to prescribe appropriately with a view to achieving overall a two-thirds reduction in the use of antipsychotic medicines over a period of two years from establishing a baseline position.

- **Workforce:** Skills for Care and Skills for Health have commissioned a scoping study which maps the workforce working with people with dementia and their education and training needs. A second report maps the existing accredited education and training available and gaps in that provision. The Department has established (July 2010) a new Workforce Advisory Group, chaired by the NCD. The Advisory Group will take forward the findings and recommendations from the initial scoping study and gap analysis in a way which supports local autonomy. There will be a move away from a top-down management model led by the Department to support greater local accountability for decisions affecting workforce supply and demand.
- **Research:** The Department provides substantial funding for health research, through the National Institute for Health Research (NIHR) and the Policy Research Programme (PRP). This is available to support high quality research in all areas of health science, including dementia.

Currently, the PRP is funding evaluations of National Dementia Strategy pilots on dementia advisers and peer support networks, on risk guidance in dementia and on the experience of people with dementia in institutional care. Research on predictors of dementia in primary care is ongoing under the NIHR School for Primary Care and five major NIHR Programme Grants (c. £2m each) are supporting work on improving dementia care in the community, hospital and care home settings.

However, it is recognised more generally that the dementia research community needs to find ways to secure a bigger share of the available funding and a Ministerial Advisory Group on Dementia Research has been established to support this. Through the Group, the Department is working with key partners, including the Research Councils, research charities, the pharmaceutical sector, as well as those caring for people living with dementia, to increase the volume, quality and impact of dementia research. The Group is exploring ways to increase the opportunities for people with dementia to take part in high quality research, such as the use of a local dementia register (a list of people who have given prior consent to be contacted about research projects).



- **The Demonstrator Site Programme:** The Department has supported a demonstrator site programme to test models of delivery for the dementia adviser role and peer support networks. The demonstrator sites support Objective 4 (enabling easy access to care, support and advice following diagnosis) and objective 5 (development of structured peer support and learning networks) in the Strategy. Given the importance of the role of carers in supporting people with dementia, there is a close alignment between this work and the National Strategy for Carers '*Carers at the heart of 21<sup>st</sup> century families and communities*'<sup>15</sup>. Forty sites were selected overall. A Project Leads Network meets several times a year to share learning. A research consortium led by Northumbria University is undertaking an independent evaluation.
- **Local action plans:** In the first year of the Strategy (by March 2010); the Department's Deputy Regional Directors for Social Care and their regional teams completed a baseline review of every PCT and Council locality in relation to implementation of priority objectives in the Strategy and supported the development of an action plan by each locality. As an example, West Sussex has developed a comprehensive action plan, which is costed with a timetable for progress. It is available on the Department's Dementia Information Portal<sup>16</sup>.

'Revisions to the NHS Operating Framework 2010-11' states localities should publish how they are implementing the National Dementia Strategy, to increase local accountability for prioritisation.

**National Audit:** During the development of the Strategy, it became apparent that information currently available on dementia services and activity gave an incomplete picture. The data routinely collected by the NHS and Social Care in England predates the Strategy and therefore does not measure its impact fully.

The Department of Health is commissioning the NHS Information Centre to undertake a National Audit of Dementia Services. The audit will collate information, which is already available as well as, subject to Review of Central Returns (ROCR) approval, a limited new data collection. The initial audit findings are expected to be available in autumn 2010.

It is recognised that a National Audit of this kind, which is process based, is unlikely to provide a measure of improved outcomes for people with dementia and their carers.

<sup>15</sup> Carers at the heart of 21<sup>st</sup> century families and communities: a caring system on your side, a life of your own, Department of Health, June 2008

<sup>16</sup> DH Dementia Information Portal  
<http://www.dementia.dh.gov.uk/userLoginRequired/>

It should, however, provide local NHS and social care organisations with a measure of their progress in areas such as the level of diagnosis of dementia, improved care in acute hospitals, expenditure and use of antipsychotic medication.

Localities will be able to use this information to inform the implementation of their local action plans. Over the longer term and as described in section 1 of this implementation plan, localities will be expected to measure and account for their own progress to local people against specific outcomes measures for dementia.

- **Good practice compendium:** The Department is developing a 'Good Practice Compendium', accessible via the Dementia Information Portal, which is aimed at bringing together examples of good practice in improving dementia care from across the regions.

## Conclusion

This implementation plan is the Department's plan for 2010/11 to help drive up quality and improve dementia care services. It reflects a shift in emphasis from structures and processes towards priorities centred around improving outcomes for people with dementia and their carers. In the context of 'Liberating the NHS: Transparency in outcomes – a framework for the NHS', health and social care localities and their delivery partners may find the approach signalled in this implementation plan helpful for local planning.

## Annex 1: Draft synthesis of outcomes desired by people with dementia and their carers

By 2014, all people living with dementia in England should be able to say:

I was diagnosed early

I understand, so I  
make good decisions  
and provide for future  
decision making

I get the treatment and  
support which are best  
for my dementia, and  
my life

Those around me and  
looking after me are  
well supported

I am treated with  
dignity and respect

I know what I can do to  
help myself and who  
else can help me

I feel part of a  
community and I'm  
inspired to give  
something back

I can enjoy life

I am confident my end  
of life wishes will be  
respected. I can  
expect a good death

Quality outcomes for people with dementia: building on the work of the National Dementia Strategy

I was diagnosed early	People will have the information they need to understand the signs and symptoms of dementia. Those concerned about dementia will know where to go for help. The time between people presenting symptoms to a doctor and being diagnosed will be as short as possible for everyone.	2, 3	1, 2
I understand, so I can make good decisions and provide for future decision making	Everyone affected by dementia will get information and support in the format and at the time that best suits them. They will be supported to interpret and act on the information so that they understand their illness and how it will impact on their lives, including any other illnesses they may already have. They will know what treatments are best for them and what the implications are and they will be supported to make good decisions.	3, 5	3, 4, 5
I get the treatment and support which are best for my dementia, and my life	Everyone living with dementia will receive the best dementia treatment and support, no matter who they are or where they live. They will feel that their personal needs have been appropriately assessed and that their treatment and potential consequences of treatment have been well planned and delivered in a coordinated way that is appropriate to their individual needs and preferences. They will be able to exercise personal choice in social care and ongoing support will be of a high quality.	1, 4, 5, 7, 8	2, 6, 8, 9, 10, 11, 13, 18
I am treated with dignity and respect	People living with dementia will report that they are treated with dignity and respect by all those involved throughout their dementia journey. They will also be open about living with dementia without fear of stigma or discrimination. It will be well recognised and understood by the public and professionals that dementia is a condition that increasing numbers of people will live with.	1	1, 13
I know what I can do to help myself and who else can help me	People living with dementia will be supported to self-manage the consequences of dementia and its treatment, to the degree they are able/wish to. They will know where to turn to get the clinical, practical, emotional and financial support they need when and where they need it. They will feel confident that they can practice their faith and spirituality and that others will help them when they need support.	1, 3, 4, 5	3, 4, 5, 6, 13

Quality outcomes for people with dementia: building on the work of the National Dementia Strategy

Those around me and looking after me are well supported	People living with dementia will feel confident that their family, friends and carers have the practical, emotional and financial support they need to lead as normal a life as possible throughout the dementia journey. They will know where to get help when they need it.	3, 4, 6, 10	3, 4, 5, 7
I can enjoy life	People living with dementia will be well supported in all aspects of living with dementia, leaving them confident to lead as full and active life as possible. They will be able to pursue the activities (including work) that allow them to be happy and feel fulfilled while living with dementia.	3, 4	1, 4, 5, 6
I feel part of a community and I'm inspired to give something back	People who have been affected by dementia and others will feel inspired to contribute to the life of their community, including action to improve the lives of others living with dementia. This includes having the opportunity to participate in high quality research.		1, 5, 16
I am confident my end of life wishes will be respected. I can expect a good death	People who are nearing the end of their life will be supported to make decisions that allow them and their families/carers to be prepared for their death. Their care will be well co-ordinated and planned so that they die in the place and in the way that they have chosen.	5, 9	12, 13