

# Independent assessment of improvements in dementia care and support since 2009

Report from the Policy Innovation Research Unit  
and the NIHR School for Social Care Research

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## Executive summary

# Independent assessment of improvements in dementia care and support since 2009

## Objectives

The Department of Health commissioned a team from the London School of Economics and Political Science and the London School of Hygiene and Tropical Medicine to consider progress in dementia care since 2009. We were asked to focus particularly on three areas: improvements in diagnosis and post-diagnostic support, changes in public attitudes, and developments in research. Two major policy documents provide the context: the *National Dementia Strategy 2009*, which is now finished, and the *Prime Minister's Challenge on Dementia 2012*, which superseded it.

Specifically, we were asked to examine the evidence available to address four policy questions:

- What improvements have been made in dementia care and support, for people with dementia and their carers, since 2009?
- What impact might these improvements have had on people with dementia and their carers, and (if evidence is available) on costs and cost-effectiveness?
- What are the gaps and remaining obstacles to delivering against the commitments in the *Prime Minister's Challenge on Dementia*?
- What are the implications of all of the above, both for the priorities for action in the final year of the *Prime Minister's Challenge on Dementia* and for the information needs to monitor future progress?

We conducted a rapid synthesis of routinely available data and national and international research evidence, as well as looking at data likely to be available in the future. Our work therefore included an element of forward looking to feed into and inform the development of a legacy document post 2015.

Evidence is reported under three main heads:

- Improving health and care
- Changing public attitudes
- Harnessing research developments

Under each heading we set out the action and initiatives taken, the improvements achieved since 2009, and the impacts of these initiatives on people with dementia and carers. This was not an evaluation of either the 2009 National Dementia Strategy or the Prime Minister's Challenge and we did not attempt to link trends to specific commitments and actions set out in either the Strategy or the Challenge document.

## Diagnosis and memory services

There remain uncertainties about both the underlying prevalence of dementia and the number of people diagnosed with this condition, and hence ongoing uncertainty about the dementia **diagnosis rate** and how best to calculate it, given available data systems. A new Delphi study reported in September, and provides the best current estimate for the denominator (prevalence); this could provide the basis for future calculations of diagnosis rates. One alternative approach would be to monitor the



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number of people reported by GPs as diagnosed with dementia; using this approach there has been steady improvement of about 7% a year since 2009.

Although there have been difficulties in measurement, there appear to have been increases in diagnosis rate since 2009. Nevertheless, many people with dementia are still **not being diagnosed**. There is therefore a continuing need to improve diagnosis rates and – more importantly – subsequent referrals on to suitable services for post-diagnostic care and support.

There are wide **inter-area variations in diagnosis rate**, linked in part to wide variations in the time taken to provide a diagnostic assessment. We do not know whether variations in diagnosis rate are artefacts arising from data deficiencies or real differences. If it is the latter, we need to understand the extent to which these differences are associated with social, ethnic, economic or geographical characteristics, differences in professional practice or judgment. A recent NHSE report points to local initiatives that appear to push up diagnosis rates, including financial incentives (greater take-up of DES payments by GPs), dementia advisors, better training for health care professionals, advance care planning and access to respite care. We suggest three other influences on diagnosis rate: having sufficient and effective post-diagnostic support (the suggested shortage of which is a key plank in the argument from some quarters for not prioritising the diagnosis rate); evidence from robust research of the benefits of timely diagnosis; and better targeting of efforts in communities with below-average awareness or willingness to refer and/or higher expected prevalence rates.

Provision and use of **memory assessment services** have grown, although it is difficult with available data to be sure precisely what changes have occurred since 2009. Progress on memory service accreditation has been slow. Better information is needed on how best to deliver memory services. Local services will and should respond to local circumstances and be more person-centred, but the wide variations currently seen in staff-mix, methods of clinical assessment and provision of post-diagnostic care are unacceptable if the aim is to equalise access to diagnosis and post-diagnostic support.

Whether there is sufficient capacity in current provision of memory clinics to meet additional referrals is unclear. The growing use of **primary care-led assessment** might have a bearing on this capacity issue.

### Post-diagnostic support

NICE Guidelines and Quality Standards provide a framework for commissioning and delivering post-diagnostic support. Developments since 2009 include emerging models of integrated dementia care, evidence on the effectiveness of specific interventions, and greater attention to end-of-life care. However, there have been reductions in social care expenditure.

**Community navigator**, case or care management, dementia advisor services, or similar ‘brokerage’ approaches can help to coordinate (or ‘integrate’) responses to the care and support preferences and needs of individual people with dementia and their carers. The appropriate model of coordination is likely to need to vary with local circumstances, and to be responsive in some respects to the preferences of individuals. The research evidence on effectiveness is mixed, but common to all such approaches if they are to be effective is a need to designate staff resources and time clearly, and to





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ensure manageable caseloads. Appropriately resourced brokerage has the potential to realise savings from the emergency inpatient admissions or premature care home admissions that might be avoided. Community navigator models may help to address concerns expressed about lower access rates in Black, Asian and Minority Ethnic communities. Each of these possibilities needs evaluating in the English health and social care context, and specifically in the context of needs associated with dementia. Community navigators need to operate within well-coordinated wider systems of health and social care provision, which adds support to wider efforts to promote better **strategic coordination of health and social care** (and other sectors such as housing and disability benefits). The need for greater **integration** of services supporting people with dementia is quite widely recognised, although currently there is little evidence on what works. There are no data on the number or quality of **integrated care plans** for people with dementia, which are surely prerequisites for good post-diagnostic support.

Post-diagnostic support should be built and delivered from a solid platform of evidence of what works. That platform is growing with investment in research on care and support. **Evidence-based interventions** should be more widely available to people who can benefit from them, although too often this does not happen. For example, there is robust evidence that cognitive stimulation therapy (CST) is both effective and cost-effective in mild-to-moderate dementia, yet it is still not offered as widely as it might. It is not clear whether funding difficulties or other factors are constraining roll-out. Clinical and cost-effectiveness evidence on pharmacological interventions is now accumulating, and utilisation (as shown by prescriptions data) has increased rapidly in just a few years.

There is less research evidence to guide delivery of **end-of-life care** or **advance care planning**. Each has attracted recent attention, but further improvements to each could considerably benefit people with dementia and their families, as well as potentially reducing hospital admission rates and unnecessary hospital deaths.

Evaluation is needed of psychosocial and other alternatives or complements to pharmacological management of **challenging behaviour** as there is still little evidence to guide commissioners or providers.

Developing better **support for carers** is surely fundamental for the longer-term affordability of a health and care system. Although there is relatively little robust evidence to inform guidance or commissioning, evidence emerging from recent evaluations such as the START study should be taken into account in planning how best to support family and other carers.

There is evidence that **personal budgets** can improve the lives of many people with social care needs, where those people are eligible for such support, and when held by carers on behalf of people with dementia this form of self-directed support can also be beneficial. Evaluation of personal health budgets, although not for people with dementia, has also shown encouraging results. But many carers are confused about eligibility for personal budgets and direct payments, and have limited understanding about how they can be used. Translating evidence from evaluation into routine practice, and supporting carers to take up available opportunities is clearly needed.

The influences of **social, economic and lifestyle factors** on use, effectiveness and cost-effectiveness of post-diagnostic support arrangements need investigating.



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## Social care spending

Reductions in **social care spending** pose a challenge. Concerns have been expressed that expenditure reductions since 2010-11 are limiting the availability of post-diagnostic services, such as home care to maintain independence, in turn leading to more crisis hospital admissions and care home admissions. Information is needed on the impact of spending reductions specifically on people with dementia and their carers. Analysis of currently available data appears to show that people with dementia may be continuing to receive home care while others (with lower level needs perhaps) are not, with the possibility that the preventive role of home care may be undermined. This is an area that urgently needs further investigation.

In principle, additional **investment in community-based social care** might be funded from health and social care savings. This would need careful use of 'transition resources' – such as those liberated through the Better Care Fund – in order to break the perennial cycle linking under-provision of community services, higher inpatient and care home admissions, hence higher spending in those sectors, and therefore fewer resources to invest in community services.

More generally, there is need to understand the relationships between levels of spending (social care, health care, self-funding) and the **outcomes** for people with dementia and their carers so as to get the biggest impact from necessarily constrained public and private budgets.

## Hospital services

Available statistics do not make it possible to gauge the potential to improve wellbeing through better **inpatient care**, or to reduce expenditure or improve cost-effectiveness by diversion or more rapid discharge. Hospital Episode Statistics on admissions of people with dementia are incomplete and inaccurate, and so the proportion of hospital beds occupied by people with dementia remains unknown.

There have been significant improvements in recognition and **awareness of the needs of people with dementia** in inpatient settings, but further improvements can and should be made, especially as patients move between treatment areas. The recent CQC report on hospitals and care homes pointed to a number of areas of poor care, even if the overall picture was of 'more good care than poor care'. A new National Audit of Dementia planned for 2015 may encourage further improvements.

Most acute hospitals now have a Senior Clinical Lead for dementia, and most have committed to becoming 'dementia-friendly'. However, the proportion of non-acute Trusts acute committed to becoming 'dementia-friendly' is only around one third. Adding an incentive to the CQUIN for having a **dementia care pathway or in-hospital protocols** would potentially bring benefits.

There has been a reduction in **antipsychotic prescribing** for people with dementia among acute hospital inpatients.

Many people with dementia **admitted to acute hospitals** could be supported and treated in their own homes. There is also CQC evidence of much higher rates of hospital admission for people living in care homes with dementia compared to those without dementia. About 40% of inpatient admissions of people with dementia



are for conditions such as urinary tract or respiratory infections, which would be better managed in the community. This requires coordinated local policies between secondary, primary, community, ambulance and social care and their implementation.

## Workforce

There has been considerable progress in health and social care **staff training** through HEE, the Royal Colleges, Skills for Care, Skills for Health, and an overarching Workforce Advisory Group. Nevertheless, more needs to be done to improve training and education curricula. The impacts of e-learning modules and maps for care pathways are not yet known, and evaluation of these initiatives is needed. In addition to traditional training courses and improved routes to gaining qualifications, it might also be useful to encourage effective mentoring, buddying and practical learning programmes. Greater involvement of people with dementia and carers in recruitment and training might also assist.

The proportion of **social care staff** trained in dementia care remains particularly low. Data in this area are also poor. It would be helpful to get better indicators of numbers of staff who have been appropriately trained, as well as better understanding of the effects of training on quality of care (including staff ability and readiness to introduce evidence-based approaches to care and support) and on quality of life for people with dementia and carers.

Some staff turnover is inevitable and probably helpful, but turnover in the long-term care sector has been too high for too long, and is known to undermine care standards. Improving **staff retention** would embed training, support continuity of care, raise care standards, reduce risk of abuse, and thereby improve outcomes. This means addressing terms and conditions of employment, even though – or perhaps *because* – care work may be an attractively flexible option for some people at some career stages.

## Care homes

Evidence from the CQC suggests a mixed picture in terms of quality in care homes, and a need for better understanding of the factors that underpin or inhibit high **quality of care**. Effective self-improvement tools for care homes providing dementia care would assist, perhaps guided by findings in the summer from the pilot of an audit tool. CQC have also suggested that homes specifically registered to provide dementia care may be less well-funded than other homes; it would be important to know whether there are economic drivers behind poorer outcomes.

There are no national data to allow monitoring of the prescribing of **antipsychotic medication** for residents of care homes to manage behavioural symptoms, although evidence from local sources suggests a marked decrease. CQC has called for more focus on managing risk, particularly reducing use of **restraint** in care homes, following high increases in restraint applications, and guidance will be issued soon. Better **routinely collected data on care homes** would help shed light on treatment and care arrangements, care quality and variations therein across the country.



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## Home care

Concerns have been widely expressed about short **home care visits** ('the 15-minute visit'), which limit what even well-trained staff can achieve, while also possibly affecting staff recruitment, retention and morale. The organisational culture of providers and regulatory safeguards are also important for ensuring appropriate care standards, alongside training.

NICE will publish guidelines on home care in July 2015, although for older people in general and not specifically for people with dementia. Research evidence is scarce in this area, but what has been studied is not widely translated into practice. **Reablement** is being emphasised as a component of home care more generally, but there is no evidence on the benefits of this approach specifically for people with dementia.

## Public attitudes

The emphasis placed on improving **awareness about and attitudes towards dementia** through campaigns such as Dementia Friends has reaped benefits. There has been rapid growth in the numbers of individuals (members of the general public, health and social care staff, and others) trained in dementia awareness, and also the numbers of schools, retail and utility providers, financial services organisations, fire and rescue services, transport providers and leisure organisations that have taken steps to become dementia-friendly.

This growth needs to be matched with better evidence on how attitudes have changed and particularly on **the consequences** that have resulted. There is no doubt that greater awareness and more positive attitudes are desirable achievements in their own right, but we also need to know what consequences flow in terms of, for example, referrals for diagnosis, greater involvement of people with dementia in decisions that affect them, patterns of admission to care homes or hospital or, of course, quality of care.

## Research

Finally, we looked at **research** and its potential to inform and guide improvements to health, quality of life and efficiency. There has been a substantial increase in funded research in the dementia field, including research on a wide range of post-diagnostic support services and arrangements.

**Participation in research** by people with dementia and carers has grown, and there has been success through ENRICH in supporting research in the non-NHS sector. The Join Dementia Research campaign is being piloted.

One result has been that the number of UK **publications in the dementia field** grew faster than the numbers in prostate cancer, diabetes, COPD or stroke. There is also evidence that the quality of UK dementia research has improved.

NIHR has appointed the first **National Director for Dementia Research**, reinforcing a commitment to research quantity, excellence and impact.

The **Dementia Summit** initiated by the UK as part of its G8 Presidency focused heavily on what research might achieve and drew commitments from G8 nations.



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### **Priorities and information needs**

We identified a number of priorities for the final year of the Prime Minister's Challenge and many information needs that might be addressed through suitably well-designed research.

### **Funding for this report**

The work that led to this independent report was supported with funding from the DH-supported programme in the Policy Innovation Research Unit and the NIHR School for Social Care Research. The views expressed in this report are those of the authors and may not reflect those of the funders.



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## 1. Background and aims

The Department of Health (DH) commissioned a team from the London School of Economics and Political Science and the London School of Hygiene and Tropical Medicine (as part of the Policy Innovation Research Unit (PIRU) and with support from the NIHR School for Social Care Research) to conduct a review to map data available and to summarise key research evidence on trends in dementia care in England over recent years, particularly since 2009. We were asked to make specific reference to the commitments set out in the *Prime Minister's Challenge on Dementia*, although this was not an evaluation of either the *Prime Minister's Challenge* or the 2009 National Dementia Strategy. The National Dementia Strategy has now ended and the *Prime Minister's Challenge on Dementia* superseded it. We do not attempt to link trends over time (or the absence of them) to specific commitments and actions set out in the Challenge document or the Strategy. We were also asked to use the review and summary as a platform for identifying likely strategic needs and issues for the future. Our work follows a 'Deep Dive' Short Review by the Cabinet Office's Implementation Unit that – by drawing on analyses of national data, interviews with national stakeholders and six locality visits – considered whether the health and care system is on track to deliver the Government's commitments on prevention, diagnosis, referral, treatment and care of dementia.

Our report is intended to inform the final year of the *Prime Minister's Challenge on Dementia*, which is due to complete in March 2015. The assessment will also support current work within the Department of Health to strengthen the key indicator set for measuring progress and impact of the Challenge. Our work therefore included an element of forward looking to feed into and inform the development of a legacy document post 2015.

The Department's interest is in understanding the evidence available that addresses, or is able to inform, the following four **policy questions**:

- What improvements have been made in dementia care and support, for people with dementia and their (family and other unpaid) carers, since 2009?
- What impact might these improvements have had on people with dementia and their carers, and (if evidence is available) on costs and cost-effectiveness?
- What are the gaps and remaining obstacles to delivering against the commitments in the *Prime Minister's Challenge on Dementia*?
- What are the implications of all of the above, both for the priorities for action in the final year of the *Prime Minister's Challenge on Dementia* and for the information needs to monitor future progress?



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## 2. Scope and methods

The project required a rapid synthesis of currently available data and research evidence, an analysis of data and evidence likely to be available in the near future, and identification of remaining gaps in knowledge. We also look forward, drawing out the implications of the analyses for understanding what could be the key strategic issues and policy needs in the future, potentially feeding into and informing the development of a legacy to shape future responses to dementia post 2015.

As agreed with the Department of Health, it was beyond the scope of the project to carry out new or original statistical analyses of data. Rather, it was agreed that the methods for the work would be:

- to identify any sources of 'routine' data and information additional to those already known to DH, including any data that may be extracted from more general (i.e. not dementia-specific) epidemiological or cohort studies, prescribing data, audits (e.g. PPA data on antipsychotics, survey of memory clinics, national dementia audits), particularly to address the first of the policy questions noted earlier on improvements since 2009;
- to identify and summarise relevant research studies that have already been published (or where findings are now emerging), as well as research currently underway that will have findings emerging over the next few years, particularly to inform the second of the policy questions identified above on impacts on outcomes for people with dementia and their carers, and perhaps also on costs;
- to identify key gaps in the 'routine' data and research evidence bases that might make it difficult to monitor change in activities or impacts;
- to draw widely on relevant evidence even where not explicitly dementia-related, and also on relevant international evidence in broadly comparable health and care systems; and
- to identify 'horizon-scanning' evidence and research on likely strategic needs and issues in the future, including information needs.

Research for this report was carried out between November 2013 and April 2014, and completed in early May 2014. Revisions were made up to early October, but it was not possible to provide a complete update on progress in dementia care, research or awareness over the intervening period.

The work resulting in this report was made possible by Policy Research Programme funding for the Policy Innovation Research Unit (PIRU) and National Institute for Health Research (NIHR) funding for the School for Social Care Research (SSCR).



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### **3. Evidence: structure of the report**

The report is structured around the four policy questions noted above. In addressing the first two questions (What improvements have been made in dementia care and support, for people with dementia and their carers, since 2009? What impact might these improvements have had on people with dementia and their carers, and (if evidence is available) on costs and cost-effectiveness?), we have organised the discussion into three main sections: improving health and care (Section 4), changing public attitudes (Section 5), and harnessing research developments (Section 6).

In Section 7 we then turn to the third policy questions: What are the gaps and remaining obstacles to delivering against the commitments in the Prime Minister's Challenge? In Section 8 we address the final question: What are the implications of the work, both for the priorities for action in the final year of the Prime Minister's Challenge and for the information needs to monitor future progress?

In organising the evidence there is no single list of commitments to provide a structure, because the programme has been, and continues to be, evolving. In the Prime Minister's Challenge there are commitments and actions, and some of the latter were subsequently deemed 'commitments' in the first annual report, and some new actions were included. The DH has a set of dementia assurance measures used to monitor progress against what were deemed to be 'high/ medium impact' commitments in the PM Challenge, drawn from the commitments and used to report on progress to the Dementia Progress Review Group. Although this report does not attempt to evaluate progress against these various commitments and actions, they are included for context where they are relevant. In our search for evidence, we have tried to be comprehensive, covering all commitments and actions. Some are harder than others to comment upon with reliable or readily available evidence.

Three areas or themes structure the next three sections of this report:

- Improving health and care
- Changing public attitudes
- Harnessing research developments





## 4. Improving health and care

Under the first theme of improving health and care, it is helpful to summarise evidence on progress under six main heads (noting that there are overlaps between them):

- Diagnosis rates
- Post-diagnostic care and support (for people with dementia)
- Support for carers
- Hospital care
- Workforce development
- Care homes and home care

Under each heading we set out the **action and initiatives** that have already been undertaken (for example, as specified in the NHS Mandate, referred to in Government announcements, included in legislation such as the Care Act (2014), as well as by non-governmental bodies such as Royal Colleges). We then identify evidence of **improvements achieved since 2009**, as well as remaining gaps and challenges, and the **impacts of these initiatives on people with dementia and carers**. In some areas, where it makes sense to do so, we have conflated the second and third subsections.

### 4.1 Diagnosis rates

#### 4.1.1 Action and initiatives

By March 2015, the aim set out in the Prime Minister's Challenge is that two-thirds of people with dementia should have a diagnosis and appropriate support. To encourage an increased rate of diagnosis, several policies have been introduced:

**NHSE programme to support and monitor CCGs:** This includes a Dementia Prevalence Calculator, an Expert Reference Group, commissioning support tools, NICE guidance on dementia diagnosis and assessment, and support to CCGs and general practices to improve the coding of dementia diagnosis.

**Health check:** From April 2013 people aged 65 to 74 will be given information to raise their awareness of dementia and the availability of memory services.

**Directed Enhanced Service (DES):** From April 2013 payment was introduced as part of the GP contract to encourage proactive case finding among those with cardiovascular risk factors, long-term neurological conditions and learning disabilities. The new DES (April 2014) further encourages a proactive approach to timely assessment by requiring a 'more comprehensive care plan for patients diagnosed as having dementia and increase support provided to carers'.

**CQUIN:** From April 2012 hospitals have financial incentive for: assessing in-patients about memory loss, as part of an assessment of delirium, and referral to memory services; ensuring sufficient clinical leadership of dementia and appropriate training of staff; and ensuring carers of people with dementia feel adequately supported.

**Challenge prizes:** From June 2012, there has been a Breakthrough Challenge/ Innovation Challenge prize for ideas for transforming NHS care, aiming to reduce the proportion of patients with undiagnosed dementia.

**Royal College of Psychiatrists Memory Services Accreditation Programme:** Since June 2009 there has been encouragement to memory clinics to participate.



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**Investment in earlier diagnostic assessment:** The Secretary of State announced in February 2014 that NHSE would invest £90 million in pursuit of the target to diagnose two-thirds of people with dementia by March 2015, particularly to work with local areas where diagnostic assessments are slow.

#### 4.1.2 Improvements made since 2009/10

##### 1. Diagnosis rates

The principal indicator of improvement in diagnosis is the proportion of those people with dementia in the population who have been investigated and diagnosed as having dementia (diagnosis rate). This presents two methodological challenges which we discuss: the need for an accurate measure of the numerator (number of people diagnosed) and of the denominator (number in the population with dementia). We then look at the diagnosis rate overall and how it varies between areas.

##### **Numerator**

The best source of data on the number of people diagnosed with dementia comes from primary care. Eligibility to receive payments under the Quality and Outcome Framework (QOF) is an incentive for GPs to establish and maintain a register of patients with a diagnosis of dementia. For each general practice, the number is based on those with a Read code for: dementia in Alzheimer's Disease (Eu00); dementia in Alzheimer's Disease, atypical or mixed type (Eu002); vascular dementia (Eu01); and unspecified dementia (Eu02z). This information can be supplemented by patients in care homes prescribed medications to alleviate the symptoms of dementia even if they do not have an explicit diagnostic code.

Numbers of people diagnosed with dementia from this source may underestimate because of a failure to include people who, despite having been diagnosed as having dementia, are not included in their GP's register. An audit of 23 general practices found 8.8% of people with a diagnosis of dementia were not included in the GP register (Russell et al 2013).

Those not registered with a GP (e.g. many of the homeless population) are unlikely to have had the opportunity to be formally investigated (i.e. referral to a memory service), so non-registration will underestimate both the numerator and denominator, resulting in little impact on the diagnosis rate.

According to QOF, since 2008/09 the number of patients with dementia in England has risen 37% from 232,430 to 319,000 in 2012/13. The latter figure is broadly consistent with the findings of a national audit carried out in 2011 which suggested 313,000 people have been diagnosed with dementia (National Dementia & Antipsychotic Prescribing Audit).

Given the issue of under-inclusion in GP registers mentioned above, it is likely that the reported number of people with dementia underestimates the true number of people diagnosed with dementia. On the limited information available and assuming 10% under-inclusion, the number diagnosed in 2012/13 would be boosted to 351,000, though such a correction would not necessarily have an impact on trends over time as under-reporting could affect all recent years.

##### **Denominator**

###### *Definition of dementia*

The key challenge in determining the prevalence of dementia is the definition of the condition, given that there is a continuum running from healthy ageing to a pre-symptomatic phase to mild cognitive impairment (MCI) to dementia.



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Diagnosis is based on an overall assessment (usually made by a multi-disciplinary team) that takes into account the person's history, the results of cognitive function tests (such as the Mini Mental State Examination) and clinical investigations such as a brain scan.

Explicit criteria for diagnosing dementia exist, the leading one being the American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders (DSM). The latest version (DSM-V) was published in 2013 and covers not only all forms of dementia but also MCI, on the grounds that treatments with certain medications and approaches may possibly only work early in the disease course. DSM-V attempts an objective distinction between MCI and dementia: MCI requires modest cognitive decline ('minor neuro-cognitive disorder') which does not interfere with capacity for independence in everyday activities; dementia ('major neuro-cognitive disorder') requires impairment that interferes with a person's independence to the point that assistance is required. In other words, the diagnostic distinction relies heavily on observable behaviour. Inevitably such distinctions increase the opportunity for variation in professional judgment determining the diagnosis of dementia. In addition, concerns have been expressed that there is a risk of 'medicalising' people who may gain no benefit and that some of those supporting a widening of the inclusion criteria have conflicts of interest through their involvement with the pharmaceutical industry. These developments increase the challenge of reaching a consensus on the prevalence of dementia.

#### *Estimates of prevalence in England*

Since 2007, the estimate of the number of people with dementia has been derived from a consensus view of an expert group convened as part of the Dementia UK study (Knapp et al 2007) that considered the six high quality British surveys available at that time (Brayne and Calloway 1989; Clarke et al 1991; Livingston et al 1990; MRC CFAS 1998; O'Connor et al 1989; Saunders et al 1993). These surveys had been conducted in the 1980s and early 1990s and were dominated by the largest and most rigorous one, Cognitive Functioning and Ageing Studies (CFAS I) funded by the Medical Research Council. Given the variation in estimates between the different studies, in 2007 a Delphi survey was conducted; this is a formal method for developing a consensus when uncertainty and variation in opinions exist. This resulted in an agreed view that 574,000 people in England had dementia, and this figure was subsequently used in official reports and documents up until 2012. In CFAS I, diagnosis was based on the use of a diagnostic algorithm that used data on the person's history and the results of the Geriatric Mental State Examination.

It should be noted that an alternative estimate of 720,000 appeared in 2011 but this was based on applying survey findings from many European countries to the England population (ALCOVE 2011). For the UK as a whole, a figure of 820,000 was suggested for 2010 (Luengo-Fernandez et al 2010).

In 2012, a new estimate was published, based on a survey carried out in England in 2008-11, as part of a repeat of CFAS, referred to as CFAS II (Matthews et al 2013). This suggested that the number was 670,000 which, given the increase in the population aged 65 and over since CFAS I in 1991, actually represented a decrease in age-adjusted prevalence from 8.3% to 6.5%. However, the new survey (CFAS II) achieved a response rate of only 56% compared to 80% in CFAS I. Although Matthews et al have suggested that response bias was negligible (based on the reasons for non-participation reported by the field interviewers), it seems plausible that non-responders would be more likely to have dementia than responders. There



is evidence from the NHS GP Patient Survey that those with dementia are less likely to respond in surveys than older people with other long-term conditions. Whereas the expected number of people with other long-term conditions (such as diabetes, COPD, arthritis) respond, the number of people with dementia responding represents only about 25% of the number expected (although this is a mailed questionnaire unlike the use of interviewers in CFAS). If the likelihood of people with dementia not responding in CFAS II was 50% higher than for those without dementia, for example, the estimated number of people with dementia in England would be 797,000 rather than 670,000. If the likelihood was twice as high the estimate would be 882,000.

Despite some questioning of the conclusion that the true prevalence of dementia has fallen over the past two decades, there is support for this notion from several other studies in the USA, Netherlands, Sweden and Denmark (Larson et al 2013). For example, a Danish study found prevalence was lower in those aged in their 90s for a cohort born in 1915 than for a cohort born in 1905 (Christensen et al 2013). Explanations include better education levels, greater economic wellbeing and reductions in vascular risk factors. These improvements could be jeopardised in the future by increasing prevalence of obesity and diabetes.<sup>1</sup>

The Alzheimer's Society commissioned a new Delphi exercise, led by Martin Prince (KCL) to consider prevalence rates, and new estimates of the total cost of dementia led by Martin Knapp (LSE). Overview findings from this study were reported in September. The new Delphi-based figures suggest that total age-standardised population prevalence of dementia among people aged 65 years and older is 7.1% (based on 2013 data). Given this estimated rate of prevalence, there will be 850,000 people with dementia in the UK in 2015 (Prince et al 2014). This number includes more than 40,000 people aged under 65 with early-onset dementia. The estimated number of people with dementia in England is 686,000.

The associated estimates of the cost of dementia in the UK show that total cost amounted to £26.3 billion (averaging £32,250 per person), of which £4.3 billion is NHS costs, £10.3 billion is spent on social care (publicly and privately funded), and £11.6 billion is the estimated value of the contributions by unpaid carers.

### **Estimated diagnosis rates**

Although there is uncertainty about both the numerator and denominator, the possible impact of the latter is much greater. For example, if the denominator in 2012/13 is 670,000, as the *Dementia: State of the Nation* report (DH 2013) suggested, then the diagnosis rate that year was 47.6%. Or if the denominator is 654,000 – which is the estimate used by the DH to date, based on the prevalence rate in the 2007 Dementia UK report applied to ONS mid-year population estimates for 2012 – then the diagnosis rate was 48.7%. However, if the true denominator was 797,000, the rate would be only 40.0%, and if the denominator is 882,000 then the rate would be 36.2%. If the numerator is underestimated by about 10% (which is plausible for the reasons mentioned above), the rates rise to 52.4%, 44.0% and 39.8% respectively. The resultant possible range of estimates is summarised in Table 1.

The difficulties are compounded when trying to make historical comparisons. In 2009, the National Dementia Strategy (DH 2009) stated that the number of people with dementia was 570,000, meaning a diagnosis rate that year of 43.6%. In other words, it is possible to conclude that from 2009/10 to 2012/13 the diagnosis rate may have increased, decreased or remained unchanged.

<sup>1</sup> Two other potential sources of data on the prevalence of dementia are too unreliable to use: deaths from dementia, which increased dramatically from 2009 to 2012, rising by 108% in men (6709 to 13984) and by 88% in women (15909 to 29873), largely reflecting changing fashion in attribution of cause of death rather than changes in real prevalence (ONS 2009, 2012); and the English Longitudinal Survey of Ageing (ELSA), but this does not identify those diagnosed with dementia (IFS).



**Table 1 Estimates of diagnosis rate in 2012/13 according to possible numerators and denominators based on CFAS II**

Denominator	Numerator	
	319 000	351 000
654,000	48.7%	53.7%
670,000	47.6%	52.4%
797,000	40.0%	44.0%
882,000	36.2%	39.8%

In view of these difficulties there are two possible approaches to monitoring progress in increasing the detection of those with dementia. One approach would be simply to monitor the *number* of those that GPs report as having been diagnosed with dementia, and to avoid trying to derive a diagnosis rate. Consideration of the former clearly shows steady improvement of about 7% a year since 2009, as shown in Table 2 (QOF 2009, 2010, 2011, 2012).

**Table 2 Number of people reported by GPs as diagnosed with dementia, and annual increase, 2008/09 to 2012/13**

	2008/09	2009/10	2010/11	2011/12	2012/13
Number of patients registered	232,430	249,463	266,697	293,738	317,000
Annual increase (%)	–	7.3	6.9	10.1	7.9

The second approach would be to achieve a consensus as to the prevalence of dementia in several age-specific groups (e.g. below 65 years, 65-74 years; 75-84 years; 85 and above years) in 2009/10 and then, assuming there is no change in the age-specific incidences of the disease over time, calculate the population prevalence for each subsequent year (i.e. allowing for demographic change). This would provide a stable denominator for annual diagnosis rates based on a transparent assumption. If the incidence is indeed falling, then the estimates of diagnosis rates will be a slight underestimate.

Given that some of the policies to enhance diagnostic rates only started in April 2013 (GP Health Check; Directed Enhanced Service; information for local commissioning), the rate of improvement may now accelerate from 2013/14.

#### **Area variation in diagnosis rates**

It has been reported that diagnosis rates vary across England. In 2012/13 the rate varied for Clinical Commissioning Group (CCG) areas from 39% to 75% (DH 2013). These proportions are based on the number of people diagnosed according to the GP QOF data divided by an estimate of local population prevalence. The latter appear to be derived using the Dementia Prevalence Calculator (<http://dementiapartnerships.com/diagnosis/dementia-prevalence-calculator>) which applies age-sex specific prevalence rates from the Dementia UK report (Knapp et al 2007) to PCT populations, weighted for the number of care home places in the area.



The map of diagnosis rates by CCG displayed in the *State of the Nation* report does not reveal any obvious associations with area factors, but it might be helpful to analyse the CCG rates to see if there are any significant associations with factors such as urban/rural, level of deprivation or provision of GPs. A recent report from NHS England (2014), based on visits to a sample of CCGs, sought to identify the characteristics associated with 'making great progress in improving dementia diagnosis rates'. Quoting from the report these were:

- the local health and care community has a coherent, focused, and clearly led plan of work to improve dementia care;
- commissioning and clinical leaders are active and visible in this pursuit, knowledgeable about what works, and proactively delivering a comprehensive strategy and action plan; working relationships are positive, and it appears that values and ambitions are shared;
- work is proactive, systematic and sustained, rather than reactive and piecemeal;
- dementia care is being mainstreamed within existing health and care services, rather than being framed as something associated with memory services alone;
- ambitions to improve diagnosis are being progressed within the wider context of raising awareness about dementia; improving knowledge and skills of health and care staff; understanding the role of primary care in dementia care, including care of patients living in care homes;
- the voluntary and community sector is a key partner both in terms of strategic planning and as a provider; development of the voluntary and community sector as a provider, and investment in this sector are key components of local dementia strategies.

The report went on to note that 'The CCGs which had made greatest improvement were able to describe a range of interventions applied across their health and care system. These include:

- high levels of Enhanced Service for Dementia (DES) amongst GPs; data cleansing and monitoring of performance;
- commissioning dementia advisor services to support timely diagnosis and post diagnostic support;
- health care professional training;
- carer training;
- advance care planning;
- access to respite care.'

Any quantitative analysis of diagnosis rates by CCG should try to explore some of these possible influences identified during the NHSE visits.

As well as variations between areas, there have also been suggestions that there are variations *within* areas, for example between ethnic groups, although evidence remains sparse.

## **2. Provision and use of memory assessment services (MASs)**

Although two national audits of memory clinics (2008-11, 2013) have been conducted it is, unfortunately, difficult to determine what changes have occurred between the two (HSCIC 2011; Royal College of Psychiatrists 2013). This is because the two audits adopted different designs – the first was focused on PCT populations, the second focused on clinic providers (and clinic attenders irrespective of their PCT) – and sought different information. Both audits were restricted to Memory and Assessment Services (MASs) run by secondary care providers such as Mental Health Trusts.





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They did not include memory assessment undertaken in primary care. (A further audit was commissioned by the DH from the Royal College of Psychiatrists, with results due autumn 2014.)

The first audit failed to identify the number of unique clinics/services in England, so it is not possible to determine what change there has been in provision since 2009/10. The figure of 337 in 2011/12 was a measure of the number of contracts that PCTs had with Memory Assessment Services, so did not take into account that more than one PCT used any given clinic/service, resulting in multiple counting of the same clinic.

The consequence of different foci in the two audits (PCTs versus clinics) means the findings cannot be compared. For example, we know the mean expenditure by PCTs in 2009/10 (£551,000), but in 2013 we know the mean income of a clinic (£625,000). In terms of numbers attending and being assessed, in 2009/10 the mean by PCT was 767 while in 2013 the mean number assessed in a clinic was 543.

Our knowledge of secular trends is therefore limited to comparing 2009/10 and 2010/11 reported in the first audit. That showed that mean PCT spend rose from £552,000 to £593,000, and the mean number of patient attendances for a PCT rose from 767 to 951. Although no information is available on the change in waiting time for a first appointment, the MASs reported that in 2012 the mean wait was 5.17 weeks, with 91% seeing referrals within 8 weeks.

Some information on the use of memory advisory services is available from the Mental Health Minimum Data Set (MHMDS). This reports that in 2012/13, 350,906 people attended memory services run by secondary care providers. (In addition, 33 816 people with young onset dementia received other services.) The number attending memory services will include new incident cases plus known cases (diagnosed in preceding years) receiving post-diagnostic support and care. It will not include the increasing number of people who receive memory services from primary care providers.

Progress on memory service accreditation, led by the Royal College of Psychiatrists, has been slow. By April 2014, 91 of the 214 memory services across England are members of the accreditation programme, and 56 have so far been accredited for diagnosis and assessment (including 34 as 'excellent'). Twenty-one have been accredited for psychosocial interventions (9 as excellent). We can only speculate on the reasons for slow progress: scepticism as to the value of accreditation, the cost of joining the accreditation scheme (reduced in April 2014 to £1900+VAT), and no obvious benefits to the MAS or the staff.

By 2014 it is apparent that the pattern of services for initial assessment of people who may have dementia is changing in ways that will have implications for future monitoring of progress. Starting with a primary care assessment service established in Newbury, Berkshire in 2003, our brief enquiries have identified memory assessment being run by primary care in several other areas including South Staffordshire & Shropshire, South Gloucestershire, Bristol and the Wirral. Although they differ slightly in their organisation and how patients are managed, they all offer integrated care with the local secondary care MAS. They are run by GPs with a special interest in dementia who have access to specialist services such as brain imaging and can prescribe anti-dementia drugs. While there is still the option of referring patients to secondary care, the development of primary care services will inevitably reduce the proportion of patients referred, with obvious financial implications for MASs run by secondary care providers.



The other consequence of the development of integrated care for memory assessment is that the numbers of people being seen in secondary care MASs will no longer provide a meaningful indicator of progress in improving the diagnostic rate. Increasingly, people with dementia will be diagnosed in primary care without recourse to secondary care. Thus the most useful indicator will be the number of patients on GPs registers with a diagnosis of dementia, regardless of where they were diagnosed.

Work by Manthorpe et al (2011) in three localities showed that few people with dementia experienced the system of memory assessment as person-centred, with waiting times often long and unexplained, and tests and assessments sometimes distressing or confusing.

#### **4.1.3 Impacts of these initiatives on people with dementia and their carers**

Justification of the policy of increasing the proportion of people with dementia being investigated and diagnosed is that there are benefits to them, their carers and to society. The following benefits have been suggested for diagnosis (e.g. see Burns and Buckman 2013 for the British Medical Association and NHS England):

- facilitates timely intervention and treatment resulting in better outcomes
- ensures comorbidity is recognised and treated
- ensures people with dementia and carers are aware of appropriate services and support which might extend independent living
- provides advice and support (including financial) to people with dementia and carers
- provides information on prognosis and expectations
- enables people with dementia to make long-term plans including advance care planning for end of life care
- increases awareness of dementia among other clinicians
- provides opportunity to participate in research studies
- can help to reduce stigma about dementia.

Given the lack of quantitative data on any measurable benefit of being diagnosed (e.g. improvement in quality of life of people with dementia or carers), it is impossible to quantify the overall benefit of an increase in the diagnosis rate. Some of these putative benefits are inevitably based only on qualitative evidence from individual people with dementia and carers; a systematic review by Werner et al (2013) discusses evidence since 2000 and some of the arguments. They found that the approach to disclosure of the diagnosis to people with dementia and their carers had evolved over time in which initial attention as to the ethics of 'truth telling' turned to concern about the opinions of clinicians about 'truth telling', and then more recently to examination of how this truth telling is delivered.

Diagnosis rates could perhaps be improved by continuing to promote population awareness of the signs of dementia; raising awareness and knowledge of GPs and hospital doctors, and also of relevant social care and housing professionals (in community and residential settings); increasing awareness among the public and professionals as to the benefits of timely diagnosis; improving information to the general public about locally available services; improving access to and quality of post-diagnostic support; and continuing to provide appropriate financial incentives.

Some of these benefits could be assessed using rigorous quantitative methods. If current research on developing means of measuring the quality of life of people with dementia and their carers proves successful, it will be possible to identify the benefits





from diagnosis and short-term interventions (discussed below in Section 4.2). Currently, evidence of the effectiveness and cost-effectiveness of diagnosis is very limited. What is known is considered in the next section on ‘Post-diagnostic care and support’.

## 4.2 Post-diagnostic care and support

### 4.2.1 Action and initiatives

Commitments and initiatives concerning post-diagnostic support are much more diverse than those for diagnosis. Post-diagnostic support is referred to in various places in the Dementia Strategy and the Prime Minister’s Challenge, and emphasised in almost all subsequent announcements. The Prime Minister’s Challenge, as well as the NHSE Mandate, made a commitment that two-thirds of people with dementia would receive a diagnosis and appropriate support by March 2015. The Prime Minister’s Challenge, in the section headed ‘Driving Improvements in Health and Care’, covered regular checks for those aged over 65, financial rewards for hospitals offering quality dementia care, a challenge prize for innovative ideas transforming dementia care, a compact signed by care homes and home care providers, and promotion of local information on dementia services. Appendix A to the Prime Minister’s Challenge (‘List of Actions’) also included a guarantee of a written integrated personalised care plan for people with dementia. The National Dementia Strategy discussed different aspects of post-diagnostic support, although focused its recommendations on joined-up planning and commissioning of services, care management and coordination, and effective interventions for people with dementia exhibiting challenging behaviour.

The NICE guideline, *Dementia: Supporting people with dementia and their carers in health and social care: Clinical guidelines CG42* (NICE, 2006, and updated subsequently), which preceded the Dementia Strategy and Prime Minister’s Challenge, addresses post-diagnostic support for people with dementia and their carers. It was updated in 2007, 2011 and 2012 following developments in the evidence base for pharmacological treatments (e.g. see NICE technology appraisal guidance 217, 2011) and again in 2014 to clarify the guidance on imaging. It covers principles of care, stating that care should be person-centred, facilitate informed decision-making and should actively involve carers. It also promotes ‘coordinated’ care, to include a combined care plan agreed by health and social care services with an assigned member of health or social care staff, and regular reviews. Additionally, it promotes support for carers (including respite care, psychosocial interventions and psychological therapies) as well as a wide range of interventions that may benefit people with dementia (including pharmacological treatment, cognitive stimulation therapy and other activities and therapies).

Two sets of NICE dementia quality standards have also been introduced, QS1 and QS30, published in 2010 and 2013 respectively. QS30, the most recent quality standard, applies to all social care settings and services working with and caring for people with dementia. It consists of ten statements of quality, covering:

- being able to discuss concerns about possible dementia
- choice and control in decisions
- reviewing needs and preferences
- leisure activities of interest and choice
- maintaining and developing relationships
- physical and mental health and wellbeing
- design and adaptation of accommodation



- planning and evaluating services
- independent advocacy
- involvement and contribution to the community.

Users of the standards are instructed that QS30 is to be interpreted in the context of QS1, which consists of ten quality statements for health and social care staff in direct contact with people with dementia in hospital, community, home-based, group care, residential or specialist care settings. These cover:

- appropriately trained staff
- memory assessment services
- written and verbal information
- assessment and personalized care plan
- decision-making (including advance care planning)
- emotional, social and psychological needs of carers
- non-cognitive symptoms and behaviour that challenges
- liaison services
- palliative care needs
- respite services for carers.

Following the independent review of the use of the Liverpool Care Pathway for the dying patient in 2013 and the subsequent announcement of its phasing-out (to be replaced with individual care planning), reference to the Liverpool Care Pathway has been removed from this quality standard. Both sets of quality standards are non-mandatory, open to local adaptation and there is no central data collection. There were arrangements planned for uploading data from local audits against these standards to a national database to facilitate local benchmarking, involving a HQIP managed system called CAKE (clinical audit knowledge exchange). However, the project was not completed due to technical and funding difficulties. Consequently, the only nationally available data relating to these standards are a small number of isolated 'examples' of initiatives, uploaded by local service organisations to the NICE website.<sup>2</sup>

Actions designed to promote effective post-diagnostic care and support have been of various kinds; they include the following:

- NICE commissioning guidance on dementia care was produced in 2013. This set out advice for commissioners for improving the integration of health and social care services and for achieving the outcomes set out in the clinical commissioning group (CCG) outcomes indicator set and other national health and social care outcomes frameworks.
- A number of Strategic Clinical Networks (SCNs) were established in 2013. Hosted by NHSE and covering 12 defined geographical areas, these Networks aimed to support commissioners of services, including for mental health, dementia and neurological conditions.
- The NHS Innovation Challenge Prize for Dementia was awarded, in 2013, to Memory First, a consortium of 162 GPs across 41 practices in Staffordshire delivering a GP-based, comprehensive memory clinic providing diagnosis and case-managed post-diagnostic care. Two other entries were highly commended: a dementia pilot in Plymouth which helped to halve the number of hospital admissions and enabled more people to be treated in or close to their own homes; and a dementia 'one-stop-shop' in the West Midlands which cut the length of nursing home stays for people with dementia with complex needs by an average of 10 months. (See below for more information on this and other local initiatives.)

<sup>2</sup> [www.nice.org.uk/using-guidance/shared-learning/implementing-nice-guidance/examples-of-implementation/examples-of-implementation.jsp](http://www.nice.org.uk/using-guidance/shared-learning/implementing-nice-guidance/examples-of-implementation/examples-of-implementation.jsp)



- The UK Home Care Association (UKHCA) produced its *Dementia Strategy and Plan (2013)* to support homecare providers to deliver high-quality dementia care services and ensure a well-trained, competent workforce (see Section 4.5 below on social care workforce).
- The DH funded 40 demonstrator sites to assess the effectiveness of Dementia Advisers and Peer Support Networks (2013); these have been evaluated (see below).
- The DH and the Homes and Communities Agency (and GLA for London-based schemes) committed up to £300m over five years to encourage local authorities to build effective partnerships with housing associations and private house-builders, in order to develop innovative housing solutions for people with long term conditions, including dementia.
- A number of actions following the National End of Life Strategy (2008) have been taken to improve end-of-life care for people with dementia, including a number of publications. In 2010, the NHS National End of Life Care Programme published *Care towards the end of life for people with dementia an online resource guide*. In 2012, the National Council for Palliative Care (NCPC) published guidance for professionals in all settings and informal carers on managing pain and distress for people with dementia approaching the end of life called *How would I know? What can I do?* (2012). NCPC also developed a training DVD for GPs called *Time to Talk, Doc?* (2013), to support GPs to initiate and continue conversations about end-of-life care with people affected by dementia. A requirement has been introduced into the GP Contract (as part of Directed Enhanced Services) to offer advance care planning to everyone diagnosed with dementia from 2014.

There has been a lack of consensus and, indeed, some scepticism, concerning what is appropriate in terms of post-diagnostic support. One view holds that there is no treatment or response that can reduce mortality or morbidity (e.g. UK National Screening Committee on Dementia, 2009). There are others who believe interventions can make a difference but who have concerns that such interventions will not be widely available in practice. Such views have led some to challenge the Government's emphasis on diagnosis, particularly in the early stages of the disease (e.g. Brayne et al., 2013). Those taking this position are concerned about raising unrealistic expectations among patients about what can be done and diverting attention and resources away from those who are already diagnosed (e.g. Brooker et al 2014). However, others have insisted that it is not true that 'nothing can be done', pointing to a priori arguments about people's right to know and to be able to plan for the future, and to some promising and emerging evidence for a range of dementia interventions (e.g. Burns and Buckman 2013).

In response, the Government recognised the need for a more comprehensive and integrated approach to post-diagnostic support. Earlier in the year, the Department of Health, NHSE, PHE, LGA, the Alzheimer's Society, the Dementia Action Alliance, NHS Improving Quality, NHS Choices and ADASS have been working closely together to inform the work on high quality care and support for people with dementia and their carers. The work, led by DH with support from a working group of key stakeholders, aims to:

- make clear 'what good looks like' in terms of post-diagnosis care,
- improve understanding of the level of care currently available,
- understand the support local commissioners need, and
- enable clearer expectations for patients and carers.



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Informed by this work, the Secretary of State announced in February 2014:

- investment of £90 million by NHSE to improve diagnosis rates;
- a named, accountable GP for every person over 75;
- an enhanced service for the most vulnerable 2% of older people in each GP practice, including same-day telephone consultations and proactive case management (Proactive Care Programme – Avoiding Unplanned Admissions);
- a new portal delivered via the NHS Choices website for people diagnosed with dementia and their carers to help them identify essential support and advice in the early stages of their condition;
- £3.8 billion in the Better Care Fund, available to local authorities and the NHS to work together and with the voluntary sector. It is expected that some of this will be used to improve care for people with dementia (e.g. dementia advisors, reminiscence services and counselling services).

These measures make relevant links to a range of national policy initiatives promoting integrated care more generally, such as:

- the Transforming Primary Care initiative, whose sub-title ‘Safe proactive, personalised care for those who need it most’ describes its aims, and which gives a great deal of emphasis to dementia
- initiatives for better shared information between health and social care (e.g. development of Care.data and Care Episode Statistics, to be piloted in somewhere between 100 and 500 GP surgeries in autumn 2014)
- personal budgets for social care and health
- a new duty (section 3, Care Act, 2014) on local authorities to promote integrated care, mirroring the duties on NHS bodies in the Health and Social Care Act 2012.

The Department of Health also plans, in 2014, to work with NICE to look at ways to improve the dementia indicators in the Quality and Outcomes Framework (QOF) for GPs (including the percentage of patients with dementia with the contact details of a named carer on their record), and also to scope a cost-benefit analysis of post-diagnostic support.

#### **4.2.2 Improvements made since 2009/10, and impacts on people with dementia and carers**

The actions described in the previous subsection demonstrate the Government’s commitment and renewed focus on post-diagnostic support for people with dementia, including a range of policies, initiatives and actions aimed at improving the availability and quality of dementia care, and emerging work on developing a comprehensive and integrated package of high quality care and support for people with dementia and their carers.

Alongside these developments, we report on four areas in which changes (although not necessarily progress) can be identified since 2009, either in practice on the ground or in available evidence of effectiveness. These are:

- changes to social care expenditure,
- emerging models of integrated dementia care,
- evidence of effectiveness for specific dementia interventions, and
- evidence on end-of-life care.



## 1. Changes to social care expenditure and provision

Although publicly funded social care accounts for only a small part of the total sector – with self-funded and unpaid care both being substantial – reductions in local authority expenditure will have an impact on levels of care and support. The National Audit Office (2014) report on adult social care in England notes that ‘local authorities’ total spending on adult social care fell 8 per cent in real terms between 2010-11 and 2012-13 and is projected to continue falling’ (p.7). In consequence, there have been significant reductions in community-based social care services, especially for older people. For example, Fernandez et al (2013) found:

- In 2012/13 there were 31% fewer older people receiving state-supported care than in 2005/06 (39% fewer after adjusting for socio-demographic factors). Reductions in the number of older people were greater than reductions for other user groups.
- Overall (at 2012/13 prices) there was a reduction of £890 million in levels of net local authority social care expenditure between 2005/6 and 2012/13 (just over £1.6 billion after adjusting for socio-demographic factors).
- In 2005/06, 59% of councils covered only ‘substantial’ or ‘critical’ needs, but this proportion had grown to 76% in 2009/10 and 80% in 2012/13. The Government plans to introduce a national minimum Fair Access to Care Services (FACS) eligibility threshold of ‘substantial needs’ in 2015, which could bring further changes.

There is, as acknowledged in the ‘deep dive’ report (Implementation Unit, 2013), limited robust information about how these changes in expenditure may have affected people with dementia or their carers.

We looked at the Referrals, Assessments and Packages of Care (RAP) data published by the Health and Social Care Information Centre. People with dementia appear to have been less affected by reductions in social care spending, both in community-based social care and residential/nursing care, compared to those with other mental health and, particularly, physical health-related needs, although our analyses have not taken into account any underlying changes in demography, context or demand.

- In 2008/09 there were 38,435 people aged 65 and over with dementia-related support needs receiving community-based social care services; by 2012/13 this had apparently increased by 15.5% to 44,380. It has been suggested to us that the RAP data on which these calculations are based under-report the numbers of people with dementia; this is because some people may have physical disability as their ‘primary need for care’ and each individual may appear in only one ‘primary client type’. What we do not know, however, is whether under-reporting was a lot higher in 2008/09 than four years later. We return to the broader question of data quality later.
- In contrast, in 2008/09 there were 93,190 people receiving care with mental health-related support needs; by 2012/13 this had *fallen* by almost 10% to 84,185.
- The greatest reductions were seen amongst those with physical health-related needs; in 2008/09 there were 1,015,975 people with physical health-related needs receiving social care, and this had fallen by around 30% to 711,730 by 2012/13.

There could be various explanations for these trends. One is a change over time in the under-reporting of dementia. Another possibility is that, as eligibility for social care has narrowed, those most affected by social care expenditure reductions are people with (relatively) lower needs and who, perhaps, are less likely to have dementia. This is consistent with the analyses by Fernandez et al (2013) which showed that the biggest reductions in service provision have affected people in the community rather than in care homes. There may also have been more people presenting to local authority social care



services with dementia, perhaps associated with increases in diagnosis rates. There may also be methodological reasons underlying the figures; for example, where someone has more than one eligible condition, assessors may now be more likely to assign dementia as the primary condition, perhaps because of changes in local policy or raised awareness of dementia. Of course, without further investigation, these are just hypotheses.

We do not know whether reductions in local authority support for non-critical/substantial cases have had the effect of limiting the preventive role of home care, with the result that support might arrive too late (and/or is too little), which in turn might have an impact on care home admission rates. This is clearly an area needing further investigation.

Within the community-based services category, there were changes in the numbers of *people with dementia* aged 65 and over receiving a range of services over the same period (2008/09 to 2012/13):

- home care users increased from 20,075 to 24,740 (+23%)
- day care users fell from 13,040 to 12,275 (-6%)
- meals service users fell from 4,865 to 3,335 (-31%)
- short-term residential care (not respite) users increased from 4,530 to 6,270 (+38%)
- direct payments users increased from 1,850 to 5,830 (+215%)
- professional support (e.g. therapy or counselling) users fell from 12,530 to 5,880 (-53%)
- equipment and adaptations users increased from 8,185 to 12,005 (+47%).

We find similar trends if we look at the number of people in receipt of eligible residential and nursing home care.

- The numbers of people aged 65 and over with dementia in receipt of eligible residential care increased from 22,025 in 2008/09 to 31,295 in 2012/13 (+42%). For all service users aged 65 and over (i.e. not just those with dementia), this figure fell from 172,980 to 164,220 (-5%).
- Similarly, the numbers of people aged 65 and over with dementia in receipt of eligible nursing care increased from 10,685 to 13,865 (+30%) over the period, while for all service users aged 65 and over (i.e. not just those with dementia), the figure fell from 87,490 to 78,925 (-10%).

The RAP dataset does not provide information on the frequency, duration or quality of social care provision, and so it is not possible to examine trends over time. In 2014-2015, RAP will be replaced with the Short And Long Term support data collection (SALT), which should provide better data (as we describe in Appendix A, section 16). One of the new 'Primary Support Reason' categories will be 'Support with memory and cognition'. Service recipients may also be assigned to one or more reported health conditions, one of which is 'Mental health condition: dementia'.

## 2. Emerging models of integrated dementia care

In this section we discuss the evolving evidence on integrated care for people with long-term conditions – and for people with dementia in particular – as well as emerging examples of integrated dementia care that have developed over the period since 2009.

### **Service coordination and integration in dementia care**

The National Dementia Strategy (p.67) stresses the need for joint commissioning strategies, while NICE dementia guidance (CG42, p.20) promotes coordination and shared care planning between health and social care, citing *Everybody's business. Integrated mental health services for older adults: a service development guide* (Department of Health, 2005) as appropriate guidance in these matters. However,





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as noted above, service arrangements for delivering post-diagnostic care are not covered in any detail in the Prime Minister's Challenge. However, as we have already discussed, emerging policy on post diagnosis support has links to initiatives designed to promote integrated care more generally.

Notwithstanding its importance in policy generally, there is currently limited available evidence on the effectiveness of integrated care. The Local Government Association says in a review of evidence about integrated care in general (not specifically in dementia care): 'There is a paucity of robust systematic reviews or peer-reviewed articles providing quantitative evidence, particularly of cost-effectiveness, in integrated care' (LGA, 2013, p.14). The evidence that does exist is primarily based on case studies; for example, Goodwin et al (2014) offer some international examples, although not specifically focused on dementia, and focus on barriers and 'good practice' principles. (See below for dementia examples.) Because dementia is a complex, long-term condition, integrated care is likely to be particularly beneficial, and so the absence of evidence is unfortunate.

At a national level, there is limited evidence of any improvements in service coordination and integration for people with dementia since 2009. We describe three examples below, but it is only possible in these cases because local experience has been written up. As reported in the 'deep dive' report (Implementation Unit, 2013), there is no available national information on the number or quality of integrated care plans for people with dementia, and such plans could be seen as minimal requirements for integration more broadly. It is also unclear how far integration has been prioritised locally. For example, a recent King's Fund survey of Health and Wellbeing Boards found that most have not identified integrated care as a priority (King's Fund, 2013).

### ***Dementia advisors, dementia navigators, case management***

There is growing interest in the role of case/care managers, dementia navigators or similar 'brokers' to help coordinate services and support involvement in decision-making by people with dementia and their carers. For example, the role of a case manager, care navigator or similar is highlighted as important in helping to ensure continuity of care in Memory Service National Accreditation Programme standards (Doncaster et al 2012, p.9).

Some reviews of case management approaches have been inconclusive (e.g. Pimouguet et al 2010). However, there have been at least two more recent reviews of the evidence that have reached more positive conclusions. In a systematic review of trials of case management for dementia, as well as selected non-trial studies and economic evaluations, Koch et al (2012) concluded that the definition of case management varied considerably across studies, and argued that it would be unjustified from the available evidence to conclude that case management was ineffective in the care of people with dementia. Furthermore, Koch et al. noted promising evidence (e.g. delays to care home entry, reduced carer stress) in studies with long follow-up periods. There would appear to be a need here for more focused research, exploring different models of case management and identifying the populations that may benefit most (Koch et al 2012; Challis et al 2010).

In another systematic review, covering a range of conditions and not just dementia, drawing on evidence from six randomised trials (each meeting PRISMA criteria), Somme et al (2012) concluded that case management can be effective for improving quality of care, patient and carer quality of life, satisfaction and compliance with recommendations.



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However, results for rates of hospitalization and institutionalization were less clear and case management was found to be not necessarily cost-saving. Somme et al (2012) also concluded that the factors that most influenced the effectiveness of case management, in those areas where it was found to be effective, were:

- the intensity of the case management intervention (using caseload as a proxy indicator), and
- the integration level of the system in which the case manager works: better integration was associated with greater effectiveness (although, we note that the better integrated the system, the less pressing the need for case management may be).

We were given early sight of a forthcoming Cochrane Review by Reilly et al (2014). Although this review awaits final sign-off, its conclusions from the international literature suggest that case management reduces the likelihood of institutionalisation (which we interpret in the terms of our model as admission to a care home), although the findings over successive time periods are not unambiguous. Reilly et al (2014) do not find evidence of significant quality of life benefits for people with dementia or for carers.

Evidence on case management approaches in the UK, even for general populations of people with long-term conditions, is very limited. Goodman et al (2010), in a study of nurse-based case management, emphasised the importance of context, concluding that there is a need for appropriate integration of case management within a multi-disciplinary context and with other primary care-based initiatives. It also identified case management as resource-intensive. However, the study also concluded that nurse case managers with an appropriate mandate can act as a force for integration, continuity of care and effective collaboration between very disparate professional groups and organisations.

In an evaluation of the first year of the North West London Integrated Care pilot, some benefits were identified for dementia patients, including increased identification of dementia and more care plans provided. In general, patients reported less time spent booking appointments with GPs and health professionals, and being asked fewer questions about their medical history, but there was no evidence of reduced hospital admissions (Nuffield Trust and Imperial College London, 2013).

Dementia Advisor services (e.g. as provided by Alzheimer's Society and Age UK) provide another mechanism for helping to 'join-up' local services. Based in community premises (memory clinics, primary care clinics or local charity centres), they offer advice, support and signposting. These services are accessed by professional referral or self-referral, and are estimated to cost around £400 per person annually (Alzheimer's Society 2009). The *Healthbridge* report (Department of Health, 2013a) found people were satisfied with Dementia Advisor services, and that such services could help 'fill a gap in support for people with dementia and carers'. It also identified potential 'resource-saving implications for the local health and social care economy' (although these are described narratively). However, the report identifies that 'in some areas service boundaries and remits were unclear, with consequent tensions' (p.7).

In conclusion, then, there is some promising but mixed evidence in favour of case-managed approaches for people with long-term conditions, including people with dementia. However, the evidence suggests that their effectiveness is likely to depend on manageable caseloads, adequate dedicated time and a minimum level of existing service integration. Similar conclusions are reflected in findings from the CARE-DEM study (see below).





### ***New emerging integrated/collaborative models of dementia care***

A number of local examples of integrated dementia care have emerged since 2009. These examples vary considerably in their design but include the following:<sup>3</sup>

- Gnosall's primary-care based, case managed 'Memory First' service, which won an NHS innovation challenge fund award of £80,000 (see [www.england.nhs.uk/challengeprizes/winners/mem-first](http://www.england.nhs.uk/challengeprizes/winners/mem-first)).
- Oxleas' advanced dementia service to help those with advanced dementia be cared for and die at home, highlighted by the Kings Fund as a good practice example of integrated health and social care ([www.kingsfund.org.uk/publications/oxleas-advanced-dementia-service](http://www.kingsfund.org.uk/publications/oxleas-advanced-dementia-service)).
- Manchester Health and Social Care Trust, which offers carers' assessments, and memory training groups, carers' support groups, and post diagnostic support (PDS) groups led by Admiral Nurses. [www.health.org.uk/publications/dementia-care/case-studies](http://www.health.org.uk/publications/dementia-care/case-studies).

Early findings from such examples are encouraging, but existing evidence of effectiveness is local and largely based on case study evidence. There is a clear need for robust evaluation of such models, both in terms of effectiveness and cost-effectiveness. However, robust evaluation requires the tracking of long-term outcomes (such as rates of decline in cognition and functionality, or delays to care home admission; factors that are also likely to drive costs). Such tracking may, however, be complicated by changes on the ground in how services are delivered over the period of the evaluation, requiring complex research designs to secure robust evidence on effectiveness. These initiatives are also diverse, reflecting varied local opportunities and circumstances, and so it would be important to pay particular attention to the question of transferability if such models were to be considered for wider adoption. This similarly applies to models that have been implemented in other countries. There is also a risk that local funding or workforce pressures may encourage attempts to roll-out successful service models in 'diluted' ways, rather than to replicate the model in its proven form.

An example is provided by the CARE-DEM project that aimed to replicate the US-based Collaborative Care Management (PREVENT) model in the UK. The PREVENT model involves an interdisciplinary team led by an advanced practice nurse integrated within primary care. The nurse works closely with caregivers and uses standard protocols (with a focus on non-pharmacological management) to initiate treatment and identify, monitor, and treat behavioural and psychological symptoms of dementia. A well-conducted evaluation of the approach found significant improvement in the quality of care and in symptoms for people with dementia and their unpaid carers (Callahan et al 2006). The PREVENT model is also the 'standardized care' intervention being used in a major National Institute of Aging-funded trial of dementia screening in the US, due to report in 2016.

In CARE-DEM ([www.kcl.ac.uk/sspp/kpi/scwru/pubs/2013/conf/10oct13.ppt](http://www.kcl.ac.uk/sspp/kpi/scwru/pubs/2013/conf/10oct13.ppt)) the project team found it difficult to recruit GP surgeries and, within GP surgeries, then to identify patients with dementia. Consequently, it took six months to recruit only 28 patient-carer dyads into the study. Problems with implementing a model of care based on the US PREVENT approach in the UK context also included:

- case management time not ring-fenced or dedicated and 'only 1 in 4 practices achieved levels of case management activity likely to impact on outcomes';
- poor integration with existing services and difficulties embedding the approach in primary care; and
- evidence of a high threshold for acting on unmet need.

<sup>3</sup> Other examples include: Integrated Care Pioneers, Leeds Community Networks, Bradford Dementia Cafes, Dorset. Examples from Tower Hamlets and Norfolk are provided in the State of the Nation report. See also 'relevant projects' at the end of this link <http://dementiapartnerships.com/improving-care-through-a-joined-up-approach>.



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### **Minority ethnic communities and dementia navigators**

The Prime Minister's Challenge makes little reference to the needs of Black, Asian and minority ethnic groups and, indeed, there is little evidence on the use or impact of dementia services specifically for people from these communities. However, it has been suggested that there may be different needs and considerations in delivering high quality dementia care to these groups. For example, the Race Equality Foundation suggests that there may be higher estimated dementia prevalence in some minority ethnic groups, because, for example, Black African-Caribbean communities have higher cardio-vascular risk (Truswell, 2013). A recent report from the All-Party Parliamentary Group (APPG) on Dementia (2013) suggested that prevalence in BAME communities could increase as much as seven-fold in the period to 2051, compared to perhaps a two-fold increase for the UK population as a whole.

The report from Truswell (2013) identified culturally specific expectations and values in some ethnic groups as potential barriers to effective care and support (see also the narrative systematic review by Sun et al 2012). This point is emphasised by the APPG, and has prompted the Alzheimer's Society to launch an initiative to provide culturally tailored information to South Asian communities to raise awareness and improve rates of access. SCIE (2011a) also describe a range of approaches to tailoring dementia services for ethnically diverse service users and report a range of successful local projects, such as day care projects in Bradford (Azam et al 2007) and in Kent (St John et al 2004), and an advocacy project in Westminster (Westminster Advocacy Service for Senior Residents/Dementia Advocacy Network, 2009). Truswell (2013) provides examples of good practice interventions, generally implemented in areas with high minority ethnic populations, and also discusses the needs of non-black minority ethnic groups (e.g. Irish and Jewish communities). The report proposes community health service navigators for some minority ethnic communities, following examples for other health care services in the US described by Rush (2012) and Jackson (2013). These navigators 'would be fluent in the community language of the person they are supporting and have lived knowledge of their cultural background' (p.9).

### **3. Evidence on effectiveness for specific dementia interventions**

There is growing evidence concerning the effectiveness of a range of psychosocial interventions for people with dementia (MacLaren et al 2013), some of which are recommended in NICE Guidelines (2006, updated in 2011 to include revised technology assessment guidance on drugs for Alzheimer's disease). Some of the new evidence base is summarised in the sections below. What we do not generally know, however, is the volume, nature or quality of these therapies as currently provided in England, nor whether provision has grown since 2009.

#### **Cognitive stimulation therapy (CST)**

There is good evidence that cognitive stimulation therapy (CST) has benefits for cognition in people with mild-to-moderate dementia over and above any medication effects, as well as improvements in self-reported quality of life and wellbeing. These conclusions come from a Cochrane review (Woods et al 2012), and were reinforced by a subsequent systematic review and meta-analysis of 15 RCTs, which also suggested improvements in staff-rated communication and social interaction, but found no differences in mood, activities of daily living or challenging behaviour (Aguirre et al 2012). Longer-term (maintenance) CST also appears to have significant cognition and quality of life effects, as well as cost-effectiveness advantages (Orrell et al 2014; D'Amico et al 2014).

Activities such as walking groups and singing for the brain are cognitively stimulating and may have beneficial effects, although evidence is so far modest.



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### **Other psychosocial therapies**

Cognitive rehabilitation therapy (CRT) has shown promise in pilot studies and is now being examined in a full trial (the GREAT study) led by Linda Clare, Bangor University – conducted across both Welsh and English sites – which is due to report in 2015.

A small, NIHR-funded pilot study of people with both dementia and anxiety found that cognitive behavioural therapy (delivered in up to ten sessions to the person with dementia and their carer) led to a significant reduction in depression symptoms (though not for anxiety) over 15 weeks (Spector et al 2014). CBT was cost-neutral.

Reviews of various therapies for people with dementia commonly find that there are no high-quality studies. However, evidence from smaller studies suggests that some therapies show promise in terms of impact on quality of life and potential to reduce agitation, at least in the short-term. These include: music therapy (Beard et al 2012); massage/ aromatherapy (Fung et al 2012; Moyle et al 2013); animal therapy (Filan et al 2006); exercise (Cochrane review: Forbes et al 2012; Potter et al 2011; also new evidence emerging suggesting cost-effectiveness too); and reminiscence therapy (Cochrane Review: Woods et al 2005; systematic review: Blake et al 2013).

There is also some positive emerging evidence for non-pharmacological approaches for managing challenging behaviour. Challenging behaviour is a common symptom of dementia, particularly in its later stages, with agitation occurring in about 50% of people with moderate or severe dementia. Robust evaluation is still needed on alternatives to traditional pharmacological management (which is frequently ineffective and can have side-effects; Banerjee, 2009). In a Cochrane review, Moniz-Cook et al (2012) found promising but inconclusive results for functional analysis, which attempts to manage agitation and behaviour that challenges by exploring the meaning or purpose of an individual's behaviour. Another Cochrane Review found evidence across four RCTs of decreased antipsychotic drug use as a result of educational approaches for nursing staff/multidisciplinary teams in psychosocial approaches for managing agitation and behaviour that challenges (Richter et al 2012). Further research in this area is in progress, such as the recently started NIHR/ESRC-funded MARQUE study led by Gill Livingston at UCL. It aims to develop, test and implement manuals to train staff in ways to reduce agitation and improve quality of life in care homes and for people with dementia who are approaching the end of their lives. An NIHR-funded review led by Daksha Trivedi (University of Hertfordshire) is currently looking at effective management of behavioural and psychological symptoms of dementia (BPSD) for people with dementia living at home and their carers, and is due to report soon.

### **Pharmacological interventions**

Evidence on the clinical benefits of the main pharmacological interventions for dementia (anticholinesterase inhibitors, galantamine, donepezil and rivastigmine, as well as memantine) has been well summarised in the technology appraisals underpinning NICE guidance in 2006 and 2011 (CG42) (Bond et al 2012). New studies continue to shed further light on the area (e.g. the DOMINO study of the effectiveness and cost-effectiveness of continuation of treatment with donepezil and memantine into more severe stages of dementia; Howard et al 2012; Knapp et al 2014).

The prescribing of medications to alleviate the symptoms of dementia has increased over the past few years. In 2010 there were 1.437 million items prescribed (Ilyas and Moncrieff 2012) in England but this had risen by 45% to 2.079 million by 2012 (HSCIC 2013).



As with the NICE guidance, the following Cochrane reviews also set out positive clinical evidence for these treatments:

- donepezil for vascular cognitive impairment (Malouf and Birks 2004)
- donepezil for Alzheimer's (Birks and Harvey 2006)
- cholinesterase inhibitors for Alzheimer's (Birks 2006)
- cholinesterase inhibitors for Parkinson's disease dementia/ Lewy Body/ cognitive impairment in Parkinson's disease (Rolinski et al 2012)
- cholinesterase inhibitors for Parkinson's disease (Maidment et al 2008)
- galantamine for Alzheimer's and MCI (Loy and Schneider 2005)
- memantine (McShane et al 2009)
- rivastigmine for Alzheimer's disease (Birks et al 2009).

NICE technology appraisals and Cochrane reviews note caveats about much of the evidence, including the short duration of trials, small effect sizes, the severity of dementia for which medications are effective, and insufficient attention paid to potential adverse effects.

There is some evidence on treatment of people with comorbid dementia and depression with antidepressants; this shows that sertraline and mirtazapine are no more effective than placebo in treating the comorbid depression, although there may be a cost-effectiveness case for mirtazapine treatment because it improves sleep patterns and reduces the burden on family carers (Banerjee et al 2011; Romeo et al 2013).

#### 4. End-of-life care

Although end-of-life care does not feature in the Prime Minister's Challenge it is an area being progressed through the Health and Care Champion Group and it is recognised as an important aspect of dementia care in the 'deep dive' report (Implementation Unit, 2013). Thirty per cent of people over age 60 will die with dementia (Brayne et al 2006), commonly with comorbidities and with communication difficulties, making symptom management more complicated.

National actions on end-of-life care have included the production of NICE *Commissioning Guidance on End of Life Care for People with Dementia* (2010) and a new requirement being introduced into the Directed Enhanced Service (DES) from 2014 to offer an advance care planning discussion to everyone diagnosed with the condition. However, there is as yet little evidence on the impact of these measures. Other than place of death, no national data are collected specifically about end-of-life care for people with dementia (National End of Life Care Intelligence Network report, 2013).

Advance care planning has particular relevance in dementia care, as patients are likely to lack capacity by the time they reach end of life (Mental Capacity Act, 2005). Empirical evidence on advance care planning is mostly from the US and has been difficult to interpret in a UK context because research studies differ in terms of interventions, advance care planning processes, service contexts and populations, as well as system context of course. Evidence on advance care planning specifically in the UK remains very limited. Robinson et al (2011), in a qualitative study with professionals in dementia care, patients/service users and carers, found that advance care planning was generally not routinely integrated into dementia services. They found that, contrary to guidance, advance care planning discussions often occur late in the illness, with subsequent proxy decision-making. They also noted that professionals find such discussions challenging, with the additional difficulties in dementia around assessment of capacity and legal dilemmas. A study by Baker



et al (2012), although not dementia-specific, has been cited in recent discussions: it considered an advance planning initiative augmented by intensive community support. The cost of additional staffing for the initiative was £125,000 (primarily for costs associated with the additional community-based support), but savings achieved from reduced hospitalization associated with the initiative were equivalent to £144,000. While cost savings from the initiative were relatively modest, there were likely to have been benefits associated with the delivery of more appropriate care, better aligned with people's preferences. The study draws attention to the need for adequate community services to support people's preferred place of care and death, and to avoid unnecessary hospitalization at end of life. Kinley et al (2014) undertook a study of 2,444 residents dying in UK nursing homes, 48% of whom had dementia. They found a high level of inappropriate hospital admissions alongside limited input from external health care providers during the last 6 months of life. They concluded that inappropriate admissions may be reduced by increasing the medical care provision to nursing care home residents and medical support to staff.

### 4.3 Support for carers

#### 4.3.1 Action and initiatives

The Prime Minister's Challenge recognised that 'Research shows that carers of people with dementia experience greater strain and distress than carers of other older people. We want to see better support for carers' (p.10). In particular, it encourages the NHS to ensure that psychological therapies are commissioned and made available to carers of people with dementia in line with NICE/SCIE guidelines, as well as to ensure that services are made available to support a couple's relationship where one person is caring for their partner with dementia.

Since 2009 there have been a number of actions and initiatives taken in relation to carers. These include:

**CQUIN for carers:** See CQUIN for 2013/14 (see above).

**Respite funding:** Additional £400m to the NHS between 2011 and 2015 to provide carers with breaks from their caring responsibilities to support them in their roles.

**Assessment/personal budgets:** Carers have the right to be assessed and their needs met. In addition, carers can take their support as a personal budget. Provision within the Care Act (section 20, 2014) includes a new duty on local authorities to meet carers' eligible needs for support. This is supported by a DH commitment to make an extra £175 million available to councils to meet additional costs of improving both assessment and support for carers. (The earlier IBSEN evaluation of 'individual budgets' offered encouraging evidence that personal budgets (social care) held by carers, either on behalf of people who use social care services or on their own behalf, can be helpful. However, this research was not specifically focused on people with dementia. Moreover, not all people with dementia will of course be eligible for personal budgets on grounds of financial means or needs.)

**Information:** The Care Act (section 4.1, 2014) requires that local authorities 'establish and maintain a service for providing people in its area with information and advice relating to care and support for adults and support for carers'.



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### 4.3.2 Improvements made since 2009/10, and impacts on people with dementia and carers

There is evidence from recent studies and reviews that shows benefits for carers from some support and respite arrangements:

- A Cochrane Review by Vernooij-Dassen et al (2011) shows that cognitive reframing – a key element of cognitive behavioural therapy – for carers of people with dementia can reduce anxiety, depression and stress, although there was no evidence that it affected carers' coping or sense of being burdened.
- The START (STrAtegies for Relatives) trial found that coping strategies taught to carers by psychology graduates without clinical qualifications (although with clinical psychologist supervision) had a significant effect on carer depression after 8 months and was cost-effective (Livingston et al 2013; Knapp et al 2013). Encouragingly, the positive effects on carers and the system-wide cost-effectiveness persisted to the 24-month follow-up point (Livingston et al 2014). There were also positive impacts on health and wellbeing of people with dementia, their use of services and the costs of their treatment and support. Results from the uniquely long-term (9.4 years) evaluation of a carer support intervention, conducted by Mittleman et al (2006) could be relevant here, although the study was conducted in New York City. Mittleman and colleagues found that improving carer wellbeing delayed nursing home admission for people with dementia.
- Although good quality respite care is valued by carers, there is limited evidence on its effectiveness. One Cochrane review was inconclusive (Maayan et al 2008), although an earlier systematic review (Arksey et al 2004) and Cochrane Review (Lee and Cameron 2004) were more positive about effectiveness and cost-effectiveness. An evidence review covering 76 international studies published between 1990 and 2012 identified a number of factors related to the relatively low take-up of respite services by carers of people with dementia (Neville et al 2014). These included lack of, or confusing, information about services and limited referrals, as well as personal factors associated with carers not recognising or accepting the need for respite, and feelings of guilt. They found that, although users of services generally report high levels of satisfaction, some studies have found that some carers are reluctant to use services because of concerns about quality. Studies also show that while some carers report positive outcomes for people with dementia such as health assessments and enjoyable stimulation, some carers were concerned about it worsening behavioural issues. Overall, Neville and colleagues conclude that the evidence can be contradictory and difficult to interpret because of the considerable heterogeneity in the characteristics and circumstances of people with dementia and their carers, and the types and design of services, as well as in research design and outcomes measured.
- A study by Kirkley et al (2011) that looked at person-centred respite care for people with dementia concluded that this approach is 'not strongly embedded in the organisational cultures of all local providers of respite-care and short-break services'.
- The 'deep dive' report (Implementation Unit, 2013) suggested that there may be a link between reduced social care spending and fewer carers of people with dementia reporting that they are satisfied with services (in the Personal Social Services Survey of Adult Carers in England (PSSSACE): the figure was 83% in 2009/10 but fell to 76% in 2012/2013. A study of PSSSACE data led by Linda Pickard and colleagues at PSSRU, LSE explored the relationship between social care service receipt (e.g. home care, meals, day care) and carers' employment status. It found an association that gives support to the hypothesis that services for the cared-for person are effective in supporting carers' employment (Pickard et al 2015).





## 4.4 Hospital care

### 4.4.1 Action and initiatives

*CQUIN:* From April 2012 the Dementia CQUIN introduced financial incentives for three aspects of care: identification of patients with dementia on admission; assessment of all patients for dementia or other causes of cognitive impairment; referral on discharge for follow-up investigation and care.

*Dementia Action Alliance:* Creation of 'dementia-friendly' NHS acute trusts committed to becoming dementia friendly, working in partnership with their local Dementia Action Alliance.

*Intermediate care guidance:* Guidance from DH (July 2009) on the need for intermediate care to be accessible for people with dementia.

### 4.4.2 Improvements made since 2009/10

#### 1. Identification of patients with dementia on admission

According to HES, of approximately 15 million hospital admissions in 2012/13, about 474,000 admissions (3.1%) were people with dementia, with dementia the primary reason for admission in 46,000 (0.3%). The figure of 474,000 was calculated based on a review of their current and any previous admissions in the past five years. Of the 474,000 admissions, the proportion for whom their dementia was recorded in the current admission was about 78% (2012/13 Q4). This was a small improvement on 2009/10 Q1 when the proportion was 74%.

The under-recording of long-term conditions in routine administrative data is certainly not unique to dementia. For example, according to HES, only 27% of patients undergoing hip replacement in England have any comorbidity, yet 78% report such conditions when asked themselves. Similarly, a recent study of diabetes in Scotland found the condition was not reported in 42% of hospital admissions (Anwar et al 2010). The observed improvement in recording for dementia (from 74% to 78%) may be a response to the introduction of CQUIN or may reflect a general underlying improvement in comorbidity recording in HES.

#### 2. Proportion of hospital beds occupied by people with dementia

If only 3.1% of admissions are people with dementia, the claim that about 25% of hospital beds are occupied by people with dementia (for example, in *State of the Nation*) is surprising. It would suggest that either the true proportion of people admitted who have dementia is considerably higher than the estimate of 3.1% according to HES, or that 25% occupancy is an over-estimate. The latter figure has been cited in official reports for several years, and appears to be based on two small studies:

- One was a study of 731 patients admitted to two Leeds hospitals in the late 1990s for fractured hips whose cognitive function was assessed during their first five post-operative days following a general anaesthetic. Dementia was diagnosed in 40% (Holmes & House 2000).
- The other was a study of 617 emergency medical admissions in people aged 70 years or older at the Royal Free Hospital in 2007. The sample, which excluded those staying less than two days, represented about 6% of admissions to the hospital in this age group. Dementia was diagnosed in 42% (Sampson et al 2009).



Although anecdotal evidence is often offered about high prevalence rates of dementia in acute hospital patients, it has not been established whether the findings from these two studies can be reliably generalised to all admissions of older people, or to other hospitals. Given that 60% of acute hospital admissions are older people, applying a prevalence of 40% dementia results in the estimate of 25% occupancy of hospital beds. For this to be consistent with the data on the number of admissions, HES would have to be missing about 90% of people with dementia, which would be surprising.

Further investigation is needed, partly to ensure appropriate treatment and care can be available in the inpatient setting, and partly to understand what potential there might be for shifting resources to community-based services that reduce hospital admission rates. A rigorous assessment should be conducted of the proportion of hospital beds occupied by people with dementia by means of, for example, a national bed census.

### **3. Assessment of admitted patients**

Since April 2012, the dementia CQUIN has rewarded hospitals for assessing patients over the age of 75 admitted as an emergency for more than three days who did not have an existing diagnosis of dementia. Subsequently, it became mandatory from April 2013 for all patients over age 75 admitted for more than three days who 'potentially have dementia' to be assessed.

Between April 2013 and January 2014 the proportion of eligible admissions identified increased from 70.0% to 82.6% (NHSE Dementia Assessment and Referral data collection, April 2014). The number referred for post-discharge follow-up also rose from 3050 (5.5%) to 4524 (9.1%). If the results in January persist (and if all acute Trusts participated), there would be 54,288 referrals from hospitals each year. This would be expected to decrease over time as the proportion of undiagnosed people with dementia in the population decreased.

### **4. Dementia senior clinical lead**

The proportion of acute hospitals with a Senior Clinical Lead, ensuring sufficient clinical leadership of dementia within providers responsible for ensuring appropriate training of staff, rose from 44% in 2010 to 81% in 2012, as shown by the two National Audits of Dementia (Royal College of Psychiatrists 2010, 2013). Before the results of the audit were available and the existing high prevalence was known, the 2013/14 CQUIN decided to reward hospitals that made such an appointment. It is not known what impact this has had. A third National Audit is currently being commissioned by NHS England (via HQIP) (probably to be conducted in 2015) and will provide such information.

### **5. Creation of 'dementia-friendly' NHS trusts**

Since October 2012, 143 NHS acute trusts (89%) and 24 non-acute trusts (36%) have committed to becoming 'dementia-friendly' in partnership with their local Dementia Action Alliance. One indication of 'dementia-friendly' Trusts is the existence of a dementia care pathway. The proportion of hospitals with such a pathway has increased six-fold from 6% in 2010 to 36% in 2012, as revealed in the two National Audits of Dementia (Royal College of Psychiatrists 2010, 2013). However, progress appears to be slow in some Trusts, as 29 of the 91 Trusts (32%) that claimed to be developing a pathway in 2010 had failed to establish one by 2012. Fifty-nine percent of hospitals had no way to ensure that staff are aware of the person's dementia when they access other treatment areas.





## 6. Reduction in antipsychotic prescribing

There was a reduction in antipsychotic prescribing for people with dementia among acute hospital in-patients between 2010 and 2012 from 28% to 19% (Royal College of Psychiatrists 2010, 2013). The proportion of people with dementia who were admitted on antipsychotics fell from 21% to 11%, and those started on the drugs declined from 12% to 8%.

The Royal College of Psychiatrists Prescribing Observatory in Mental Health conducted a survey in 2010 to look at antipsychotic prescribing in 39 mental health trusts. It found that 16% of people with dementia without comorbid psychosis were prescribed antipsychotics for behavioural and psychological symptoms of dementia (BPSD); 75% had received a documented medication review in the preceding six months, the majority (90%) of reviews being conducted by secondary care services. The lack of any subsequent audit means this source provides no information on progress.

## 7. Quality of hospital care

The Care Quality Commission (2014) very recently published the report on their 'thematic review of the care people living with dementia receive as they moved between care homes and acute hospitals.' Whilst the overall picture was of 'more good care than poor care in the care homes and hospitals', there were wide variations in assessment, planning, delivery and monitoring that 'puts people living with dementia at risk of experiencing poor care.' In 56% of the hospitals inspected they found 'assessments were not comprehensive in identifying all of a person's care needs'; and in 42% of hospitals, they found 'aspects of variable or poor care in relation to people's mental health, emotional and social needs.'

### 4.4.3 Impacts of these initiatives on people with dementia and their carers

While explicit quantitative evidence on the benefits that may have resulted from these improvements in the processes of hospital care are not available, it is reasonable to assume that the care that people with dementia receive will have improved as a result of timely diagnosis (for the reasons outlined in Section 4.2 on post-diagnostic support) and from the greater attention that people with dementia will receive as a result of hospitals having a senior clinical dementia lead and being committed to 'dementia-friendly'. In addition, as in other settings, a lower use of antipsychotic medications in hospitals will have reduced the risk of adverse health effects such as falls and injuries (as a result of the risk of excessive sedation, dizziness and unsteadiness), Parkinsonism (tremors and rigidity), accelerated cognitive decline, and stroke (Kleijer et al 2009; Department of Health 2009).

## 4.5 Workforce development

### 4.5.1 Actions and initiatives

*Royal Colleges:* The Department of Health is working with the Royal Colleges to encourage commitments to ensure that their members are capable and competent with dementia care. The DH has worked with the Royal College of General Practitioners Clinical Champions to raise awareness and understanding of dementia and to encourage GPs to take forward educational opportunities on dementia. RCGP has been commissioned by the DH to develop a web-based navigation aid (the 'Dementia Roadmap') to support GPs and other primary care staff. The Roadmap will be rolled out to all clinical commissioning groups and will provide national and local information about dementia from health, social care and the third sector to assist primary care staff to more



effectively support patients, families and carers at the time of diagnosis and subsequently. A second phase of work on the Dementia Roadmap has recently been commissioned, for completion by March 2015. The Royal College of Nursing is committed to promoting clinical leadership and better training. The DH has commissioned the RCN to develop five principles for improving dementia care in general hospitals (published in 2011) and supporting resources for staff (including a 'how to' guide and film) to support their implementation. As far as we are aware, no formal evaluation of these is as yet planned.

**Dementia Clinical Networks:** Pilots were launched in September 2012 to spread clinical expertise. Twelve Dementia Clinical Networks began reporting on their results or strategies in autumn 2013.

**Prime Minister's Nursing and Care Quality Forum:** This forum was established after an independent forum published initial recommendations on how to support people with complex needs, such as dementia as part of its work to spread best practice in nursing and care in all care settings (May 2012).<sup>4</sup> The Prime Minister's Challenge named four leads, focused on values and culture, promoting accountable nurse leaders, ensuring nurses have enough times to give quality care, and patient feedback in April 2012.

**DH nursing vision and strategy:** A model has been developed for dementia nursing that demonstrates how all nurses can be involved in the dementia care pathway and improve outcomes. The DH published a new nursing vision and strategy for dementia care in March 2013, which makes clear that every nurse can make a difference to the care of people with dementia. The resource aims to raise the profile of the wider nursing contribution to dementia care, describing what is expected of all nurses to meet the level and quality of care expected in all care settings.

**Health Education England:** In early 2013, the NHS Mandate committed HEE to support training for staff (particularly the primary care workforce) to diagnose early symptoms of dementia, provide foundation-level dementia training to all NHS staff that look after patients with dementia, raise awareness of the mental health problems that present alongside dementia, review content of nurse education and develop specific postgraduate training for nurses working with older people with complex needs.

**Workforce Advisory Group:** The DH established the National Dementia Strategy Workforce Advisory Group in July 2010, chaired by the National Clinical Director, to support the delivery of objective 13 of the National Dementia Strategy on an informed and effective workforce for people with dementia and went on to advise on the implementation of the education and training aspects of the Prime Minister's Challenge on Dementia. Its work covers pre- and post-registration education and training for health and social care professionals, as well as family carers and housing staff. The DH has commissioned a wide range of projects on dementia education and training with the support of the Group, including:

- Skills for Care and Skills for Health developed the Common Core Principles for Supporting People with Dementia (2011), and ran two series of 'train the trainer' workshops (2011/12 and 2012/13) to support the implementation of the principles in the health and care sectors;
- e-learning for Healthcare to develop a series of ten e-learning sessions on dementia, available free of charge to health and social care staff through the e-learning for Healthcare portal;
- Dementia UK and the Princess Royal Trust for Carers provide training and support to family carers of people with dementia;

<sup>4</sup> [www.gov.uk/government/publications/nursing-and-care-quality-forum-make-recommendations-to-prime-minister](http://www.gov.uk/government/publications/nursing-and-care-quality-forum-make-recommendations-to-prime-minister)



- Skills for Care developed a resource and information pack to support the workforce who are supporting carers of people with dementia, supported by a series of ‘train the trainer’ workshops; Skills for Care developed a learning and development support guide for managers working in social care settings, which supports them to implement workforce development excellence (also supported by a series of ‘train the trainer’ workshops);
- training for social care and housing staff on reminiscence and life story work, working with National Museums Liverpool and the Life Story Network, and subsequently rolled out to museums and galleries across the North of England and the Midlands, with financial support from DH;
- the Gold Standards Framework to develop and deliver training on end of life care for people with dementia;
- fifteen funded places on a postgraduate certificate in dementia for practitioners with a special interest at the University of Bradford, enabling places on the programme to be offered to practitioners from outside the Yorkshire and Humber region;
- Skills for Care developed a learning and development guide on dementia and supporting workshops for the domiciliary care sector;
- the English Community Care Association developed the Dementia Pledge for care home staff and to subsequently extend the Pledge to domiciliary care, day care and local authorities;
- Worcester University, Skills for Health, NHS Worcestershire and North East Worcestershire College extended the ‘Stand By Me’ e-learning and film resource on dementia to emergency care, domiciliary care and primary care;
- Age Related Diseases and Health Trust, working with the Dementia Action Alliance, developed training on dementia for community pharmacists;
- Dementia Pathfinders developed specialist dementia training for domiciliary care workers and Personal Assistants;
- Skills for Health, working with Health Education England, developed a Core Skills and Knowledge Framework for dementia.

*Dementia Workforce Development Fund:* In 2012 DH made available a £2.4m Dementia Workforce Development Fund to social care employers, administered by Skills for Care, to support the completion of accredited social care qualifications by members of the workforce who support people with dementia. This was supported by a further series of Common Core Principles workshops for social care staff (funded from the overall £2.4m).

#### **4.5.2 Improvements made since 2009/10, and impacts on people with dementia and carers**

##### **1. Health care staff training**

NICE recommends that all staff working with older people should receive dementia care training that is consistent with their roles and responsibilities. As outlined in the previous subsection, the work of the National Dementia Strategy Workforce Advisory Group has led to the commissioning by DH of a range of workforce development activities.

Between 2010 and 2012, as shown by the National Audits of Dementia (Royal College of Psychiatrists 2010, 2013), the proportion of hospitals reporting several aspects of training had improved:

- Hospitals having a training and knowledge framework or strategy that identifies necessary skill development in working with and caring for people with dementia increased from 23% to 78%.
- Hospitals reporting that training in awareness of dementia was mandatory for all staff rose from 5% to 59%.



- Hospitals reporting liaison teams from local mental health and learning disability services offer regular training for healthcare professionals who provide care for people with dementia in the hospital increased from 39% to 65%.

The 2010 National Audit of Dementia surveyed 2211 staff (Royal College of Psychiatrists 2010) and provided more information but it has not been repeated (although we understand that there are plans to do so; source David Cox). The proportions of staff reporting they had sufficient learning and development in different areas were:

- 46% in dealing with challenging/aggressive behaviour
- 33% in when and when not to use restraints/sedations and the risks associated, particularly for older patients.
- 32% in dementia care, including awareness training and skills based training.
- 67% in using the principles of person-centred care.
- 52% in involving people with dementia/carers in decisions on care and treatment
- 42% in the Mental Capacity Act and how to assess capacity.
- 37% in assessing cognitive ability.

It appears that more efforts need to be made to ensure that a higher quality workforce is recruited with adequate training to meet needs of people with dementia (Health Education England).

The Government mandate required HEE to ensure 100,000 staff providing NHS services receive dementia-awareness training by March 2014. Plans were set out by HEE (2013) to ensure all NHS staff looking after people with dementia have dementia-awareness training. This target was met by November 2013, with 109,000 staff completing training, some through an e-learning module (three 30-minute sessions, option for ten additional 30-minute sessions). The impact of the module on staff capacity to provide care for patients with, or suspected to have, dementia has not yet been evaluated.

People with dementia and carers are often involved in giving feedback on service improvement, but less than half of memory services involve these individuals when appointing new staff, planning changes to service organisation, or helping to support other people with dementia and their carers (National Audit of Memory Services 2013). This Audit also reported that, in 2013, 32% of 177 memory services included people with dementia or their carers in staff training but it is unclear whether this represents any change from earlier years.

As with other initiatives there is a lack of quantitative evidence of benefit. Although it might seem reasonable to expect benefits from NHS staff being better informed about dementia, the EVIDEM-ED trial of a customised educational intervention for GPs, combining practice-based workshops and electronic support material, did not find evidence that it altered the documentation of clinical management of patients with dementia, nor did it increase case identification (Wilcock et al 2013).

## **2. Social care workforce**

Objective 13 of the National Dementia Strategy identified a crucial role for training and workforce development to develop 'an informed and effective workforce for people with dementia' and set the aim that all social care staff should receive a minimum level of dementia training. The Prime Minister's Challenge urged that 'We need to make sure that whether people are being cared for in their own home, or in care homes, the staff who work with them have the knowledge and skills to help them lead as fulfilling a life as possible' (p.9).



The National Minimum Dataset for Social Care (MNDS-SC) is managed by Skills for Care, and collects information from all social care service providers (care homes, day centres, home care services and so on), and including individuals who employ their own care and support staff. It collects data on a range of workforce issues including qualifications and training, pay and staff turnover. Data are provided online and is submitted voluntarily, although incentivised by various benefits including that responding organisations that report data for at least 90% of their workforce are eligible for funding from the Workforce Development Fund. The dataset also includes individual service users who employ personal assistants (from their direct payments), who are incentivised by eligibility for staff training. Approximately 60% of CQC-registered establishments participate.

According to these data, the number of establishments providing services to people with dementia has increased since 2009. The proportion of establishments providing their main service to people with dementia has increased by 7.3 percentage points, from 8,303 of 26,852 establishments (30.9%) in December 2009 to 9,851 of 25,782 establishments (38.2%) in January 2014. Since 2009, the number of establishments providing care to older people with dementia as an 'other' service (not the main service) has also increased by 6.3 percentage points, from 64.8% to 71.1% of all establishments.

Qualifications have been added over time, making trend data difficult to interpret. In particular data on dementia-related qualifications were only collected from 2011. Furthermore, problems with early data included high levels of missing data and difficulties in distinguishing item non-response from having no qualifications. Currently, however, we know that 41.3% of all social care workers (covering management, professional and direct care) working with older people (aged 65 and over) with dementia hold no qualifications at all, while 50.2% have a level 2 NVQ or higher qualification. For care workers these percentages are 44.7% and 49.6%, respectively. A low 'qualification base' potentially makes it harder to introduce new ways of working (such as delivery of cognitive stimulation therapy in care homes or day centres; see above) and harder to retain staff in the sector.

Looking just at dementia related qualifications, in January 2014, we find that of the 335,378 (54.4 %) of workers (covering management, professional and direct care), who work at an establishment providing services to older people (aged 65 and over) with dementia:

- 1022 (0.3%) had an Award in Awareness of Dementia (Level 2) qualification
- 191 (0.06%) had an Award in Awareness of Dementia (Level 3) qualification
- 735 (0.02%) had a Certificate in Dementia Care (Level 2) qualification
- 139 (0.04%) had a Certificate in Dementia Care (Level 3) qualification
- 512 (0.02%) had a Diploma in Health and Social Care (Dementia Pathway)
- 322 (0.01%) had a Diploma in Health and Social Care (Dementia Pathway).

There are similar problems in identifying trends in dementia training (short courses not leading to a qualification). However, we know that currently, for workers at establishments offering services to people with dementia for whom a response to this question was given (123,938 workers), 43% have received such training. If, however, one takes all the worker records for establishments completing at least one worker record as the base (which suggests a willingness and intent to complete the section and makes it more likely that the section was left blank to indicate no training rather than just not completed) then the percentage reduces to 23% (of a total of 296,744 workers). Staff at HSCIC suggest that the real figure probably lies somewhere



between these two figures. Again, as noted earlier, low levels of skills training could constrain delivery of high-quality, dementia-specific care.

Hussein and Manthorpe (2012), in their analysis of data from the Minimum National Data Set – Social Care (MNDS-SC), find that there are some important differences between the dementia care workforce and other parts of the social care workforce. The dementia care workforce is more likely to be female, to work part-time, to be employed by agencies and to be less qualified.

Staff turnover is a persistent feature of the social care workforce, commonly thought to be because of low wages (the average hourly rate for a care worker is currently £6.65; NMDS-SC, 2014) and poor career pathways. High turnover is a barrier to embedding training, and presents a challenge to attempts to achieve a consistent and high standard of care. According to NMDS-SC data, annual staff turnover for all social care workers (covering management, professional and direct care workers), working with older people (aged 65 and over) with dementia, is currently 25.4%, up from 21.3% in December 2009.] For care workers only, this figure is as high as 31.4%, up from 28.4% in December 2009. The National Care Forum's members' survey (2013) of 40 providers (covering around 51,000 social care employees) found similar figures, with 17.3% staff turnover in residential care settings and 29.9% turnover among domiciliary care staff.

Staff turnover has been found to be related to poor care standards. For example, in their inspection programmes, CQC found a link between death notifications and higher staff turnover rates in care homes (although the same association was not found for staff vacancies). It is difficult to know how this information should be interpreted; poor outcomes could be related to discontinuities in care or, for example, to poor organisational culture or management influencing both staff retention and quality of care. More generally, inexperienced or poorly trained staff members continue to present a risk of poor care. For example, in 2013 CQC conducted a survey and found that 'some social care staff said they had been asked to provide care or support unsupervised where they felt unsafe (3%) or unprepared (5%)'.

Approaches to training or inducting new workers may also not always be appropriate. A CQC survey (2013) found that 'buddying with an experienced worker and shadowing them was the most common approach, and the one cited as the most helpful. E-learning was said to be the least helpful.' This echoes views expressed by a senior manager for a leading care home operator (private meeting) who commented that care staff are often people who found school and traditional educational approaches difficult and prefer to learn more practically, 'on the job' (and see Moriarty et al 2013). It has been suggested to us that levels of training in dementia care research may be worse among the home care workforce than the care home workforce, and that home care staff also have fewer opportunities for 'buddying' and observing good practice (Jo Moriarty, personal communication).

## 4.6 Care homes and home care

### 4.6.1 Action and initiatives

*Dementia Care and Support Compact:* The Dementia Care and Support Compact was signed by leading care home and home care providers. In March 2014 there were 173 signatories to the Compact, representing nearly 3,000 care services committed to delivering high-quality, personalised care to people with dementia and





their carers. Every registered care provider is now able to show the public how they meet the Compact using their on-line quality profile, which is available on the NHS Choices website. We have also earlier made reference to the Dementia Pledge for care home staff, which will later be extended to home care, day care and other services.

**Capital funding for care homes:** Capital funding was being made available in 2013/14 (£25 million for the NHS and £25 million for local authorities) to work with providers to create care environments to help people with dementia live well with the condition. Findings and evidence from the pilot projects will be used to develop future guidance in this area.

**NICE Guideline:** In July 2012 a referral was made by the Department of Health to NICE to produce guidelines on 'home care: the delivery of personal care and practical support to older people living in their own homes'. These are expected to be published in July 2015. People to be covered are 'older people living at home and in receipt of home care. This includes those who organise or fund their own care. ... The aim is to ensure it is specific enough to provide recommendations that benefit the majority user group. In addition to those with protected characteristics under the Equality Act 2010, other subgroups that may be of specific interest include those: aged 85 and older, who lack capacity or have communication difficulties, living on their own, approaching the end of their life.'

#### **4.6.2 Improvements made since 2009/10, and impacts on people with dementia and carers**

##### **1. Quality of care**

CQC conducted a programme inspecting the care provided to older people in 500 care homes, looking at issues of respect, dignity and nutrition (CQC, 2012/ 2013). It found that people with dementia living at care home postcodes are more likely to be admitted to hospital multiple times (10% more multiple admissions) and to be admitted to hospital for conditions which are potentially avoidable (30% more avoidable admissions) compared to similar people living at care home postcodes without dementia. These rates were even higher in nursing homes (e.g. 39% more avoidable admissions).

They also found that homes caring for people with dementia were less likely to meet safeguarding standards, stating that 'not all staff caring for people with dementia had the appropriate skills, knowledge and experience' and 'not all staff understood the Mental Capacity Act ... or the implications for people they care for' (p.28). CQC also reported that around 1 in 6 of homes that they inspected 'failed to provide choices of activities and options for people to support their independence – particularly for people with dementia' (p.31). CQC conducted a themed inspection on dementia in 129 care homes and 20 acute hospitals that report in October 2014, concluding that 'Overall we found more good care than poor in the care homes and hospitals we visited, but the quality of care for people with dementia varies greatly and it is likely that they will experience poor care at some point along their care pathway. Clear guidance has been available for years, but improvements in care are still needed and overdue' (CQC 2014, p.7). Among others findings, in 29% of the 129 care homes inspected they found 'assessments were not comprehensive in identifying all of a person's care needs'; and in 34% of care homes, they found 'aspects of variable or poor care in relation to people's mental health, emotional and social needs.' The report contains a lot of other valuable insights into dementia care in these settings that we have not summarised here.





As noted above, there are now 173 signatories to the Dementia Care and Support Compact, and these providers set out how they meet the Compact as part of the online quality profile on the NHS Choices website and in other places (own website, organisational strategies etc.). However, there are no centrally collected data on quality of care associated with the Compact and no further available data we are aware of – beyond the CQC inspection data – on national progress in improving quality of care in care homes; this is a concern given the CQC evidence just noted. NICE produces quality standards on the mental wellbeing of older people in care homes (QS50), which can be applied in local audits.

## **2. Dementia Care Audit Tool**

In June 2013, the Royal College of Psychiatrists successfully piloted the Dementia Care Audit Tool (DCAT) in nine care homes. The online audit tool includes a series of questions about the organisation and information for five residents with dementia, designed to analyse each care home's policies, procedures and performance, which between them cover some important aspects of quality of care. Measures and questions draw broadly on NICE Quality Standards (QS30), as well as CQC inspection and expert opinion.

The DH Social Care Directorate is currently funding a wider pilot, managed by the Healthcare Quality Improvement Partnership (HQIP) and involving up to 250 care homes recruited through SCIE. Data are currently being collected for this pilot and aggregated data should be available in summer 2014. The data are based on a self-selecting sample, which limits their usefulness, but the pilot is designed to test the tool. Care homes that take part in the pilot will be able to review and benchmark their services against others. HQIP will be approaching the Department of Health in April 2014 with proposals and options for further development of the audit tool. These may include adding in a measure of relative/friend satisfaction with care and observation of residents to assess quality of care (an approach strongly recommended by Warmington et al 2014). Tools available for assessment by observation include the short observation framework for inspection, SOFI, used by CQC or the well-established Dementia Care Mapping approach). If the tool was rolled out, there would also be a need to consider an appropriate facility for benchmarking.

Whether or how the audit will be funded or utilized in future is currently unclear. However, evidence from CQC inspections, described above, suggests a need for increased understanding of quality in dementia care within care homes, including the factors that underpin and inhibit high quality care, as well a need for effective self-improvement tools for care homes providing dementia care.

## **3. Antipsychotic prescribing in care homes**

There has been a dramatic reduction in the prescribing of antipsychotic medication in care homes over the past few years, in response to a report from the Department of Health (2009) and recommendations in the National Dementia Strategy. There are no national data that allow trends to be examined. We have therefore collected information from two large care home companies who report that by early 2014 the proportions of their residents on antipsychotics were 10% (based on about 900 residents in 15 homes) and 13% (based on 22,000 residents in 450 homes). Further evidence of the low level of current use comes from the Borough of Islington in London which reports that of about 1000 residents of care homes, only 1-2% are on antipsychotics, and from a mix of care home residents and people with dementia living in their own homes in Buckinghamshire (based on 52 general practices) where the proportion was 8% in 2012-13.



#### 4. Managing risk

In January 2014, CQC issued its fourth annual report into the Deprivation of Liberty Safeguards (DoLS). Deprivation of Liberty Safeguards are an amendment to the Mental Capacity Act 2005, which allows restrictions and restraint to be used, but only if they are in the best interests of a person who lacks capacity to make the decision themselves. In this context restraint has a wide definition, covering a range of actions designed to prevent someone doing something they want to do. In such circumstances, care homes or hospitals must formally ask either a local authority or health body if they can deprive a person of their liberty. CQC reported that, for people aged 75 to 84, there had been an 81% increase in the number of such restraint applications and, among those aged over 85, a 69% increase. Most of these applications and authorisations related to older people with dementia living in care homes. CQC also found that two-thirds of care homes applying for DoLS failed to notify the regulator of their applications or their outcomes. It is unclear whether this represents an actual increase in use of restraint applications or whether this apparent increase is the result of closer scrutiny. In response to these findings, CQC called for more focus on reducing the use of restraint and also demanded more transparency from care homes.

Some progress has been made. *Nothing Ventured, Nothing Gained* (DH, 2010) remains current, providing guidance on managing risk in the care of people with dementia. However, in response to on-going concerns about the use of restraint in social care settings (including the Government's review of the incidents at Winterbourne View, 2013), the Department of Health has commissioned the Royal College of Nursing to lead a consortium to develop guidance on alternatives to physical restraint in adult social care settings and special schools. This work builds on the Royal College of Nursing's earlier report, *Let's talk about restraint - rights, risk and responsibility* (2008). A consultation for the initiative closed in mid-February 2014 and the guidance is due to be published later in 2014.

#### 5. Funding of care homes

According to the Care Quality Commission report, *The state of health care and adult social care in England, Technical Annex 2: Adult social care funding* (2013), homes specifically registered to provide dementia care had, when compared to homes not specifically registered to provide dementia care, a higher proportion of places which were local authority-funded without top-up (46% compared to 41%) and a lower proportion of places where people pay for their own care (34% compared to 40%). These data were not centrally collected previously, so we cannot be certain whether there are trends in this respect, although the changes to social care funding set out in the Care Act (2014) are likely to alter patterns of funding. Contracts between local authorities and care homes provide opportunities (in principle at least) to influence the quality of care. Care home providers complain that the market power of public purchasers has driven down prices, thereby undermining attempts to improve quality of care. This is anecdotal, but there is certainly evidence of a price-quality gradient in care homes: higher fees are associated with better quality (Forder and Allan 2014). There is also evidence of a positive correlation between the rating of a care home (for example from CQC) and the outcomes experienced by residents (for example as measured by ASCOT) (Netten et al 2012).

#### 6. Home care

The National Dementia Strategy (objective 6) promoted specialist home care dementia services to support people to live independently; it described home care as, next to unpaid (informal) care, 'probably the most important service involved in supporting



people in their own homes' (p.47). However, the Strategy also articulated concern about the level and quality of social care in the community, including concern about 'short (e.g. 15-minute) periods are particularly problematic for people with dementia' (p.47). These concerns continue to arise; for example, Leonard Cheshire Disability reported in October 2013 that 60% of English local authorities commissioned 15-minute visits, but this policy was defended by the Association of Directors of Adult Social Services as not necessarily inappropriate in all circumstances. The response from the DH (22 October 2013) noted 'There are too many examples of councils buying rushed care visits and the department is working to change this. Better care is needed for the 300,000 people currently receiving home care and for the millions more who will need it in years to come'.<sup>5</sup>

A study that will report in 2015 may provide greater insight into how the provision of home care (generally) might impact on people with dementia. This project, funded by NIHR and led by David Challis (Manchester University) is looking at patterns of home support provided to people with dementia and their carers, as well as its costs and effects at different stages of the condition.

### 7. Reablement

Growing attention is now being focussed on re-ablement as a component of home care, either as a specialist service or embodied within home care more generally. The core aim is to help people learn or re-learn the skills necessary to live independently (SCIE, 2013). Some specialist dementia reablement services have been developed, such as Solent Mind's Dementia Reablement Project, which supports people in hospital and helps them prepare for discharge, referring them to appropriate reablement and home care services as required. However, while there is evidence on effectiveness and cost-effectiveness of reablement services for older people in general (Glendenning et al 2010; Glasby et al 2010; SCIE 2011; SCIE 2013), there has been no evaluation of reablement specifically for people with dementia. The only suggestion of a benefit for people with dementia comes from Glendenning et al (2010). They reported that 'some workers mentioned that they expected much smaller achievements for [service users with dementia or other mental health problems] but once service users got a sense of routine, their self-esteem would improve and eventually they would need less long-term support' (p.124).

<sup>5</sup> [www.gov.uk/government/news/ending-15-minute-care-department-of-health-response](http://www.gov.uk/government/news/ending-15-minute-care-department-of-health-response)



## 5. Changing public attitudes

Negative attitudes, poor awareness and ignorance about dementia complicate a number of elements in the ‘care pathway’: they could make it less likely that people worried about their cognition will seek help, less likely that relatives will encourage them to have a diagnostic assessment, harder perhaps for health care professionals to share ‘bad news’, more difficult for people with dementia to gain access to the post-diagnostic support they need, tougher for working carers to get support from their employers, and tougher for people with dementia to continue to play valued and valuable roles in their families and communities.

Both the National Dementia Strategy and the Prime Minister’s Challenge placed considerable emphasis on changing public attitudes to dementia.

### 5.1.1 Action and initiatives

Two sets of commitments were made in the Prime Minister’s Challenge in relation to attitudes and approaches to dementia. One set was to build dementia-friendly communities:

- By 2015, up to 20 cities, towns and villages will have signed up to become more dementia-friendly (see below for what this can mean in practice).
- Galvanise support from leading businesses for the *PM’s Challenge* to play a part in creating a more dementia-friendly society and to raise awareness of dementia.

The other set of commitments was to raise public awareness:

- From autumn 2012, the Department of Health will invest in a nationwide campaign to raise awareness of dementia, to be sustained to 2015. This will build on lessons learned from previous campaigns and will inform future investment.
- A major event over the summer (2012), bringing together UK leaders from industry, academia and the public sector, to take forward the *PM’s Challenge*.

### 5.1.2 Improvements made since 2009/10, and impacts on people with dementia and carers

#### 1. Funding

The Alzheimer’s Society and the Dementia Action Alliance (a network of over 900 organisations), which the Society hosts, have taken leading roles in driving forward the dementia friendly agenda. The Department of Health, through the IESD, provided funding of £537,000 over three years to support the development of local Dementia Action Alliances, and some further funding to support the national Alliance. Much of the progress described below is, therefore, discussed in greater detail in reports published by the Alzheimer’s Society and the Dementia Action Alliance.

#### 2. Dementia Friendly Communities, local Dementia Action Alliances and Dementia Friends

The Dementia Friends (DF) campaign, run by the Alzheimer’s Society and funded by the Department of Health and Cabinet Office, was launched in 2012. The most recent statistics (October 2014) indicate that there were over 519,000 Dementia Friends. The ambition is to have a million Dementia Friends by 2015 (Department of Health, 2013). The Alzheimer’s Society is responsible for delivering 200,000 Dementia Friends, and Public Health England is responsible for the other 800,000.

The Dementia Friendly Communities initiative was also established in 2012 with fourteen ‘early adopters’. The programme was then rolled out more widely, building



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on local Dementia Action Alliances (local partnerships aimed at improving the lives of people living with dementia in their area). Prospective Dementia Friendly Communities participate in a 'recognition process', requiring them to submit a six-month progress update to the Alzheimer's Society and undertake an annual self-assessment. The Alzheimer's Society is also currently working with the British Standards Institute to develop a standard for communities as part of the recognition process.

By May 2014, 51 communities had signed up to the Dementia Friendly Communities Recognition Process, with a target of 75 communities by March 2015. The activities of dementia friendly communities are diverse and their activities are designed to reach a large number of people and organisations within their local area. For example, in an interview we conducted with representatives from the Dementia School of Social Science and Social Work, University of Plymouth (January 2014), we learnt that around one thousand people in the Plymouth Dementia Community have undergone dementia training, including people with public facing roles such as bus drivers, local police, shop keepers, local Royal Navy personnel, University of Plymouth staff, Plymouth City Council staff, and local health care providers. Other initiatives undertaken as part of the Plymouth Dementia Community include local solicitors agreeing different fee structures for people with dementia, human resource departments of local businesses establishing more flexible policies to help carers of people with dementia, and local banks allocating more time to perform face-to-face transactions with people with dementia. Dementia has also been incorporated as part of the curriculum in several subjects in the local community college, the local basketball team has helped in a local campaign to raise awareness of dementia and there have been a range of arts events involving local reminiscence groups, local artists and local arts organisations and museums. A number of initiatives and groups for people with dementia to meet with each other locally have also been organised. Details of the activities of another Dementia Friendly community in Yorkshire are described in the recently published *Dementia Friendly Yorkshire: First steps on the journey* (Joseph Rowntree Foundation, 2014).

The Dementia Action Alliance aims to establish more local Alliances to achieve 100% geographical coverage, compared to its current 41%, and to increase its local authority membership from 32 authorities to 76 (50% of upper tier authorities). It also plans to establish a network of local Dementia Action Alliance coordinators.

A nationwide campaign to raise awareness of dementia ran at the end of 2012. Currently, Public Health England, working with external marketing agencies, is establishing a public campaign to run from 2014 until 2015. As well as aiming to raise awareness, the campaign will encourage people to join the Dementia Friends programme and encourage businesses and communities to become dementia-friendly.

As described in the Annex to the first Annual Report of progress on the Prime Minister's Challenge, an evaluation of the 2012 awareness campaign reported that the campaign reached out to over 37 million people. The evaluation findings show that:

- Three-quarters of respondents agreed that the campaign would help people with dementia and their families;
- 86% agreed that some people with dementia can still take part in everyday activities;
- 83% agreed that they would encourage a relative or friend to visit a GP if they thought they had symptoms of dementia.

The overall impact of the campaign looked broadly favourable, and suggested that referral rates would be likely to increase with greater awareness.



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### 3. Dementia-friendly housing

Housing is also defined as a health-related service in the Care Act (section 3, 2014) such that the new duty upon local authorities to promote integrated care with health services applies. This reflects the promotion of dementia-friendly housing as part of an integrated approach to dementia care, helping people with dementia live independently for as long as possible (e.g. Andrews et al 2013, and other reports from the Dementia Services Development Centre, University of Stirling; Care and Repair England, 2013).

Investment has been made, in collaboration with the Homes and Communities Agency and the Greater London Authority, to encourage local authorities to build effective partnerships with housing associations and private house-builders to meet the needs of those with long-term conditions, including dementia (see above).

Evidence on the availability or provision of dementia-friendly housing since 2009 or on the likely impact of such services is relatively limited. Evans et al (2014), in a systematic review of extra care housing, provide a comprehensive summary of the evidence surrounding extra care housing, building on an earlier review of evidence on extra-care housing and dementia for Housing21 and the Joseph Rowntree Foundation (Dutton et al 2009). Dutton and colleagues concluded that 'In the UK there have been very few studies to date of extra care housing which focus on tenants who have dementia', identifying just one longitudinal study, with other evidence coming from case studies and evaluations of single schemes, most of them descriptive and/or qualitative and conducted in the US.

Evans et al. (2012) identified five UK peer-reviewed papers on care and support provision in extra care housing. One paper, by Wright et al (2010) noted that the absence of an agreed definition of 'extra care' can make it difficult to know whether provision is appropriate for people with dementia, and for different levels of severity and support need. In another paper, Brooker et al (2009) identified high levels of mental health need in extra care housing. A third paper evaluated the Enriched Opportunities Programme. This initiative adopted a whole scheme approach to supporting people with dementia that included specialist staff, leadership, staff training, individualised care-work, community liaison and the provision of appropriate activities. A cluster-randomized controlled trial in ten settings found that those receiving the service were less likely than residents in control sites to move to a care home or to be admitted to a hospital inpatient bed. They were also more likely to be seen by a range of community health professionals (Brooker et al 2011). Means et al (2006) identified three issues that require particular consideration in delivering extra care housing to those with dementia; access to health care, training of staff and providing a sufficiently stimulating environment. Finally, a scoping review by O'Malley and Croucher (2005) explored the evidence base for housing provision for people with dementia and identified a number of gaps, including in relation to end of life care.

Since the Dutton and Evans reviews, a useful report by the National Federation of Housing (2013) gives examples of good practice covering dementia-friendly design and supporting people to live independently, with the aim of avoiding unnecessary hospital admissions and supporting safe discharge from hospital. However, this report does not contain any useful quantitative data (for example, on levels of provision, trends over time or outcomes).

### 4. Sector-specific initiatives

There are currently six Task and Finish Groups coordinated by the DH, covering assistive technology (the group is currently consulting on a draft charter on dementia friendly technology), rural communities, civil society and the voluntary sector, power of attorney and data sharing, dementia friendly retailers and dementia friendly employers. Three more Task and Finish Groups are to be set up in summer 2014 covering leisure, transport and personal services.





There have been a number of sector-specific initiatives, described below. Currently, with the exception of the Intergenerational Schools Project (see below), there has been no evaluation of the impact of these initiatives, although one might expect the degree of education and awareness-raising and the very practical actions involved in many of the initiatives to have had some positive effects.

In the financial sector, Lloyds Banking Group, Nationwide, Aviva and 24 other financial service organisations and industry bodies, working with the Alzheimer's Society, published the *Dementia Friendly Financial Services Charter*. This is designed to help financial services organisations recognise, understand and respond to the needs of customers living with dementia and their carers. The Alzheimer's Society aims to establish further charters for other sectors or industries by March 2015.

A number of retail and utility providers have taken steps to become dementia friendly. For example:

- the Direct Marketing Association has developed a best practice guide for call centres regarding vulnerable customers, making specific reference to people with dementia;
- British Telecom has developed a factsheet for staff to raise awareness of dementia;
- E.ON is creating dementia champions within their specialist customer service teams;
- Tesco are currently engaged in looking for ways to increase dementia awareness and understanding among their staff.
- On 28 February 2014, the Secretary of State announced that four major British businesses have pledged staff to become 'Dementia Friends': 60,000 staff at Marks & Spencer, 70,000 at Lloyds Pharmacy, 50,000 at Home Retail Group (Argos and Homebase) and 11,500 at Lloyds Bank.

The Alzheimer's Society has stated that there are currently ten businesses supporting engagement with dementia friendly communities, a number that they hope to increase to 50 by March 2015 (private meeting, February 2014). The Alzheimer's Society will also launch a foundation-stage recognition process for businesses, building on the already established process for Dementia Friendly Communities. This is to be introduced in June 2014, with the aim of having ten major businesses signed up by March 2015.

The Intergenerational Schools Project, funded by the Department of Health, involved 22 pioneer schools, which developed a range of activities and projects for pupils to learn about dementia. The Dementia Resource Suite has been produced to share the good ideas from the 22 pioneer schools and was awarded the Quality Assurance Mark by the PSHE Association. The Intergenerational Schools Project, overall, was positively evaluated (using primarily qualitative methods) by the Association for Dementia Studies, Warwickshire University, and Coventry and Warwickshire NHS Trust. It found that pupils gained an increased awareness of dementia, that the initiative reduced stigma and fear, that it promoted an appreciation of the caring role and how to support carers and increased awareness of how to help people with dementia to live well, and the challenges and negative attitudes they may face.

The Fire and Rescue Service has made a *Pledge on Dementia* to take action to increase the safety of people with dementia and increase awareness amongst their staff. The Association of Chief Police Officers (ACPO) now offers guidance to all police forces in England and Wales, including British Transport Police, on dementia, with several police forces having developed an Emergency 'E card' or 'Keep Safe' card for people with dementia to carry with them.





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Several transport organisations have also committed to becoming dementia-friendly. For example, First Group plc are providing 17,000 of their bus drivers with dementia awareness training, developing a dementia module for their Driver Certificate of Professional Competence and are developing safe journey cards for passengers with dementia. Transport for London has introduced the Travel Support Card aimed to make travel easier for people with hidden disabilities.

Leisure organisations, such as the Bingo Association and the British Museum have also taken steps to become dementia friendly.

In April 2014, the chair of the Local Government Association called on council leaders across England and Wales to become dementia friends to 'drive public knowledge and awareness of the illness'. He called for each council to designate a council staff member as a local Dementia Friends champion and to cascade learning to other staff, as well as to promote greater awareness in the community by making council premises available for training.

In 2014, the Alzheimer's Society is planning to hold Dementia Friendly Awards for ambitious and innovative initiatives of the kinds described here.

### **5. Measuring public attitudes**

A number of surveys of public attitudes towards dementia have been undertaken using a range of non-random probability sampling methods. During the awareness campaign in 2012, the Department of Health commissioned three consecutive polls from MORI. The polls found modest increases in levels of public agreement with statements such as 'dementia can happen to anyone' and 'some people with dementia can still take part in everyday activities'.

Outside the UK, we identified only two studies of public attitudes to dementia, both based on convenience samples. Patterns of association in the data are worth noting. An Israeli/American study developed a 62-item scale (FS-ADS) to measure the stigma perceived by adult children of people with dementia (Werner et al 2011). The tool was then used in a face-to-face survey with a convenience sample of 185 adult children of people with dementia. Results showing perceived stigma to be associated with increased caregiver burden as well as decreased involvement in the care of their parents (Werner et al 2012).

*The World Alzheimer Report 2012: Overcoming the stigma of Dementia* was published by Alzheimer's Disease International in 2012. Reported findings were based on responses to an online survey, completed by just over 2,500 people with dementia and their family carers. The survey respondents were recruited through a range of dementia-related and other community-based organisations in 54 countries. The majority of responses were to the English version of the questionnaire and over half (55%) of responses were from the United States. The survey included a wide range of questions, but overall, recorded widespread experiences of perceived stigma and social exclusion.

In 2014, a number of questions about dementia are to be included in the Scottish Social Attitudes Survey. This is a survey based on well-developed survey questions and a statistically representative sample of Scottish citizens. The Department of Health may wish to consider asking similar questions of the population in England, using the British Social Attitudes survey. This survey is funded to explore public attitudes on a range of topics, ensuring well-developed suites of questions and surveying a statistically representative sample of between 1100 and 3300 people.



## 6. Harnessing research developments

Well-conducted, relevant research has the potential to make major improvements to health, quality of life and efficiency. Both the National Dementia Strategy and the Prime Minister's Challenge recognised the need for more and better research in the dementia field.

We adopt a different structure here from that used in Sections 4 and 5, conflating action, improvements and impact into one. This is because the 'impact' of newly commissioned research will not be seen for some years to come. It should also be noted that in Sections 7 and 8 we discuss gaps and priorities, including those that are clearly linked to research.

### 6.1.1 Action, improvements and impacts

#### 1. Funding for research

The PM Challenge document included a number of specific plans for increasing research funding and activity in pursuit of the Challenge commitments. One commitment was to more than double overall government funding for dementia research – through the National Institute for Health Research (NIHR), Medical Research Council (MRC) and Economic and Social Research Council (ESRC) – so that it reached £66.3m in 2014/15. According to *The State of the Nation* report in 2013, government funding for dementia research had grown from £28.2 million in 2009/10 to £52.2 million in 2012/13. In addition, Alzheimer's Research UK funding grew from £4.2 million to £6.8 million, and Alzheimer's Society funding from £2 million to £5.3 million. We have not seen figures for 2013/14.

Some of the plans set out in the PM Challenge and some of the funding growth concerns **basic and biomedical research** which is unlikely to work through to have impacts on treatment, care or support for some years. We note these particular plans here, but do not discuss them further:

- The MRC allocated over £3m to support the UK brain bank network.
- The MRC is also a leading partner in two international initiatives in the area of neuro-degeneration research: the European 'Joint Programming' initiative (JPND) and the Centres of Excellence Network in Neurodegeneration (CoEN). Some of the JPND-supported studies (funded through the ESRC in this case) are concerned with 'healthcare evaluation', and four of these relevant to dementia will be partly conducted in England. They are just starting.
- The MRC Laboratory of Molecular Biology (LMB) moved into new facilities with an expanded budget of £29m with a major part of its research dedicated to dementia/neuro-degeneration.
- MRC made a major additional investment in dementia research using the BioBank, with the aim of rolling out brain scanning to 50,000–100,000 participants.
- The *UK Dementias Research Platform (UKDP)*, led by John Gallacher, University of Cardiff (2013-18; £5 million funding from MRC) is a multi-centre project of six universities that will create a single, easily accessible resource for medical research in dementia by bringing together 22 existing UK cohorts (together including 2 million participants), and linking cohort data with biomarker data and dementia outcomes from routine clinical care records. It will also develop a methodology to identify dementia cases from within general population cohorts, deliver cognitive tests sensitive to dementia-related change to over 100,000 healthy and prodromal cohort members, and establish a dementia discovery cohort of 10,000 cases focused on the prodromal stages. The resource will be used to identify cognitive, genetic, physiological and imaging markers whose changes are associated with early stages of dementia before and around the time of diagnosis.



- Martin Rossor, UCL, is developing a *library of nerve cells* taken from people with genetic traits that cause them to develop dementia. This valuable resource will be made available to scientists around the world.
- The establishment of a national institute for dementia research is currently under discussion.

There has been substantial investment (£36m committed over 5 years) for a new NIHR dementia **translational research** collaboration to turn biomedical discoveries into practice changes that have the potential to improve health and wellbeing.

There have also been developments in the funding and initiation of care and **support research** for people with dementia and carers, including:

- Of the 13 new NIHR *Collaborations for Leadership in Applied Health Research & Care (CLAHRCs)* funded for 2013-18, four (Oxford; South West Peninsula; East; Wessex) have dementia as one of their designated priority themes. In addition, most of the other nine CLAHRCs are including long-term conditions and frailty in older people, which will presumably encompass some work on dementia.
- The 14 *Integration Pioneers* include four with a major focus on dementia. These will be evaluated over the coming few years.
- The NIHR completed a themed call for proposals in dementia research (jointly with the ESRC), committing £22 million to new projects. The 21 projects funded include studies of: memory and brain function, antibiotics, screening, the better management of behavioural and psychological symptoms, statins to prevent delirium, pain management, shared decision-making, better treatment of people with dementia with hip fractures, visual impairment, homelessness, comorbid 'physical' health problems, assistive technology, cognitive rehabilitation, and dementia care mapping.
- NIHR and ESRC are jointly supporting a £20 million programme of social science research on dementia, announced in December 2013 and starting in early 2014. We have referred to some of the six projects already. They are looking at: (1) neighbourhoods and networks of people with dementia, including dementia-friendly neighbourhoods (John Keady, University of Manchester, 2014-19); (2) how social and lifestyle changes may help reduce the risk of developing dementia and disability, and the effectiveness of a social intervention to support independence and quality of life (Martin Orrell, UCL, 2014-19); (3) increasing knowledge of agitation, and developing and implementing a manual to train staff to reduce agitation and improve quality of life in care homes (Gill Livingston, UCL, 2014-19); (4) modelling the future costs, outcomes and cost-effectiveness of ways to support people with dementia and their carers (Martin Knapp, LSE, 2014-18); (5) identifying what helps people to live well in the context of having dementia or caring for a person with dementia (Linda Clare, Bangor University, 2014-19); and (6) investigating the effects of visual aids on the wellbeing and quality of life of people with dementia and carers (Sebastian Crutch, UCL, 2014-18).
- The NIHR School for Social Care Research has supported a range of projects in the dementia area (or relevant to dementia). These include: (1) Improving effective integrated home support for people with dementia and their carers: development of a service fidelity index (Robert Jones, University of Nottingham, completed); (2) Developing best practice in social care and support for adults with concurrent sight loss and dementia within different housing settings (Karen Croucher, University of York, finishes April 2014); (3) Using participatory video to enhance social participation and wellbeing for people with dementia in residential care (Andrea Capstick, University of Bradford, finishes April 2014); (4) The roles of carers in assessment, support planning and managing personal budgets, especially for people with cognitive or communication impairments (Wendy Mitchell, University of York, finished);



(5) Direct payments systems for people who lack the mental capacity to consent (Eva Cyhlarova, Mental Health Foundation, finished). (We did not find publications from or current research in the field of dementia being undertaken within either the NIHR School for Primary Care Research or School for Public Health Research.)

*A Route Map for Dementia Research* was published by the Ministerial Advisory Group on Dementia Research (MAGDR) in June 2011, and has provided a platform for recognising the greater role that research should play in improving treatment and care, in turn leading to some of the above initiatives. The DH is also supporting capacity-building efforts in dementia research, focusing on the medical and nursing professions.

## 2. Participation in research

An important corollary of the investment in research has been the opportunity for people with dementia and carers to participate in studies. The commitment in the PM Challenge was to work towards recruiting 10% of dementia patients into clinical trials. As the number of people with dementia who are diagnosed and treated grows, so this 10% target becomes harder to achieve. (We were not clear whether only 'clinical trials' should be included in this count, given that there are other types of dementia study underway.) The NIHR Dementias & Neurodegenerative Diseases Research Network (DeNDRoN), one of NIHR's Clinical Research Networks, was established in 2005 to encourage and facilitate research in dementia (as well as other neurodegenerative conditions).

The *State of the Nation* report noted that in 2012/13 there were 11,859 people with dementia recruited to studies for which DeNDRoN was the main network, equivalent to 3.7% of people diagnosed with dementia (although if the estimate of diagnosis was to change, this percentage would also need to be recalculated). Figures provided to us (14 April) by Martin Rossor, National Director for Dementia Research (see below), suggest that the number was 12,500 in 2013/14 (3.9%) and is projected to be 13,500 in 2014/15 (4.2%). Continued efforts are being made to enrol more people into dementia studies, including through the 'Join Dementia Research' campaign (joint between NIHR, Alzheimer's Research UK and the Alzheimer's Society, currently being piloted) that seeks to enable people to register their interest in dementia research and be matched with potentially suitable studies.

Care homes accommodate many people with dementia, but relatively few studies have been conducted in these settings. One important reason for this has been the cost (in terms of staff time) of participation in research. The ENRICH (Enabling Research in Care Homes) toolkit was developed by the Dementia and Neurodegenerative Diseases Research Network (DeNDRoN), drawing on work from the NIHR School for Social Care Research. The aim of ENRICH is to support the growth of research to improve quality of life and quality of care for all care home residents, especially people with dementia. An evaluation of ENRICH found a small but increasing number of studies involving care homes (Davies et al 2014). It also demonstrated that care home research networks have the potential to increase recruitment to studies, but 'highlighted the need for care home training for researchers.' A major contribution of ENRICH is to support the promotion of research in the non-NHS sector.

## 3. G8 Dementia Summit

In December 2013, Health Ministers and some Science Ministers from the G8 nations met in London for a Dementia Summit. This unprecedented event was initiated by the UK as part of its G8 Presidency. At the end of the Summit the Ministers issued both a Declaration and a Communique. These statements spelt out many ambitions, including a joint commitment to research. Details agreements in the Declaration included:



- ‘... to identify a cure or a disease-modifying therapy for dementia by 2025 and to increase collectively and significantly the amount of funding for dementia research to reach that goal ...;’
- increase the number of people in dementia related research studies;
- ... identify strategic priority areas, including sharing initiatives for big data, for collaboration and cooperation;
- develop a co-ordinated international research action plan which accounts for the current state of the science, identifies gaps and opportunities, and lays out a plan for working together to address them;
- encourage open access ... to all publicly funded dementia research and to make the research data and results available for further research as quickly as possible...;
- take stock of our current national incentive structure for research, ... and consider what changes could be made to promote and accelerate discovery and research and its transformation into innovative and efficient care and services.’

#### 4. Research publications

PubMed is an online facility managed by the US National Library of Medicine; according to its website it ‘comprises more than 23 million citations for biomedical literature from MEDLINE, life science journals, and online books. Citations may include links to full-text content from PubMed Central and publisher web sites.’ Using the data contained within PubMed we can see from Table 3 the trends in British research publications between 2009 and 2013 for dementia and for some other long-term conditions. The number of publications in the dementia field grew faster than the numbers in prostate cancer, diabetes, COPD or stroke. (We offer this analysis simply for illustrative purposes. We did not have time to search other data bases that might better cover social care studies.)

**Table 3 Trends in British publications in dementia and other fields, 2009 to 2013**

	Dementia	Prostate cancer	Diabetes	COPD	Stroke
2009	596	368	1430	279	784
2010	638	408	1596	264	859
2011	726	431	1633	297	916
2012	730	465	1681	322	971
2013	820	439	1771	348	1054
<b>Change 2009-13</b>	<b>38%</b>	<b>19%</b>	<b>24%</b>	<b>25%</b>	<b>34%</b>

Not only has the quantity of research output increased, but there is also evidence that the *quality* of research conducted in the UK has improved. In 2007, 101 of the 686 (13.9%) articles on Alzheimer’s disease included in the Web of Science were among the 10% most cited articles in the world (Menard 2014). By 2012 the proportion of highly cited articles had risen to 190 of 1034 (17.0%).

There is obviously a lag between the funding of a research study and (most of) its published outputs, and so the trends in Table 3 cannot be attributed to commitments made in the PM Challenge, and probably not to the impact of the National Dementia Strategy, but they show a welcome growth in scientific attention paid to dementia.



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### **5. National Director for Dementia Research**

NIHR has appointed the country's first National Director for Dementia Research: Martin Rossor, Institute of Neurology, University College London. As announced on the NIHR website, 'This new post will provide the leadership needed to facilitate and support the Department of Health's research response to commitments under the Prime Minister's Dementia Challenge and the G8 Dementia Summit. This will involve activity across NIHR activity as well as work with single components of NIHR. Other work will involve engagement with external stakeholders, such as NHS England, research charities and other research funders, including industry. Martin will draw on the expertise of the Evington Group, and work with the Dementia Innovation Envoy. Professor Rossor will work closely with staff in the DH R&D Directorate, with the NIHR Clinical Research Network, particularly Jonathan Sheffield and Ian McKeith, and with other NIHR research infrastructure, especially Simon Lovestone and the NIHR Dementia Translational Research Collaboration, as well as Alistair Burns, NHS England's National Clinical Director for Dementia.'





## 7. Gaps and remaining obstacles

The third of the policy questions that we were asked to address was: What are the gaps and remaining obstacles to delivering against the commitments in the *Prime Minister's Challenge on Dementia*? The subsections below therefore look at the gaps and remaining obstacles in relation to:

- Diagnosis and memory services
- Post-diagnostic support
- Support for carers
- Hospital care
- Workforce
- Care homes and home care
- Dementia-friendly communities

Where possible, we try to identify the obstacles to be overcome to fill the gaps and so achieve further improvement.

We have already used evidence from a number of relevant datasets to populate earlier sections of this report, and we have also considered data availability for the purposes of addressing evidence *gaps*. In Appendix A we have collated short summaries of a range of health and social care datasets that either contain information about people with dementia and their caregivers, or that might be expected to do so in the future to enrich what is known about the experiences of people with dementia and their carers.

### 7.1 Diagnosis and memory services

Regardless of the uncertainties about how best to estimate the **diagnosis rate**, it is clear that a large proportion of people with dementia were still not being diagnosed in 2012/13. This implies a continuing need to promote population awareness of the signs of dementia, and to encourage a range of professionals across health, social care and other relevant systems (such as housing) of the benefits of timely diagnosis, recognition and response. Campaigns such as Dementia Friends should help in this general regard. An obstacle to higher diagnosis rates appears still to be the scepticism in some quarters as to the benefits of timely diagnosis, linked in part to the perception that post-diagnostic support is inadequate in availability and/or effectiveness, and therefore the possibility that unrealistic expectations may be raised and/or that scarce resources could be diverted away from areas where some clinicians feel they could be more effective.

Attempts to increase diagnosis rates and the number of referrals to memory clinics may also include:

- raising awareness and knowledge of GPs and hospital doctors (although noting that some initiatives – such as the inclusion of the dementia element in the *NHS Healthcheck* programme and Directed Enhanced Service – are still less than a year old, yet were identified by the NHSE report on CCGs as important contributors to improvement);
- increasing awareness among the public and professionals as to the benefits of timely diagnosis;
- improving information to the general public about locally available services;
- continuing to provide appropriate financial incentives (DES; CQUIN);
- understanding the reasons for wide inter-area variations in the time taken to provide a diagnostic assessment (reported to be as long as 25 weeks in some areas);
- understanding the reasons for greater success in increasing diagnosis rates in other countries, such as in Scotland.





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## 7.2 Post-diagnostic support

One of the challenges of developing and improving post-diagnostic support is the complex context in which it is commissioned, delivered and monitored: health, social care, housing and disability benefit systems are all potentially involved; providers span the public, private and third sectors; funding routes include contracts from public agencies, direct payments and self-funding; staff in some service areas are low-skilled and with high turnover rates; extending choice for service users and carers is a key policy and practice emphasis, yet some people lack capacity; and change is managed through locally driven processes rather than by central direction.

As noted earlier, developing and ensuring availability of effective post-diagnostic support would help to encourage diagnosis, since – it has been argued – a perceived lack of appropriate support is a barrier.

Available evidence suggests promoting **community navigator**, case or care management, or similar ‘brokerage’ approaches. While approaches would likely need to vary according to local circumstances, a common feature is that effective approaches require clearly designated staff resources and time, as well as manageable caseloads. They need to operate within well-coordinated wider systems of health and social care provision. Appropriately resourced brokerage has the potential to realise savings from the emergency inpatient admissions or premature care home admissions that might be avoided.

In addition to such ‘case-level’ coordination, there is clearly also a need to continue to promote more **strategic coordination of health and social care** – and other relevant sectors (such as housing and disability benefits). As we noted in Section 4.2.2, there is only limited evidence on what works, despite ‘integration’ being a policy emphasis for what has now been a few decades. A number of models are emerging for integrating dementia care (recognised, for example, by the Innovation Challenge Prize and good practice case study work by the King’s Fund.). The programme of Integrated Care Pioneers announced in 2014 includes four projects that explicitly focus on dementia care. With appropriate attention given to transferability issues, the Pioneers have the potential to generate learning for other localities. It is particularly important that the over-arching management and evaluation of the Pioneers programme as a whole does not miss the opportunity to learn and communicate specific lessons for dementia care. The £3.8 billion Better Care Fund also provides an opportunity to integrate post-diagnostic support for people with dementia, although there is little evidence in this general area to provide guidance. However, the money is being taken from existing service delivery, requiring the new integrated models of care to deliver immediate equivalent benefits. Money for the fund will come from both NHS and local authority budgets with the greater proportion from the NHS, made possible by an expected reduction in hospital activity. All of this involves difficult financial and cultural challenges. The fund is not offering additional money, but a new way of working with joint decisions made locally. Because the resources are taken from existing service delivery, this requires the new integrated models of care to deliver immediate equivalent benefits.

It is important that **evidence-based interventions** are available to people who would benefit from them. NICE guidelines will help to point the way, but the complex context noted earlier erects its own barriers. For example, there is robust evidence that cognitive stimulation therapy (CST) is both effective and cost-effective in mild-to-moderate dementia, yet it is still not offered as widely as it might (although it is



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not easy to find out how widely it is available). CST – which includes reminiscence as part of its approach – can be delivered to groups of people with dementia in day centres or care homes, and staff in those settings can be trained to deliver it. It has been evaluated as an individualised intervention (led by Martin Orrell, UCL) and results will be in the public domain quite soon. But almost all day centres and care homes are in the private or third sectors, and funded from a variety of sources. It is not clear whether it is the funding arrangements or other factors that have limited roll-out.

We do not mean to privilege CST over other treatments or care arrangements in this discussion; we simply offer it as an example of an approach that has solid research evidence behind it, that is liked by people with dementia, but which appears (although we do not know for sure, because there are no reliable data) not to be as widely available as it could be.

An area of post-diagnostic support where research evidence is less plentiful but which is getting increasing emphasis is **end-of-life care**. A linked topic is advance care planning. Improvements to both may have benefits to people with dementia and their families, as well as potentially reducing the need for acute hospital admission. (A systematic review of the economic case for advance care planning in the UK will soon be published; Dixon et al 2014). Better community support looks to be an effective and affordable approach on the basis of the (albeit limited) evidence available. An evaluation of Admiral nursing has been conducted but is as yet unpublished.

Government fiscal policy includes reductions in local government funding, which in turn has led to reductions in **spending on social care**. This poses a challenge. While it is clear that there is unmet need for community-based social care, more information is needed about the impact of reductions to social care budgets on people with dementia and their carers. Critics of the push to improve diagnosis rates have argued that this would increase pressure on currently available diagnostic and post-diagnostic services. There could also be a concern that reduction in spending could lead to more crisis hospital admissions and care home admissions for people with dementia, although robust evidence is hard to find. Jose-Luis Fernandez and colleagues (PSSRU at LSE), in unpublished analysis for the Department of Health of data collected between 1995 and 2000 in the ECCEP project (Evaluating Community Care for Elderly People; see Davies et al 2000), found that community-based social services reduce hospital costs by around a fifth of the cost of the social care support. The effect was greatest for people with most dependency in relation to activities of daily living (ADL) and instrumental ADLs, living alone, with cognitive impairment and with the most stressed and anxious caregivers.

Additional investment in community-based social care – ‘lower-cost care, closer to home’ – might in principle be funded from savings elsewhere in the health and social care systems, but getting resources released is never easy, and there is little spare money available for ‘transition costs’. Service integration initiatives and the Better Care Fund might offer some opportunities.

The need for greater **integration** of services is recognised but at present there is little scope for assessing the extent or success of integration. Current work to develop measures of patients’ experiences of integration (in general, not just for people with dementia) will assist.



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### 7.3 Support for carers

Although access to assessment, information, advice, support and respite care all appear to have improved in recent years, there is some distance still to travel. Support offered to carers should be better informed by evidence, and this is an area where there is still a paucity of evidence-informed guidance. We have already mentioned the results from the START study: a manual-based coping strategy delivered at relatively low cost by psychology graduates had significant short- and medium-term (up to 24 months after end of intervention) health and quality of life benefits for family carers and also cost-effectiveness gains (Livingston et al 2013, 2014; Knapp et al 2013). Further analyses show that, over a longer period the intervention appears likely to delay admissions to care homes. Although START has already attracted interest, it is uncertain how well or how quickly this evidence might translate into changes on the ground.

Another intervention that appeared to show benefits was when personal budgets (social care) are held by carers, either on behalf of people who use social care services or on their own behalf. The IBSEN evaluation of 'individual budgets' offered encouraging evidence, but, according to a Carers Trust report 'there is still confusion amongst carers over their eligibility for personal budgets and direct payments, and limited understanding about how personal budgets can be used.' That confusion may stem from the financial and needs-based eligibility thresholds. Again the issue seems to be one of translation of evidence from evaluation (in this case of a national pilot) into routine practice.

### 7.4 Hospital care

There is evidence that many people with dementia admitted to acute hospitals (one study suggests 40%) could be supported and treated in their own homes (or in care homes if that is their normal place of residence). Given the serious risks of unnecessary admissions for such vulnerable people (e.g. development of delirium; increased confusion), it is important that the health and social care systems strive to minimise such admissions. This requires coordinated local policies between secondary, primary, community, ambulance and social care. CQC evidence on the much higher rates of hospital admission for people living in care homes with dementia compared to those without dementia are pertinent here too. The recently published themed inspection by CQC (2014) pointed to poor quality in some acute hospitals and poor transition between services, even though overall quality (across the full sample of facilities) was found to be good.

### 7.5 Workforce development

Despite considerable progress in the provision and uptake of training opportunities by health and social care staff, it is important that more staff have training and are aware that people with dementia have distinct needs. It is not known what impact e-learning modules and maps for care pathways will have, and so evaluation of these initiatives is needed to help identify the optimum approach. Improving training and education curricula for care givers, especially opportunities to enhance qualifications, would help achieve this aim.

Care staff may value the flexibility that care work offers and relatively high levels of staff turnover may be a long-term feature of the sector. However, improving staff retention would surely be beneficial (to embed training, to ensure continuity of care, to raise care standards, to reduce risk of abuse, and thereby to improve outcomes), which means addressing terms and conditions of employment, difficult though that will obviously be given the structure of the provider market and funding constraints.



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## 7.6 Care homes and home care

Evidence from CQC suggests a need for better understanding of quality of dementia care in care homes, including the factors that underpin and inhibit high-quality care, as well as a need for effective self-improvement tools for care homes providing dementia care. CQC evidence also suggests that homes specifically registered to provide dementia care may be less well-funded than other homes.

Concerns have been expressed about the inadequate duration of homecare visits (e.g. 'the 15 minute visit'), including in the National Dementia Strategy, but also more recently (for example, as in the Leonard Cheshire Disability report 2013). Visits of such short duration limit what even well-trained staff can achieve, and are also likely to affect recruitment, retention and morale. Indeed, given levels of staff turnover in home care (over 20% annually according to the NMDS-SC), the organisational culture of providers and regulatory safeguards are also important for ensuring appropriate care standards, alongside training.

The CQC (2014) themed inspection of dementia care in care homes and acute hospitals stressed the importance of 'comprehensive assessments that support personalised care – delivered by knowledgeable, skilled staff who have the time to care and in an appropriate environment' (p.44). Other areas given emphasis include 'sharing information between providers, managing risks and monitoring and improving the quality of care' (p.44).

## 7.7 Dementia-friendly communities

Considerable emphasis is being placed on improving awareness about and attitudes towards dementia through campaigns such as Dementia Friends. What is needed is better evidence on how attitudes have changed and with what consequences.

Although greater awareness and more positive attitudes might be seen as desirable achievements in their own right, it would also be very useful to know what consequences might flow as a result. To what extent do referrals for diagnosis increase as a result of greater awareness among the general public? To what extent does a reduction in the stigma of dementia encourage individuals or families to seek assessment? Are people with dementia more likely to be meaningfully involved in decisions that affect them? Do improvements in awareness and attitudes eventually feed through to have an impact on health outcomes and quality of life, or patterns of admission to care homes or hospital, speed of discharge, and system-wide costs?

There is no evidence with which to answer these questions, but some learning might be possible from other areas. For example, public beliefs about people with mental illness influence individual outcomes such as self-stigma, help-seeking and empowerment among people with mental illness (Evans-Lacko et al 2012). Lesbian, gay, and bisexual students living in US states and cities with more protective school climates report fewer past-year suicidal thoughts than those living in states and cities with less protective climates (Hatzenbuehler et al 2014). Another US study shows that attitudes held by clinicians about race, particularly stereotyping about race and treatment compliance, are associated with markers of poor visit communication and poor ratings of care. In European countries with more negative public attitudes about mental illness, people who have experienced these illnesses face greater difficulties in getting and keeping paid employment, and the disadvantage faced worsened during the economic recession (Evans-Lacko et al 2013).



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## 8. Priorities and information needs

The final policy question that we were asked to address was: What are the implications of the analysis of developments since 2009 both for the priorities for action in the final year of the *Prime Minister's Challenge on Dementia* and for the information needs to monitor future progress? We will refer to some of the available datasets described Appendix A.

### 8.1 Diagnosis and memory services

We raised questions earlier about the measurement of the dementia diagnosis rate, with issues identified in relation to both the numerator (diagnosis) and denominator (prevalence). During 2014/15 the GP Extraction Service could provide better data on the number and characteristics of people with a diagnosis of dementia than the QOF.

There are other possibilities for data collection to help monitor and understand future trends, and thereby inform policy and practice discussion. Changes to cognitive measures in the English Longitudinal Study of Ageing (ELSA) for the 2014/15 Wave – covering approximately 11,000 people aged 50 plus – will contribute further valuable information in early 2016 (see Appendix A, section 2), and will generally enhance ELSA as a resource for dementia research across many health, lifestyle, socio-demographic, economic and other domains. Although not helpful until the longer term, and for a smaller sample, the ‘coming of age’ of members of the National Survey of Health and Development cohort (born in 1946) will begin to deliver rich data to aid interpretation of life-course risk factors given that the health and lifestyles of this cohort have been intensively studied since before birth.

The Delphi study led by Martin Prince at King's College London and funded by the Alzheimer's Society (recently published) offers an estimate of prevalence that builds on CFAS II and other expertise. If age-specific incidence rates were assumed to be constant, it would be possible to generate a stable denominator for calculating subsequent annual diagnosis rates. An assumption about changing incidence rates could be built into the calculation.

Given difficulties in accurately measuring both the numerator and denominator, we floated the suggestion earlier that an alternative to monitoring diagnosis rates would be to monitor the *number* of people reported by GPs as having been diagnosed with dementia. As noted earlier, if this approach is used then there has been steady improvement of about 7% a year since 2009.

Maps of the country in the 2013 *State of the Nation* report showed wide area-level (CCG) variations in diagnosis rate across the country, and also wide variations in waiting times. There is a need to understand the extent to which those reflect artefacts arising from data deficiencies, random variation or real differences. The latter need to be investigated to see if rates are associated with social, geographical and population characteristics of CCGs. Variations may also reflect differences in professional practice and judgment as to the usefulness of diagnosing dementia. The latter could be explored during NHSE visits of the kind carried out earlier in the year.

There may also be important variations in social, economic and lifestyle factors that are not adequately captured in the algorithm that generates local estimates of prevalence, and/or which have an impact on diagnosis rates. Ethnicity is also likely to be relevant as both a source of difference in prevalence and an influence on referral rates, but is not used to generate estimates of prevalence or diagnosis rates for the map. Better targeting of efforts in certain communities could bring important improvements.



Concerns have been expressed that there may be lower rates of use of memory assessment services and possibly higher prevalence rates in **Black, Asian and Minority Ethnic communities**. The reasons for this inequality need to be understood. Community navigator models may assist, but again research is needed to test this possibility. As noted earlier, the Alzheimer's Society is testing an approach in South Asian communities to raise awareness and improve access. Hopefully, generalizable lessons for other communities will emerge.

There is a need for better information on how best to provide and arrange memory services. Currently there is considerable variation in their staff-mix, methods of clinical assessment and provision of post-diagnostic care. In addition, as assessment is increasingly undertaken in primary care led by GPs with a special interest (encouraged by Enhanced Service payments to general practices and reductions in expenditure for secondary care for CCGs), any evaluation of the impact of diagnosis and post-diagnostic support will need to encompass such developments of integrated care. Whilst there will always be a need for some local differences to respond to local circumstances, it is suggested by the maps of diagnosis rates and waiting times that some part of the observed variation is clearly unacceptable if the aim is to equalise access to diagnosis and thence post-diagnostic support.

It is unclear whether there is sufficient capacity in the current provision of **memory clinics** to meet additional referrals, although if more patients are managed entirely in primary care there may be no shortfall. The current capacity of memory clinics requires investigation to establish whether more resources need to be committed to this area or whether improvements in productivity could cope with any increase in referrals. Indeed, the effectiveness and cost-effectiveness of different models of memory and assessment services is currently unknown although information on the organisation and components of secondary care memory services will emerge in 2015/16 from the study funded by DH PRP and led by Sarah Smith at the London School of Hygiene and Tropical Medicine. This should help inform longer-term discussion as to whether or not increased provision is needed. That study will also provide evidence as to the impact of diagnosis and post-diagnostic support over the first six months on the quality of life of people with dementia and their carers.

## 8.2 Post-diagnostic support

Some of the scepticism about the benefits of diagnosis arises from the extent of rigorous evidence as to the advantages of post-diagnostic support for the people with dementia and their carers.

We noted earlier that there are **treatment and support approaches** which have a good research base to indicate both effectiveness and cost-effectiveness, but which appear not to be as widely available as a commitment to high-quality post-diagnostic support would imply. We used cognitive stimulation therapy (which includes reminiscence approaches) as an illustration. However, there are no data on the extent to which cognitive stimulation therapy or other evidence-based treatments are used, or on their volume, nature or quality. The absence of data on CST and other treatments is merely an inconvenience for a report such as this, but a much more pertinent consideration is that it presumably reflects an absence of knowledge both locally and nationally about what is being delivered. Louise Robinson, University of Newcastle, was awarded an NIHR Translational Professorship in 2012 to improve the quality of community care for people with dementia and their families, and we believe





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that one area of her work is the translation (or not) of CST research evidence into practice, and the reasons why.

More generally, evaluation is still needed to examine **psychosocial** and other alternatives to pharmacological management of challenging behaviour, particularly with recognition of the inappropriateness of antipsychotic medications. There is still very little available evidence to guide commissioners or providers.

Other areas where the available research evidence looks sparse (specifically in relation to people with dementia) include: needs associated with incontinence and continence services; personal budgets; advance care planning; the NHS Choice portal.

We also identified a need for research that explored different models of brokerage (including **case or care management, dementia advisors, dementia support workers** and so on), including a better understanding of how best to deploy and perhaps target such arrangements in different local organisational and funding contexts. Any benefits of such approaches might not fully reveal themselves in the short run, which would have implications for research design.

Models of integration between health, social care and other relevant services need evaluating and some are being explored now in the Integrated Care Pilots. The roles and effectiveness of Health and Wellbeing Boards in aiding or encouraging coordinated strategic working also need to be understood.

There are no data on the number or quality of integrated care plans for people with dementia, which are surely prerequisites for more coordinated post-diagnostic support. We found a few local examples, each of them offering encouraging evidence of improvements in effectiveness, and there are probably other local examples that have not been well-documented (and certainly evaluated), but it is not possible to get an overall picture of progress in this regard. There is a need for robust evaluation of these approaches, and also for the local transferability, feasibility and acceptability of particular models of integrated post-diagnostic care to be understood. (The difficulty experienced in the CARE-DEM project to transfer the PREVENT model from the US provides an illustration of the potential challenge.)

It is obvious that there is need to understand the relationships between levels of spending (social care, health care, self-funding) and the outcomes for people with dementia and their carers. This is not just to know what the consequences might be of reduced levels of local authority social care spending – including spending on what might be seen as ‘preventive’ home care – but more generally to understand how to get the biggest impact from necessarily constrained public and private budgets. Nationally available data – through RAP for example – are not up to the task.

On the question of **data**, we understand that, as part of its work on post-diagnostic support, the DH is planning to introduce a user experience indicator in both the Adult Social Care Outcomes Framework (ASCOF, 2F, currently held with a place-holder) and the National Health Service Outcomes Framework (NHSOF, currently held with a place holder 2.6(ii) effectiveness of post diagnosis care in sustaining independence and improving quality of life). DH is considering proxy measures from the GP Patient Survey (GPPS), the Personal Social Services User Experience Survey of Carers and the Alzheimer Society Survey as appropriate vehicles for measuring post diagnosis support in the interim. The limitations of these indicators need to be noted. The GPPS is a postal survey with a low overall response rate (35%). In addition, it is estimated





that, unlike for other long-term conditions, people with dementia are seriously under-represented with only about 25% of the expected numbers responding. Questions in the survey are also very broad (covering feeling involved, listened to, and so on). There have also been improvements in the identification of people with dementia in HES data, although there is still some way to go before these can generate the kind of intelligence needed for local or national decision-making.

Potential and planned changes to the Health Survey for England (HSE) and the English Longitudinal Study of Ageing (ELSA) may generate more information on post-diagnostic support, although it is not possible to be more specific at this stage. Referrals, Assessments and Packages of Care (RAP) data will be replaced next year with the Short and Long Term support data collection (SALT) and will include a new category or 'primary support reason' of 'problems with memory and cognition', separately recorded for those aged under and over 65. The Health and Social Care Information Centre was planning, as part of the care.data programme, to produce Care Episode Statistics (CES) covering data extracted from GP systems (including prescriptions, referrals and results of clinical tests), linked to Hospital Episode Statistics (HES) and adult social care data. In Appendix A we offer further details of these and other data collections.

Evidence will flow from new **research studies**. Three studies commissioned by NIHR/ESRC in 2013-14 can be mentioned here. One, called PRIDE, is led by Martin Orrell, University College London (finishing in 2019), and will design and evaluate an intervention based on social and lifestyle changes delivered in memory services. The IDEAL study, led Linda Clare, University of Bangor (finishing in 2018) will identify what helps or hinders people to live well in the context of having dementia or caring for a person with dementia. The MODEM multi-centre study, led by Martin Knapp, London School of Economics (finishing February 2018), will model the outcomes and cost impacts to 2040 of making more widely available a range of evidence-based care, support and treatment arrangements for people with dementia and carers. In other words, what would be the health, quality of life and economic benefits nationally of giving people optimal care and support?

Despite all these initiatives, the influences of social, economic and lifestyle factors on use, effectiveness and cost-effectiveness of post-diagnostic support arrangements need investigating. There are also implications for preventive strategies.

### 8.3 Support for carers

Information on the impact of memory clinics on people with dementia and their carers' quality of life will become available in 2015 from a study currently funded by the DH and led by Sarah Smith at LSHTM. This will provide evidence about the impact that the diagnosis and initial six months of post-diagnostic support has on the quality of life and the burden of responsibility for carers. It will be able to relate those outcomes to changes in the level of formal health and social care received as a consequence of diagnosis.

More generally, there is still relatively little evidence on what works in terms of carer support. Nor is very much known about the consequences of carer wellbeing (and 'burden') for the wellbeing of individuals with dementia. A range of research designs is needed to generate the intelligence needed for better commissioning and provision.



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## 8.4 Hospital care

Although many hospitals report improvements in assessment of all older patients on admission, there appears to be **under-reporting of patients with dementia** in Hospital Episode Statistics. (We noted earlier our uncertainty about the robustness of the estimate that 25% of people in hospital beds have dementia, given that this figure comes from two small local studies.) Without accurate estimates it is not possible to gauge the potential to improve wellbeing through more appropriate inpatient care, or to reduce expenditure or improve cost-effectiveness by diversion or more rapid discharge. There is a need for:

- improvement in the completeness and accuracy of HES data to record admissions of people with dementia. This requires increasing the awareness of clinical staff to record dementia as a secondary diagnosis in the case record and for clinical coders to ensure it is included in the HES record.
- assessment of the impact of the CQUIN introduced in April 2012 should be rigorously assessed to see if further actions need to be instituted.
- assessment of the proportion of hospital beds occupied by people with dementia. This could be achieved by means of a national bed census as part of the next National Audit of Dementia, currently being commissioned by NHSE via HQIP.
- assessment of hospitals' recognition and awareness of the needs of people with dementia. Further improvements can and should be made. The next National Audit of Dementia should encompass information on patients' moves between treatment areas.

The **Dementia CQUIN** introduced (from April 2012) financial incentives for identification of patients with dementia on admission, assessment of all patients for dementia or other causes of cognitive impairment, and referral on discharge for follow-up investigation and care. Adding an incentive for having a dementia care pathway or in-hospital protocols would potentially bring benefits.

The 2013/14 CQUIN rewarded hospitals that had appointed a **Senior Clinical Lead** for dementia. Subsequently it was found that 81% of acute hospitals had already achieved this. The next National Audit of Dementia should show what impact this incentive has had, particularly on the quality of care in light of the mixed findings from the recently published CQC themed inspection.

Another aspect requiring attention is the avoidance of **inappropriate admissions** of people with dementia. Even in the most dementia-friendly hospitals, admission can exacerbate confusion and cause additional delirium. About 40% of admissions of people with dementia are for conditions such as urinary tract or respiratory infections, which would be better managed in the community. Improvements require the involvement of out-of-hospital services (primary care, community care, social care) coordinated with hospital services and ambulance services. Again, more information on this should be available in the next National Audit of Dementia.

## 8.5 Workforce development

HEE should consider how to support not just traditional training courses and improved routes to gaining qualifications, but also effective mentoring, buddying and practical learning programmes. Greater involvement of people with dementia and carers in recruitment and training might also assist in this regard.



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The *National Audit of Dementia* will be repeated in 2015, with findings available in 2016. The PM's Nursing and Care Quality Forum has called for the introduction of minimum staffing levels. It is unclear what impact this will have on dementia care as NICE guidance on acute adult in-patient wards will not be available until July 2014.

The 'Dementia Roadmap' developed to raise awareness and understanding of dementia among GPs and to encourage them to take up educational opportunities needs evaluation. Similarly, the RCN's principles for improving dementia care in general hospitals should be evaluated to understand what their impact.

The proportions of social care staff trained in dementia care remain very low; indeed, it appears that two-fifths of all social care staff working with older people with dementia hold no qualifications at all. Data in this area are poor, however, and so it would be helpful to get better indicators of numbers of people who have been appropriately trained and trends therein overtime. It would also be useful to know what effect training has on the quality of care (including the ability to introduce evidence-based approaches to care and support) and the quality of life and other outcomes for people with dementia and their carers. High staff turnover rates in social care undermine attempts to establish continuity of care, as well as the ability to offer evidence-based approaches.

## **8.6 Care homes and home care**

We cited earlier the evidence from the CQC themed inspections that there is a need for better understanding of dementia care quality in care homes, and that quality remains highly variable. Hospital admission rates were higher from care homes for people with dementia than from care homes that were not for people with dementia, and they were also less likely to meet safeguarding standards. The themed inspection in care homes and acute hospitals in 22 local authority areas shows that further progress is needed.

CQC also found that homes specifically registered to provide dementia care may be less well-funded than other homes. We do not know whether there are any economic drivers behind poorer outcomes specifically for people with dementia living in care homes, but what we do know from wider evidence is that care home fee levels are associated with quality of care for older people, and that quality ratings of homes are associated with resident wellbeing and outcomes (see Section 4.6 above).

The Care Home Audit tool, currently being piloted by HQIP with 250 care homes that volunteered for participation through SCIE (results expected during 2014), will if successful be made widely available and all care homes encouraged to use it. If data were collected centrally and aggregated, national estimates of the quality of care in care homes, although with the caveat that they would be self-selected and so maybe not representative.

NICE guidelines on home care will not be published until July 2015, and so beyond the final year of the PM Challenge. They will range widely and will include reablement. The technology appraisal will provide an opportunity to generate considerable improvement in awareness of available evidence, not just to underpin the deliberations of the NICE Guideline Development Group (leading in due course to the published guidelines for care and support) but more widely. Evidence is scarce in this area, but what is known is not widely appreciated.



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Although there has been a very marked reduction over recent years in the prescribing of antipsychotic medication for residents of care homes to manage the behavioural symptoms of dementia, there are in fact no national data to allow monitoring or to show trends. One possibility would be to collect these data as part of the Care Home Audit (see above). Such a collection could monitor a wide range of treatment and care arrangements (such as the use of medications to alleviate the symptoms of dementia, antidepressants and psychosocial therapies, for example).

The number of signatories to the Dementia Care and Support Compact has reached 173, according to the figures available in April 2014. No data are collected centrally on the implications of the Compact for improvements to quality of care.

A scoping review by Katharine Orellana (King's College London), commissioned by the NIHR School for Social Care Research, has looked at care home managers, what we know about them and their work, and what are the research gaps; this should be publicly available soon.

The challenge of trying to assess the quality of life of people with severe dementia in care homes is planned to be addressed by the study led by Sarah Smith at LSHTM. Given that many such residents may not have a lay carer to act as a proxy respondent, that research will be investigating the use of dementia advocates to take on such a role. Results should be available by 2016.

## **8.7 Dementia-friendly communities**

In looking for a measure of public attitudes on dementia, the Department of Health could draw on experience being gained in the Scottish Social Attitudes Survey in measuring attitudes to dementia, perhaps funding a similar suite of questions through the British Social Attitudes Survey in England. As noted earlier, it would be useful to know what impacts are achieved as a result of changing public attitudes.



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## 9. Conclusions

Our review of progress in dementia care in England since 2009 has ranged over three main areas: improving health and care, changing public attitudes and harnessing research developments. In each area we described the actions and initiatives taken – particularly those prompted by the National Dementia Strategy and the Prime Minister’s Challenge on Dementia – the improvements observed since 2009, and – in so far as it was possible – also the impacts of these initiatives on people with dementia and carers. The review was not, however, an evaluation of either the National Dementia Strategy or the Prime Minister’s Challenge.

We found evidence of improvements and impacts across most areas, but also gaps in delivery. Where we could identify them, we described the obstacles that have slowed progress. This led us to suggest priorities for action in the final year of the Prime Minister’s Challenge, the information that would be needed to monitor future progress, and related needs for research.

In concluding we briefly summarise key gaps and associated priorities.

- Uncertainty about the diagnosis rate for dementia continues, hampered by difficulties in estimating both the denominator (the underlying prevalence) and the numerator (the number of people diagnosed).
- Although the diagnosis rate appears to be increasing, many people with dementia do not have their condition diagnosed. Without a diagnosis it is not possible to get appropriate (dementia-specific) post-diagnostic support. Efforts to improve the diagnosis rate could include raising public awareness of symptoms and the availability of treatment and support; raising awareness among health, social care and other professionals; clarifying the benefits of timely diagnosis (including access to and quality of post-diagnostic support); and providing appropriate financial incentives.
- There are wide variations across the country in diagnosis rate. Higher diagnosis rates could also be encouraged by targeting efforts on communities with below-average awareness or willingness to refer.
- There is little information on the best models of memory services, and there are currently wide variations in staff-mix, assessment methods and post-diagnostic support. If diagnosis rates increase, it is unclear what capacity there is in memory services to meet the additional demand, although growth in primary care-led assessments might eventually have a bearing on this issue.
- There are wide variations across the country in waiting times for diagnostic assessment. These are unacceptable if the policy aim is to equalise access to diagnosis and post-diagnostic support.
- In organising post-diagnostic support, models of brokerage such as community navigators and care management may be able to support coordinated responses to individuals’ needs and preferences, although research evidence remains mixed. The most appropriate model of coordination will need to be decided in light of local circumstances. Staff time for such coordination needs to be protected by keeping caseloads manageable, or else the potential advantages of such models – to improve quality of life, to reduce emergency inpatient admissions and premature care home admissions, and thereby to release resources – will not be achieved.
- Coordination through community navigator or similar approaches might help address apparently lower access rates from people with dementia in Black, Asian and Minority Ethnic communities.



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- Case-level coordination might work best when the approach is consistent with efforts to achieve better strategic coordination of health and social care (and other relevant sectors). It is not known how many integrated care plans there are for people with dementia, or how good they are.
  - Progress has been made in delivery of post-diagnostic support, although again data limitations hamper a full assessment. It is especially hard to judge whether local health and care systems are delivering evidence-based interventions, and our impression is that is not happening consistently across the country. An example is cognitive stimulation therapy, which is effective and cost-effective in the mild-to-moderate stages of dementia, and also enjoyed by people who receive it, yet which is still not as widely available as it might be.
  - There is little evidence on whether or which psychosocial or other ways to manage challenging behaviour in people with dementia are being used, alongside or instead of medications. Nor is there much evidence on the effectiveness of non-pharmacological management, leaving commissioners and providers with little to guide them.
  - Evidence is also very limited on end-of-life care and advance care planning. Improvement in each has the potential to improve quality of life as well as change patterns of inpatient hospital use.
  - It hardly needs to be said that better support for carers would improve their lives and therefore potentially also the lives of people with dementia, including their ability to continue to live in their own homes if this is their preference. Support arrangements vary across the country, with still relatively little evidence to guide commissioning. The recently published findings from the START study on coping strategies look promising on both effectiveness and cost-effectiveness grounds.
  - Likewise, there is some encouraging evidence that personal (social care) budgets can improve people's lives while also being cost-effective. But many carers remain confused about eligibility and how personal budgets can be used. This is one of a number of areas where better translation is needed from research evidence to practice.
  - Reductions in social care spending since 2010-11 could lead to increases in crisis admissions to hospitals and care homes, although the impact of spending trends specifically on people with dementia and their carers is hard to establish. The preventive role of home care may be undermined by expenditure reductions. 'Transition resources' such as the Better Care Fund might help to break the cycle linking under-provision of community services, higher inpatient and care home admissions, greater spending in those sectors, and hence a shortage of resources to invest in community services.
  - The relationships between levels of spending (social care, health care, self-funding) and the outcomes for people with dementia and their carers are unknown, which makes it hard to know how to get the best out of available public and private resources.
  - More could be done to divert people with dementia from unnecessary admissions to acute hospitals. About 40% of inpatient admissions of people with dementia are for conditions such as urinary tract or respiratory infections, which would be better managed in the community. This requires better coordination between secondary, primary, community, ambulance and social care services.
  - Hospital Episode Statistics on admissions of people with dementia are incomplete and inaccurate, and so the proportion of hospital beds occupied by people with dementia is unknown. This makes it impossible to gauge the potential to improve wellbeing through better inpatient care, or to reduce expenditure or improve cost-effectiveness by diversion or more rapid discharge.



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- Despite significant improvements in recognition and awareness of the needs of people with dementia in inpatient settings, there is still a lot of room for further improvement, as shown by the October 2014 CQC report. Difficulties sometimes arise when patients move between treatment areas, for example. Adding an incentive to the CQUIN for having a dementia care pathway or in-hospital protocols could bring benefits.
  - There has been considerable progress in health and social care staff training, although it is not yet possible to see the effects on quality of care. The impacts of e-learning modules and maps for care pathways are not yet known, for example. Encouragement of effective mentoring, buddying and practical learning programmes might prove valuable. People with dementia and carers are rarely involved in recruitment or training of health or care professionals.
  - Staff turnover rates in social care are high, which threatens care continuity and standards, increases risk of abuse, and generally leads to poor outcomes for people with dementia. Terms and conditions of employment in the social care sector are poor.
  - There is a need for better understanding of the quality of dementia care in care homes. Homes specifically registered to provide dementia care may be less well-funded than other homes, but it is not known whether this has led to poorer outcomes.
  - Data are not routinely collected on care homes, which makes it difficult to monitor arrangements for support, patterns of treatment (for example, antipsychotic medications used to manage behavioural symptoms) or quality of care. The recent CQC report found more good care than poor care, but nevertheless pointed to areas where improvements are needed.
  - Concerns have been expressed about short home care visits ('the 15-minute visit'). It is argued that such short visits limit what can be achieved, while also possibly affecting staff recruitment, retention and morale. Evidence on what works in home care is relatively scarce, although NICE is currently pulling it together in order to draw up guidelines for publication in July 2015.
  - There has been considerable emphasis both on improving awareness about dementia and on changing public attitudes. Success in recruiting individuals as Dementia Friends and Champions, and recruiting businesses and organisations to be dementia-friendly now needs to be matched with further evidence not just on how attitudes have changed but with what consequences, for example in terms of referrals for diagnosis, involvement in decision-making, patterns of admission to care homes or hospital, or quality of life.
  - There has been substantial growth in dementia research, including on post-diagnostic support services and arrangements. Participation in research by people with dementia and carers has also grown, and could be further encouraged through the Join Dementia Research campaign. One challenge now is to commission research to address the many gaps in knowledge identified by this review.





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## Glossary

A&E – Accident and Emergency  
ACPO – Association of Chief Police Officers  
ADASS – Association of Directors of Adult Social Services  
ADL – Activities of Daily Living  
ALCOVE – EU Joint Action on Alzheimer’s initiative  
APPG – All-Party Parliamentary Group  
ASC–FR – Adult Social Care Finance Returns  
ASCOF – Adult Social Care Outcomes Framework  
ASCOT – Adult Social Care Outcomes Toolkit  
AVA – Abuse of Vulnerable Adults Return  
BAME – Black, Asian and Minority Ethnic  
BMA – British Medical Association  
BPSD – Behavioural and psychological symptoms of dementia  
CAKE – Clinical Audit Knowledge Exchange  
CARE–DEM – Collaborative Care for People with Dementia in Primary Care  
CASSR – Councils with Adult Social Services Responsibilities  
CCG – Clinical Commissioning Group  
CES – Care Episode Statistics  
CFAS – Cognitive Functioning and Ageing Studies  
CLAHRC – Collaborations for Leadership in Applied Health Research  
CMHT – Community Mental Health Teams  
CoEN – Centres of Excellence Network in Neurodegeneration  
COPD – Chronic Obstructive Pulmonary Disease  
CQC – Care Quality Commission  
CQRS – Calculating Quality Reporting Service  
CQUIN – Commissioning for quality and innovation  
CRT – Cognitive Rehabilitation Therapy  
CST – Cognitive Stimulation Therapy  
DCAT – Dementia Care Audit Tool  
DeNDRoN – Dementias & Neurodegenerative Diseases Research Network  
DES – Directed Enhanced Service  
DF – Dementia Friends  
DH – Department of Health  
DoLS – Deprivation of Liberty Safeguards  
DOMINO – Donepezil and Memantine for Moderate-to-Severe Alzheimer’s Disease  
DSM – Diagnostic and Statistical Manual of Mental Disorders  
ECCEP – Evaluating Community Care for Elderly People  
ELSA – English Longitudinal Study of Ageing  
ENRICH – Enabling Research In Care Homes  
EQ–5D – European Quality of Life – 5 Dimensions  
ESRC – Economic and Social Research Council  
EVIDEM–ED – Evidence Based Interventions in Dementia – Early Diagnosis  
FACS – Fair Access to Care Services



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FS-ADS – Family Stigma in Alzheimer’s Disease Scale  
GLA – Greater London Authority  
GP – General Practitioner  
GPES – Health and social care information centre General Practitioner Extraction Service  
GPPS – General Practitioner Patient Survey  
GREAT – Goal-oriented cognitive rehabilitation in early-stage dementia  
HEE – Health Education England  
HES – Hospital Episode Statistics  
HQIP – Healthcare Quality Improvement Partnership  
HSCIC – Health and Social Care Information Centre  
HSE – Health Survey for England  
IADL – Instrumental Activities of Daily Living  
IBSEN – Individual Budgets Evaluation Network, research study  
ICD – International Classification of Diseases  
IDEAL – Improving the experience of Dementia and Enhancing Active life: Living well with dementia  
IFS – Institute for Fiscal Studies  
JPND – European Union Joint Programme– Neurodegenerative Disease Research  
KCL – King’s College London  
LGA – Local Government Authority  
LMB – Laboratory of Molecular Biology  
LSE – London School of Economics and Political Science  
LSHTM – London School of Hygiene and Tropical Medicine  
MAGDR – Ministerial Advisory Group on Dementia Research  
MARQUE – Managing Agitation and Raising Quality of Life  
MAS – Memory Assessment Services  
MCI – Mild Cognitive Impairment  
MHMDS – Mental Health Minimum Data Set  
MMSE – Mini Mental State Examination  
MODEM – Modelling costs and outcomes for dementia  
MORI – Market and Opinion Research International  
MRC – Medical Research Council  
NASCIS – National Adult Social Care Intelligence Service  
NCPC – National Council for Palliative Care  
NHSE – National Health Service England  
NHSOF – National Health Service Outcomes Framework  
NICE – National Institute for health and Care Excellence  
NIHR – National Institute for Health Research  
NMDS-SC – National Minimum Dataset for Social Care  
NVQ – National Vocational Qualification  
Ofsted – Office for Standards in Education  
ONS – Office for National Statistics  
PCT – Primary Care Trust



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PDS – Post Diagnostic Support  
PHE – Public Health England  
PIRU – Policy Innovation Research Unit  
PM – Prime Minister  
PPA – Prescription Pricing Division  
PREVENT – Effectiveness of collaborative Care for older adults with Alzheimer disease in primary care: a randomized controlled trial  
PRISMA – Preferred Reporting Items for Systematic Reviews and Meta-Analyses  
PRP – Policy Research Programme, Department of Health  
PSHE – Personal Social Health and Economic Education  
PSS-EX1 – Personal Social Services Expenditure and unit costs  
PSSRU – Personal Social Services Research Unit  
PSSSACE – Personal Social Services Survey of Adult Carers in England  
QOF – Quality and Outcome Framework  
QS – National Institute for health and Care Excellence Quality Standard  
RAP – Referrals, Assessments and Packages of Care  
RCGP – Royal College of General Practitioners  
RCN – Royal College of Nursing  
RCT – Randomised controlled trial  
SALT – Short and Long Term support data collection  
SAR – Safeguarding Adults Return  
SCIE – Social Care Institute for Excellence  
SCN – Strategic Clinical Network  
SHA – Strategic Health Authority  
SOFI – Short Observation Framework for Inspection  
SSCR – NIHR School for Social Care Research  
START – Strategies for Relatives  
TIC – Telephone Interview for Cognitive Status  
UCL – University College London  
UKDP – United Kingdom Dementias Research Platform  
UKHCA – United Kingdom Home Care Association  
VAT – Value Added Tax





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## **Appendix: coverage of dementia in data collections**

In this Appendix we describe a number of health and social care data collections, most of them routine and still current, and their coverage (or not) of people with dementia and/or their carers. In order of appearance, the data collections covered are:

1. ONS Mortality Statistics
2. English Longitudinal Survey of Ageing
3. Cognitive Function & Ageing Studies (CFAS)
4. Hospital Episode Statistics
5. National Audit of Dementia (care in general hospitals)
6. NHS Inpatient Survey
7. RCPsych Prescribing Observatory for Mental Health (POMH)
8. NHS GP Patient Survey (GPPS)
9. HSCIC GP Extraction Service (GPES)
10. Quality & Outcomes Framework
11. HSCIC GP Practice Prescribing, Presentation-level data
12. National Dementia & Antipsychotic Prescribing Audit
13. National Audit of Memory Services
14. National Dementia Care Audit
15. Health Survey for England
16. Referrals, Assessments and Packages of Care (RAP)
17. Personal Social Services Expenditure and unit costs (PSS-EX1)
18. National Minimum Dataset for Social Care (NMDS-SC)
19. Adult Social Care Survey
20. Personal Social Services Survey of Adult Carers in England
21. Abuse of Vulnerable Adults (AVA) Return



## 1. ONS Mortality Statistics

<b>Source</b>	<p>ONS:  <a href="http://www.ons.gov.uk/ons/rel/vsob1/mortality-statistics--deaths-registered-in-england-and-wales--series-dr-/index.html">www.ons.gov.uk/ons/rel/vsob1/mortality-statistics--deaths-registered-in-england-and-wales--series-dr-/index.html</a>  <a href="http://www.ons.gov.uk/ons/rel/vsob1/mortality-statistics--deaths-registered-in-england-and-wales--series-dr-/2009/index.html">www.ons.gov.uk/ons/rel/vsob1/mortality-statistics--deaths-registered-in-england-and-wales--series-dr-/2009/index.html</a></p> <p>Further information and related reports (including methodology):  <a href="http://www.ons.gov.uk/ons/rel/vsob1/mortality-statistics--deaths-registered-in-england-and-wales--series-dr-/2012/index.html">www.ons.gov.uk/ons/rel/vsob1/mortality-statistics--deaths-registered-in-england-and-wales--series-dr-/2012/index.html</a></p>
<b>Design</b>	Cross-sectional.
<b>Timing</b>	Annual. Monthly and weekly reports also available.
<b>Participation/ response</b>	All deaths registered in England and Wales.
<b>Findings</b>	<p>The data includes information by age-group and sex (with one- and ten-year comparisons available), standardized mortality ratios by area of usual residence, and underlying cause of death (classified by ICD-10 code, rules of which are used when more than one cause of death occurred with no acceptable causal sequence), place of occurrence (ie at home or in hospital), years of life lost to mortality from certain underlying causes. This data source also includes a geographical breakdown of mortality statistics.</p> <p>In 2009, deaths in men 6,709 (2.8%) and in women 15,909 (6.3%). In 2012 men 13,984 (5.8%) and in women 29,873 (11.5%).</p>
<b>Limitations</b>	Dementia not necessarily coded as cause of death. Propensity to record dementia on death certificates probably changed over time.



## 2. English Longitudinal Survey of Ageing

<p><b>Source</b></p>	<p>The dynamics of ageing: Evidence from the English Longitudinal Study of Ageing 2002-10 (Wave 5), Institute for Fiscal Studies: <a href="http://www.ifs.org.uk/ELSA/publicationDetails/id/6367">www.ifs.org.uk/ELSA/publicationDetails/id/6367</a></p> <p>Health domain reference tables: <a href="http://www.ifs.org.uk/elsa/report12/rf3.pdf">www.ifs.org.uk/elsa/report12/rf3.pdf</a></p> <p>Social domain reference tables: <a href="http://www.ifs.org.uk/elsa/report12/rf2.pdf">www.ifs.org.uk/elsa/report12/rf2.pdf</a></p>
<p><b>Design</b></p>	<p>Longitudinal study of representative sample of men and women in England commenced in 2002 with 11 000 people aged 50 years and above. Continuation of cohorts in 1998-2001 in Health Survey for England. Face-to-face interviews and self-assessment questionnaires. Data collected every two years.</p> <p>Questions on cognitive impairment have changed over time. Wave 6 (2012/13) has fluid intelligence (number series) but no animal naming. The main aim has been to include tests which are consistent with the Health and Retirement Survey in the US.</p> <p>Wave 7 (2014/15) will introduce some new questions in the cognitive function section designed to get at lower level cognitive problems, to effect a dementia screen with comparable accuracy to the MMSE (TICs, see below) and be more aligned with the cognitive function questions used in the Health and Retirement Study in the US.</p> <p>These new questions include serial 7 (counting back in sevens from 100), backwards counting from 20 and naming objects (cactus, scissors, president etc). Combined with the animal naming questions we have had and orientation in time and self-assessed memory they can be used to calculate a Telephone Interview for Cognitive Status (TICs) score.</p> <p>In addition the ‘diagnosed conditions section’ asks whether a doctor has ever told the respondent they have Alzheimer’s disease or cognitive impairment. If they have previously reported on this and are doing a personal interview, in the interview complex questions are asked to check whether the record of the previously diagnosed condition is correct. The ‘diagnosed conditions tables’ on the IFS website don’t report these data but the number reporting AD or cognitive impairment is thought to be very low.</p>
<p><b>Timing</b></p>	<p>Wave 5 carried out in 2010-11.</p>
<p><b>Participation/ response</b></p>	<p>10,274 participants in 2010/11.</p>
<p><b>Findings</b></p>	<p>Does not identify those diagnosed as suffering from dementia but includes cognitive function defined by measurement of: memory, speed and mental flexibility. The effect of cognition is not explored within the report. Numeracy questions (involving solving mathematical problems) were omitted at wave 5 and literacy questions previously used at wave 2 were reintroduced.</p> <p><b>Cross-sectional (2010/11)</b></p> <p>Mean cognitive function (Table H6a): declines with age in both sexes; women have better memory and executive functioning than men though gap is narrower at older ages and disappears in those aged 80 and over; lowest in the lowest wealth group (Table H6b).</p> <p>Difficulties with getting to services (Tables S8a-b): The percentage of women experiencing difficulties with getting to services typically increases with age, however the trend for men is less clear. The percentage of women reporting difficulties is also greater than the percentage of men doing so. The percentage of Women aged 80+ reporting difficulties is far greater than women of any other age band, and this is also true for men, with the exception of difficulties with getting to a dentist. The lowest wealth band holds the highest percentage of men and women reporting difficulties with getting to services.</p> <p>Satisfaction with accommodation (Tables S9a-c): Rates of satisfaction do not appear to be very different between genders overall. For both genders, the percentage reported to be ‘very satisfied’ increases with age, with the exception of the oldest age band. The percentage being ‘very satisfied’ also increases with wealth for both genders, and for each other category, decreases with wealth.</p>



## 2. English Longitudinal Survey of Ageing

<p><b>Findings</b></p>	<p>Again for men and women, the percentage reporting satisfaction as ‘very satisfied’ for accommodation owned outright or mortgaged was higher than for those renting. Those renting typically had higher rates of dissatisfaction or indifference compared to those owning their accommodation outright or via mortgage.</p> <p>Receives help with mobility, ADL or IADL problems (Tables S13a-b): The percentage receiving help increases with age for both genders, with women reporting higher percentages within each age band. The percentage of people receiving help decreases with wealth for both genders.</p> <p><b>Longitudinal (2002–2010/11)</b></p> <p>Mean cognitive function (memory) (Table HL7a): declines over time in each age group and in both sexes; larger decreases in older age groups; decline slightly steeper for women than for men; decreases similar across the five wealth groups (Table HL7b).</p>
<p><b>Limitations</b></p>	<p>Self reported dementia almost certainly seriously underestimates true prevalence. Methodology for cognitive functions and memory tests has varied over time limiting possibilities of secular trends. Wave 5 datasets are not currently available on web.</p>



### 3. Cognitive Function & Ageing Studies (CFAS)

<b>Source</b>	Mathews FE, Arthur A, Barnes LE et al. A two-decade comparison of prevalence of dementia in individuals aged 65 years and older from three geographical areas of England: results of the Cognitive Function & Ageing Study I and II. <i>Lancet</i> 2013; 382:1405-12.
<b>Design</b>	Cross-sectional population surveys of prevalence of dementia. Three geographical areas; all residents 65 years and older; interviewer administered.  CFAS I: A 20% sample assessed with Geriatric Mental State (GMS) instrument; algorithmic approach to diagnosis.  CFAS II: All respondents assessed with GMS.
<b>Timing</b>	1991 and 2011.
<b>Participation/ response</b>	1991: 7635 respondents (80%); 2011: 7796 respondents (56%).
<b>Findings</b>	Dementia prevalence in 1991 (standardised to 2011 population): 8.3%. Equivalent to 884 000 in England. In 2011, estimated to be 6.5% or 670 000 (24% lower); OR 0.7, 95% CI 0.6-0.9; p=0.003 (adjusted for age, sex, area, deprivation). But, this assumes prevalence in non-responders same as in responders.  Prevalence higher in: women; older; more deprived. Prevalence in care settings increased from 56% to 70%.  If non-responders were 50% more likely to have dementia than responders, population estimate would be 7.7% (797 000); if 100% more likely, estimate 8.5% (882 000). Authors doubt these assumptions likely as interviewers trained to identify and report reasons for refusal.
<b>Limitations</b>	Lower response rate in 2011 means caution needed in comparing secular trend in dementia prevalence. Estimates dependent on assumptions about response bias.
<b>Future developments</b>	CFAS II will be augmented with CFAS (Wales), reporting in 2016. Building on an earlier study in North Wales and a new cohort in South Wales, the core of the data will be shared with CFAS II to give a combined sample of 12,500 older people.



## 4. Hospital Episode Statistics

<b>Source</b>	HSCIC: <a href="http://www.hscic.gov.uk/hes">www.hscic.gov.uk/hes</a> Full summary report for 2011-2012 dataset: <a href="https://catalogue.ic.nhs.uk/publications/hospital/inpatients/hosp-epis-stat-admi-pati-care-eng-2011-2012/hosp-epis-stat-admi-head-figs-11-12-rep.pdf">https://catalogue.ic.nhs.uk/publications/hospital/inpatients/hosp-epis-stat-admi-pati-care-eng-2011-2012/hosp-epis-stat-admi-head-figs-11-12-rep.pdf</a>
<b>Design</b>	Cross-sectional.
<b>Timing</b>	Patient care data since 1989, outpatient attendance data since 2003 and A&E from 2008.
<b>Participation/ response</b>	All NHS inpatient treatment, outpatient appointments and A&E attendances in England. Includes private patients treated in NHS hospitals, patients resident outside of England and care delivered by all ISTCS, funded by the NHS.
<b>Findings</b>	<p>Clinical information on diagnoses (primary and secondary) and operations, administrative information (wait time, dates, emergency/elective admission, and place of admission and discharge). Patient information includes age group, sex, ethnicity, where they were treated and area where they live.</p> <p>Dementia is normally recorded as a secondary diagnosis because it is not normally the primary reason for admission. If dementia is coded, data will be available on primary diagnosis, any secondary considerations, procedure codes and all other HES reported data.</p> <p>If discharge is delayed, HES records excess bed days after discharge decision is made, which can be indicative of lags or issues in integration to primary or community care.</p>
<b>Limitations</b>	Diagnosis of dementia is under-reported as either condition not detected or not recorded.
<b>Future developments</b>	In future the intention is that these data will be linked to primary care held data and social care data through the care.data initiative with a view to producing Care Episode Statistics.





## 5. National Audit of Dementia (care in general hospitals)

<b>Source</b>	Royal College of Psychiatrists: <a href="http://www.rcpsych.ac.uk/pdf/NAD%20NATIONAL%20REPORT%202013%20reports%20page.pdf">www.rcpsych.ac.uk/pdf/NAD%20NATIONAL%20REPORT%202013%20reports%20page.pdf</a>
<b>Design</b>	Cross-sectional audits of acute general hospitals.
<b>Timing</b>	2010 and 2012 (plans for 2014).
<b>Participation/ response</b>	<p><b>Core audit (2010)</b></p> <ul style="list-style-type: none"> <li>• all general acute hospitals in England eligible (n= 238)</li> <li>• organisational audit (80 items); 210 (88%) participated</li> <li>• RCRR (at least 40 consecutive patients with dementia diagnosis who stayed 5 or more days); 50 items; 206 (86%) participated; 78% recruited at least 40 cases; n=7934; reliability poor for 18 items.</li> </ul> <p><b>Enhanced audit (2010)</b></p> <ul style="list-style-type: none"> <li>• 56 hospitals, 3 wards each; 150 wards participated</li> <li>• organisational audit (n=145 wards)</li> <li>• staff questionnaires; 25 staff per ward</li> <li>• patient &amp; carer experience questionnaire; 87 wards participated; 5 or more patients per ward; only 13 wards achieved this</li> <li>• Person, Interactions and Environment (PIE) observation tool; 4 hours on each ward</li> </ul> <p><b>Core audit (2012)</b></p> <ul style="list-style-type: none"> <li>• all general acute hospitals in England eligible (n=215)</li> <li>• organisational audit (120 items); 206 (96%) participated</li> <li>• RCRR (at least 40 consecutive patients with dementia diagnosis who stayed 5 or more days); 76 items; 206 (86%) participated; 78% recruited at least 40 cases; n=7987.</li> </ul>
<b>Findings</b>	<p><b>Governance</b></p> <p>81% of hospitals have a senior clinician responsible for the implementation of the care pathway, which is either in place or in development. Just over a third of hospitals had a care pathway in place for people with dementia and around half had one in development.</p> <p>Executive Boards are not regularly involved in reviewing key information related to the care of people with dementia. Readmissions, delayed discharges and in-hospital falls are reviewed by less than 50% of Executive Boards. 82% of hospitals have a champion for dementia at directorate level and around three quarters of hospitals have a champion for dementia at ward level.</p> <p><b>Assessments</b></p> <p>89% had nutritional assessment; over 90% had an assessment of mobility and a pressure sore risk assessment; over 85% had been asked about any continence needs and the presence of any pain; 38% had an assessment for delirium; half had multidisciplinary assessment includes assessment of mental state.</p> <p><b>Antipsychotic prescription (protocol and practice)</b></p> <p>19% were prescribed antipsychotics during their admission to hospital (existing and new prescriptions); 8% of these contained prescriptions made during the admission (drop of 10% since 2010 and a drop of 4% for in-hospital prescription); 8% left hospital with a prescription for antipsychotics.</p> <p><b>Liaison psychiatry services</b></p> <p>96% of the hospitals had access to a liaison psychiatry service provided by a specialist mental health team; one third had access to an older people's service both during the day, and out-of-hours during evenings and weekends; 16% referred to liaison psychiatry of which 42% seen within two days.</p>



## 5. National Audit of Dementia (care in general hospitals)

<p><b>Findings</b></p>	<p><b>Hospital discharge and transfers</b>                      19% level of cognitive impairment included in discharge information (9% of those who lived in a care home); for 80% discussions had taken place with the person’s carer about appropriate place of discharge and support needs; 57% had included the person with dementia, when this was possible; half had received information about support on discharge.</p> <p><b>Information and communication</b>                      Approximately half of hospitals ensure that staff are aware of the person’s dementia; 59% of hospitals have no system in place to ensure that staff are aware of the person’s dementia or condition whenever the person accesses other treatment areas.</p> <p><b>Staff training</b>                      Over three quarters of hospitals had a training and knowledge framework or strategy that identifies necessary skill development in working with and caring for people with dementia compared with under 25% in 2010. 41% hospitals do not include dementia awareness training in their staff induction programmes. Dementia awareness training provided by 75% hospitals to doctors and allied healthcare professionals; 89% to nurses and 90% to healthcare assistants; 60% to support staff.</p>
<p><b>Limitations</b></p>	<p>Limited to patients admitted with established diagnosis of dementia. No information on those with undetected dementia. Mostly self-assessment by hospital staff so validity and reliability of data uncertain. Can only compare 2010 and 2012.</p>



## 6. NHS Inpatient Survey

<b>Source</b>	<p>CQC: <a href="http://www.cqc.org.uk/public/reports-surveys-and-reviews/surveys/inpatient-survey-2012">www.cqc.org.uk/public/reports-surveys-and-reviews/surveys/inpatient-survey-2012</a></p> <p>Historical comparison with 2011: <a href="http://www.cqc.org.uk/sites/default/files/media/documents/20130318_ip12_historical_comparisons_tables_v3_0.pdf">www.cqc.org.uk/sites/default/files/media/documents/20130318_ip12_historical_comparisons_tables_v3_0.pdf</a></p> <p>Technical document: <a href="http://www.cqc.org.uk/sites/default/files/media/documents/20120311_ip12_technical_document_final.pdf">www.cqc.org.uk/sites/default/files/media/documents/20120311_ip12_technical_document_final.pdf</a></p> <p>From Picker, Copy of 2013 survey: <a href="http://www.nhssurveys.org/Filestore/Inpatient_2013/IP13_Core_Questionnaire_v1.pdf">www.nhssurveys.org/Filestore/Inpatient_2013/IP13_Core_Questionnaire_v1.pdf</a></p>
<b>Design</b>	Cross sectional survey of patient experience.
<b>Timing</b>	Annual since 2002. Most recent, Sept 2012-Jan 2013.
<b>Participation/response</b>	2013: 64,505 participants, 51% response rate.
<b>Findings</b>	<p>2012-13 survey included questions about A&amp;E experience, waiting lists and planned admissions, waiting for a bed, hospital and ward, confidence and trust in doctors or nurses, care or treatment, operations or procedures, leaving hospital and overall experience.</p> <p>Includes information on: experience in ward, access to same or shared sex facilities, help with food, cleanliness, involvement in care, clarity of/communicating proposed course of action, discharge experience, whether hospital staff considered home situation.</p> <p>Does not ask if patients have dementia.</p>
<b>Limitations</b>	Not able to distinguish in-patients with dementia.



## 7. RCPsych Prescribing Observatory for Mental Health (POMH)

<p><b>Source</b></p>	<p>Royal College of Psychiatrists:  <a href="http://www.rcpsych.ac.uk/workinpsychiatry/qualityimprovement/nationalclinicalaudits/prescribingpomh/prescribingobservatorypomh.aspx">www.rcpsych.ac.uk/workinpsychiatry/qualityimprovement/nationalclinicalaudits/prescribingpomh/prescribingobservatorypomh.aspx</a></p> <p>Barnes TRE, Banerjee S, Collins N et al. Antipsychotics in dementia: prevalence and quality of antipsychotic drug prescribing in UK mental health services. <i>British Journal of Psychiatry</i> 2012; 201:221-226.</p> <p>POMH: helps mental health services members (39 mental health Trusts in England) monitor and improve prescribing practice.</p>
<p><b>Design</b></p>	<p>Cross-sectional surveys in variety of topics. Have included: high dose and combined antipsychotics in acute adult inpatient settings (several); prescribing of medications to alleviate the symptoms of dementia; use of antipsychotics in dementia.</p>
<p><b>Timing</b></p>	<p>Anti-psychotic prescribing in 2011.</p>
<p><b>Participation/ response</b></p>	<p>Data on 10,199 patients with a diagnosis of dementia, with information coming from 447 clinical teams (includes providers from Wales and private sector).</p>
<p><b>Findings</b></p>	<ul style="list-style-type: none"> <li>• 1620 (16%) were prescribed antipsychotics for behavioural and psychological symptoms of dementia (BPSD).</li> <li>• Use associated with age, patient setting, type and severity of dementia.</li> <li>• Of those prescribed anti-psychotics, 619 (38%) for up to 6 months, 326 (20%) for 6-12 months, and 675 (42%) over a year. 748 (75%) Had received a documented medication review in last 6 months.</li> <li>• The majority (90%) of these reviews were conducted by secondary care services, with the remainder conducted by secondary and primary care (6%) and just primary care (4%).</li> </ul>
<p><b>Limitations</b></p>	<p>Generalizability of findings unclear as self-selected Trusts and self-selected wards. No information on representativeness. No data made available on Web; limited to one journal article based on the data.</p>



## 8. NHS GP Patient Survey (GPPS)

<b>Source</b>	Ipsos-MORI, summary report: <a href="http://www.gp-patient.co.uk/results/download/_y7q2/Y7W2%20National%20Summary%20Report.pdf">www.gp-patient.co.uk/results/download/_y7q2/Y7W2%20National%20Summary%20Report.pdf</a>  Technical annex: <a href="http://www.gp-patient.co.uk/results/download/_y7q2/Y7W2%20Technical%20Annex.pdf">www.gp-patient.co.uk/results/download/_y7q2/Y7W2%20Technical%20Annex.pdf</a>
<b>Design</b>	Cross sectional surveys.
<b>Timing</b>	Annual, some questions change from year to year but ones pertaining to LTCs and age have been constant.
<b>Participation/ response</b>	971,232 (35%) responses from 8,129 practices in 2012-13. Roughly a quarter of respondents 55 years or more. Since 2010 response rates fairly consistent across age groups.
<b>Findings</b>	Identifies those reporting Alzheimer’s disease or dementia (Q31): 5851 (about 0.5%). Includes info on whether received enough support from local services or organisations to manage their condition (Q32); confidence in managing own health (Q33); and EQ-5D (5 level version for 2012-13).  2012-13 survey included questions about accessing GP, making appointments, waiting times, last GP/nurse appointment, opening house, overall experience, managing your health, out-of-hours services, and NHS dentistry.
<b>Limitations</b>	Generalisability (selection bias) uncertain given 35% response rate. In addition, only 0.5% prevalence of dementia suggests under-reporting (inevitable given it depends on self-completion).



## 9. HSCIC GP Extraction Service (GPES)

<b>Source</b>	GPES, Dementia benefits plan: <a href="http://www.hscic.gov.uk/article/3520/Facilitating-timely-diagnosis-and-support-for-people-with-dementia-ES">www.hscic.gov.uk/article/3520/Facilitating-timely-diagnosis-and-support-for-people-with-dementia-ES</a>
<b>Design</b>	Cross sectional data extraction.
<b>Timing</b>	April 2013-March 2014. Currently conduct weekly extraction, with plans to change this to a monthly extraction.
<b>Participation/ response</b>	GPES will be used to monitor the uptake of dementia screening at a practice level to ensure symptoms are noticed early, increasing the effectiveness of treatment. Financial incentive (Enhanced service) is designed to encourage practices to take a proactive approach to the timely assessment of patients who may be at risk of dementia.
<b>Findings</b>	To monitor the uptake of dementia screening at practice level, expected to lead to substantial time savings for commissioners and service providers in recording, checking, submitting and approving achievement for Calculating Quality Reporting Service (CQRS).  No data yet available.
<b>Limitations</b>	Will only provide data on the number of patients registered with a practice who have had a memory test. Denominator based only on age (suggestion of tighter definition based on those 'at risk of dementia' rejected).





## 10. Quality & Outcomes Framework

<b>Source</b>	Health and Social Care Information Centre: <a href="http://qof.hscic.gov.uk/index.asp">http://qof.hscic.gov.uk/index.asp</a>
<b>Design</b>	<p>Composite indicator, based on four domains: clinical (96 indicators over 22 clinical areas, max. points 669), organizational (42 indicators over six areas, 254 points), patient experience (one indicator, 33 points), and additional services (9 indicators in four service areas, 44 points). Total points available: 1000.</p> <p>Dementia in clinical domain: 20 points in 2009-10 and 2010-11; 26 points in 2011-12 and 2012-13.</p>
<b>Timing</b>	Annual, since 2004/5, measures change each year since 2006.
<b>Participation/ response</b>	Voluntary reporting by practices but almost 100%.
<b>Findings</b>	<p>2010/11: 8,245 practices; 98.1% out of 20 possible points for dementia indicators</p> <p>2009/10: 8,305 practices; 97.5% out of 20 possible points for dementia indicators</p> <p>Dementia indicators used (both years):</p> <p>DEM01: practices have a register of patients diagnosed with dementia.</p> <p>DEM02: percentage of those with dementia reviewed in preceding 15 months.</p> <p>2011/12: 8,123 practices; 93.8% out of 26 possible points.</p> <p>2012/13: 8,020 practices; 92.0% out of 26 possible points.</p> <p><b>Dementia indicators:</b></p> <p>DEM01: The practice can produce a register of patients diagnosed with dementia</p> <p>DEM02: The percentage of patients diagnosed with dementia whose care has been reviewed in the preceding 15 months</p> <p>DEM04: The percentage of patients with a new diagnosis of dementia recorded between the preceding 1 April to 31 March with a record of FBC, calcium, glucose, renal and liver function, thyroid function tests, serum vitamin B12 and folate levels recorded 6 months before or after entering on to the register</p> <p>Prevalence in 2012/13 was 8.5% higher than in 2011-12.</p>
<b>Limitations</b>	<p>Changes in prevalence may reflect greater rates of screening and detection rather than true changes in prevalence. Only provides aggregated data for practices rather than individual patient data.</p> <p>10 new dementia indicators for 2014/15 in 4 clinical areas: four on mental health and behavioural conditions and one that deals with the percentage of patients with dementia who have a record of attendance at a memory assessment service. Another is on the percentage of patients with dementia with the contact details of a named carer on their record.</p> <p><a href="http://www.bmj.com/content/347/bmj.f4902">www.bmj.com/content/347/bmj.f4902</a></p>



### 11. HSCIC GP Practice Prescribing, Presentation-level data

<b>Source</b>	HSCIC: <a href="http://www.hscic.gov.uk/searchcatalogue?q=title%3A%22presentation+level+data%22&amp;area=&amp;size=10&amp;sort=Relevance">www.hscic.gov.uk/searchcatalogue?q=title%3A%22presentation+level+data%22&amp;area=&amp;size=10&amp;sort=Relevance</a>
<b>Design</b>	Cross-sectional.
<b>Timing</b>	Monthly data extraction.
<b>Participation/ response</b>	All general practices.
<b>Findings</b>	The data includes all medicines, dressings and appliances prescribed and dispensed each month by SHA, PCT practice code, British National Formulary name and code. Information is presented by total number of items prescribed and dispensed, net ingredient cost, actual cost and total quantity.
<b>Limitations</b>	<p>No summary statistics found, just raw data files available. Only includes data for prescribing associated with a GP practice. Does not include patient level information to allow analysis of use of specific drugs by those with dementia or even patient age.</p> <p>It may be possible to request special analyses that distinguish patients with dementia from the NHS Prescribing Pricing Authority (which are only available to the DH).</p> <p><a href="http://www.nhsbsa.nhs.uk/PrescriptionServices/3167.aspx">www.nhsbsa.nhs.uk/PrescriptionServices/3167.aspx</a></p>



## 12. National Dementia & Antipsychotic Prescribing Audit

<b>Source</b>	HSCIC: <a href="https://catalogue.ic.nhs.uk/publications/clinical/dementia/nati-deme-anti-pres-audi-summ-rep/nati-deme-anti-pres-audi-summ-rep.pdf">https://catalogue.ic.nhs.uk/publications/clinical/dementia/nati-deme-anti-pres-audi-summ-rep/nati-deme-anti-pres-audi-summ-rep.pdf</a>
<b>Design</b>	Cross-sectional information from GP clinical systems on patients with dementia and prescriptions of anti-psychotics.
<b>Timing</b>	Annual for 2006-2011.
<b>Participation/ response</b>	3,850 General Practices (45.7%). Participation ranged by PCT from 2.4-95.4%. Total records 298,812; unique patients 196,695.
<b>Findings</b>	<p>Number of newly diagnosed people with dementia increased by 67.7% from 18,762 in 2006 to 31,455 in 2011. Consistent with 313 000 people with dementia recognized by GPs on their systems. Prevalence varied between practices from 0% to 2%.</p> <p>Most (66.3%) were women; over 65 years (94.7%) at time of diagnosis. 46.6% were 75-84 years.</p> <p>Antipsychotic medication: Decrease of 10.25% in prescriptions for people diagnosed with dementia. Down from 17.05% in 2006 to 6.80% in 2011. Also a decrease for those newly diagnosed (within 12 months of diagnosis), from 14.25% in 2006 to 4.46% in 2011.</p> <p>45.3% of those with dementia prescribed antipsychotic medication were 75-84 years.</p> <p>Decreasing proportion of dementia sufferers receiving antipsychotics: in 2006 9,378 of 55 000 (17.1%); in 2011 9724 of 143 000 (6.8%).</p>
<b>Limitations</b>	Increase in prevalence of diagnosis of dementia probably due to better recognition and recording on practice clinical systems rather than real increase. Based on only half of general practices so may not be generalizable.



### 13. National Audit of Memory Services

#### (a) 2011 report

<b>Source</b>	NHS Information Centre: <a href="https://catalogue.ic.nhs.uk/publications/mental-health/surveys/est-mem-serv-res-surv-pct-fin-2011/est-mem-serv-res-surv-pct-fin-2011-rep.pdf">https://catalogue.ic.nhs.uk/publications/mental-health/surveys/est-mem-serv-res-surv-pct-fin-2011/est-mem-serv-res-surv-pct-fin-2011-rep.pdf</a>
<b>Design</b>	Cross-sectional survey of 149 PCTs and Care Trusts which commission memory assessment services for dementia.
<b>Timing</b>	2008-2011.
<b>Participation/ response</b>	119 (80%) responses; not all participants responded to the survey in full.
<b>Findings</b>	<p>112 PCTs reported they commissioned memory services.</p> <ul style="list-style-type: none"> <li>• Mean PCT spending on memory services pa: £486k, £551k, £593k (22% increase between 2008/9 and 2009/10).</li> <li>• Mean number of people per PCT pa using a memory service: 605, 767, 951 (57% increase).</li> <li>• Number of MASs in England in 2011: total number commissioned 337 but includes double and treble counting as cannot assume unique to single PCT. Another 106 planned in 2011/12 (again not unique).</li> <li>• 8 recommended features present in a MAS: home based assessment; counselling; specialised diagnostic equipment; provision of full explanation of diagnosis; provision of information on prognosis and care options; provision of advice and support; pharmacological treatment; and follow-up.</li> </ul>
<b>Limitations</b>	Total number of memory services over-estimated due to multiple counting by commissioners. Only 80% response rate will have underestimated number.
<b>Usefulness</b>	1 (Diagnosis) 2 (Post-diagnostic care and support) 5 (Workforce development)

#### (b) 2013 report

<b>Source</b>	Royal College of Psychiatrists & NHS England. English National Memory Clinics Audit Report. October 2013.
<b>Design</b>	Cross-sectional survey of memory services (clinics) identified from RCPsych Memory Services Register, Memory Services National Accreditation Programme, internet search, CMHT directors.
<b>Timing</b>	July-Sept 2013.
<b>Participation/ response</b>	177 of 214 services responded (83%).
<b>Findings</b>	<ul style="list-style-type: none"> <li>• 65.6% memory clinics are provided as part of a wider service, not a stand-alone clinic.</li> <li>• On average memory clinics cost £625,077 each per year, but this figure varies widely.</li> <li>• The average operating hours were 37.6 hours per week.</li> <li>• Memory clinics can assess a maximum of 18.0 new patients each week, on average.</li> <li>• In the last 12 months, memory clinics each assessed an average of 543.4 patients and saw an average of 1205.1 patients in total, a near fourfold increase since 2010/11.</li> </ul>

Continued >



**13. National Audit of Memory Services *continued***

**(b) 2013 report**

<p><b>Findings <i>continued</i></b></p>	<ul style="list-style-type: none"> <li>• On average, people wait 5.17 weeks from the point of referral to receiving their memory assessment, and an additional 8.34 weeks from the point of having the assessment to receiving the diagnosis.</li> <li>• 49.2% people diagnosed with dementia over the last 12 months were in the early stages of the condition.</li> <li>• 98.3% of memory clinics can initiate treatment with medications to alleviate the symptoms of dementia and 97.7% of clinics also review medication.</li> <li>• 92.1% of clinics provide home-based assessments.</li> <li>• 73.4% of clinics have access to specialist post-diagnostic counselling, 66.1% have access to Cognitive Stimulation Therapy, 93.8% provide access to education and support for carers and 62.7% have access to Life Story Work.</li> <li>• On average, each clinic provided 260.3 people with specialist post-diagnostic counselling, 52.8 people with Cognitive Stimulation Therapy, and 250.5 carers with education and support in the last 12 months.</li> <li>• 72.9% of memory clinics ask people with dementia to register their interest in taking part in research.</li> <li>• 33.9% of memory clinics are members of the Memory Services National Accreditation Programme.</li> </ul>
<p><b>Limitations</b></p>	<p>May have missed some clinics in the denominator. Response rate 83%. Quite high non-response to some specific items: 37% on funding; 11% on stand-alone or integrated; 44% on use of Cognitive Stimulation Therapy and specialist counselling.</p>



## 14. National Dementia Care Audit

<b>Source</b>	Healthcare Quality Improvement Partnership/SCIE: <a href="http://www.hqip.org.uk/dementia-care-audit-pilot">www.hqip.org.uk/dementia-care-audit-pilot</a>
<b>Design</b>	<p>Development of tool (Dementia Care Audit Tool) to provide a measure of the care provided to people with dementia living in a care home. Based on NICE Quality Standards so that participating homes will have evidence about their achievement as regards:</p> <ul style="list-style-type: none"> <li>• Involvement of residents and carers/relatives;</li> <li>• Collection and use of personal information about the resident;</li> <li>• Activity and participation;</li> <li>• Choice;</li> <li>• Staff training and support;</li> <li>• Policies and procedures the information that is held about the resident with dementia and how this is used.</li> </ul> <p>Currently developing a two-part audit tool which will cover (i) organisational factors necessary for the provision of good quality care and (ii) care plans and daily notes held about residents and how it supports their well-being. In future, planned to include the experience of residents.</p>
<b>Timing</b>	Piloting in 250 care homes during Jan-March 2014.
<b>Participation/ response</b>	Not yet known.
<b>Findings</b>	<p>From pilot available summer 2014. Data will be collated, analysed and a report produced for the participating homes to allow comparison and identify areas for improvement within their service:</p> <ul style="list-style-type: none"> <li>• identify what they are doing well and what they might need to improve</li> <li>• improve their practice by identifying strengths and weaknesses in a logical, measurable way</li> <li>• prepare for CQC inspections by providing evidence of current practice against national guidelines</li> <li>• compare their performance against NICE Dementia Care Quality Standards and against other care homes</li> <li>• increase efficiency by identifying what works well and what does not work well in practice</li> <li>• support their learning and development plan</li> <li>• provide evidence about the quality of care in a service to establish confidence amongst stakeholders including residents, carers, commissioners, funders etc.</li> </ul>
<b>Limitations</b>	Restricted to input and process measures.



## 15. Health Survey for England

<b>Source</b>	Health and Social Care Information Centre Summary of key findings for 2011: <a href="https://catalogue.ic.nhs.uk/publications/public-health/surveys/health-survey-eng-2011/HSE2011-Sum-bklet.pdf">https://catalogue.ic.nhs.uk/publications/public-health/surveys/health-survey-eng-2011/HSE2011-Sum-bklet.pdf</a> Catalogue of resources for the 2011 survey: <a href="http://www.hscic.gov.uk/catalogue/PUB09300">www.hscic.gov.uk/catalogue/PUB09300</a>
<b>Design</b>	Cross-sectional series of surveys for a representative sample at a national and regional level. Certain age groups are asked questions on certain topics only, and each year there is a different topic of health that forms the focus of the questionnaire (health of older people was the focus for 2000 and 2005, although dementia was not explored). The focus for the 2011 survey was wellbeing and cardiovascular health.
<b>Timing</b>	Surveys issued annually from 1994. Children aged 2-15 included within the sample from 1995, and infants under 2 were included from 2001 onwards.
<b>Participation/response</b>	For 2011, 8,610 adults and 2,007 children (5,715 and 1,257 respectively had a nurse visit). Household response rate was 66%. For the first time in several years, there was no child boost sample in 2011.
<b>Findings</b>	<p>Among people aged 65 and over, a third of women (36 per cent) and just over a quarter of men (27 per cent) reported a need for help in the last month with at least one Activity of Daily Living. Help was needed most often with getting up and down stairs (20 per cent and 31 per cent respectively).</p> <p>The highest levels of need for help with Activities of Daily Living and/or Instrumental Activities of Daily Living were among people aged 85 and over. For example, 48 per cent of men and 70 per cent of women in this age group needed help with shopping for food, with 40 per cent and 55 per cent respectively receiving help with this activity.</p> <p>Although 25% of people over 65 said they needed help getting up and down the stairs, only 6% reported receiving any help over the past month. This gap between need and care provision was also apparent in relation to basic needs such as going to the toilet and bathing. Of the 5% of over 65s who report that they need help using the toilet, only two-fifths (around 180,000 people) said that they had help in the last month.</p>
<b>Limitations</b>	Neither presence of dementia nor cognition is measured.





## 16. Referrals, Assessments and Packages of Care (RAP)

<b>Source</b>	<p>National Adult Social Care Intelligence Service NASCIS Online Analytical Processor: <a href="https://nascis.hscic.gov.uk/Portal/Tools.aspx">https://nascis.hscic.gov.uk/Portal/Tools.aspx</a> (sign-in required)</p> <p>Health and Social Care Information Centre: Social care collections 2013: <a href="http://www.hscic.gov.uk/socialcarecollections2013">www.hscic.gov.uk/socialcarecollections2013</a></p> <p>2013 Proformas: <a href="http://www.hscic.gov.uk/media/11549/RAP-Proformas-2012-13-v11/pdf/RAP_Proformas_2012-13_v1.1.pdf">www.hscic.gov.uk/media/11549/RAP-Proformas-2012-13-v11/pdf/RAP_Proformas_2012-13_v1.1.pdf</a></p> <p>2015 collections (SALT guidance and Proformas): <a href="http://www.hscic.gov.uk/socialcarecollections2015">www.hscic.gov.uk/socialcarecollections2015</a></p>
<b>Design</b>	<p>Aggregate figures for social care services receipt, collected annually for all councils with adult social services responsibilities (CASSRs) within England.</p> <p>In RAP, service recipients are categorized by 'Primary Client Type', covering the categories of 'Physical disability', 'Mental health', 'Learning disability', 'Substance misuse' and 'Other vulnerable people'. Some data is further disaggregated by sub-category, including 'Mental health: of which dementia'. Data are also disaggregated by age band. For most data the age bands are 18-64 and 65+, with the exception of the number of reviews, for which the age bands are 18-64, 65-74 and 75+.</p> <p>In 2014-2015, RAP will be replaced with the Short And Long Term support data collection (SALT). Instead of 'Primary Client Type', service recipients will be categorized by 'Primary Support Reason', including the category, 'Support with memory and cognition'. Service recipients may also be assigned to one or more reported health conditions of which 'Mental health condition: dementia' is one, although this will be mandatory only for the 'autism' and 'Asperger's syndrome/higher functioning autism' categories. Data will also be disaggregated by age band (18-64 and 65+).</p>
<b>Timing</b>	<p>Data has been collected since 2005-2006. The final year of RAP will be 2013-2014, after which it will be replaced by the 'Short And Long-Term data collection' (SALT).</p>
<b>Participation/response</b>	<p>All CASSRs in England. Mandatory return.</p>
<b>Coverage/findings</b>	<p>To date, the following data has been collected by the category 'Mental health: of which dementia'.</p> <ul style="list-style-type: none"> <li>• Numbers in receipt of services by 'community-based services', 'residential care', and 'nursing care' (both within the previous 12-months and on the last day of the period).</li> <li>• Numbers in receipt of community-based services by 'home care', 'day care', 'meals', 'short-term residential (not-respite)', 'direct payments', 'professional support', 'equipment and adaptations' and 'other' services (both within the previous 12-months and on the last day of the period).</li> <li>• Numbers in receipt of a review (within the previous 12 months).</li> </ul> <p>Under the SALT data collection, the following data will be collected by the category 'Support with memory and cognition'.</p> <ul style="list-style-type: none"> <li>• Numbers in receipt of long-term support (both within the previous 12 months and on the last day of the period)</li> <li>• Numbers in receipt of long-term support by 'nursing', 'residential' and 'community care' (both within the previous 12 months and on the last day of the period).</li> <li>• Numbers in receipt of 'community care' services by 'direct payments only', 'part direct payments', 'personal budget' and 'CASSR commissioned support only' (both within the previous 12 months and on the last day of the period).</li> <li>• Numbers of people in receipt of long-term support on the last day of the period who have been accessing long-term support for over 12 months (by 'nursing', 'residential' and 'community care', and by sub-categories of 'community care').</li> </ul>

Continued >



**16. Referrals, Assessments and Packages of Care (RAP) *continued***

<p><b>Coverage/findings <i>continued</i></b></p>	<ul style="list-style-type: none"> <li>• The type of support that is provided following a period of short-term support (e.g. ‘ongoing low-level support’, ‘short-term support’ or ‘no support’).</li> <li>• Support provided to carers (reported by the ‘Primary Support Reason’ of the cared for person), by ‘direct payments/ part-direct payments’ (for the carer); ‘CASSR-managed personal budget’ (for the carer), ‘CASSR commissioned support only’, ‘information, advice and other services/ sign-posting’ and ‘no direct support’. Also recorded is relevant support provided to the cared for person (e.g. respite services).</li> </ul> <p>SALT will collect a number of (potentially relevant) data, but not disaggregated by ‘Primary Support Reason’. These include:</p> <ul style="list-style-type: none"> <li>• Number of older people who are at home 91 days after being discharged from hospital into reablement/ rehabilitation services.</li> <li>• Change in setting (e.g. nursing care, residential care, level of long-term care) as a result of an unplanned review or, for those making a transition into a care home, as a result of either an unplanned or planned review.</li> <li>• Those experiencing a change in setting who have been in receipt of long-term support for over 12 months.</li> </ul>
<p><b>Limitations</b></p>	<ul style="list-style-type: none"> <li>• RAP and SALT data about service receipt covers only eligible social care, that forms part of a care plan managed by the CASSR or an NHS health partner and follows a community care assessment.</li> <li>• ‘Primary Client Type’ (RAP) and ‘Primary Support Reason’ (SALT) are used to record only the main reason for support. Hence, for example, people with mild dementia and severe physical disabilities are most likely to be categorised by their physical disability.</li> <li>• In SALT, inclusion within the ‘Support with Memory and Cognition’ category is not limited only to those with dementia but also includes those with acquired brain injury, for example. However, for older people, we would expect this category to be predominantly populated by people with dementia.</li> <li>• In SALT, data on what services are used is much less detailed than in RAP (reflecting greater use of personal budgets and direct payments).</li> <li>• In RAP and SALT there is very limited information on the frequency and intensity of support, none of which is recorded by dementia or a related category of support need.</li> <li>• Comparisons over time are not possible for every RAP table due to changes in the data collected over time.</li> </ul>



## 17. Personal Social Services Expenditure and unit costs (PSS-EX1)

<p><b>Source</b></p>	<p>Health and Social Care Information Centre 2012-2013 final report:  <a href="https://catalogue.ic.nhs.uk/publications/social-care/expenditure/pss-exp-eng-12-13-fin/pss-exp-eng-12-13-fin-rpt.pdf">https://catalogue.ic.nhs.uk/publications/social-care/expenditure/pss-exp-eng-12-13-fin/pss-exp-eng-12-13-fin-rpt.pdf</a></p> <p>Health and Social Care Information Centre Social Care Collections 2013:  <a href="http://www.hscic.gov.uk/socialcarecollections2013">www.hscic.gov.uk/socialcarecollections2013</a></p> <p>2013 Proformas: <a href="http://www.hscic.gov.uk/media/11502/illustrative-pro-forma-for-the-collection-period-1-April-2012--31-March-2013-v11-PDF/pdf/PSS-EX1_IllustrativeProForma_2012-13_v1.1.pdf">www.hscic.gov.uk/media/11502/illustrative-pro-forma-for-the-collection-period-1-April-2012--31-March-2013-v11-PDF/pdf/PSS-EX1_IllustrativeProForma_2012-13_v1.1.pdf</a></p> <p>Adult Social Care Financial Returns (ASC-FR) guidance and proformas:  <a href="http://www.hscic.gov.uk/socialcarecollections2015">www.hscic.gov.uk/socialcarecollections2015</a></p>
<p><b>Design</b></p>	<p>An annual collection of income and expenditure data on adult social care services for councils with Adult Social Services Responsibilities (CASSRs) based on mandatory returns. Many of the activity data on PSS-EX1 are sourced from the RAP (Referrals, Assessment and Packages of Care) data return and should be consistent with RAP data (see separate entry for RAP for more detail). Although consistent with RAP data, unlike in the RAP return, councils are not asked to disaggregate any of the data by subcategories (including the 'Mental health: of which dementia' sub-category) hence no dementia-specific information can be extracted from it.</p> <p>2013-2014 will be the last year of the PSS-EX1 Form. It will be replaced by the Adult Social Care Finance Return (ASC-FR). In the new return:</p> <ul style="list-style-type: none"> <li>• Data will be disaggregated by 'Primary Support Reason' including 'Support with Memory and Cognition' (categories also newly introduced to the replacement for the RAP return, SALT – see separate entry on RAP).</li> <li>• Disaggregating data by older (65+) and younger people will be mandatory. Further disaggregating data for the older people category into 65-74, 75-84 and 85+ will be voluntary.</li> <li>• Service categories will include short- and long-term support. Within long-term support, aggregate cost data will be recorded for 'nursing care', 'residential care', 'supported accommodation', 'fairer charging income' and 'community services' (separated into 'direct payments', 'home care', 'supported living' and 'other').</li> </ul> <p>Expenditure on assistive equipment and technology will not be separated by 'Primary Support Reason' in the new ASC-FR.</p>
<p><b>Timing</b></p>	<p>PSS-EX1 has been completed annually since 2000-2001. The final year will be 2013-2014, after which point PSS-EX1 will be replaced by ASC-FR.</p>
<p><b>Participation/ response</b></p>	<p>All CASSRs in England. Mandatory return.</p>
<p><b>Coverage/findings</b></p>	<p>Currently, no data can be identified by dementia and/or memory and cognition problem.</p>
<p><b>Limitations</b></p>	<ul style="list-style-type: none"> <li>• To date PSS-EX1 data has not been disaggregated by dementia.</li> <li>• In the newly introduced ASC-FR, data will be recorded by 'Primary Support Reason', including 'Support with Memory and Cognition'. However, since this represents the main reason for support, some people with dementia support needs may be excluded. For example, if somebody had severe physical disabilities and mild dementia it is likely that they would be recorded under a physical disability category.</li> <li>• Inclusion in the 'Support with Memory and Cognition' category is not limited to those with dementia. It may also include, for example, people with acquired brain injury. However for older people we expect the category to be predominantly populated by people with dementia.</li> </ul>



**18. National Minimum Dataset for Social Care (NMDS-SC)**

<p><b>Source</b></p>	<p>NMDS-SC website – Key information and statistical reports (January 2014): <a href="http://www.nmds-sc-online.org.uk/research/researchdocs.aspx?id=10">www.nmds-sc-online.org.uk/research/researchdocs.aspx?id=10</a></p> <p>NMDS-SC Briefing issue 9- older people: <a href="http://www.nmds-sc-online.org.uk/Get.aspx?id=285975">www.nmds-sc-online.org.uk/Get.aspx?id=285975</a></p> <p>Workforce dashboards: <a href="http://www.nmds-sc-online.org.uk/ReportEngine/Dashboard.aspx">www.nmds-sc-online.org.uk/ReportEngine/Dashboard.aspx</a></p> <p>Establishment data items: <a href="http://www.nmds-sc-online.org.uk/Get.aspx?id=735643">www.nmds-sc-online.org.uk/Get.aspx?id=735643</a></p> <p>Worker data items: <a href="http://www.nmds-sc-online.org.uk/Get.aspx?id=827516">www.nmds-sc-online.org.uk/Get.aspx?id=827516</a></p> <p>Latest (September 2013) establishment level dataset: <a href="http://www.nmds-sc-online.org.uk/Get.aspx?id=834326">www.nmds-sc-online.org.uk/Get.aspx?id=834326</a></p> <p>User guide (describing variables): <a href="http://www.nmds-sc-online.org.uk/Get.aspx?id=834314">www.nmds-sc-online.org.uk/Get.aspx?id=834314</a></p>
<p><b>Design</b></p>	<p>Establishments (a single location or workplace where care is provided or organized) providing social care (care homes, domiciliary care, etc.) may register and submit data to NMDS-SC. Data covers establishment-level information as well as individual-level information for employees. Organizations (e.g. a care home group) may have multiple establishments. Data is collected and reported at establishment level, although organizations may request a report of their data at organizational level covering all their constituent establishments. Individuals that hire care workers (personal assistants) directly may also submit data. As with establishments, these employers provide information about themselves as well as their personal assistants.</p> <p>Data is published at the following times and in the following formats:</p> <ul style="list-style-type: none"> <li>• Online ‘dashboard’. This is continually updated and data can therefore change from day-to-day.</li> <li>• A full, anonymised establishment-level dataset is published twice yearly, in September and March. The most recently published dataset is available online.</li> <li>• A range of monthly ‘headline’ data reports, from 2007 onwards, are also available online.</li> </ul> <p>Establishment-level datasets from previous periods need to be requested directly from Skills for Care. More detailed ‘monthly cuts’ of the whole dataset can also be requested. These cover individual level worker data, including whether employees hold dementia-related qualifications.</p> <p>Previous studies have linked establishment level data in the NMDS-SC to data on local characteristics (rurality, income and employment levels etc.) and with the English Indices of Multiple Deprivation.</p>
<p><b>Timing</b></p>	<p>The NMDS-SC launched in October 2005 and the first monthly report was available on the website in July 2007.</p>
<p><b>Participation/ response</b></p>	<ul style="list-style-type: none"> <li>• At September 2013, data was recorded for 25,788 establishments and 750,000 individual workers.</li> <li>• For local authorities, the return was made mandatory in 2011 and replaced the Social Services Department Staffing (SSDS001) return for local authorities.</li> <li>• For other providers, participation is entirely voluntary, but establishments are offered various benefits to participate. These include (subject to providing information on over 90 per cent of their workforce) eligibility for the Department of Health Workforce Development Fund. Individuals employing personal assistants are encouraged to participate with eligibility for free training for the personal assistants they employ.</li> <li>• At September 2013, approximately 60 percent of CQC registered establishments were on the database.</li> </ul>

*Continued >*



## 18. National Minimum Dataset for Social Care (NMDS-SC)

<b>Coverage/findings</b>	<p>Coverage at establishment level includes:</p> <ul style="list-style-type: none"> <li>• The types of people the establishment provides care to (e.g. 'older people with dementia')</li> <li>• The sector the establishment is in (e.g. 'statutory', 'private', 'voluntary' etc.)</li> <li>• Details of registration (with CQC, OfSted)</li> <li>• One main service and any number of other services provided (e.g. 'care home with nursing', 'community support and outreach' etc.)</li> <li>• A head count of staff by job role ('senior management', 'social worker', 'care worker' etc.)</li> <li>• Vacancies and information to assist in calculating turnover rates</li> <li>• Information on whether workers are migrant workers (from 2010 onwards)</li> </ul> <p>Coverage at individual worker level includes:</p> <ul style="list-style-type: none"> <li>• Demographics</li> <li>• Status of induction training</li> <li>• Employment status (e.g. 'full-time', 'part-time')</li> <li>• Rate of pay and length of time in current job</li> <li>• Qualifications held, including:                             <ul style="list-style-type: none"> <li>– Award in Awareness of Dementia (Level 2)</li> <li>– Award in Awareness of Dementia (Level 3)</li> <li>– Certificate in Dementia Care (Level 2)</li> <li>– Certificate in Dementia Care (Level 3)</li> <li>– Diploma in Health and Social Care (Dementia Pathway) (Level 2)</li> <li>– Diploma in Health and Social Care (Dementia Pathway) (Level 3)</li> </ul> </li> <li>• Training courses completed</li> </ul>
<b>Limitations</b>	<ul style="list-style-type: none"> <li>• Periodic changes are made to the dataset. New categories of qualifications are routinely added. Two new job categories were added in 2011 and 2013 and two data items (monthly basic pay and continuity of employment) were removed in 2011.</li> <li>• A growing number of people with dementia or their families may employ care workers (personal assistants) using personal budgets. However, the numbers of such respondents is low (74 older people with dementia or their families at February 2014) and it is likely that a relatively low percentage of these are people with dementia or their families.</li> <li>• The progressive nature of the dataset, whereby there have been more establishments submitting data over time, may make identifying trends difficult.</li> <li>• Up until 2011, when the return was made mandatory for local authorities, there was an over-representation of workers in the independent sector (voluntary and private) and an underrepresentation of workers in the statutory sector.</li> <li>• There may be some inaccuracies or missing values due to the fact that establishments enter data for the individuals they employ.</li> </ul>
<b>Related studies</b>	<p>Hussein, S. and Manthorpe, J., 2012, The dementia social care workforce in England: Secondary analysis of a national workforce dataset <i>Aging &amp; Mental Health</i> 16(1), 110-118.</p> <p>Hussein, S., Manthorpe, J. and Stevens, M., 2011, Social care as first work experience in England: a secondary analysis of the profile of a national sample of migrant workers. <i>Health &amp; Social Care in the Community</i>, 19: 89-97.</p>



## 19. Adult Social Care Survey

<b>Source</b>	<p>Health and Social Care Information Centre: Personal Social Services Adult Social Care Survey, England 2012-2013: <a href="https://catalogue.ic.nhs.uk/publications/social-care/surveys/per-soc-ser-adu-soc-car-sur-eng-2012-13-fin/per-soc-ser-adu-soc-car-sur-eng-2012-13-fin-report.pdf">https://catalogue.ic.nhs.uk/publications/social-care/surveys/per-soc-ser-adu-soc-car-sur-eng-2012-13-fin/per-soc-ser-adu-soc-car-sur-eng-2012-13-fin-report.pdf</a></p> <p>Link to 2012-13 questionnaires: <a href="http://www.hscic.gov.uk/article/2215/User-Experience-Survey-Adult-Social-Care-Guidance-2012-13">www.hscic.gov.uk/article/2215/User-Experience-Survey-Adult-Social-Care-Guidance-2012-13</a></p>
<b>Design</b>	<p>Annual postal survey of a stratified sub-sample of those included in the RAP (Referrals, Assessments and Packages) data collection (covering adults receiving eligible social care services). The sample is stratified by</p> <ul style="list-style-type: none"> <li>• service users with a learning disability</li> <li>• all other service users aged 18 to 64</li> <li>• service users aged 65 or over (without a learning disability) who are in residential care 4)</li> <li>• service users aged 65 or over (without a learning disability) who are resident in the community.</li> </ul> <p>Different versions of the postal questionnaire are produced for those living in the community and those living in care homes. Requests can be made by participants to have the survey administered as a face-to-face interview or telephone interview, although 98 per cent of respondents responded by post in 2012-2013. Local authorities send out the questionnaires (followed by a reminder letter) and return data back to the Health and Social Care Information Centre (HSCIC) along with information on respondents covering demographics, 'Primary Client Type' category (see separate entry on RAP for more detail), receipt of services and costs of care package.</p>
<b>Timing</b>	The survey began in 2010-2011.
<b>Participation/ response</b>	In 2012-2013, the postal questionnaire was distributed to approximately 177,915 service users out of an eligible population of 890,710. The achieved sample size was 68,770, a response rate of 39 per cent. There were relatively high levels of complete or near complete responses; 70 per cent of respondents completed the whole questionnaire and 13 per cent completed 31 of the 32 questions.
<b>Structure and coverage</b>	The survey gathers a range of data including satisfaction with social care and support, quality of life, purchase of additional care or 'topping up' care, advice and information and health. Presence of dementia/ memory or cognition problem is not included in the survey and although Primary Client Type is recorded, its sub-categories (including 'Mental health; of which dementia') is not. Hence there are no dementia-related findings. Potentially some relevant data could be extracted if 'Primary Support Reason' were included within the dataset in future.
<b>Limitations</b>	<ul style="list-style-type: none"> <li>• Dementia or a related support category not recorded.</li> <li>• Postal survey, low response rate and risk of response bias likely to mean poor representation of those with dementia and/or memory and cognition problems.</li> </ul>



## 20. Personal Social Services Survey of Adult Carers in England

<b>Source</b>	<p>Health and Social Care Information Centre 2012-2013 final report experimental statistics (includes questionnaire): <a href="http://www.hscic.gov.uk/catalogue/PUB12630/per-soc-ser-sur-ad-car-eng-2012-13-fin-rep.pdf">www.hscic.gov.uk/catalogue/PUB12630/per-soc-ser-sur-ad-car-eng-2012-13-fin-rep.pdf</a></p> <p>Provisional data: <a href="http://www.hscic.gov.uk/catalogue/PUB12630/per-soc-ser-sur-ad-car-eng-2012-13-fin-annex-tables.xlsx">www.hscic.gov.uk/catalogue/PUB12630/per-soc-ser-sur-ad-car-eng-2012-13-fin-annex-tables.xlsx</a></p> <p>2012-2013 data return: <a href="http://www.hscic.gov.uk/media/10637/Carers-Survey-Data-Return-2012-13/xls/Carers_Survey_Data_Return_v4.3_FINAL.xls">www.hscic.gov.uk/media/10637/Carers-Survey-Data-Return-2012-13/xls/Carers_Survey_Data_Return_v4.3_FINAL.xls</a></p>
<b>Design</b>	<p>The Personal Social Services Survey of Adult Carers in England is a biennial postal survey, so far conducted twice (in 2009-2010 and 2012-2013). Eligible carers for the survey are aged 18 or over and care for someone aged 18 or over in receipt of services funded wholly or in part by social services. Local authorities administer the survey and then submit responses to HSCIC together with some locally held data on the individual respondents, including demographic information about the carer and record of receipt of various carer services as recorded within RAP (including a personal budget or direct payments).</p> <p>There is a question in the survey, ‘Does the person you care for have ... ?’, which has the option ‘Dementia’, thus allowing information provided in the survey to be analysed by whether someone is a carer of someone with dementia. However, the publicly available anonymized individual level dataset does not contain this information and a dataset with this variable would need to be requested.</p>
<b>Timing</b>	<p>The survey began in 2009-2010. Significant changes were made to the questionnaire in 2012-2013, including changes to some questions and reducing the total number of questions from 58 to 27.</p>
<b>Participation/ response</b>	<p>In 2012-2013, 57,860 carers responded out of a total sample of 126,755 (46% response rate).</p>
<b>Coverage/findings</b>	<p>The survey collects data on a range of topics including the following:</p> <p><b>Services that they and/or the person they care for receive</b></p> <ul style="list-style-type: none"> <li>• How long they have been a carer</li> <li>• Hours per week spent caring</li> <li>• Whether they have a disability</li> <li>• Carer satisfaction with the services received by the services received by the carer and person being cared for collectively</li> <li>• Training and support to continue employment while caring</li> <li>• The ability for the carer to enjoy their time</li> <li>• Control over day life</li> <li>• Ability for the carer to look after him/herself</li> <li>• Concerns of personal safety</li> <li>• Level of social contact and feelings of encouragement or support</li> <li>• Employment situation and feelings of support from their employer.</li> </ul>

*Continued >*





**20. Personal Social Services Survey of Adult Carers in England**  
*continued*

<p><b>Coverage/findings</b> <i>continued</i></p>	<p><b>Questions that were previously asked but were removed from the questionnaire in 2012-2013 include:</b></p> <ul style="list-style-type: none"> <li>• How many people the carer cares for</li> <li>• The relationship to the person being cared for</li> <li>• The gender of the person being cared for</li> <li>• Carers self-reported receipt of carer services (in relation to their perceived need)</li> <li>• Type of organisation the carer is receiving most support from (social services, voluntary or private organisation)</li> <li>• Self-rated quality of life</li> <li>• Self-rated health</li> <li>• Perceived needs for training</li> <li>• How the carer has been affected by caring (e.g. depression, tiredness etc.)</li> <li>• How difficult the carer finds it to arrange services for the carer and/or person being cared for</li> <li>• Whether services are available at times convenient for the carer</li> </ul>
<p><b>Limitations</b></p>	<ul style="list-style-type: none"> <li>• Lack of trend data to date in variables of interest because of changes to questions and a significantly reduced coverage in 2012-2013.</li> <li>• Includes only carers caring for someone in receipt of services funded wholly or in part by social services and is therefore not representative of the wider population of carers.</li> <li>• Postal survey with consequent low response rate and risk of response bias.</li> <li>• The question ‘does the person you care for have ... ?’ has the option ‘dementia’. However it also has the options ‘a health problem’ and ‘problems associated with ageing’ and some carers of people with dementia might classify someone in one of these ways instead (e.g., if not formally diagnosed). In 2009-2010, 89 per cent of carers who, according to local authority information, were caring for someone categorized within the Primary Client Type sub-category, ‘Mental health; of which dementia’, recorded that the person they were caring for had dementia in the questionnaire.</li> </ul>



## 21. Abuse of Vulnerable Adults (AVA) Return

<p><b>Sources and references</b></p>	<p>2012-2013 guidance document: <a href="http://www.hscic.gov.uk/media/11170/AVA-Guidance-2012-13-v10/pdf/AVA_guidance_2012-13_FINAL.pdf">www.hscic.gov.uk/media/11170/AVA-Guidance-2012-13-v10/pdf/AVA_guidance_2012-13_FINAL.pdf</a></p> <p>2012-2013 Proformas: <a href="http://www.hscic.gov.uk/media/11590/AVA-Proformas-2012-13-v12/xls/AVA_Proformas_2012-13_v1.2.xls">www.hscic.gov.uk/media/11590/AVA-Proformas-2012-13-v12/xls/AVA_Proformas_2012-13_v1.2.xls</a></p> <p>2013-2014 SAR proforma: <a href="http://www.hscic.gov.uk/media/11585/SAR-Proformas-2013-14/xls/Safeguarding_Adults_Return_2013-14_Proforma.xls">www.hscic.gov.uk/media/11585/SAR-Proformas-2013-14/xls/Safeguarding_Adults_Return_2013-14_Proforma.xls</a></p>
<p><b>Design</b></p>	<p>Aggregate data for adults aged 18 and over, collected annually from all councils with adult social services responsibilities (CASSRs) within England.</p>
<p><b>Timing</b></p>	<p>Introduced on a voluntary basis in 2009-2010 and made mandatory in 2010-2011. AVA will be replaced by the Safeguarding Adults Return (SAR) in 2013-2014.</p>
<p><b>Participation/ response</b></p>	<p>Adults aged 18 and over in England whose alleged abuse has been noted by a local safeguarding team.</p>
<p><b>Coverage/findings</b></p>	<p>Currently, one of the nine published AVA tables reports data disaggregated by 'Primary Client Type' ('Physical disability', 'Mental health', 'Learning disability', 'Substance misuse' or 'Other vulnerable people'), and its subcategories (of which 'Mental health: of which dementia' is one). The data recorded within this table includes number of alerts, referrals, repeat referrals and completed repeat referrals, with these data further disaggregated by gender and by age band (18-64, 65-74, 75-84 and 85+).</p> <p>The SAR return (which replaces the AVA return from 2013-2014) will request data about the number of individuals (both previously known and unknown to the local authority) for whom a safeguarding referral has been made by 'Primary Support Reason', including the category 'Support with Memory and Cognition'. It may also be recorded by sub-category based on reported health conditions. 'Mental health condition: dementia' is one of these sub-categories. However reporting by sub-category is mandatory for the autism and Asperger's syndrome/ higher functioning autism categories only.</p> <p>A further data table will record the number of people assessed as lacking capacity (although not necessarily because of dementia) following a concluded referral (and the number of these people supported by an advocate, family member or friends) separated by age band (18-64, 65-74, 75-84, 85-94, 95+).</p> <p>It is not planned to collect the following data by primary support reason.</p> <ul style="list-style-type: none"> <li>• type of abuse</li> <li>• location of abuse</li> <li>• outcome of action taken</li> <li>• alleged perpetrator (e.g. organisation, known individual or stranger)</li> <li>• substantiation of abuse allegations, or</li> <li>• number of serious case reviews with an outcome of death.</li> </ul>
<p><b>Limitations</b></p>	<ul style="list-style-type: none"> <li>• Limited to cases of alleged abuse known to a local safeguarding team.</li> <li>• 'Primary Client Type' and 'Primary Support Reason' identify the main support need. Hence, someone with mild dementia and severe physical disabilities may not be categorized under 'Support with Memory or Cognition' but rather under one of the physical disability categories.</li> <li>• Inclusion within the 'Support with Memory and Cognition' category is not limited to those with dementia. It may include people with acquired brain injury, for example. However, for older people, we expect the category to be predominantly populated by people with dementia.</li> </ul>

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