A TIMELINE OF POLICY FOR THE PROVISION OF DEMENTIA CARE: ENGLAND (2001-2013)
A broad overview of government policy guidance with regards to dementia care in England; 2001-2013.

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AMBITION OF THIS SYNTHESIS

This report provides a broad overview of Parliaments attempts to recognise and engage with the increasing need for effective dementia services via the production of key policy drivers. This review includes succinct summaries of the principle documents that reflect the political energy expended upon dementia over the past decade.

It is designed to enable the reader to gain an introductory understanding of the key legislation that has guided the development of dementia care in the recent past. It is written for a wide audience ranging from the specialist clinicians working in this area who may struggle to find time to read all of the relevant publications to the trainee clinical psychologist who may be about to embark upon their older adult core placement who would benefit from understanding at least the political landscape of the services they are about to work in. Our IAPT workforce who have limited exposure to clients with dementia may also benefit from understanding the wider political agenda with reference to dementia services.

With regards to political impetus, some saw the most significant shift coming with the production of the country’s first National Dementia Strategy in 2009 which was developed in part, due to the lack of national policy in regards to dementia care. It followed the National Service Framework for Older People (2001) and was reviewed in 2010 by the National Audit office, concluding that significant positive progress has been made, though there had been a lack of implementation in certain aspects of dementia care.

In summary, it seems as though the prevalence of dementia is increasing with every given year, as is the media and government coverage of the syndrome. Important progress has been made in the quality and quantity of dementia care, both in social and healthcare settings. However this progress is somewhat overshadowed by the fact that dementia care is a financially crippling issue both to informal caregivers and numerous health and social care settings and the government has not yet successfully implemented a cost effective way of helping those with dementia and their families. This is having, and will continue to have, a negative impact upon the level of care that people with dementia and their carers receive in the UK currently.

It should be noted that this report focuses on influential policy and guidance developed at a government level and includes publications from the Department of Health and the National Institute for Health and Clinical Excellence. Audits conducted under the supervision of the government or National Health Service have also been included. This is not to say that guidance and reports conducted by non-governmental agencies such as the Alzheimer’s Society, MIND, the Joseph Rowntree Foundation, and Age UK have not been influential in shaping Britain’s care of those with a diagnosis of dementia, but merely that they are beyond the scope of this report.

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The aim of the National Service Framework for Older People (NSFOP) was to promote good mental health in older people and it placed an emphasis on the treatment and support of older people with dementia and depression. The rationale for constructing this guidance came largely from figures relating to the cost of caring for the older population which, taking into account the costs of informal caring and the expenses to all statutory agencies, had been estimated to be £6 billion per year (Bosanquet, May & Johnson, 1998).

It was also noted that older people’s mental health care should incorporate the Care Programme Approach and address the significant under-detection of mental illness within the older generations. The NSF also outlined basic information on dementia, including statistics of prevalence and stressed the importance of early diagnosis in order to provide high quality care and interventional pathways.

Key interventions outlined regarding dementia and older people in the NSF-S7:

The NSF for older people stated that improving care of older people with depression or dementia depends on the provision of high-quality evidence-based care. It also drew upon the fact that carers of older people with mental health problems may need access to information, advice, and practical help to support them in caring for the older person.

The NSFOP drew upon the then recently implemented Modernisation Program (2000) released by the Ministry of Health, which allocated £40 million to 42 Primary Care Trusts in order to convert the majority of nightingale wards into more appropriate ward layouts. The conversion was meant to include some wards specific to accommodating the needs of older people who have dementia.

The NSFOP also stated that Specialist Mental Health Services should be available for consultation and should have the means to treat both the most common mental health disorders in old age (depression, dementia, schizophrenia, etc) and the ‘less common’ disorders including anxiety and dependency problems’. The NSF stated that a range of services should be readily available for diagnosis and treatment of more complex problems, and community and in-patient services for those with a clinical need should be provided. The emphasis should be on promoting the independence of older people with mental health problems and supporting them, and their carers, in the community wherever possible and practical. Referral to the specialist Mental Health Service should be considered for those with suspected dementia if risk and safety issues arise, an uncertainty of diagnosis is apparent, there are negative psychological and behavioural systems present, the consideration of anti-dementia drugs, and for complex / multiple problems including dual diagnosis.

It also inferred that local councils and the National Health Service should work with care home providers in their area in order to be certain that there is a more
substantial range of services that meet the needs of older people with mental health problems, in particular specialist residential care for people with a diagnosis of dementia.

According to the NHS the treatment of dementia should include satisfactory information on the disorder to be given to carers and the service user, making appropriate referrals in regards to other problems such as fear, anxiety, practical and financial issues, using non-pharmacological management as a first port of call, and pharmacological agents (anti-psychotics) as a last resort (excluding dementia specific medication as this can be administered straight after a diagnosis of certain dementia types).

It also stressed the problematic issues of treating and caring for people with dementia, such as the behavioural and psychological symptoms associated with the illness which can present difficulties in diagnosis and strain on the carers involved. Recent research had shown that antipsychotic drugs were being prescribed at a high level to people with dementia, especially when they were a resident in a care home or in-patient unit. However the NSFOP recognised that due to the lack of significant differences in behaviour, paired with the adverse side effects that are more likely to emerge in older people, a fuller understanding of how best to treat the behavioural and psychological symptoms of dementia was needed. The NSFOP did not state that antipsychotics should not be used; it instead suggested that the new and updated pharmacological drugs should be prescribed as opposed to the older versions as these may cause fewer adverse effects.

The National Institute for Clinical Excellence (NICE) had recommended at the time of this publication (2001) that the dementia specific drugs Donepezil, Rivastigmine and Galantamine should be available in the NHS as one of the main components in managing mild and moderate Alzheimer’s disease. The NSFOP outlined that the following conditions be met before prescription:

- Mini Mental State Examination (MMSE) score 12 points or over
- Diagnosis of Alzheimer’s disease made in a specialist clinic
- Treatment follows specialist assessment of cognitive, global, and behavioural functioning
- Compliance of treatment must be likely
- Treatment must be initiated by relevant clinical specialists
- Response to treatment must be reviewed after 2-4 months and only continue if there is significant evidence of benefit to the person
- A review should be carried out using the MMSE every 6 months
Figure 1: Example of Dementia Care Pathway in accordance with the NSF for older people 2001, p102.
EVERYBODY’S BUSINESS: INTEGRATED MENTAL HEALTH SERVICES FOR OLDER ADULTS; A SERVICE DEVELOPMENT GUIDE, EVERYBODY’S BUSINESS: KEY MESSAGES FOR COMMISSIONERS, AND EVERYBODY’S BUSINESS: INFORMATION FOR HEALTH AND SOCIAL CARE PROFESSIONALS (NOVEMBER 2005) - DEPARTMENT OF HEALTH

This guidance, produced by the DoH and implemented by the Care Services Improvement Partnership (CSIP), aimed to build on the service models outlined in the National Service Framework for Older People (2001) and the principles promoted in Securing Better Mental Health for Older Adults (2005), in describing the foundations and key elements of a comprehensive older adult mental health service.

**Foundations for Developing a Comprehensive Older Adult Mental Health Service:**

The Everybody's Business guidance gathered a series of basic foundations that were felt to be vital to developing a comprehensive older adult mental health service in relation to mental health in general (not specifically dementia related). These foundations were involving service users and their carers in decision making, promoting good health, assessment and care planning, the development of culturally appropriate services, workforce development, the commissioning of integrated services and high-quality leadership. For more information see the Service Development Guide (2005) pages 10-22.

Assistive technology, telecare, residential settings, specialist groups, and care within a general hospital setting are also covered within the guidance in regards to general mental health.

**Primary and community care**

**Home care services:** Everybody’s Business stated that home care services should provide help with personal care and daily living activities, however it identified that staff may be limited in time to complete all tasks such as these to a high standard. Instead it recognised the need for specialist domiciliary care services (who often focus specifically on people with dementia).

**Specialist day care centres:** Everybody’s business stated that these should provide care for people with moderate to severe needs such as people with schizophrenia, depression, anxiety and also moderate to severe dementia. These centres should have flexible opening hours and could also be run by statutory, voluntary or independent sector organizations, which should work closely with specialist mental health teams that can provide additional support and training.

**Housing:** Sheltered housing schemes and extra care housing should be used when an individual is no longer functioning in the setting of their own home. Everybody’s Business highlighted that given the growing number of people being diagnosed with a form of dementia, extra care housing would likely become the most able to
accommodate people with dementia. The DoH set aside £147 million (2004-2008) in order to increase the rate of extra care housing available.

**Intermediate care**

At the time of this publication evidence suggested that older people with mental health problems, in particular people diagnosed with a dementia were historically excluded from mainstream intermediate care. Everybody’s Business identified two models that had been developed in response to these findings:

1) The development of skills for staff in mainstream services with additional specialist support to be implemented.

2) The development of separate specialist teams/resources where the primary need is a mental health problem

**Other specialist mental health services**

**Memory assessment services:** The publication stated that the purpose of the memory assessment should be to aid early detection and diagnosis of dementia and identify and assist with any treatable causes of cognitive impairment. There were two models of service delivery for memory assessment and early intervention identified in Everybody’s business:

1) Extension of the community mental health team: The Department of Health (DoH) stated that extending the CMHT would have the advantage of using an efficient existing infrastructure and a multi-disciplinary team. The negative of the use of CMHTs would be that early intervention work could in theory take second place to emergency tasks.

2) A separate resource (memory clinics): The publication identified weaknesses in the design of memory clinics. These were the hospital focus, narrowness of intervention, and lack of integration with local services. However the DoH inferred that with redesign and support these disadvantages could be overcome.

**Psychological therapies:** The DoH identified that access to psychological therapies was a consistently unmet need at the time of this publication. Best practice guidelines from the DoH (2004) stated that psychological therapy is essential to the care of people with mental health problems, and should therefore be routinely considered as a treatment option. These guidelines also recommended that attention be given to the needs of older people in relation to psychological therapies. Everybody’s Business guidance placed an emphasis on the importance of therapies being readily accessed by older people, and not being restricted by unreasonable waiting lists. It was recommended that psychological therapy clinical governance strategies were implemented by mental health trusts in order to monitor the quantity and quality of therapies within each organisation, including services for older people.

**Inpatient care:** Inpatient services were identified as dealing with a high level of individual need. Due to this the publication outlined that wards should be staffed accordingly for the safety and wellbeing of both service user and staff, and that inpatient care in regards to older people would be needed for two main groups:
1) Older people with an organic brain disorder, for example dementia.

2) Older people with functional disorders such as depression, schizophrenia and other psychoses.

The publication stated that the care of frail older adults on younger wards is considered bad practice and inappropriate as it would be placing them at risk, therefore, as well as medical and care assistant staff, ward based environments should include dieticians, physiotherapists, chiropodists, dentists, psychologists and occupational therapists to facilitate rehabilitation.
The NICE-SCIE guideline set up a series of recommendations and vital implementations based on research conducted into each aspect of dementia specific care in the UK, from environmental design in care homes to support services and risk factors.

Key priorities for implementation of the NICE-SCIE guideline were as follows:

1) **Non-discrimination**: People who have a diagnosis of dementia should not be alienated or excluded from any service due to their diagnosis, age or learning disability.
2) **Valid Consent**: The person with dementia should always be informed of decisions and options. The document emphasised the importance of making sure the person feels they are in some way in control of the decisions made in regards to their illness, however the Mental Capacity Act 2005 should be followed if there is a lack of capacity.
3) **Carers**: It is the job of health and social care managers to ensure that carers should have the right to receive an assessment of needs which is set out in the Carers and Disabled Children Act (2000) and the Carers (Equal Opportunities) act (2004). Psychological therapy should also be offered to carers who are exhibiting some form of psychological distress.
4) **Coordination and integration of health and social care**: ‘Health and social care managers should coordinate and integrate working across all agencies involved in the treatment and care of people with dementia and their carers, including jointly agreeing written policies and procedures. Joint planning should include local service users and carers in order to highlight and address problems specific to each locality’ (p4).
5) **Memory assessment services**: These should be the single point of referral for people querying a diagnosis of dementia.
6) **Structural Imaging for Diagnosis**: Magnetic Resonance Imaging and Computed Tomography should be used in order to exclude any cerebral pathologies in diagnosis, and to assist in early diagnosis and the detection of vascular changes.
7) **Behaviours that challenge**: Non-cognitive symptoms of dementia should be assessed at the earliest opportunity to highlight a way in which the behaviour can be improved. Individual care plans were emphasised in the document as key and
systematic reviews and record keeping were also seen as vital components of care.

8) **Training:** Dementia-care training should be readily available to anyone working with older people and should be consistent with specific roles and responsibilities.

9) **Mental health needs in acute hospitals:** Planning and provision should be carried out in general and acute hospitals to ensure that people with dementia receive care tailored to themselves.

NICE-SCIE set out the following principles of care for people with dementia:

**Equality, diversity and language**
People with dementia should not be discriminated against (in being excluded from services) due to their age and should be treated with respect and dignity. Individual needs of people with dementia should be identified by health and social care staff, for instance ethnicity and religion; all care packages and residential homes should address these needs. People who do not have a formal diagnosis of dementia but do have a cognitive impairment should still have access to services. Any form of barrier (language impairment, English as a second language, hearing or vision impairment etc) should be overcome through use of education of care staff and adaptive tools.

**Younger people with dementia and those with a learning disability and dementia**
These two client groups will have specialist requirements and services should be equipped accordingly to be able to give a high quality service. For example people with learning disabilities are more at risk of developing dementia; staff who predominately work with people with learning difficulties should therefore be educated in dementia.

**Ethics, consent and advanced decision making**
The Mental Capacity Act (2005) should be followed for those people with dementia who no longer hold the capacity to make their own decisions, capacity and consent should always be established by health and social care. Confidentiality should be of the upmost importance, and again the Mental Capacity act should be adhered to if a person’s mental state deteriorates and other parties of care / families / carers need to be informed. These parties of care should also be educated by health care professionals in regards to advance statements and lasting power of attorney.

**Information**
People with dementia and their carers should be given adequate information and support regarding abuse and neglect of vulnerable adults, and the impact of dementia on personal relationships. They should also be informed about whether they are eligible for individual budgets and payments and if so, helped to obtain them. Information should also be given regarding the differences between NHS care and local authority providers.

**Management and co-ordination of care**
Care and support of people with dementia should follow the framework of care in each trust. Managers should ensure that care plans are based on all aspects of that person’s life (physical health, mental health, life history, family circumstances etc).
Each person with dementia should be assigned to a named health or social care staff member to implement the care plan which should combine both professional groups input; reviews of the care plan should be frequent.

**Training and development of staff**
All staff that are in some way involved with dementia care should have access to dementia awareness and care training. This training should be consistent with their particular role. The following elements should be included in dementia training:

- Early signs and symptoms that indicate a dementia
- Different types of dementia and their symptoms and the consequences of being diagnosed with a dementia
- The assessment process and the pharmacological treatments available
- The application of the person-centred approach to care should be explained and emphasised
- Communication skills when working with people with dementia and their carers; verbal and non-verbal should be included in the training
- Outreach techniques and the differentiation between roles in the health and social care services
- Basic policy and procedure in regards to vulnerable adults
- The Palliative Care Approach should also be incorporated

**Environmental design**
Health and social care managers should ensure that all living arrangements for people with dementia meet their needs and comply with the Disability Discrimination Act (1995 and 2005). All environments should aid orientation and care should be taken when choosing flooring, colour schemes and lighting. The mix and amount of staff should be based on the amount and mix of residents and should at all times be therapeutic and supportive.

**Acute Hospitals**
Acute hospital trusts should provide a service to people with dementia that is equivalent in quality to the service provided to people who are not cognitively impaired. Specific needs of people with dementia should be addressed and appropriate care provided. The acute trusts should always refer anyone under their care with a query or diagnosis of dementia to their specialist dementia liaison services.

**Integrated Health and Social Care**
‘Everybody’s Business’ should be used by health and social care staff in concurrence with this publication for the implementation and delivery of care. There should be a co-ordination between all agencies of care in order to provide the best care possible. People with dementia and their carers should also have access to up to date information regarding services in their local area, including voluntary sectors.

**Risk factors, prevention and early identification**
The NICE-SCIE guideline stated that ‘general population screening for dementia should not be undertaken’ (p20). However vascular and other risk factors (smoking, diabetes, obesity etc) should be reviewed and treated where possible. Wherever there is a diagnosis of a dementia with an identified genetic factor, family members should be offered genetic counselling from regional services. Vitamin E, statins,
hormone replacement therapy and non-steroid anti-inflammatory drugs should not be prescribed as a specific dementia treatment.

**Early Identification of dementia**
People who have a mild cognitive impairment (MCI) should be referred by primary care to the memory clinics as more than 50% of people with a mild cognitive impairment eventually develop a dementia. People with a MCI should be monitored by the memory assessment services for any cognitive decline.

**Specialist services**
Memory assessment services should be the single point of referral for a query of dementia. The memory assessment services should be able to provide a responsive service with all diagnostic and treatment services available to accommodate all dementia types. They should also have an integrated approach in partnership with local authorities.

**Non-pharmacological interventions for cognitive symptoms of dementia**
Each trust should have a structured group Cognitive Stimulation Programme for people with mild to moderate dementia. It should be commissioned and provided by health and social care staff and offered regardless of drug treatment.

**Non-pharmacological interventions for non-cognitive symptoms of dementia**
An assessment should be given at the earliest opportunity of factors that may contribute to the non-cognitive symptoms of dementia (challenging behaviour), from this individual care plans should be put in place to help alleviate the symptoms and help the person with dementia, as well as helping the staff / carers.

**Conclusion**

The NICE-SCIE guidance was based on the ‘best available evidence’ (p12), however the guidance also stated that there were limitations in the evidence base due to there still being very limited data on the long term benefits of pharmacological and non-pharmacological treatments, and on the extent to which each individual intervention can improve or affect a person’s quality of life

For more information on the devised implementation guidance for the above key priorities and for more information on each element of care please refer to the full NICE-SCIE guideline (see references).
LIVING WITH DEMENTIA: A NATIONAL DEMENTIA STRATEGY- DEPARTMENT OF HEALTH (FEBRUARY 2009).

‘The aim of the strategy is to ensure that significant improvements are made to dementia services across three key areas: improved awareness, earlier diagnosis and intervention, and a higher quality of care (p9)’. The strategy included 17 recommendations / objectives in total and described itself as potentially being a catalyst for change in the treatment of people with dementia in England.

In 2009 there was still a shortcoming in the provision of dementia services in the UK. Dementia was costing the UK £17 billion a year and it had been consistently calculated that the rate of people with dementia was on the increase, and would continue to increase for the foreseeable future.

The purpose of the strategy
The purpose of the National Dementia Strategy (2009) was to provide a specific qualitative framework for which local services could improve their dementia services. However it was not designed to be a detailed clinical guidance as the NICE and SCIE guidelines would serve this purpose; instead it was designed as a strategy that would be specifically inclusive of dementia.

Objectives: How the NDS proposed the deliverance of its recommendations

1) Improving public and professional awareness and understanding of dementia: Objective one stemmed from the revelation that people with dementia are prevented access to diagnosis through a counter-productive cycle of misinterpretation, mis-attributes and stigma. The National Dementia Strategy (NDS) proposed that improving public and professional awareness and understanding of dementia should be successfully delivered by developing a general public information campaign, including a prevention message of ‘what’s good for your heart is good for your head’. Campaigns specific to regions should also be produced as well as campaigns for other groups such as schools, religious organisations etc.
2) **Good quality early diagnosis and intervention for all:** At the time of this publication it was estimated that only one third of people with dementia were receiving a formal diagnosis, a large percentage of which were already in the later stages and are therefore less likely to significantly benefit from certain interventions. The deliverance of this objective should have been from the commissioning of good quality services available locally for early prevention and diagnosis, which could take on the case load of all new cases occurring in that area. The guidance also highlighted the primary care trusts reluctance to be directly involved in the diagnosis of dementia; the NDS stated that specialist services should be available to GPs in order to refer people who have a query of cognitive impairment.

3) **Good quality information for those with diagnosed dementia and their carers:** According to the NDS the key to the deliverance of objective three would lie in reviewing existing relevant information sets and developing and distributing quality information on dementia, including information on all the services available which would be relevant during diagnosis and throughout the course of care.

4) **Enabling easy access to care, support and advice following diagnosis:** At the time of this publication it was identified that services for people with dementia would usually discharge the person once their behaviour and health had stabilised, and an adequate care package was in place to follow. There was a steady and ongoing message from qualitative interactions with people diagnosed with dementia and their carers, which was that they felt it would be beneficial to have someone they can approach for help at any time. Due to these points, objective four inferred the need for dementia advisors whose primary role would be to facilitate easy access to care, support and advice. This role would be a new implementation that would need piloting prior to implementation. The NDS stated that after the piloting, the commissioning of local dementia advisor services would provide a point of contact for all those with dementia and their carers.

5) **Development of structured peer support and learning networks:** This could be delivered through the evaluation of current (at time of publication) models of good practice in order to provide a backdrop for development. The NDS stated that there should in turn be a development in local peer support and learning networks for people with dementia and their carers. Third sector services commissioned by health and social care should also be supported.

6) **Improved community person support services:** The deliverance of objective six was based on the implementation of the Putting People First concordat by utilising the Transforming Social Care Grant. The concordat was designed to give more choice and control to service users. The NDS stated that an evidence base for effective specialist services in supporting people with dementia in their own homes should be established, and commissioners should be brought in to implement best practice models.

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1 For more information on the concordat please refer to *putting people first: A shared vision and commitment to the transformation of adult social care*—HM Government (2007).
7) Implementing the carer’s strategy: The NDS outlined the importance of carers. Promoting the development of breaks that would benefit both the person with dementia and their carer should be considered, and all carers should be offered a needs assessment.

8) Improved quality of care for people with dementia in general hospitals: A senior clinician within the general hospital should be identified to take the lead for quality improvement of dementia care in hospitals. An explicit care pathway for the management of people with dementia in general hospitals should also be established. Specialist liaison within general hospitals was already being promoted in the NICE-SCIE guidelines. The NDS therefore wanted existing data on the nature and impact of liaison services specialising in older people’s mental health in general hospitals to be gathered and reviewed with a view to giving commissioners a comprehensive and rounded model for specialist team working in the general hospitals.

9) Improved intermediate care for people with dementia: The needs of people with dementia should be included and addressed in the revision on the Department of Health’s 2001 guidance on intermediate care. Rehabilitation of people with dementia was not being offered at the time of publication due to the amount of time approximated to be needed to yield significant rehabilitation results; intermediate care should be accessible and needs met.

10) Considering the potential for housing support, housing-related services and telecare to support people with dementia and their carers: The development of housing models (including extra care housing) should be monitored in order to make sure the needs of people with dementia and their carers are being met. Staff that work within housing settings should be supported in developing the skills needed to provide the best care possible. A watching brief should also be set up to look into assistive technology and telecare, and if successful implementation should ensue.

11) Living well with dementia in care homes: Senior staff members should be identified to take the lead for quality improvement. Local strategies for management and care for people with dementia living in a care home need to be developed. The NDS emphasised that the use of anti-psychotic medication should be at a minimum and appropriate level. The process of commissioning specialist in-reach services from older people’s mental health services to work in care homes would also be beneficial, as would the commissioning of other services such as dentistry etc. Readily available, accurate guidance should be constructed for care home staff regarding best practice in dementia care.

12) Improved end of life care for people with dementia: The NDS referred to the Department of Health End of Life Care Strategy in that people with dementia and

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their carers should be actively involved in planning their end of life care. Local authorities should also take into account their own end of life strategies in regards to dementia care.

13) An informed and effective workforce for people with dementia: Health and social care staff should all be given training and continuous education in order to provide the best care possible for people with dementia. The Department of Health Adult Social Care Workforce Strategy (2009), Skills for Care, and Skills for Health documents were identified as being vital to the development of a skilled and trained workforce for dementia care. As was consultation with the General Social Care Council, the Social Care Institute for Excellence, and the National Skills Academy.

14) A joint commissioning strategy for dementia: Local commissioning should determine the needs of people with dementia and their carers and how best to meet those needs. World Class Commissioning guidance should be adhered to (NDS-Annex 1, p79-92).

15) Improved assessment and regulation of health and care services and how systems are working for people with dementia and their carers: Inspection regimes should be carried out in care homes and other services to make sure quality service is being delivered.

16) A clear picture of research evidence and needs: All evidence and research into dementia should be readily available and gaps must be seen to be filled. This should be initiated by the Medical Research Council and the Department of Health arranging a summit of parties interested in dementia research.

17) Effective national and regional support for implementation of the strategy: National and regional support should be available to assist the local implementation of the Dementia Strategy.
LIVING WELL WITH DEMENTIA – THE NATIONAL DEMENTIA STRATEGY: JOINT COMMISSIONING FRAMEWORK FOR DEMENTIA. DEPARTMENT OF HEALTH (JUNE 2009)

The joint commissioning framework was part of the NDS’s implementation support programme and provided additional information about what was (at the time of publication) available to commissioners to enhance the deliverance of the recommendations made in the NDS. A particular emphasis was placed on objective 14; a joint commissioning strategy for dementia. The framework drew upon the Putting People First vision and the World Class Commissioning program in order to encourage health and social services to work cohesively to deliver high quality care to those diagnosed with dementia.

The framework specified the following points of how the commissioner should function in regards to implementing the NDS:

- ‘Commission to secure local delivery of the full range of services set out in the strategy’ (p9).
- ‘Influence commissioners of other services, such as acute hospital care, to help them understand the requirements of people with dementia who will access the services they commission’ (p9).

The framework also specified key principles that should be integrated into all commissioning activity, these included keeping the person with dementia and their carer centre to the commissioning, clear communication between all commissioning agents, equality dignity and quality being key, legal rights to be adhered to, promoting independent functioning of service users where possible, and commissioners including all groups affected by dementia; younger adults, alcohol related dementia, people with learning disabilities and dementia etc.

For more information regarding the commission of each individual objective outlined in the National Dementia Strategy refer to pages 22-44 of the full guidance.
THE NATIONAL DEMENTIA STRATEGY: IMPLEMENTATION PLAN - DEPARTMENT OF HEALTH (JULY 2009)

Due to the fact that the National Dementia Strategy did not clearly outline how the Strategy should be implemented, this plan was published to give Primary Care Trusts a guideline of how the Department of Health would support the National Dementia Strategies implementation, both nationally and regionally.

However this plan was not designed to be dictatorial as it does not specify which services should be commissioned nor did it provide an accurate time scale of implementation. The plan stated that this was because the speed would depend on the circumstances of local authority areas.

The following objectives were stated to be of top priority for action:

- Joint Commissioning strategies for dementia care
- Living with dementia in care homes
- Workforce to be informed and efficient
- Quality early diagnosis and intervention
- Dementia and general hospitals; improvement in quality of treatment
- Carer’s Strategy to be implemented
- Community support services to be improved

Figure 3: Phases of implementation of the strategy. p9 of the NDS implementation guide.
In terms of resources available to help implement the strategy, £150 million was made available; £60 million 2009/10 and £90 million 2010/11. The plan stated that the use of this funding should include evaluation and evidence gathering. Funding of the further three years would be made after the initial 2 years of evaluation.

For more information in regards to implementing each individual objective of the NDS please refer to Annex one of the implementation plan, pages 25-30.
The National Audit office (NAO) used the Capability Review Framework (Civil Service, 2009) as the outline for this report into the success of the National Dementia Strategy. The Capability Review specified a focus on outcomes, common purposes, and evidence based choices as the criteria for an effective strategy. The report also identified risk areas in the strategy that could affect its success.

Findings of the NAO report were as follows:

**Awareness of the strategy amongst front line staff was low:** There still appeared to be a lack of local leadership for dementia health related services. In 2009 21% of old age psychiatrists reported a known senior clinician lead for dementia in their acute hospital and fewer front line staff could identify leaders of dementia care. Comparatively, strong leadership for the National Dementia Strategy was found in the social care sector.

**Health and social care services still needed to join and work together.** In 2007 it was identified that there was a lack of joined up health and social care services which could account for the unnecessary admittance to general hospitals and premature residence in full time care. These damaging occurrences were therefore providing a barrier to a high standard and cohesive dementia care service. In this 2010 report it was noted that joined up working was still sporadic; examples of good practice were found but had not yet been adopted on a wider, national basis.

The strategies implementation report (2009) clearly stated that the funding for the strategy was to be ingested through efficiency savings (unnecessary use of general hospital beds) which would be re-directed to other areas of care (with an emphasis on early diagnosis and intervention in regards to allowing people to stay in their own homes for as long a possible). The impact assessment of the NDS (2009) found that if entry to care homes could be delayed for a longer period of time then annual savings of up to £130 million could be met from 2013-2014. This estimated amount of money was much needed considering that dementia care costs the NHS and social services approximately £8.2 billion a year (2007) and does not yet appear to provide value for money. Due to the publication of the NDS dementia care and cost was seen as a national priority, however the DoH had not at time of this publication, successfully implemented objectives that would significantly affect the cost and effectiveness of dementia care in the UK. The initial strategy publication also failed to estimate the cost of training for NHS and social care staff which would be key to the implementation process.

It was not possible to account for how the fund appointed by the Department of Health following the NDS (£150 million for Primary Care Trusts split over 2009/10 and 2010/11) had been used for 2009/10. It was identified that the calculation of accountability would not be possible until baseline reviews of services had been carried out.
The NAO also outlines the timeframe of events leading to the implementation of the Dementia Strategy:

Figure 4: Timeline of the development and implementation of the National Dementia Strategy (NAO, 2010)
DEMENTIA QUALITY STANDARDS - NATIONAL INSTITUTE FOR HEALTH AND CLINICAL EXCELLENCE (JUNE 2010).

The NICE quality standard set out the standard of care expected for this client group and was aimed at the public, health and social care professionals, commissioners, and service providers. The standard covered care provided by health and social care professionals who were in contact with people with dementia in hospital, community, home, residential, and specialist care settings. It emphasised the importance of an integrated approach to the provision of services in order to ensure the delivery of high quality care.

Care standards taken from the guidance:

1) People with dementia receive care from staff appropriately trained in dementia care.
2) People with suspected dementia are referred to a Memory Assessment Service which specialises in the diagnosis and initial management of dementia.
3) People newly diagnosed with dementia and/or their carers receive written and verbal information about their condition, treatment and the support options in their local area.
4) People with dementia have an assessment and an ongoing personalised care plan which is agreed across health and social care, identifies a named care coordinator, and addresses individual needs.
5) People with dementia, while they have capacity should have the opportunity to discuss and make decisions together with their carer/s, about the use of:
   - Advance statements
   - Advance decisions to refuse treatment
   - Lasting Power of Attorney
   - Preferred Priorities of Care

6) Carers of people with dementia are offered an assessment of emotional, psychological and social needs and, if accepted, receive tailored interventions identified by a care plan to address those needs.
7) People with dementia who develop non-cognitive symptoms that cause them significant distress, or who develop behaviour that challenges, are offered an assessment at the earliest opportunity to establish generating and aggravating factors. Interventions to improve such behaviour or distress should be recorded in their care plan.
8) People with suspected or known dementia using acute and general hospital inpatient services or emergency departments have access to a liaison service that specialises in the diagnosis and management of dementia and older people’s mental health.
9) People in the later stages of dementia are assessed by Primary Care teams to identify and plan their palliative care needs.
10) Carers of people with dementia have access to a comprehensive range of respite / short-break services that meet the needs of both the carer and the person with dementia.
In addition to the NICE standards highlighted above, the document had further details specifically tailored to the commissioning of dementia care. For further information on each standard please see the full guidance which can be found on: http://publications.nice.org.uk/dementia-quality-standard-qs1/introduction-and-overview
This implementation plan built upon the National Dementia Strategy (2009). The main reason for the revision was due to the need for the implementation plan to fit with the following documents; *Equity and Excellence: Liberating the NHS* (2010) and *Liberating the NHS: Transparency in outcomes - a framework for the NHS* (2010). It also aimed to provide information on the Department of Health’s role in supporting the implementation of the NDS at a local level.

*The Equity and Excellence: Liberating the NHS* (2010) paper stated that separate frameworks for the NHS, the public sector, and social care would be developed to replace the then intertwined regime. This meant that a more focused and balanced set of national outcome indicators relating to the effectiveness of services, and the safety and experience of patients would be put into practice. This was to enable the Department of Health to take a more enabling, and less directive role. It should be noted that the implementation plan was not prescriptive and highlighted the fact that the pace of implementation would vary greatly depending on NHS and Local Authority area.

The department of health made the decision to focus on four priority areas of implementation:

1) Good quality early diagnosis and intervention for all
2) Improved quality of care in general hospitals
3) Living well with dementia in care homes
4) Reduced use of antipsychotic medication

The quality outcome report specified that work towards the above areas of implementation should work in parallel to the key aspects of the original NDS, such as support for carers, provision of information following a diagnosis etc.
The quality outcomes report also identified ‘key enablers’ to change that have been / are in the process of being implemented. These were:

- Revision to the NHS Operating Framework 2010-11 which concluded that dementia was one of the areas of health that was not being given sufficient attention (please see the Development of Policy Guidance for Older Adult’s Mental Health: A Timeline, 2012).
- The appointment of Professor Alistair Burns as the first National Clinical Director (NCD) for Dementia in order to promote clinical and professional engagement into the managing and design of services.
- The NHS National Quality Board (NQB) was established to look into the ways in which the quality of care can be improved and as part of this, is looking into dementia pathways.
- The NICE quality standards for Dementia was launched in June 2010, building on the 2006 NICE / SCIE guideline (See page 19-20 for a summary of these standards).
- The appointment of National Dementia Champions; Martin Green (independent sector), Sir Ian Carruthers (NHS), and Jenny Owen (social care).
- The development of a National Dementia Declaration.
- A reduction in the use of antipsychotic medication to treat people with dementia.
- The development of the Good Practice Compendium.
- There were also various research projects / audits / programs underway exploring various aspects of dementia care.
A Call to Action

Working in partnership with the initial signatories, people with dementia and their family carers described seven outcomes they would like to see in their lives. They provide an ambitious and achievable vision of how people with dementia and their families are supported by society. All individuals and organisations, large and small, can play a role in making it a reality.

1. I have personal choice and control or influence over decisions about me
   - I have control over my life and support to do the things that matter to me.
   - I have received an early diagnosis which was sensitively communicated.
   - I have access to adequate resources (private and public) that enable me to choose where and how I live.
   - I can make decisions now about the care I want in my later life.
   - I will die free from pain, fear and with dignity, cared for by people who are trained and supported in high quality palliative care.

2. I know that services are designed around me and my needs
   - I feel supported and understood by my GP and get a physical checkup regularly without asking for it.
   - There are a range of services that support me with any aspect of daily living and enable me to stay at home and in my community, enjoying the best quality of life for as long as possible.
   - I am treated with dignity and respect whenever I need support from services.
   - I only go into hospital when I need to and when I get there staff understand how I can receive the best treatment so that I can leave as soon as possible.
   - Care home staff understand a lot about me and my disability and know what helps me cope and enjoy the best quality of life every day.
   - My carer can access respite care if and when they want it, along with other services that can help support them in their role.

3. I have support that helps me live my life
   - I can choose what support suits me best, so that I don't feel a burden.
   - I can access a wide range of options and opportunities for support that suits me and my needs.
   - I know how to get this support and I am confident it will help me.
   - I have information and support and I can have fun with a network of others, including people in a similar position to me.
   - My carer also has their own support network that suits their own needs.

4. I have the knowledge and know-how to get what I need
   - It's not a problem getting information and advice, including information about the range of benefits I can access to help me afford and cope with living at home.
   - I know where I can get the information I need when I need it, and I can digest and re-digest it in a way that suits me.
   - I have enough information and advice to make decisions about managing, now and in the future, as my dementia progresses.
• My carer has access to further information relevant to them, and understands which benefits they are also entitled to.

5. I live in an enabling and supportive environment where I feel valued and understood
• I had a diagnosis very early on and, if I work, an understanding employer which means I can still work and stay connected to people in my life.
• I am making a contribution which makes me feel valued and valuable.
• My neighbours, friends, family and GP keep in touch and are pleased to see me.
• I am listened to and have my views considered, from the point I was first worried about my memory.
• The importance of helping me to sustain relationships with others is well recognised.
• If I develop behaviour that challenges others, people will take time to understand why I am acting in this way and help me to try to avoid it.
• My carer’s role is respected and supported. They also feel valued and valuable, and neither of us feel alone.

6. I have a sense of belonging and of being a valued part of family, community and civic life
• I feel safe and supported in my home and in my community, which includes shops and pubs, sporting and cultural opportunities.
• Neither I nor my family feel ashamed or discriminated against because I have dementia. People with whom we come into contact are helpful and supportive.
• My carer and I continue to have the opportunity to develop new interests and new social networks.
• It is easy for me to continue to live in my own home and I and my carer will both have the support needed for me to do this.

7. I know there is research going on which delivers a better life for me now and hope for the future
• I regularly read and hear about new developments in research.
• I am confident that there is an increasing investment in dementia research in the UK.
• I understand the growing evidence about prevention and risk reduction of dementia.
• As a person living with dementia, I am asked if I want to take part in suitable clinical trials or participate in research in other ways.
• I believe that research is key to improving the care I’m receiving now.
• I believe that more research will mean that my children and I can look forward to a range of treatments when I need it and there will be more treatments available for their generation.
• I know that with a diagnosis of dementia comes support to live well through assistive technologies as well as more traditional treatment types.
The History of the Declaration: A call to action
Dementia is one of the greatest challenges facing our ageing society. There has been major progress in recent years in securing public and political commitment to responding more effectively to dementia. We now need to ensure that this commitment is turned into concerted action. With the publication of this National Dementia Declaration we announce the launch of a Dementia Action Alliance and a major plan of action to change the experience of living with dementia in England for good. The organisations signed up to this Declaration call on all families, communities and organisations to work with us to transform quality of life for the millions of people affected by dementia.

The scale of the challenge
There are 800,000 people living with dementia in the UK now and by 2025 there will be over one million. Dementia is an incurable condition caused by diseases of the brain which over time seriously impairs the ability of someone with dementia to live independently. Symptoms can include severe memory loss, mood and personality changes and behaviour that challenges others such as serious confusion, agitation and aggression. Many people with dementia also have other medical conditions or develop them during the course of their illness.

Families currently provide the majority of care and support for people with dementia and this can be both tiring and stressful - physically, emotionally and financially. A large number of people with dementia also live alone and can be at particular risk of isolation or abuse. However, if people with dementia are diagnosed early, and they and their families receive help, they can continue to live a good quality of life.

The financial cost of dementia in the UK is £23 billion a year and rising. Two thirds of people with dementia live in their own homes and one third live in care homes. One in four people in hospital have dementia and two thirds of people in care homes have dementia.

This National Dementia Declaration has been created by people with dementia, carers of people with dementia and a large number of organisations who seek radical change in the way that our society responds to dementia. We seek a similar level of change as has been seen in our society's response to cancer over recent decades.

All organisations that are signatories to this National Dementia Declaration are setting out publicly what they intend to do by 2014 to transform quality of life for people with dementia and their family carers.

The Dementia Action Alliance will seek support from partners in civic organisations, businesses and professions to deliver dementia supportive communities.
Why is there a need for a National Dementia Declaration?

- Public awareness of dementia is high but understanding about it is still very poor. Fear of dementia also remains high; there is a reluctance to seek help and few people understand that it is possible to live well with dementia. In addition there is limited understanding of the fact that dementia can affect people in many different age groups.
- NHS and social care systems have not historically developed to reflect the fact that people with dementia are now a key group using many services.
- Only one third of people with dementia receive a specialist diagnosis and many are receiving that diagnosis late. GPs often report being reluctant to diagnose dementia either because they lack the knowledge to do so, do not see the benefits of early diagnosis or because they are aware of the lack of specialist support and services available for people after a diagnosis.
- Following diagnosis many people with dementia and carers report receiving no information about their condition or about what support might be available.
- Reports from regulator the Care Quality Commission (CQC) and its predecessor the Commission for Social Care Inspection (CSCI) show that although there are examples of excellent dementia care in care homes, many providers are struggling to deliver quality of life for people in the later stages of the condition.
- Equally, some people with dementia struggle for too long in their own homes without the help they need when better person-centred care or a good care home could provide a more stimulating and supportive environment.
- The All-Party Parliamentary Group on Dementia and Professor Banerjee have both produced reports revealing people with dementia are being inappropriately prescribed or over-prescribed antipsychotic drugs which increase risk of death and reduce quality of life.
- Health and social care staff routinely report that they have not received training in how to treat or care for people with dementia, despite the fact that they are now increasingly in contact with people with dementia.
- The National Audit Office and Parliamentary Public Accounts Committee have found that there is very ineffective use of current resources to deliver quality of life for people with dementia. For example the NAO has highlighted the potential for the NHS to identify savings of at least £284 million per year through improving dementia care. In addition to the costs borne by public services people with dementia and carers face high costs for care.
- UK spending from all sources on dementia research is low compared to other disease groups and by international standards.

Government action on dementia

In 2009 the then government in England published a five-year National Dementia Strategy. As part of this work, strategies on end of life care and carers are also in place. NICE/SCIE guideline 2006 and Dementia Quality Standards describe what good dementia care should look like.

The coalition government has stated its commitment to implement the National Dementia Strategy; however, it can only do so much. The Department of Health, as a signatory to the Declaration, will set out what it intends to do to help improve the lives of people with dementia. However, radical and sustainable change will only
come about through the action of individuals and organisations working together
locally and nationally to challenge what is wrong and to do things better.

There is overlap between these outcomes and the draft outcomes in the Department
of Health's National Dementia Strategy Implementation Plan. Both the Department of
Health's draft outcomes and those described below will need to be developed
further. In addition work will need to be done to better understand how to measure
these outcomes.

What do organisations signing up to the National Dementia Declaration
commit to?
Separate to this Declaration, each signatory organisation will be setting out what it
intends to do by 2014 (the date when the current National Dementia Strategy comes
to an end) in order to deliver better quality of life for people living with dementia and
their carers. These plans are being published separately. Each organisation is
committed to the following principles:

- Ensuring that the work they do is planned and informed by the views of
  people with dementia and their carers and showing evidence for this
- Being an ambassador for the National Dementia Declaration and securing
  commitment from partners for the second phase of the Declaration
- Reporting publicly on their progress against the plan they have set out to
  support delivery of the National Dementia Declaration
- Working in partnership with other organisations to share knowledge about
  best practice in dementia
- Improving understanding about dementia.

How will the Declaration be tracked and monitored?
Organisations signed up to the National Dementia Declaration commit to making
public the information about what they are doing to deliver better quality of life for
people with dementia. They will be expected to publicise their contribution to the
Declaration widely, especially to people with dementia, carers and the organisations
representing them. In that way organisations can be held to account, particularly by
their local population, to ensure they deliver what they have signed up to. There will
be quarterly reporting on the outcomes and an annual report so it is possible to see
what progress there has been.

How do I become an Alliance member?
To sign up to the National Dementia Declaration and become a member of the
Dementia Action Alliance, you will need to read the Declaration and then fill in an
Action Plan. This can then be emailed to the Secretariat, who will review your Action
Plan and get back to you with comments and next steps.

- Download a PDF version of the National Dementia Declaration
'NOTHING VENTURED, NOTHING GAINED': RISK GUIDANCE FOR PEOPLE WITH DEMENTIA. DEPARTMENT OF HEALTH (NOVEMBER 2010).

This guidance was produced for anyone involved in caring for or supporting people with dementia. Its focus was on ‘identifying and balancing the positive benefits of taking risks against the risk of an adverse event occurring’ (p6). This guidance referred both to physical risk (falling, getting lost) and to psychosocial risk (affecting a person’s mental wellbeing and sense of self).

It also touched on the principles of the Mental Capacity Act (2005); a framework for making decisions on a person’s behalf if their ability to make decision has become impaired, for instance through a deterioration in ability due to a dementia. It also provided information on Lasting Power of Attorney; a person, whilst having capacity can appoint another person to make decisions on their behalf in regards to finances, welfare and health.

Areas of risk that were reviewed (using case studies as examples of practice and situations of risk) included were dealing with a diagnosis of dementia, managing money, driving, defensible decisions, managing social care, assistive technology, walking and going outside, living alone/being left alone, medication, minimising restraint, and communal settings.

Please refer to full guidance for more details (see references).

The compendium was designed to be a local enabler for change as specified in the Department of Health’s Quality Outcomes for People with Dementia document. It gives examples of good practice and progress from each region in the UK.

The following is a summary of the examples of good practice given by the North West region in regards to the care of people with dementia.

**Early Dementia User’s Cooperative Aiming To Educate (EDUCATE) – Stockport**
The aim of EDUCATE was to enable volunteers who were in the early stages of dementia, to share their experience and skills in order to raise awareness of dementia in Stockport. The achievements of this venture were that the EDUCATE volunteers took part in training programs on communicating with people with dementia to a wide range of professional bodies. Both staff and service users were therefore aiding the improvement of health and social care for people with dementia.

**The Flexible Outreach Service – Age Concern Lancashire and Age Concern Central Lancashire.**
The purpose of the Flexible Outreach Service was to give people in the early stages of dementia, the opportunities to continue to pursue their hobbies and interests, and to develop / maintain / retain social contacts and independence. The service used individually tailored support programmes for service users. These included helping a service user to continue running and cycling, helping people continue to garden, teaching service users how to text family members etc.

**Shore Green Extra Care Sheltered Housing Scheme for Older People with Dementia and Other Memory Loss Conditions – Manchester**
Shore Green was a ten unit specialist extra care scheme for people with dementia or other memory conditions. They noted that for many people who moved into these bungalows, care packages actually decreased as level of independence increased.
A MISSED OPPORTUNITY: INQUIRY INTO THE FUNDING OF THE NATIONAL DEMENTIA STRATEGY- HOUSE OF COMMONS ALL-PARTY PARLIAMENTARY GROUP ON DEMENTIA (MARCH 2011)

Findings

‘Two thirds of Primary Care Trusts in this analysis were unable to demonstrate allocation of their NDS funding, with half of these stating that they could not separate this money from other funding or spending’ (p1).

The inquiry found that the development of memory and early diagnosis services by PCTs was being strongly implemented. However other areas of priority highlighted in the NDS, such as workforce development and the quality of care home care were not being prioritised. There was evidence that the joining of dementia strategies by local authorities and PCTs was being put into practice, however not all PCTs had this in motion by the deadline set by the NDS (March 2010).

Recommendations- Extract from a Missed Opportunity (2011) p2-3:

- Primary Care Trusts (PCTs) should be able to account for the full allocation of the 2010/11 National Dementia Strategy funding.
- All relevant aspects of the National Dementia Strategy should be prioritised in relation to funding and investment, by the PCTs.
- Every Primary Care trust should have an appointed clinical lead on dementia, as should every hospital.
- These clinical leads should focus on outcomes and key performance indicators, including reducing the diagnosis gap.
- An emphasis should be placed upon improving the quality of care for people with dementia living or staying in care homes.
- These care homes should have access to a wide range of appropriate health services (psychiatrists, pharmacists, GPs etc)
- External health services should support care homes in reducing the use of antipsychotics, improving the quality of care and subsequently the quality of life for the service users, reducing acute hospital admission and reducing overall costs.
- Primary Care Trusts should ensure that their workforce is well informed about all aspects of care for people with dementia, and are effective in their application of care through appropriate training which should be included in their budgets. The private sector should also be involved in regards to training staff in the PCTs; services should only be commissioned if they have a proven record of effective training in dementia care.
- The All Party Parliamentary Group expects that all strategies relating to the care of older people with mental health problems prior to the publication of the National Dementia Strategy, be reviewed in terms of intentions and effectiveness.
- Younger people who are diagnosed with dementia should be recognised and their needs specified and met.
• Joint commissioning between PCTs and local authorities should be the top priority and implementations should be monitored. All strategies relating to joint commission should be available to the public.

• The Department of Health has issued a deadline (March 2012) for each PCT to have a strategy in place for joint commissioning. Those PCTs who fail to meet the deadline should be monitored accordingly.

For a more in-depth review of successful and unsuccessful implementation of the National Dementia Strategy please refer to full guidance (see references). Please note this inquiry was released prior to the dissolution of PCT’s in England.
DEMENTIA: THE NICE-SCIE GUIDELINE ON SUPPORTING PEOPLE WITH DEMENTIA AND THEIR CARERS IN HEALTH AND SOCIAL CARE—AMENDED TO INCLUDE GUIDELINE 42 (MARCH 2011).

The NICE-SCIE guideline was amended to include the NICE technology appraisal TA217 in relation to Alzheimer’s disease drugs. The amendment stated that the Acetylcholinesterase Inhibitors Donepezil, Galantamine and Rivastigmine were the recommended drugs for people diagnosed with mild to moderate Alzheimer’s disease. Memantine was to be prescribed to people diagnosed with moderate Alzheimer’s who were intolerant to the other three drugs, or people diagnosed with severe Alzheimer’s.

It also stated that when assessment scales were used to determine severity of impairment, all communication difficulties, physical impairments, sensory or learning difficulties should be taken into account and appropriate adjustments should be made.

For more information see Amendment to Dementia Clinical Guideline 42 - March 2011.
THE NATIONAL AUDIT OF DEMENTIA CARE IN GENERAL HOSPITALS: ROYAL COLLEGE OF PSYCHIATRISTS (APRIL 2011)

In 2008 the Healthcare Quality Improvement Partnership funded the National Audit of Dementia (care in general hospitals). The audit focused on the general hospitals ability to care and the quality of that care for people with dementia. The audit was also split into a hospital level ‘core’ audit (hospital organisational checklist and a retrospective case note audit) and a ward level ‘enhanced’ audit (ward organisational and environmental checklists, staff questionnaires, carer / patient questionnaires, and observations of care interactions).

The data collection spanned from March 2010 to April 2011 and 89% of eligible hospitals, representing 99% of trusts / health boards in England and Wales participated in the audit.

Main findings of the audit

The analysis of the hospital level audit showed a low level of performance, and there appeared to be a wide variation of results depending on the individual participating hospital. The audit also found that the presence of a hospital policy put in place for the care of people with dementia did not seem to be a marker of good practice.

The following are summaries of the key findings according to topic.

Governance: whether an organisation has put in place systems and resources that meet the needs of people with dementia

Only 6% of hospitals involved in the audit had a care pathway in place for patients with dementia. There appeared to be a lack of leadership both at trust / health board and hospital level. For example only 8% of hospitals reviewed the re-admissions of people with dementia and less than a third of hospital boards / trust executive boards regularly looked at information relating to the delayed discharge of people with dementia. Availability of specialist services such as occupational therapy, social services and psychiatry was limited in the majority of hospitals during the weekends and after 5pm on a weekday.

Assessment: whether people with dementia are offered a comprehensive assessment of their physical and mental health needs, and ongoing care.

Though hospital guidelines often included a list of expected assessments to be carried out, important elements of assessment were not routinely completed; 84% of hospital guidelines included an assessment of function (activities of daily living, gait and balance etc) but only 26% of the case notes analysed included these assessments. 24% of hospitals did not have guidelines that expected a mental health assessment to be carried out during admission and 24% of case notes did not include any questions to the patient regarding whether they were experiencing any pain. This portrayed a large gap between policy and practice in the majority of general hospitals.
Mental health and liaison psychiatry: people with dementia usually require access to a specialist mental health service provided by a liaison team. The team should respond to both routine and emergency referrals.

90% of hospitals had (at the time of publication) access to a liaison psychiatry service and approximately a third of those hospitals were able to offer out of hours services. However in the case note analysis it was found that approximately one third of urgent referrals waited over 4 days to be seen. The audit showed an overall widespread provision of psychiatric liaison services, though due to limited availability (9-5pm / Monday-Friday) the rate at which the service could respond to emergency referrals was significantly limited.

Mental health and liaison psychiatry: antipsychotic medication and assessment

According to the audit, reviewing a patient with dementia’s ongoing needs (including mental health) should be a routine procedure upon discharge from general hospitals. However only 28% of case notes analysed contained information regarding behavioural and psychological symptoms of dementia at discharge. Only 6% of people with dementia had their level of cognitive impairment assessed at admission and discharge.

Nutrition:

The audit found that people with dementia did not always receive a nutritional assessment whilst in hospital. The need for help with eating and drinking for some people with dementia was not always resourced adequately. It was implied that there was much to be done to deliver a sufficient system for nutrition assessment and aid with mealtimes.

Information and communication:

A lack of guidance was found for the involvement of families in discharge plans; only 45% of families were given the name of a professional to contact for help or advice. There was little evidence to suggest that families were asked about behavioural triggers and strategies that were known to help the patient feel safer in a hospital (unfamiliar) environment.

Staff training:

The audit identified (through staff questionnaires and observations of ward environments) that there were major gaps in the staff’s knowledge of dementia care. Only 5% of hospitals had dementia awareness as a mandatory training programme for all staff. When asked, the majority of staff members across all roles acknowledged that further training would be beneficial in improving the level of care given to this client group.

Staffing and staff support:

It was found that 93% of wards had a system to ensure that at least the minimum amount of staffing levels were in place, though less than a third of staff on the wards felt that they had sufficient numbers to provide an adequate degree of care. 60% of wards offered clinical supervision to qualified nurses, but only 40% offered it to healthcare assistants.
Physical ward environment (helping patients with dementia to orient to time and place):
It appeared that attention to noise levels and the confusion this can cause for people with dementia could be improved across trusts. For example only 47% of wards could provide an area away from the ward environment. 56% of wards stated that a clock was in sight for all patients on that ward, though only 5% of wards had a calendar placed within each patient’s eye line.

Discharge planning and discharge procedures:
67% of case notes analysed in the audit contained an up to date discharge plan, though only 41% of these stated that a copy had been given to the patient and/or carers. On the other hand 80% of the notes showed that discharge procedures and support needs had been discussed with the carer of the patient with dementia.

The audit also found that though a large percentage of the hospitals have a commitment to beginning a discharge plan within 24 hours of admission, less than half could show any evidence for this, and no reason could be given for this discrepancy.

Observations of care carried out within the audit.
There appeared to be little evidence of a person-centred ward approach and the content of patient/professional interactions tended to be task related and impersonal in manner. Boredom, lack of stimulation for patients, and excess noise were also identified to be a major issue in most hospitals. No ward environments were identified as being ‘dementia friendly’.

Note: There were a number of individual staff members identified as delivering high quality person-centred care, but no overall staff groups, wards, hospitals or trusts.

The audit also drew attention to the NICE guidelines and ‘common core principles’ for caring for and managing people with ‘challenging behaviour.’ In these guidelines it clearly stated that the use of medication to treat behaviour should be either a last resort or used when there is an immediate risk to self or others. Bearing this in mind, only 34% of hospitals had clear protocols for staff to use when managing patients with ‘challenging behaviour.’ 28% of the sample received antipsychotic medication whilst in hospital, 12% of these had not been prescribed this medication prior to admission. In 18% of these cases no reason for prescribing was given in the notes.

The audit concluded that mental health needs were still being overlooked in general hospitals given the low rate of assessment during admission and discharge.

Recommendations made by the report

- A senior clinical dementia lead should be put in place for each hospital, in part to review and develop that hospital’s dementia pathway.
- Supervision and support should be given to staff who are caring for someone with dementia.
• Orientation aids should be incorporated into each ward environment (colours, aids, personal items etc) and guidance should come from the Department of Health as to how to design dementia friendly wards.
• All staff should receive basic dementia awareness training, and based on the level of skill and input, some staff should receive higher levels of training.
• Staffing levels should be able to cater for the additional support needed for people with dementia.

For further information and the full list of recommendations made by the report please refer to the full report and executive summary.
THE COMMISSIONING FRAMEWORK FOR DEMENTIA-DEPARTMENT OF HEALTH (JULY 2011)

The commissioning pack was launched by Paul Burstow (Minister for Health) and Professor Alistair Burns (National Clinical Director for Dementia) alongside the Handbook for Commissioning Dementia (Department of Health, July 2011) as a revision of the 2010 / 11 Operating Framework. It was developed following the consultation of health and social care commissioners and providers, service users and their families, and advocacy groups. Overall it set out a framework for commissioning the delivery of person-centred integrated care and the elaborated VIPS model (Brooker 2007).

Figure 6: The key principles for commissioning a person centred approach

The framework also set out the following six phases of the dementia journey in order to illustrate the changing needs of the person with dementia, and the people around them:

1) When memory problems have prompted me, and /or my carers to approach my GP with concerns
2) Learning that the condition is dementia
3) Learning more about the disease, options for treatments and care, self management and support for me and my carer / family
4) Getting the right help at the right time to live well with dementia, prevent crises, and manage together
5) Getting help if it is not possible to stay at home, or if hospital care is needed
6) Receiving care, compassion and support at the end of life

Commissioning framework, page 8

3 VIPS (Brooker, 2007) – Value base which asserts the absolute value of all human lives, Individualised approach recognising uniqueness, understanding the world from the Perspective of the service user, positive Social psychology in which a person with dementia can experience relative well being
For more information concerning all six phases and their commissioning options please see full commissioning document.

Figure 7: A diagram to show the services that should be included in commissioning dementia care

This document outlined the arrangements and requirements for the NHS organisations in 2012 / 13.

Four key themes were identified in this document for all NHS organisations to focus upon:

1) Putting patients at the centre of any decision (an outcomes approach to service delivery), whilst meeting essential standards of care and maintaining patients dignity at all times.
2) The completion of the last year of transition to the new system (separate frameworks for the NHS, public sector, and social care, as opposed to an intertwined regime). Building upon clinical commissioning groups and supporting the implementation of health and wellbeing boards.
3) Increasing the rate of delivery of the quality, innovation, productivity, and prevention (QIPP) challenge.
4) Closely monitoring the service and financial performance, with an emphasis on making sure that the NHS’ principle of the ‘right to treatment within 18 weeks’ is met.

Multiple areas requiring particular attention were outlined in the document. Though the majority of these areas are indirectly linked to the care of people with dementia, those more closely linked with this client group are as follows:

**Dementia and the care of older people**
Commissioners should ensure that providers of care are always aware and compliant with the NICE quality guidelines. They should also work together with GP practices in order to maintain ongoing improvements in the quality of community services, and reduce the number of avoidable hospital admissions.

The document also emphasised the need for a reduction in the prescription of antipsychotic drugs to people with dementia, and expected at least a two thirds reduction in this. It also expected a continuation in the improvement of diagnosis rates, and to increase the amount and value of staff training in dementia.

**Supporting carers of people with physical health needs / mental health needs / learning disabilities etc**
The framework stated that any plans to support carers should be in line with The Carer’s Strategy, and that local authorities and voluntary agencies should have agreed plans with their PCT cluster in terms of policies, plans and budgets. Information concerning the NHS’s financial contribution to support carers should have been published on the PCT cluster’s website by 30th September 2012.

**Mental health services in general**
No Health Without Mental Health accentuated the importance of equal importance of mental health and physical health needs. For 2012 / 13 particular focus should have been on improving access to psychological therapies, with a recovery rate of at least 50% for fully established services by 2015. During the period of 2012 /13 there
should also be an increase in access for black and minority ethnic groups, and older people.

The Prime Ministers Challenge set out a programme of work designed to make a positive difference in dementia care and research by 2015, emphasising that the improvement is both a challenge to the government as well as to the wider society.

It outlined progress made subsequent to the implementation of the National Dementia Strategy (2009):

- 94% of Primary Care Trusts had (at the time of publication), a memory service for dementia and the average number of people using the service increased by 57% between 2008/9 and 2010/11.
- Progress had been made by the NHS and social care services in reducing the rate of antipsychotic medication prescribed to those diagnosed with a dementia.
- Over 90 organisations had joined the Dementia Action Alliance (DAA) since October 2010.
- A dementia commissioning pack was developed in July 2011.

The Prime Ministers Challenge focused on three areas:

1) Driving improvements in health and social care
2) Creating dementia friendly communities that understand how to help
3) Better research

Three champion groups had been allocated to report on and assist with the development of the three focus areas. Progress was hoped to be reported upon in March of 2013.

For further information regarding the challenge and the three key areas of commitment, please see the full document.
The mandate set out a non-exhaustive list of the NHS and government's priorities in their commitment to delivering high quality care. These were as follows:

1) Preventing people from dying prematurely
2) Enhancing quality of life for people with long-term conditions
3) Helping people to recover from episodes of ill health or following injury
4) Ensuring that people have a positive experience of care
5) Treating and caring for people in a safe environment
6) Freeing the NHS innovate
7) The broader role of the NHS in society
8) Finance
9) Assessing progress and providing stability

Out of the nine priority areas, number two was the only one directly related to dementia care. The mandate expected the NHS commissioning board to make significant progress in the diagnosis, treatment and care of people with dementia. It also emphasised the importance of the involvement of people in their own care decision, the use of technology, and a better integration of services. It highlighted the lack of attention dementia had received in the past, regardless of its increasing prevalence. The mandate stated that the government’s goal for dementia care was for the level of care offered in the UK to be one of the best in Europe (see the Prime Minister’s Challenge on Dementia; March 2012 for more detail).

![Figure 8: Enhancing quality of life for long-term illness (including dementia)](image-url)
The quality standards applied to any services (including commissioners) working with / caring for people with dementia. It stated that is should be used in conjunction with the NICE Dementia Quality Standard produced in 2010. It should also be used to by health and social care staff in concurrence with the Adult Social Care Outcomes Framework 2013-2014 (2012), the NHS Outcomes Framework 2013-2014 (2012), and the Public Health Outcomes Framework for England 2013-2016 (2012).

The quality standard explained that it should be used to support anyone who is living with a cognitive impairment, and does not have to be used solely for someone with a formal diagnosis of dementia.

There are ten quality statements in the guidance document, all of which are designed to be ‘specific, concise and measurable’ (p7).

**Quality Standard Statements**

1) People worried about possible dementia in themselves or someone they know can discuss their concerns, and the option of seeking a diagnosis, with someone with knowledge and expertise.

2) People with dementia, with the involvement of their carers, have choice and control in decisions affecting their care and support.

3) People with dementia participate, with the involvement of their carers, in a review of their needs and preferences when their circumstances change.

4) People with dementia are enabled, with the involvement of their carers, to take part in leisure activities during their day based on individual interest and choice.

5) People with dementia are enabled, with the involvement of their carers, to maintain and develop relationships.

6) People with dementia are enabled, with the involvement of their carers, to access services that help maintain their physical and mental health and wellbeing.

7) People with dementia live in housing that meets their specific needs.

8) People with dementia have opportunities, with the involvement of their carers, to participate and influence the design, planning, evaluation and delivery of services.

9) People with dementia are enabled, with the involvement of their carers, to access independent advocacy services.
10) People with dementia are enabled, with the involvement of their carers, to maintain and develop their involvement in and contribution to their local community.
The Prime Minister’s Challenge on Dementia (2012) was designed to assist in the positive growth of dementia care and research by 2015. This progress report outlined the extent to which the report had been implemented in the year since its original publication.

The report focuses on the key successes made over the last year in dementia care. The successes in ‘driving improvements in health and care’ were outlined as:

- The NHS set out the first national ambition to improve dementia diagnosis rates
- The new Enhanced Service for GP’s has meant that GP’s are now rewarded for having a pro-active approach to dementia assessment and this aspect of care was integrated into their commissioning contracts for 2013/2014
- The Dilnot Commission on Funding Care and Support (2011) set out reforms for social care funding and should help protect people with dementia against the high cost of care once implemented in 2016
- Dementia was named one of the seven high level priorities of Public Health England
- The Dementia Action Alliance launched the ‘Dementia Care and Support Compact’ to support the implementation of the Prime Minister’s Challenge. The compact now includes over 148 signatories which represent almost 3,000 care services in the UK
- The Commissioning for Quality and Innovation (CQUIN) reward for hospitals was established subsequent to the Prime Minister’s Challenge, which meant that all people over the age of 75 who were admitted as an emergency admission should be offered dementia risk-assessments. In 2013 the CQUIN was extended to ‘the quality of dementia care delivered and support for carer of people with dementia’ (p5).
- Since the Prime Minister’s Challenge 118 acute and 22 non-acute trusts have committed to becoming ‘dementia friendly’ in partnership with the Dementia Action Alliance.

The successes in ‘creating dementia-friendly communities that understand how to help’ were outlined as:

- The Dementia Friends program run by the Alzheimer’s Society (co-funded by the DH and Cabinet Office) was launched in 2013. Since then over 2747 people volunteered as Dementia Friend Champions.
- Over 50 cities have taken local action to become more dementia friendly.
- Local Dementia Action Alliances have been established in over 20 areas.
• 21 schools have taken part in a dementia education pioneer programme to evaluate the best approaches to educating children about dementia.
• Nearing the end of 2012 a nationwide campaign to educate people about dementia.

The successes in ‘better research’ were outlined as:

• There has been a 50% increase in neuroscience programmes and resources, a major part of which was dedicated to the research of dementia and neurodegeneration.
• £22 million additional funding has been approved by the National Institute for Health Research (NIHR) for 21 research projects.
• The NIHR Translational Research Collaboration was created following the Prime Minister’s Challenge document, the collaboration focused on translating scientific discoveries and research into something which can be used to benefit dementia patients.
• In 2012 the Department of Health and the Economic and Social Research Council (ESRC) asked for research proposals to be put forward for a £13 million fund for social science research.
• £9.6 million was provided by the MRC to look at brain scanning.
• In October 2012 the UK’s dementia research and resources were showcased.
• Two facilities have been developed to enable people with dementia to take part in research if they wish; ENRICH (home care research advice and information toolkit), and ‘consent for approach’ (ability to offer registration of interest for research).

The report outlines what is currently known about dementia care, support and research in England. It highlights where improvements have been made, however it also looks at the areas in which improvements are still needed. The report did not outline how or when improvements should be made, but pointed out what the Department of Health hoped could be achieved in the future in regards to dementia care.

Improvement / actions identified from the report are as follows:

Prevention

The NHS Health Check uptake must be increased in order to educate people about the risk factors associated with dementia; encouraging healthy lifestyle choices. We must also learn more about the risk factors associated with dementia, in order to create an effective approach to disease prevention.

Diagnosis

In the report the Department of Health called for action from CCGs and local authorities to fulfil the ambition that by 2015 two thirds of people with dementia should have a diagnosis and have access to post diagnostic support.

Living with dementia

Carers: The DH asked for support from the NHS, social care, voluntary and independent sectors to help achieve the goals set out in the Dementia Action Alliance launch ‘Carers Call to Action’ (November 2013). The goals are as follows:

- Carers of people with dementia have recognition of the unique experience of caring for someone with dementia
- They are recognised as essential partners in care
- They have access to expertise in dementia care for personalised information and support
- They have assessments and support to identify changing needs, in order to maintain their own health and wellbeing
- Carers of people with dementia should have confidence that they are able to access good quality care provided by skilled staff (both for the carer and the person they are caring for).

Care at home: The Homecare Survey (4) (July 2012) highlighted that people desire ‘respect, time and control’. The DH therefore called for:

4 Care is not a Commodity report- United Kingdom Home Care Association limited (July 2013)
• Commissioners to build service specifications based on what people value most and to make sure these priorities are protected.
• People to be given more control over what their resources (allocated to their care) can be spent on, in order to access services which they value.
• More homecare providers to be giving a higher level of training to care staff, including specialist dementia care training.

Care in hospital: The DH would like all hospitals dedicated to being dementia friendly in terms of appropriate environment, workforce training, identification and assessment of cognitive impairment, supporting people with dementia to be discharged back home, and the use of person centred planning.

Care in care homes: The DH encourages more care providers to sign the Dementia Care and Support Compact (March 2012) and to engage the wider community in improving support for people with dementia.

Reducing inappropriate prescribing of antipsychotic medication: The DH recognises that there has been a national decrease in the amount of people with dementia prescribed antipsychotics (2012) (5). However it also identifies that there is still widespread variance of antipsychotic prescription. The DH aims to re-run the audit in 2014 in order to monitor the spread of prescriptions regionally.

End of life care: More professionals need to be aware of the alternatives to hospitalisation and more ‘planning ahead’ conversations should be taking place with people with dementia and their families.

Dementia education and training

Health Education England (HEE) feels that all NHS staff need to be aware of the early signs of dementia and wants to exceed the government target of 100,000 staff completing the dementia foundation level training by March 2014. The DH also emphasised the importance of more social care staff being trained in dementia awareness.

Dementia friendly communities

Public attitudes to dementia: The DH wants the public perception of dementia to change, and have the confidence to engage with people with dementia. The Department of Health feel the best way to achieve this is for more individuals and organisations to join the Dementia Friends Programme to increase their understanding of the illness.

In terms of creating dementia friendly communities the Department of Health would also like to see:

• Local leaders committed to creating dementia friendly communities

5 The National Dementia and Antipsychotic Prescribing Audit (July 2012) – Health and Social Care Information Centre; NHS
• All communities in England signing the Dementia Friendly Communities recognition progress.
• National businesses working with the Alzheimer's Society and Dementia Action Alliance to encourage dementia awareness.
• More people in England signing up to become Dementia Friends and Dementia Friends Champions.

In conclusion the Department of Health would like to see:

1) **Faster progress** towards achieving earlier diagnosis, improved assessment and treatment, and better management and care.
2) **More dementia research** and more participants in research
The first NHS Outcomes Framework was developed for 2011 / 2012 (DH 2010) as a document which clearly outlined areas which the NHS was keen to cover in terms of improvement and activity. The 2011 / 2012 document did not include any specific ambitions for dementia care. It outlined the broader domains in which aspects of care would be assigned to either indicators or improvement areas. The domains were as follows:

1) Preventing people from dying prematurely
2) Enhancing quality of life for people with long-term conditions
3) Helping people to recover from episodes of ill health or following injury
4) Ensuring that people have a positive experience of care
5) Treating and caring for people in a safe environment and protecting them from avoidable harm

The next publication for 2012 /2013 placed dementia care in domain two as a placeholder; (‘enhancing the quality of life for people with dementia’). A placeholder meant that the NHS were committed to developing a full indicator in this area, but in doing so also recognised that it may take time to do this.

The NHS Outcomes Framework 2013 / 2014 (2012) publication highlighted any key changes that had been made for each indicator over the last year. In terms of dementia care, since the publication of the last framework, the Prime Minister had announced a ‘dementia challenge’ with a focus upon increasing diagnostic rates, improving research and creating communities which were dementia friendly.

Finally the 2014 / 2015 NHS Outcomes Framework (2013) looked again at key changes across each domain. The placeholder / indicator for dementia had been extended to ‘a measure of the effectiveness of post-diagnosis care in sustaining independence and improving quality of life for people with dementia’. The indicator for dementia was documented as still being at placeholder level (a need had been identified but an indicator had yet to be developed). The document stated that the Department of Health had commissioned a research team to look at patient reported outcome measures for dementia, the data release date being estimated at 2016 / 2017.
G8 DEMENTIA SUMMIT DECLARATION- UNITED KINGDOM
G8 HEALTH MINISTERS (DECEMBER 2013)

The summit declaration acknowledged the global push to address the issues that arise from the prevalence of dementia, including the Dementia: A Public Health Priority (World Health Organisations, 2012) document.

‘In accordance with the national, sub-national and local responsibilities’ the G8 Health Ministers committed to the following points:

1) The call for greater innovation to improve quality of life for people with dementia and their carers (including addressing emotional and financial burden). The G8UK therefore ‘welcome the UK’s decision to appoint a global Dementia Innovation Envoy’ in order to coordinate international efforts in attracting sources of finance to support dementia innovation.

2) The G8 committed themselves to identifying a cure or disease-modifying therapy by 2025. They also agreed to increase the amount of dementia funding in order to help reach the above goal. The summit plan to report (every two years) on the progress made in dementia research.

3) They commit to working together and sharing information regarding research.

4) To develop co-ordinated international research plans to identify gaps and opportunities and to work collaboratively to address these.

5) To encourage open access to publically funded dementia research (where possible).

6) To work in partnership with the OECD6 to consider which changes could be made to accelerate research discovery and efficient care services.

7) To hold a series of fora in 2014 (with OECD, WHO7, JPND8, the European Commission, and the civilian society) to develop partnerships across the sectors.

8) Committed to calling upon the WHO and OECD in supporting countries to strengthen the health and social care systems for people with dementia.

9) To call upon the UN Independent Expert to look into the perspective of older people affected by dementia into their work regarding human rights for older people

10) To call upon all sectors to treat people with dementia with dignity and respect at all times and to contribute to the prevention, treatment and care of people with dementia where possible

11) To call upon society to continue to reduce stigma, exclusion and fear of people with dementia.

12) The G8 also committed to meeting in February 2015 (in the United States) with other experts to review the progression of research.

6 Organisation for Economic Co-operation and Development
7 World Health Organisation
8 Joint Programme on Neurodegenerative Disease (European Union)
Figure 9: A timeline of dementia care 2001-2010


September 2010: Quality outcomes for people with dementia. Department of Health


June 2010: Dementia Quality Standards National Institute for Health and Clinical Excellence

March 2011: NICE-SCIE Guideline: Amended to Include Guideline 42
National Institute for Health and Clinical Excellence and the Social Care Institute for Excellence

March 2011: Inquiry into the Funding of the National Dementia Strategy.
All Party Parliamentary Group.

April 2011: National audit of dementia care in general hospitals.
Royal College of Psychiatrists.

April 2011: National audit of dementia care in general hospitals.
Royal College of Psychiatrists.

April 2012: The Prime Ministers Challenge.
Department of Health

April 2013: Quality Standards for Supporting People to Live Well with Dementia.
NICE

May 2013: The Prime Minister's Challenge on Dementia.
Department of Health

November 2011: Operating Framework
Department of Health

November 2011: Operating Framework
Department of Health

November 2012: The Mandate
Department of Health

November 2012: The Mandate
Department of Health

Department of Health

Department of Health

December 2013: G8 Dementia Summit Declaration.
G8 Health Ministers

January 2011: Good Practice Compendium
Department of Health

July 2011: Commissioning Framework
Department of Health

July 2011: Commissioning Framework
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