

South West Dementia Partnership



Guidance on the Commissioning of Memory Assessment Services

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www.southwestdementiapartnership.org.uk

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Introduction

This guidance has been developed by an Expert Reference Group (Appendix 1), on behalf of the South West Dementia Partnership.¹ It has been subject to extensive consultation.

The guidance sets out specifications for a specialist assessment service for people with a possible or suspected diagnosis of dementia.

The term 'Memory Service' is used to describe this type of service throughout this document.

This guidance has drawn from existing service specifications across the South West, positive practice, and advice and guidance provided by a range of commissioners, providers, and people with lived experience.

The guidance is intended to be a resource and tool to inform the commissioning and delivery of Memory Services in the South West in 2011/12 and beyond. It is in line with the National Dementia Strategy (2009) and the NHS Operating Framework 2011/12. It offers a focus and guidance on capacity planning for Memory Services, and includes the role of the General Practitioner in the memory assessment and diagnosis pathway.

The Memory Service should act as a single point of referral for people² and gateway to the dementia pathway for people with a possible dementia, and their

¹ The South West Dementia Partnership is a multi agency steering group which brings together organisations from health and social care, the voluntary sector and people using dementia services to drive forward improvements and take an over view of the implementation of the National Dementia Strategy across the South West.

families/carers. It should provide a lead for the local health and social care community both in the early detection of dementia, and in developing services for those with a dementia and their families/carers. It should provide a greater understanding of the disease and how to manage the impact of the illness as it progresses. Through signposting and links with other services, the Memory Service should support the person with a dementia and their carer(s) in navigating their journey along the dementia care pathway.

The role of the General Practitioner and primary health care team

Primary care is often the first point of contact for people with memory problems and suspected dementia and therefore is key to ensuring early detection and intervention as well as effective ongoing management. The diagnosis of a dementia, and fifteen-month reviews are captured in general practice via the Quality and Outcomes Framework (QOF).³

² National Institute for Health and Clinical Excellence Dementia Quality Standards Programme Quality statement 2 states 'People with suspected dementia are referred to a memory assessment service specialising in the diagnosis and initial management of dementia.' The accompanying quality measure states 'evidence that memory service assessment services specialising in the diagnosis and initial management of dementia are the single point of referral for people with a possible diagnosis of dementia'

³ The Quality and Outcomes Framework (QOF) is a voluntary annual reward and incentive programme for all GP surgeries in England, detailing practice achievement results. The QOF contains four domains: Clinical Domain, Organisational Domain, Patient Experience Domain and Additional Services Domain. Each domain consists of a set of achievement measures, known as indicators, against which practices score points according to their level of achievement. The 2009/10 QOF measured achievement against 134 indicators; practices scored points on the basis of achievement against each indicator, up to a maximum of 1,000 points. www.qof.ic.nhs.uk

Screening for, and diagnosis of a dementia can be made within primary care.⁴ This will include investigations for possible co-morbidities that may affect cognition. Section 2 (page 12) sets out the screening and assessment process that may be undertaken by a general practitioner.

Referral to a specialist Memory Service is required if a more specialist assessment is indicated, a diagnosis is in doubt, the General Practitioner has concerns regarding worrying social factors, and/or if the patient or their carer requests it. General Practitioners may be asked to refer earlier than they would normally do by concerned relatives, and will judge whether it is better to refer at that stage in order to maintain patient and carer confidence. This may include the referral of people with mild cognitive impairment who may need to be reassessed periodically.

The dementia care pathway is multifaceted: separate service specifications cover commissioning of the care, support and non-pharmacological treatments for people following a diagnosis of a dementia.

⁴ Mini Mental State Examination MMSE is often used as guidance www.minimental.com. The results require clinical judgement, as MMSE is dependent on previous academic achievement. Commissioners should consider encouraging General Practitioners to make referrals for people who have an MMSE score of 25 or under to achieve earlier diagnosis of dementia.

1.1 Functions

The key functions of the Memory Service are:

- to provide person-centred, early and responsive assessment, diagnosis and intervention for people identified as possibly having dementia and requiring a specialist dementia assessment;
- to provide specialist assessments, following initial assessment by primary care that will have already included physical and medical investigations;
- to support and enable people accessing the service, and their carers, to manage their condition with support from primary and community services;
- to provide time limited advice, information and support to users of the service and their carers;
- to reduce the need for ongoing specialist care by signposting to, and making explicit links/referrals with primary, community and voluntary and community services;
- to raise awareness and understanding by providing advice, information and support to primary care workers to enable people to be managed and supported to live well after diagnosis;
- to ensure the outcome of the assessment and diagnosis is communicated to the relevant General Practitioner for inclusion in the Quality Outcomes Framework register, and to ensure arrangements are in place for ongoing treatment, care and reviews as appropriate.

1.2 Service principles

The principles underpinning the Memory Service are that:

- the Service embraces the Equality Act 2010⁵ and is therefore age inclusive and does not discriminate on the grounds of disability, race, gender, religion and belief, sex and sexual orientation;
- the Service does not exclude individuals on the grounds of any co-existing disabilities or medical problems;
- the Service is respectful and personalised, upholding dignity and privacy and ensuring people are well informed about the services available to them;
- the Service tailors assessments and interventions to individuals and their carers including responding to cultural, spiritual and ethnic considerations;
- the Service assesses the needs of carers, and signposts carers to local support services as appropriate;
- the Service supports people and their carers to understand the assessments, diagnosis and interventions offered;
- the Service communicates the diagnosis, and the implications of it, effectively and with empathy to the person with a dementia and families/carers;
- the Service provides information, advice and guidance, and signposts people to appropriate services, resources and sources of support within their community;

⁵ http://www.equalities.gov.uk/equality_act_2010.aspx

- the Service promotes and maintains independence, maximises the individual's health and well being, and promotes choice;
- the Service promotes collaborative, multi-professional and joint agency working to provide integrated, seamless care pathways and experiences for people living with a dementia and carers;
- the Service involves people using services in its planning and delivery, and promotes social inclusion;

1.3 Service standards

The Service will adhere to the National Institute for Health and Clinical Excellence Clinical Guideline 42 on supporting people with dementia and their carers in health and social care (NICE 2006) ⁶ and NICE Technology Appraisal 111 Alzheimer's disease - donepezil, galantamine, rivastigmine (review) and memantine: guidance (NICE, 2007 amended 2009). ⁷

The Memory Service will adhere to the relevant Quality Standards for dementia (National Institute for Health and Clinical Excellence (NICE), July 2010) ⁸.

Standards for a Memory Service are set out within the Memory Services National Accreditation Programme (MSNAP) (Royal College of Psychiatrists' Centre for Quality Improvement, 2009) ⁹. These standards are set out in Appendix 2.

The commissioner will require the Memory Service:

⁶ <http://www.nice.org.uk/nicemedia/pdf/CG042NICEGuideline.pdf>

⁷ <http://www.nice.org.uk/nicemedia/live/11600/45349/45349.pdf>

⁸ <http://www.nice.org/aboutnice/qualitystandards/dementia>

⁹ <http://www.rcpsych.ac.uk/PDF/MSNAP%20Standards%20First%20Ed.%20FINAL%202009-10.pdf>

- to undertake, at agreed intervals, a self assessment of progress in delivering the MSNAP standards, and/or to apply for accreditation from the MSNAP programme or comparable assessment framework;¹⁰
- to demonstrate how any shortfalls identified within the self assessment (or application for accreditation) will be addressed, within an agreed time frame;
- within the self assessment, to demonstrate compliance with relevant guidance, adherence to guidelines about consent and assessing capacity, and that outcomes are person-centred; promoting dignity, privacy and respect;
- to deliver the Service within the agreed specified timeframes;
- to demonstrate that the Service has competent and appropriately skilled multi-disciplinary team(s) supported by annual appraisal and clinical/professional supervision;
- to strive continuously to improve service delivery by using the experiences of people with a dementia ,their carers, and those providing the Service.

1.4 Referrals

Referrals to the Memory Service are normally made by a General Practitioner; in some areas arrangements will be in place to support self-referral.

¹⁰ Requirements about accreditation will be agreed with Service commissioners.

An initial assessment leading to a preliminary diagnosis of significant memory impairment or a dementia will normally have taken place in primary care or during an inpatient stay in a general, acute or community hospital.

Referral of adults with symptoms of early onset dementia may be directed to a local neurological department for assessment prior to a Memory Service

The Memory Service will have in place a detailed, local referral protocol based on best practice agreed with the commissioner (see Appendix 3) which includes referral to national or regional specialist centres where appropriate. The Memory Service will liaise with primary care to form a view regarding the appropriateness of referrals for assessment of people showing signs of mild cognitive impairment.

The Memory Service will provide assessment and diagnosis of memory problems for people of all ages, including younger people with a possible dementia, people who have a learning disability, people who have a dementia and problem drug and alcohol use, people with Acquired Immune Deficiency Syndrome (AIDS) related dementia, and people with a dementia and co-existing disabilities.

The Service will not provide assessment for people reporting memory problems following a traumatic head injury.

Referrals that are not appropriate will be referred on to a relevant service or to the person's General Practitioner.

1.5 Service delivery

The Memory Service will have a single point of entry to enable referrals to be triaged, and bookings to be made in line with local protocols and standards.

The date and time of the assessment will be agreed with the patient within [x working days]¹¹ of receiving the referral.

The Memory Service will ensure that no patient waits more than 4 weeks for an assessment.¹²

The assessment will take place at a time and environment that is acceptable to all parties. This may include home assessments or mobile/peripatetic facilities. Where possible, individuals will be offered a choice of location for their assessment.¹³

The Memory Service will have access to translators and interpreters.

An appointment to offer the outcome of the assessment will be offered within [20 working days]¹⁴ of the assessment.

The Memory Service will provide high quality information about its services and other supporting literature relating to memory problems, for both people with a possible dementia and their families/carers. The information will be available in a range of settings, and in a range of languages, large-print and Braille. An easy-read format will be available for people with learning disabilities (minimum content is set out in Appendix 4).

All general practices will hold information about the Service. Information will be offered to patients referred to the Service during the consultation in which the referral is agreed with the patient, and offered to families/carers as appropriate.

¹¹ Locally agreed standard

¹² Ambition, South West Strategic Framework for Improving Health, 2008/09 to 2010/11.

¹³ Assessments offered in a clinic will meet the standards specified within the MSNAP <http://www.rcpsych.ac.uk/PDF/MSNAP%20Standards%20First%20Ed.%20FINAL%202009-10.pdf>

¹⁴ Locally agreed standard

The Memory Service will work with its partners to minimize the number of professionals having contact with the person with a possible dementia and their families/carers. This will also remove the need for repeated assessments by different services.¹⁵

The Memory Service will have in place a policy regarding the sharing of information between identified personnel and agencies in accordance with the Data Protection Act (1998),¹⁶ the Mental Capacity Act (2005)¹⁷ and their Codes of Practice.

The Memory Service will form good relationships with providers of all relevant patient transport services so that transport to and from the Service can be arranged where needed.

The Memory Service will proactively manage its cancellation policy.

The Memory Service will be expected to foster and develop key partnerships for the delivery of an integrated service which links with all relevant pathways appropriately. The Memory Service will be required to demonstrate that it has successfully secured, developed and continued to maintain these partnerships, where necessary developing service specifications or service level agreements with each partner, with agreed levels of accountability.

The Memory Service will clearly define functions, roles and responsibilities of the Memory Service team in job descriptions, operational policies and protocols. Employment checks and professional registration of staff will be monitored. Training will be delivered in line with MSNAP guidance, professional registration

¹⁵ Guideline on Supporting people with Dementia and their Carers in Health and Social Care (NICE, SCIE, 2006) <http://www.scie.org.uk/publications/misc/dementia/dementia-fullguideline.pdf>

¹⁶ <http://www.legislation.gov.uk/ukpga/1998/29/contents>

¹⁷ <http://www.legislation.gov.uk/ukpga/2005/9/contents>

standards, and the national Qualifications and Credits Framework. The service will have access to clear written policies and procedures, including the management of clinical incidents. Records will be contemporaneous, of high quality and kept in accordance with relevant legislation.

The Service will be compliant with statutory guidance on the protection of vulnerable adults.

The Service must ensure that policies and procedures relating to safeguarding are adhered to, and that staff have undertaken training appropriate for their professional role. All staff working with vulnerable adults will have undertaken an enhanced Criminal Records Bureau check. The Service should be represented on the local safeguarding board.

1.6 Population served; service times and locations

The Memory Service is provided to patients and their families/carers registered, or temporarily registered with [insert locality(s)] general practitioners.

The Memory Service will be delivered in the [insert locations].

The Memory service will be delivered between [x hours and x hours] on [x days per week].

2 Assessment and diagnosis

2.1 Screening

The purpose of screening by the patient's General Practitioner is to rule out other conditions that may have symptoms similar to dementia and that may be

treatable. These conditions may include depression, chest and urinary infections, severe constipation, vitamin and thyroid deficiencies, and brain tumours.

It is required to rule out other possible causes of confusion such as poor sight or hearing; emotional changes and upsets, such as moving or bereavement; or the side-effects of certain drugs or combinations of drugs.

Prior to making a referral to a Memory Service, health and social care professionals should ensure that a basic screening has been completed in line with NICE guidance, and the relevant information forwarded on to the Memory Service either for a home assessment or Memory Service appointment.

Health screening for dementia should include:

- history taking
- a brief cognitive assessment using a standardised tool such as the 6-CIT. (Optional), MMSE (mini mental state examination), AMT (abbreviated mental test), GP-COG;
- physical examination;
- a review of medication in order to identify and minimise use of drugs including over the counter products, that may adversely affect cognitive functioning;
- routine haematology, full blood count;
- bio-chemistry tests (including electrolytes, calcium, glucose and renal and liver function);
- thyroid function tests;

- serum vitamin B₁₂ and foliate levels;
- a midstream urine test should always be carried out if delirium is a possibility;
- clinical presentation will determine whether investigations such as chest X-ray or electrocardiogram are needed;
- the identification of a nominated carer.

Tests should be completed within one working week following the initial consultation with a General Practitioner.

Where referral to a Memory Service is indicated, the General Practitioner should provide a full medications list, the patient's physical and mental health history, and the outcome of investigations, which have informed the screening.

2.2 Assessment

People who are assessed for the possibility of a dementia should be asked if they wish to undergo the assessment process, whether they wish to know the diagnosis and the possible implications, and with whom this should be shared.

Pre-diagnostic counselling for the individual and carer will be offered and provided by suitably qualified and experienced staff.

Local protocols will be in place to determine the type and range of information to be gathered. This should include, as a minimum, the following investigations and information:

- a front sheet containing patient information to include comments on capacity and consent to sharing information;
- current concerns – the patient’s and families/carers’ views.
- systematic review of symptoms of cognitive domain with examples;
- standardised neuro-psychiatric assessment (ACE-R, MMSE, recommended). Those interpreting the scores should take full account of other factors known to affect performance, including educational level, skills, prior level of functioning and attainment, language the test was given in (if it is not the first language of the individual), any sensory impairments, psychiatric illness or physical/neurological problems;
- personal history to include scholastic achievements;
- current social situation including strengths, finance, accommodation, transport, support needs, hobbies and activities;
- assessment of current activities of daily living including diet, cooking, mobility, present care, current levels of support, and driving;
- consideration as to whether an assessment of need for community care services or personal budget is required
- family history to include genogram, child protection or adult safeguarding issues, and inherited diseases;
- medical history to include dementia risk factors, review of senses, current contact with General Practitioner, recent investigations;
- medication including self-medication; allergies;

- previous mental health history; history of drug and alcohol use;
- mental state examination;
- physical examination including weight, blood pressure, temperature, respirations;
- risk assessment; including Health of the National Outcome Scale; Care Programme Approach where appropriate;
- formulation and outcome, including further assessment indicated.

Formal neuropsychological testing should form part of the assessment in cases of mild or questionable dementia, to clarify diagnostic categories.

Examples of assessment documentation can be found at www.southwestdementiapartnership/early-diagnosis/

2.3 Carer's information; carer's assessment

Within the patient's assessment, the needs of carers/families should also be considered. As a minimum carers should be offered, and be signposted to information, guidance, and sources of support. Assessors should either offer and undertake an assessment of the carer's needs or ensure prompt referral to the appropriate point, as identified within the care pathway.

2.4 Assessment for people with a learning disability, or communication difficulties

Where a person has a learning disability, or whose communication may be impaired, alternative causes of the person's presentation must be investigated

and excluded in a systematic way. This will involve checks of vision, hearing and mobility, together with general health screening including thyroid function tests. Consideration must be made as to whether the symptoms are related to physical pain or discomfort, stress, recent life events such as bereavement or another co-morbid mental health problem.

When screening for sensory problems, it is important to use tests appropriate for the population concerned, for example optometry in people with learning disabilities may be best carried out using the Cardiff Acuity Test. If no other causes are identified, or if after identifying such problems and treating them, there is still cause for concern, the next stage is to carry out more specific dementia assessment tests such as the Cambridge Cognitive Examination (CAMCOG), Cambridge Examination for Mental Disorders of the Elderly (CAMDEX), Dementia Questionnaire for Mentally Retarded Persons (DMR), Gedye's Dementia Scale for Down Syndrome (DSDS) and Dalton's Brief Praxis Test (BPT).

The progress of the condition may continue to be monitored using the DSDS and BPT. At the time of diagnosis, an assessment using the Assessment of Motor and Process Skills (AMPS) may be used as part of the development of an appropriate care plan.

2.5 Diagnosis

The Memory Service will ensure that a diagnosis of dementia is made only after appropriate professionals undertake a NICE-compliant comprehensive and holistic assessment of the person's needs.

At the time of diagnosis of a dementia, and at regular intervals subsequently, assessments should be made for medical co-morbidities and key psychiatric features associated with dementia including depression and psychosis to ensure optimal management of co-existing conditions.

Diagnosis of subtypes should be made by healthcare professionals with expertise in differential diagnosis using international standardised criteria as illustrated in the table below.

Table 1 Type of dementia and diagnostic criteria

Type of dementia	Diagnostic criteria
Alzheimer's disease	Preferred criteria: NINCDS/ADRDA. Alternatives include ICD-10 and DSM-IV
Vascular dementia	Preferred criteria: NINDS-AIREN. Alternatives include ICD-10 and DSM-IV
Dementia with Lewy bodies	International Consensus criteria for dementia with Lewy bodies
Frontotemporal dementia	Lund-Manchester criteria, NINDS criteria for frontotemporal dementia

Key:

- DSM-IV, Diagnostic and Statistical Manual of Mental Disorders, fourth edition;
- ICD-10, International Classification of Diseases, 10th revision;
- NINCDS/ADRDA, National Institute of Neurological and Communicative Diseases and Stroke/Alzheimer's Disease and Related Disorders Association;
- NINDS–AIREN, Neuroepidemiology Branch of the National Institute of Neurological Disorders and Stroke–Association Internationale pour la Recherche et l'Enseignement en Neurosciences.

Where indicated, the Service will arrange for structural imaging to be used in the assessment of people with suspected dementia in order to exclude other cerebral pathologies and to help establish the subtype diagnosis. It is not expected that this is undertaken routinely, but decided on clinical need and relevance on a case by case basis. The age / frailty of the patient, and potential for distress, should be taken into account when considering whether a scan is required. In these circumstances, a scan should only be requested if other causes of cognitive impairment are suspected.

Magnetic resonance imaging (MRI) is the preferred modality to assist with early diagnosis and detect subcortical vascular changes, although computed tomography (CT) scanning could be used.

Specialist advice should be taken when interpreting scans in people with learning disabilities.

Perfusion hexamethylpropyleneamine oxime (HMPAO) single-photon emission computed tomography (SPECT) should be used to help differentiate Alzheimer's disease, vascular dementia and frontotemporal dementia if the diagnosis is in doubt. People with Down's syndrome may show SPECT abnormalities throughout life that resemble those in Alzheimer's disease, so this test is not helpful in this group.

If HMPAO SPECT is unavailable, 2-[¹⁸F]fluoro-2-deoxy-D-glucose positron emission tomography (FDG PET) should be considered to help differentiate between Alzheimer's disease, vascular dementia and frontotemporal dementia if the diagnosis is in doubt.

Dopaminergic iodine-123-radiolabelled 2β-carbomethoxy-3β-(4-iodophenyl)-N-(3-fluoropropyl) nortropane (FP-CIT) SPECT should be used to help establish the diagnosis in those with suspected dementia with Lewy bodies (DLB) if the diagnosis is in doubt.

Referral for cerebrospinal fluid examination should be made if Creutzfeldt–Jakob disease or other forms of rapidly progressive dementia are suspected.

Electroencephalography should be considered if a diagnosis of delirium, frontotemporal dementia or Creutzfeldt–Jakob disease is suspected, or in the assessment of associated seizure disorder in those with dementia.

Brain biopsy for diagnostic purposes should be considered only in highly selected people whose dementia is thought to be due to a potentially reversible condition that cannot be diagnosed in any other way.

Healthcare professionals working with people who are likely to have a genetic cause for their dementia (for example familial autosomal dominant Alzheimer’s Disease or frontotemporal dementia, cerebral autosomal dominant arteriopathy with subcortical infarcts and leukoencephalopathy [CADASIL], or Huntington’s Disease) should offer to refer them, and their unaffected relatives, for genetic counselling.

2.6 Making a diagnosis

The Service will advise a patient and families/carers about a diagnosis appropriately by making time available to discuss the diagnosis and its implications with the person with dementia, and also with families/carers members. The Service will have a training and development plan to ensure all staff have the necessary skills, support and supervision to undertake this challenging role.

The Service will offer advice, information and appropriate support for the person with a dementia and families/carers, signposting people to community resources and facilities. [Insert here the role of dementia advisors, where relevant.]

People with a dementia and their families/carers may need ongoing support to cope with the difficulties presented by a diagnosis. The Service will refer on to primary care psychological therapy services and other support services as necessary.

2.7 Information

An early diagnosis of dementia allows people with a dementia and their families/carers to take control of their health and lives. An early diagnosis of dementia gives the person with a dementia and families/carers more time to plan and make arrangements for the future. This could include dealing with legal and financial matters, such as appointing a lasting Power of Attorney or preparing an Advance Directive. For some, the time may be spent focussing on more personal life goals, such as planning to spend time with loved ones or starting or finishing an important project.

Following a diagnosis of dementia, unless the person with a dementia indicates to the contrary, the Memory Service should provide the person and family/carer with written information about:

- the diagnosis (a copy of the letter to the referrer may suffice here);
- the signs and symptoms of dementia;
- the course and prognosis of the condition;
- options for care and treatment, including coping methods and strategies and information about assistive technology and telecare;
- local care and support services, including social services assessment/support;
- support groups;
- sources of financial and legal advice, and advocacy; in order to provide 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;

- medico-legal issues, including driving;
- local information sources, including libraries and voluntary organisations;
- information on how people with dementia can improve their general health, live positively and maximise their quality of life after diagnosis, e.g. using mental exercise, physical activity, and dietary advice, and
- right to a carers' assessment.

Any advice and information given should be recorded in the notes.

The Service will provide the above information in an information pack developed in partnership with patients and carers.

2.8 Care after diagnosis

Interventions by the diagnostic Memory Service are normally time limited. Local care pathways / protocols will determine future contact (for example for follow up or review). The Service should notify and transfer the person diagnosed with a dementia, with the agreed plan of care, back to the General Practitioner. This should include identification of the service responsible for prescribing and reviewing medication related to the diagnosis. In line with the local dementia care pathway, the Memory Service should also signpost people to other local support services such as dementia advisors, memory cafes, carers' groups, and training and education about dementia.

2.9 Measuring patient and carer experience and satisfaction

The Service will ensure that everyone assessed and their families/carers will be offered an opportunity to rate the quality of the service they received including their views on how well the diagnosis was made.

The Service will develop a patient and carer experience questionnaire in partnership with patients and carers for this purpose. This should include questions to identify whether an individual's needs as part of the Equality Act 2010 were met.

The Service will ensure that there are clear policies and procedures for managing complaints and evidence of audit, action and feedback from complaints and suggestions.

The Service will ensure that information is provided about how to make complaints.

The Service will involve people with dementia and their family/carers in monitoring the findings of the patient and carer experience questionnaire and subsequent actions.

2.10 Commitment to service improvement

The Service will agree with commissioner the frequency of an audit and service evaluation. The audit will include a survey of General Practitioners inviting

feedback about their experiences of using the service. The Service will agree the action plan arising from this annual audit with the commissioner.

2.11 Prevalence, activity levels and costs

Table 2 Estimated prevalence levels in X locality

(Commissioner to insert below the profile of current prevalence and predicted prevalence of local population)

People aged 65 and over predicted to have dementia projected to 2025						
	2007	2008	2010	2015	2020	2025
Population aged 65 and over predicted to have dementia						
% increase		+%	+%	+%	+%	+%
People under 65 predicted to have dementia						

The NICE memory assessment services commissioning and benchmarking tool (NICE, December 2007) ¹⁸ enables the commissioner to calculate the relevant activity to be commissioned based on the population for the locality and the indicative benchmark rate. The guidance refers to the average number of people requiring referral to a memory service as 19 per year based on an average

¹⁸ <http://www.nice.org.uk/usingguidance/commissioningguides/memoryassessmentservice/commissioningtool.jsp>

practice list size of 10,000 or 0.19% of the full list (or 0.91% of the list aged 60 years and over).

The commissioner to complete the following statement:

Based on the calculation from this tool the expected annual number of referrals for the service is X, (or a quarterly referral rate of X).

This compares with 2009/10 annual referral rates of X people with a possible or suspected diagnosis of dementia.

Based on this expected number of referrals the Service will conduct X number of assessments in 2012/13 including X assessments for people with learning disabilities. (An illustration is set out in Appendix 5.)

Table 3 Indicative numbers of assessments per practice

(Commissioner to insert data below)

Practice	Estimated prevalence over-65s	% of over-65s	No. assessments (non-learning disabilities)	No. assessments (learning disabilities)	Total no. assessments over 12 months
A					
B					
C					
D etc.					

2.12 Reducing the diagnosis gap

This will be demonstrated by improving the numbers of people with a diagnosis of dementia recorded on General Practices' Quality and Outcomes Framework [DEM1] dementia registers. Commissioners should set a trajectory for increase in rates of diagnosis, and delivery of 15-month reviews [DEM2].

Commissioners and general practice dementia leads should consider training and education required at practice level to support screening, assessment, diagnosis and regular review of patients with a dementia, including a review of the needs of their carers/families.

Commissioners should also ensure that local systems for prompt data capture are in place to complete QOF requirements, including the transfer of data on diagnosis from Memory Services to practices for inputting to practice dementia registers.

3 Costs of memory service

Note for commissioner: The NICE memory assessment services commissioning and benchmarking tool ¹⁹ (Originally published December 2007; last revised April 2010) enables the commissioner to calculate the recurrent provider costs of any services that may be commissioned over a 4-year period based on the number of new referrals. This model assumes that these people will be treated in clinics and provides indicative unit costs. Additional cost elements and unit costs may be added to reflect local arrangements. The commissioner may therefore indicate the percentage of assessments to be undertaken in clinic settings and adjust the calculation to allow for an indicative extra cost per home assessment. The tool allows calculation of non-recurrent cost that may be incurred in setting up a memory assessment service.

¹⁹ <http://www.nice.org.uk/usingguidance/commissioningguides/memoryassessmentservice/commissioningtool.jsp>

Information and performance monitoring of outcomes

The overarching outcomes desired by people with dementia and their carers are listed in Table 5 below. These are taken from the Quality outcomes for people with dementia: Building on the work of the National Dementia Strategy (Department of Health, September 2010).²⁰

These outcomes underpin information and performance monitoring requirements. The outcomes listed in Table 4 are mapped to NICE Quality Statements (NICE, June 2010) and the Objectives in the National Dementia Strategy (Department of Health, February 2009).²¹

TABLE 4 Quality outcomes for people with dementia: building on the work of the National Dementia Strategy

Outcome	Descriptor	NICE QS	NDS Objective
I was diagnosed early	People will have the information they need to understand the signs and symptoms of dementia. Those concerned about dementia will know where to go for help. The time between people presenting symptoms to a doctor and being diagnosed will be as short as possible for everyone.	2, 3	1, 2

²⁰ http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_119828.pdf

²¹ http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_094058?IdcService=GET_FILE&dID=183634&Rendition=Web

Outcome	Descriptor	NICE QS	NDS Objective
I understand, so I make good decisions and provide for future decision making	Everyone affected by dementia will get information and support in the format and at the time that best suits them. They will be supported to interpret and act on the information so that they understand their illness and how it will impact on their lives, including any other illnesses they may already have. They will know what treatments are best for them and what the implications are and they will be supported to make good decisions.	3, 5	3, 4, 5
I get the treatment and support which are best for my dementia, and my life	Everyone living with dementia will receive the best dementia treatment and support, no matter who they are or where they live. They will feel that their personal needs have been appropriately assessed and that their treatment and potential consequences of treatment have been well planned and delivered in a coordinated way that is appropriate to their individual needs and preferences. They will be able to exercise personal choice in social care and ongoing support will be of a high quality.	1, 4, 5, 7, 8	2, 6, 8, 9, 10, 11, 13,18

Outcome	Descriptor	NICE QS	NDS Objective
I am treated with dignity and respect	People living with dementia will report that they are treated with dignity and respect by all those involved throughout their dementia journey. They will also be open about living with dementia without fear of stigma or discrimination. It will be well recognised and understood by the public and professionals that dementia is a condition that increasing numbers of people will live with.	1	1, 13
I know what I can do to help myself and who else can help me	People living with dementia will be supported to self-manage the consequences of dementia and its treatment, to the degree they are able/wish to. They will know where to turn to get the clinical, practical, emotional and financial support they need when and where they need it. They will feel confident that they can practice their faith and spirituality and that others will help them when they need support.	1, 3, 4, 5	3, 4, 5, 6, 13
Those around me and looking after me are well supported	People living with dementia will feel confident that their family, friends and carers have the practical, emotional and financial support they need to lead as normal a life as possible throughout the dementia journey. They will know where to get help when they need it.	3, 4, 6, 10	3, 4, 5, 7

Outcome	Descriptor	NICE QS	NDS Objective
I can enjoy life	People living with dementia will be well supported in all aspects of living with dementia, leaving them confident to lead as full and active life as possible. They will be able to pursue the activities (including work) that allow them to be happy and feel fulfilled while living with dementia.	3, 4	1, 4, 5, 6
I feel part of a community and I'm inspired to give something back	People who have been affected by dementia and others will feel inspired to contribute to the life of their community, including action to improve the lives of others living with dementia. This includes having the opportunity to participate in high quality research.	1, 5, 16	
I am confident my end of life wishes will be respected. I can expect a good death	People who are nearing the end of their life will be supported to make decisions that allow them and their families/carers to be prepared for their death. Their care will be well co-ordinated and planned so that they die in the place and in the way that they have chosen.	5, 9	12, 13

NICE Quality Standards are listed below with potential measures, for illustrative purposes.

Table 5 NICE Dementia Quality Standards 2010

Quality Statement	Numerator	Denominator
2. People with suspected dementia are referred to a memory assessment service specialising in the diagnosis and initial management of dementia	The number of people who are referred to a memory assessment service	The number of people with suspected 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	The number of people newly diagnosed receiving written and verbal information about their condition, treatment and support options in their local area	The number of people newly diagnosed with dementia

Quality Statement	Numerator	Denominator
<p>5. People with dementia, while they have capacity, 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</p>	<p>The number of people who are given the opportunity to discuss advance decision making</p> <p>The number of carers who are given the opportunity to discuss advance decision making</p>	<p>The number of people with dementia</p> <p>The number of carers of people with dementia</p>
<p>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</p>	<p>The number of carers offered an assessment of their needs</p> <p>The number of carers receiving interventions tailored to their needs</p>	<p>The number of carers of people with dementia</p> <p>The number of carers of people with dementia who have an agreed care plan</p>

The commissioner and provider will agree the collection of activity data to inform the monitoring and improvement of the service. Table 6 provides an illustrative list.

TABLE 6 Activity data to inform monitoring and improvement.

	Data	Frequency	Target
Service activity	Numbers referred to service by practice for previous month and cumulative for year	Monthly	As per activity schedule
	Number of self-referrals for previous month and cumulative for year (subject to local protocol)	Monthly	N/A
	Percentage of assessments agreed with the patient within (x working days) of receiving the referral	Monthly	90%
	Number of referrals not accepted, with reason for non acceptance	Monthly	
Service activity	Number offered choice of location for their assessment	Monthly	
	Numbers of home assessments for previous month and cumulative for year	Monthly	N/A
	Number of Memory Clinic assessments for previous month and cumulative for year	Monthly	N/A

	Data	Frequency	Target
Service activity	Number of people including those with a Learning Disability assessed by service for previous month and cumulative for year	Monthly	As per activity schedule
	Number of people including those with a Learning Disability diagnosed by service for previous month and cumulative for year	Monthly	As per activity schedule
	Numbers diagnosed with dementia and owning care plan within 4 weeks of diagnosis for previous month and cumulative for year	Monthly	100%
	% of diagnosis notifications to GPs issued within 5 days for previous month and cumulative for year	Monthly	100%
	Numbers diagnosed with dementia and offered information pack for previous month and cumulative for year	Monthly	100%
	Number where MMSE <10 and ACIs continued and a record is made of active decision to continue	Monthly	
	Waiting times	Average wait time from referral to assessment for previous month and year	Monthly
Percentage offered outcome of assessment within (20 days) of assessment		Monthly	

	Data	Frequency	Target
Inequalities	The number of patient records with measurement item completed: ethnicity, gender, age, patient's GP and patients postcode	Monthly	100%
	Number of assessments from BME groups	Quarterly	Estimated number from population
Attrition	Combined Do Not Attends & Cancellations	Monthly	<=10
Customer feedback	Number of complaints, compliments and comments received	Quarterly	
	Results from Patient Satisfaction and Experience Questionnaires	Quarterly	N/A
	Results from Carer Satisfaction and Experience Questionnaires	Quarterly	N/A
	Results from annual service audit	Quarterly	N/A

4 Training and education

The Memory Service will ensure that a programme is in place which will meet the Memory Service National Accreditation Programme (MSNAP) standards (The Royal College of Psychiatrists Centre for Quality Improvement (CCQI), June 2009).²²

Staff within the memory service will have the skills required of their roles and functions. Continuing professional development will be facilitated, so that:

- all staff are able to access the training that they require;
- staff have access to study facilities and study time;
- there are arrangements for staff cover to allow staff to attend training;
- professionals working within the memory service have received the following training:
 - the natural history of the different types and subtypes of dementia, the main signs and symptoms, the progression and prognosis, and the consequences for the person with dementia and his or her carers, family and social network;
 - basic introduction to local adult protection policy and procedures, including the reporting of concerns or malpractice and, in particular who to contact;

²² <http://www.rcpsych.ac.uk/PDF/MSNAP%20Standards%20First%20Ed.%20FINAL%202009-10.pdf>

- dementia-care training including applying the principles of person-centred care;
- the importance of and use of communication skills, including counselling skills, breaking bad news;
- capability training, where possible;
- the assessment and pharmacological treatment of dementia;
- non-pharmacological interventions;
- the Mental Capacity Act, 2007;
- Deprivation of Liberty Safeguards.

The Memory Service will provide evidence of the above for the commissioner as required. This Service Specification will be subject to ongoing review to take note of emerging best practice.

Dated

Name

Appendix 1: Expert Reference Group members

Kate	Anderson	Consultant Clinical Psychologist/Manager	NHS Plymouth
Dr Martin	Anstell	Consultant Psychiatrist	2Gether NHS Foundation Trust
Emma	Bird	Commissioning Manager Older People	NHS Bristol
Dr Anton	Bohner	Clinical Psychologist	Devon Partnership NHS Foundation Trust
Dr Roger	Bullock	Consultant Old Age Psychiatrist	Avon & Wiltshire Mental Health Partnership NHS Trust
Andrew	Cole	Service Manager, Older Persons Services	Somerset Partnership NHS Foundation Trust
Tracey	Compson	Dementia/QIPP MH Project Lead	NHS Swindon
Paul	French	Clinical Lead on the PEC for Dementia Services	NHS Bournemouth & Poole
David	Hill	Project Manager	Dorset Healthcare Foundation Trust
Christine	Howell	Commissioner	NHS Bournemouth & Poole
Kate	Mitchell	NHS Cornwall & Isles of Scilly	NHS Cornwall & Isles of Scilly
George	O'Neill	Head of Commissioning	Wiltshire Council
Ann	Redmayne	Mental Health Commissioning Manager	Torbay Care Trust

Jenny	Richards	Joint Strategic Planning & Commissioning Manager (Older People's MH)	NHS Devon/Devon County Council
Kate	Schneider	Programme Lead, Mental Health and Wellbeing; Dementia	South West Strategic Health Authority, on behalf of the South West Dementia Implementation Support Group - chair of meeting
Stephen	Thorpe	Associate Development Consultant	South West Development Centre, on behalf of the South West Dementia Implementation Support Group
Helen	Vaughan	Commissioning Development Manager for Dementia Services	NHS Gloucestershire

Appendix 2: The Memory Service National Accreditation Programme standards

Section 1 Management

Service planning and commissioning

1.1 Health and Social Care Commissioners take an evidence-based approach to commissioning

1.1.1 Health and Social Services Commissioners and Providers and Primary Care Trusts have formally commissioned memory services

1.1.2 Health and Social Services Commissioners and Providers have in place a detailed analysis of the demographic and ethnic profile of their population provision of services for the assessment and diagnosis of memory, to assess needs and plan for current and future problems

1.1.3 Health and Social Services Commissioners and Providers have undertaken a joint needs assessment and a review of the current service provision of services for the assessment and diagnosis of memory problems

1.1.4 Primary Care Trusts, in consultation with local partners, people with memory problems/dementia and carers, have a local integrated care pathway based on best practice, which includes referral to national or regional specialist centres, where appropriate

1.1.5 People with memory problems/dementia and their carers are involved in service planning, developing and monitoring the service

Quality assurance and service development

1.2 The memory service demonstrates that there is a commitment to ongoing quality improvement

1.2.1 The memory service conducts audit and/or service evaluation on compliance with relevant guidelines, at least once every two years

Guidance: *e.g. compliance with NICE, SIGN, etc*

1.2.2 The memory service conducts audit and/or service evaluation on referrals to the memory service, at least once every two years **Guidance:** *e.g. including demographic cultural issues, waiting times, etc, as appropriate*

1.2.3 The memory service conducts audit and/or service evaluation on adherence to guidelines around consent and assessing capacity, at least once every two years

1.2.4 Local GPs are surveyed about their experiences of using the service, at least once every two years

1.2.5 People with memory problems/dementia and their carers are asked about their experiences of using the service at least once a year, and their feedback has been used to improve the service

Guidance: *this might include customer surveys or suggestions*

Complaints and untoward incidents

1.3 All complaints and untoward incidents are dealt with in accordance with appropriate Trust rules and guidelines

- 1.3.1** There are policies and procedures for managing complaints
- 1.3.2** Information is provided for people with memory problems/dementia and their carers about how to make a complaint about any aspect of the service
- Guidance:** *this should include information on how to report abuse or inappropriate care and might include giving out information leaflets or displaying a poster in the waiting area*
- 1.3.3** There is evidence of audit, action and feedback from complaints and Suggestions

Supporting vulnerable people

- 1.4** The memory service has systems and procedures to ensure the safety of vulnerable adults, in accordance with appropriate Trust rules and guidelines and relevant statutory guidance

Section 2: Resources available to support assessment and diagnosis

Accessibility of the service

- 2.1 The Memory Service is accessible to people with memory problems and their carers**
- 2.1.1** The clinic is accessible to the local population
- Guidance:** *e.g. accessible by public transport, car parking available, etc*
- 2.1.2** Where the service is provided in (a) clinic setting(s), free transport to and from the memory service is available

2.1.3 The assessment takes place at a time and in an environment that is acceptable to all parties

2.1.4 The service has the capacity to make home assessments if necessary

2.1.5 The service has adequate access to translators and interpreters to meet the needs of the people using the service

Guidance: *consider needs associated with language, learning disability, sensory impairment, etc*

2.1.6 The service has access to a variety of assessment tools to meet the needs of the people using the service

Guidance: *consider needs associated with language, learning disability, sensory impairment, etc*

Staffing for the memory service

2.2 There are sufficient numbers of appropriately skilled and qualified staff

The following professionals have dedicated sessional time to contribute to the processes of assessment and diagnosis of memory problems / dementia:

- A medical lead - most commonly a consultant old age psychiatrist, but can include neuropsychiatrists, neurologists, geriatricians, GPs with a special interest, etc
- A mental health nurse
- A clinical psychologist or neuropsychologist
- An occupational therapist

2.3 The service has access to adequate administrative support

Guidance: *ascertain whether the level of available support meets current demand*

2.4 **The Memory Service has access to or can refer to the following professionals for advice / support during the processes of assessing and diagnosing people with memory problems / dementia:**

- A speech and language therapist
- A dietician
- A physiotherapist
- A social worker
- A geriatrician
- A neurologist
- An old age psychiatrist
- A specialist dementia nurse

Guidance: *this might be an experienced and qualified member of the team, or an admiral nurse, or equivalent*

Functioning of the memory service team

2.5 **Memory Service staff work effectively as a multidisciplinary team**

2.5.1 There is a named designated service lead with adequate dedicated sessional time to carry out the tasks associated with the role

Guidance: *ascertain whether the number of sessions meets current demand*

2.5.2 There are opportunities for the multidisciplinary team to meet at least once a week to discuss clinical matters

2.5.3 There are opportunities for the multidisciplinary team to meet at least once a month to discuss business/governance/administrative matters

2.5.4 There are systems in place that support the staff involved in assessment and diagnosis to work efficiently and effectively as a multi-disciplinary team

Guidance: *this might include IT systems, communication books, bulletin boards, email, up-to-date contact numbers, formal systems for relaying messages*

2.5.5 There is clear leadership and an up-to-date line management structure, with clear lines of accountability within the service

2.5.6 The roles and responsibilities of the team members are defined

Guidance: *e.g. in up-to-date job descriptions, including the appropriate grade for the position*

2.5.7 There are systems in place to ensure that staff morale is monitored on an on-going basis

Guidance: *e.g. via team building exercises, feedback from exit interviews, supervision*

2.5.8 The memory service prioritises continuity of care

Guidance: *e.g. by ensuring that a core and consistent team work in the service every week*

2.5.9 Feedback from staff is routinely monitored to influence service provision

Staff supervision and support mechanisms

2.6 Staff receive regular appraisal and supervision and know how to gain additional advice and support when they need it

2.6.1 There is a strategy and policy for staff annual appraisal, personal development planning and supervision

2.6.2 Staff know how to gain additional advice and support when they need it

2.6.3 Staff receive adequate individual professional supervision

Guidance: *consider whether the frequency of supervision is sufficient and whether a person with appropriate experience and qualifications carries it out*

2.6.4 Staff receive adequate individual clinical supervision

Guidance: *consider whether the frequency of supervision is sufficient and whether a person with appropriate experience and qualifications carries it out*

2.6.5 Staff receive adequate individual management supervision

Guidance: *consider whether the frequency of supervision is sufficient and whether a person with appropriate experience and qualifications carries it out*

Staff training and development

2.7 Staff working within the Memory Service are well-trained for their jobs and their continuing professional development is facilitated

2.7.1 Staff have access to study facilities and study time

2.7.2 The training and development budgets enable all staff to meet requirements for their continuing professional development and the Knowledge and Skills Framework

2.7.3 There are arrangements for staff cover to allow staff to attend training

2.8 Staff have access to training and development opportunities commensurate with their role within the service. This includes training and/or guidance on:

- **Dementia knowledge and awareness** *e.g. the natural history of the different types of dementia, the main signs and symptoms, the progression and prognosis, and the consequences for the person with dementia and his or her carer and family*
- **An introduction to local adult protection policy and procedures** *e.g. how to report concerns or malpractice, who to contact*
- **Dementia-care training** *e.g. applying the principles of person-centred care*
- **Communication skills relevant to the role** *e.g. the importance of and use of communication skills, including counselling skills, breaking bad news, the use of different communication methods and visual aids, the use of appropriate language, recognising when people might be suggestible/acquiescing*

- **Awareness of local demographic factors, including ethnic/cultural diversity and use of culturally appropriate measures**
- **The assessment and pharmacological treatment of dementia** *e.g. this would include the administration of medication and monitoring of side effects*
- **Non-pharmacological interventions** *e.g. psychological therapies*
- **The roles of the different health and social care professionals, staff and agencies involved in the delivery of care to people with dementia**
- **The Mental Capacity Act**
- **Undertaking nutritional screening using a validated nutritional risk assessment tool**
- **Screening for risk of swallowing difficulties**

Joint working

2.9 The Memory Service works closely with other professionals, agencies and providers to support the processes of assessment and diagnosis

2.9.1 The service has agreed protocols with the General Practitioners / Primary Care Trust in relation to the basic dementia screen and blood tests required at the time of presentation

2.9.2 There is a policy in place regarding the sharing of information between identified personnel and agencies in accordance with the Data Protection Act and Mental Capacity Act or Adults with Incapacity (Scotland) Act (or equivalent) and their codes of practice

- 2.9.3** Systems allow staff to access and share patient information, such as hospital records and investigative results, without undue delay

Liaison

2.10 The Memory Service offers a range of supports to promote early identification and referral into the service

- 2.10.1** Written information about the Memory Service is distributed to GP surgeries and other public places in languages and formats that can be understood by local people

- 2.10.2** The service provides advice to other professionals and staff whose responsibilities include providing care and treatment of older people with mental health problems

Guidance: *e.g. primary care, including GPs; residential care and nursing homes, and sheltered housing; domiciliary care; day care; hospital care, including acute inpatient services*

- 2.10.3** The service provides training to other professionals and staff whose responsibilities include providing care and treatment of older people with mental health problems

Guidance: *e.g. primary care, including GPs; residential care and nursing homes, and sheltered housing; domiciliary care; day care; hospital care, including acute inpatient services*

- 2.10.4** The service provides outreach to other professionals and staff whose responsibilities include providing care and treatment of older people with mental health problems

Guidance: *e.g. primary care, including GPs; residential care and nursing homes, and sheltered housing; domiciliary care; day care; hospital care, including acute inpatient services*

The clinic environment (where applicable)

2.11 Any clinic run by the memory service is accommodated in an environment that is appropriate to the needs of people with memory problems / dementia

2.11.1 The clinic is clean and comfortable and has a welcoming atmosphere

2.11.2 The environment is suitable for people with memory problems/dementia and their carers

Guidance: *e.g. firm seating at the right height, handrails, good lighting, large signs, accessible for people with physical disabilities, clocks etc*

2.11.3 There is easy access to suitable toilet facilities

2.11.4 Assessment rooms are quiet, comfortable and private

2.11.5 Conversations cannot be heard outside of meeting rooms

2.12 Any clinic run by the memory service provides the necessary facilities and resources for staff to effectively carry out their duties

2.12.1 A spacious room is available for the memory service team to meet to discuss findings and make plans

2.12.2 The memory service has the facility to store and access records and other key materials when required

Section 3: Assessment and diagnosis

Referral and access to the memory service

3.1 The memory service provides timely access to assessment and diagnosis

3.1.1 There are policies and protocols for referring into the service

3.1.2 Initial contact is made with all people who are newly referred within two-three weeks of referral

3.1.3 The assessment process begins no later than four-six weeks of referral

Dignity, consent, capacity, and confidentiality

3.2 The memory service is designed and managed so that the respect and dignity of people with memory problems/dementia and their carers is preserved

3.2.1 Staff are courteous and treat people and their carers with dignity and respect at all times

3.2.2 Staff ensure that people and their carers understand what is being done in the assessment process, and why

3.3 Staff follow clear procedures for gaining consent and ensure that people with memory problems/dementia are well-informed of their rights regarding consent

Guidance: *this must include adhering to guidance outlined in the Mental Capacity Act 2005, the Adults with Incapacity (Scotland) Act 2000, or equivalent*

3.3.1 The service provides access to an advocacy service that includes Independent Mental Capacity Advocates

3.3.2 There are policies/guidelines on gaining consent

Guidance: *this should include a list of procedures for which written consent is required*

3.3.3 There are policies/guidelines on assessing capacity

3.3.4 Staff check whether or not people have understood information that they have been given

3.3.5 Staff check whether or not people have been involved in decision-making processes and that there is no coercion

3.3.6 Staff check whether or not people continue to consent over time

3.3.7 There are systems in place to ensure that the service takes account of any advance directive that the person has made

3.4 Personal information is kept confidential unless this is detrimental to the person's care

3.4.1 People who are assessed for the possibility of dementia are asked if they wish to know the diagnosis

3.4.2 People who are assessed for the possibility of dementia are asked with whom the outcome should be shared

3.4.3 People are informed of the process of how and when to access their current records if they wish to do so

Assessment and diagnosis

3.5 The memory service ensures that a diagnosis of dementia is made only after a NICE-compliant comprehensive and holistic assessment of the person's needs by appropriate professionals, either within the service or elsewhere.

3.5.1 Basic dementia screen and blood tests

Guidance: *this might include:*

- *erythrocyte sedimentation rate (ESR) or C-reactive protein*
- *routine haematology, full blood count*
- *biochemistry tests (including urea and electrolytes, calcium, glucose, and renal and liver function)*
- *thyroid function tests*
- *serum vitamin B12 and folate levels*
- *simple urinalysis (available on referral)*
- *lipid profile/cholesterol*

3.5.2 History taking

3.5.3 A physical examination and other appropriate investigations

3.5.4 A review of medication in order to identify and minimise the use of drugs, including over-the-counter products that may adversely affect cognitive functioning

3.5.5 A cognitive assessment and mental state examination

Guidance: *this might include:*

- *examination of attention and concentration, orientation, short and long-term memory, praxis, language and executive function*
- *formal cognitive testing using a standardised instrument, e.g. the Mini Mental State Examination (MMSE)*
- *more in-depth neuropsychological testing as indicated, e.g. for early onset or complex dementia*

3.5.6 A subjective and objective assessment of a person's life, social, family and carer history, circumstance and preferences, as well as their physical and mental health needs, and current level of functioning and abilities, including an interview with an informant

3.5.7 An assessment of vision, hearing and mobility

3.5.8 An assessment for medical co-morbidities

3.5.9 An assessment for key psychiatric features, including depression and psychosis

3.5.10 A risk assessment covering areas appropriate to the individual

Guidance: *e.g. falls, risk to self*

3.5.11 Internationally recognised standards and criteria (i.e. ICD-10, DSMIV or NINCDS-ADRDA) are used for the diagnosis of Alzheimer's disease and other types of dementia

3.5.12 Interpretation of the scores from cognitive tests (such as the MMSE) should take full account of other factors known to affect performance

Guidance: *this should include educational level, skills, prior level of functioning and attainment, language, and any sensory impairments, psychiatric illness or physical/neurological problems*

3.6 The outcome of the assessment is communicated to all relevant parties in a timely manner

3.6.1 The letter/information sent to the referrer contains the following components:

- diagnosis
- conclusions concerning the care needs of the person with memory problems/dementia and their carer

3.6.2 People are asked if they would like to receive a copy of the letter sent to the referrer

3.6.3 People are asked if they would like their carer to receive a copy of the letter sent to the referrer

3.6.4 The person is asked if they would like to receive an informal, nonmedical and personalised letter containing information about their diagnosis and the care needs for the person and their carer

3.6.5 Where diagnosis is not disclosed a clear record of the reasons is made

3.6.6 People who drive are informed of the necessity to report the diagnosis to the DVLA

Assessment and diagnosis of specific conditions

3.7 Additional tests and investigations are carried out in accordance with individual and clinical need, including:

- Structural imaging in the assessment of people with suspected dementia to exclude cerebral pathologies and to help establish the subtype diagnosis
- Electrocardiogram
- Chest x-ray
- Testing for syphilis, serology or HIV

Guidance: *this must be with the person's consent and with appropriate counselling services made available*

- Specialist advice when interpreting investigations/assessments/scans in people with learning disabilities

Support for people and their carers

3.8 The memory service is able to offer appropriate support, advice and information to people with memory problems/dementia and their carers at the time of assessment and diagnosis, as needed

3.8.1 People and their carers are given the opportunity to discuss what might come out of the assessment before it is carried out

3.8.2 Information is communicated sensitively and in a timely manner

3.8.3 When communicating important information to people, staff are able to dedicate adequate time

3.8.4 People are given adequate opportunities to talk through the implications of their diagnosis with members of the team, immediately after and/or during the days after receiving a diagnosis

Guidance: *ascertain whether the supports offered were sufficient to meet the needs*

3.8.5 People and their carers are able to access post-diagnostic support groups

Guidance: *i.e. groups run by the service or other local providers*

3.8.6 The service is able to provide people and their carers with a variety of written information about the following:

- the signs and symptoms of dementia
- the course and prognosis of the condition
- options for care and treatment, including coping methods and
- strategies
- local care and support services/support groups; including Carers Assessment
- sources of financial and legal advice, and advocacy
- medico-legal issues, including driving
- local information sources, including libraries and voluntary organisations
- information on how people with dementia can improve their general health, live positively and maximise their quality of life after diagnosis,

e.g. using mental exercise, physical activity, dietary advice alongside drug therapy

3.8.7 Information is available in a range of formats, including languages other than English, and in forms which people with cognitive, specific language, sight, learning and other disabilities can use

3.8.8 The service has access to a specialist post-diagnostic counselling service

Guidance: *counselling services provided by an appropriately qualified professional*

3.8.9 Any advice given is recorded in the notes

Section 4: Ongoing care

Management and follow up care management

4.1 The memory service ensures that each person with memory problems / dementia has a care plan

4.1.1 The service supports care planning or refers people on to appropriate agencies/services for care planning

4.2 Professionals working within the memory service ensure that the person (and their carer, where appropriate) is able to access a range of post-diagnostic supports and interventions

4.2.1 The service provides or can signpost/refer on to services that will offer assessment and intervention for people who develop non-cognitive symptoms

Guidance: *e.g. mood disorders, psychotic symptoms and behaviour that challenges*

4.2.2 The service provides or can signpost/refer on to services that will offer information, advice and support to assess and manage pharmacological treatment

4.2.3 The service can signpost/refer on to voluntary organisations and support groups such as Age Concern, For Dementia, and the Alzheimer's Society for follow up support and information for the person and their family/carer.

4.2.4 The service provides or can signpost/refer on to services that will offer information, advice and support with communication problems

4.2.5 The service provides or can signpost/refer on to services that will offer information, advice and support on modifiable risk factors for dementia

Guidance: *e.g. smoking, excessive alcohol consumption, obesity, diabetes, hypertension and raised cholesterol*

4.2.6 The service provides or can signpost/refer on to services that will offer information, advice and support on dietary interventions to help the person adapt dietary intake to help achieve full nutritional requirements

4.2.7 The service provides or can signpost/refer on to services that provide a range of psychological and social interventions

Guidance: *e.g. cognitive stimulation therapy and reminiscence groups*

4.2.8 The service provides or can signpost/refer on to services that provide individual or group psychoeducation

- 4.2.9** The service provides or can signpost/refer on to services that can advise on welfare benefits
- 4.2.10** The service provides or can signpost/refer on to peer support / self-help groups
- 4.2.11** The service provides or can signpost/refer on to specialist dementia nursing
- 4.2.12** The service provides or can signpost/refer on to dementia adviser services
- 4.2.13** The service provides or can signpost/refer on to a range of respite / short-break services
- 4.2.14** The service provides or can signpost/refer carers on for a full assessment of their needs
- 4.2.15** The service provides or can signpost/refer on to services that offer information, advice and support on a range of legal matters associated with the loss of capacity, including: power of attorney, managing finances, advance directives etc
- 4.2.16** The service is able to refer to genetic counselling for people and their unaffected relatives (where there is likely to be a genetic cause for their dementia)
- 4.2.17** The service is able to refer to a specialist neurological centre for a possible brain biopsy (if dementia is thought to be due to a potentially reversible condition that cannot be diagnosed in any other way)

Follow-up

4.3 The memory service ensures that each person with memory problems/dementia is followed up

4.3.1 The service follows up and reviews the people they have treated, or refers them on to appropriate agencies/services for follow-up

Appendix 3: Locally agreed detailed referral protocol

(To be inserted by local commissioner)

Appendix 4: Information

Locally agreed information about services for both people with a possible dementia and their families/carers

(To be inserted by local commissioner)

Appendix 5: Expected number of referrals and assessments 2011/12

Illustrated example from NHS Cornwall agreement with Cornwall NHS
Partnership Foundation Trust 2010/11.

Practice	Estimated prevalence over-65s	% of over-65s	No. assessments (non-learning disabilities)	No. assessments (learning disabilities)	Total no. assessments over 12 months
A	74	8%	17	1	18
B	81	8%	8	2	20
C	243	7%	55	5	60