

10 Key Steps



**Improving diagnosis of dementia:
10 key steps
for Commissioners and Clinical Commissioning Groups**

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Introduction


This Briefing has been prepared as a resource for Commissioners, Clinical Commissioning Groups and local partners to develop and deliver comprehensive action plans to improve the rate of diagnosis of dementia, the diagnosis pathway.

It is supplemented by additional resources, including:

 [Improving dementia care in primary care: 10 key steps for General Practice](#) (South West Dementia Partnership, 2012)

 [Dementia Care in Primary Care Toolkit](#) (South West Dementia Partnership, 2012)

 [Guidance and Standards for Diagnosing Dementia](#) (South West Dementia Partnership, 2012)

 [New Models of Care for Dementia](#) (South West Dementia Partnership, 2012)

Why a diagnosis?

In the UK today 60 per cent of people with dementia have no formal diagnosis. Avoiding 'naming' memory problems and possible dementia is a key factor preventing people seeking, and being offered the treatment and support they need, early enough.

People's needs; people's rights

GPs and primary health care teams are key to enabling people to have often difficult conversations about memory problems, and to help people to live as well as possible with dementia as the disease progresses – whether they are living at home, with support; and when they need more intensive support. The needs of people living with dementia and the needs of their carers/families will change over time; they will need timely, responsive and flexible support.

- Prompt referral to specialist memory services will ensure that people with memory problems, and their carers/families receive early diagnosis, and planned care and support.
- Where dementia is established, a formal diagnosis will help the person with dementia and their carers/families, and services supporting them to ensure that care and support is planned and reflect their needs and preferences – whether they are living at home, or in care homes.

Why is the rate of diagnosis important?

The diagnosis rate is defined as the rate of identified cases of dementia expressed as a percentage of the local estimated prevalence for dementia. Diagnosis is captured via general practices, through the NHS Quality and Outcomes Framework reward and incentive programme.

- A higher diagnosis rate may indicate that more people are accessing treatment, care and support for dementia.

The diagnosis rate is not an indicator of quality: commissioners will need to ensure that standards of care underpin the local diagnosis pathway.

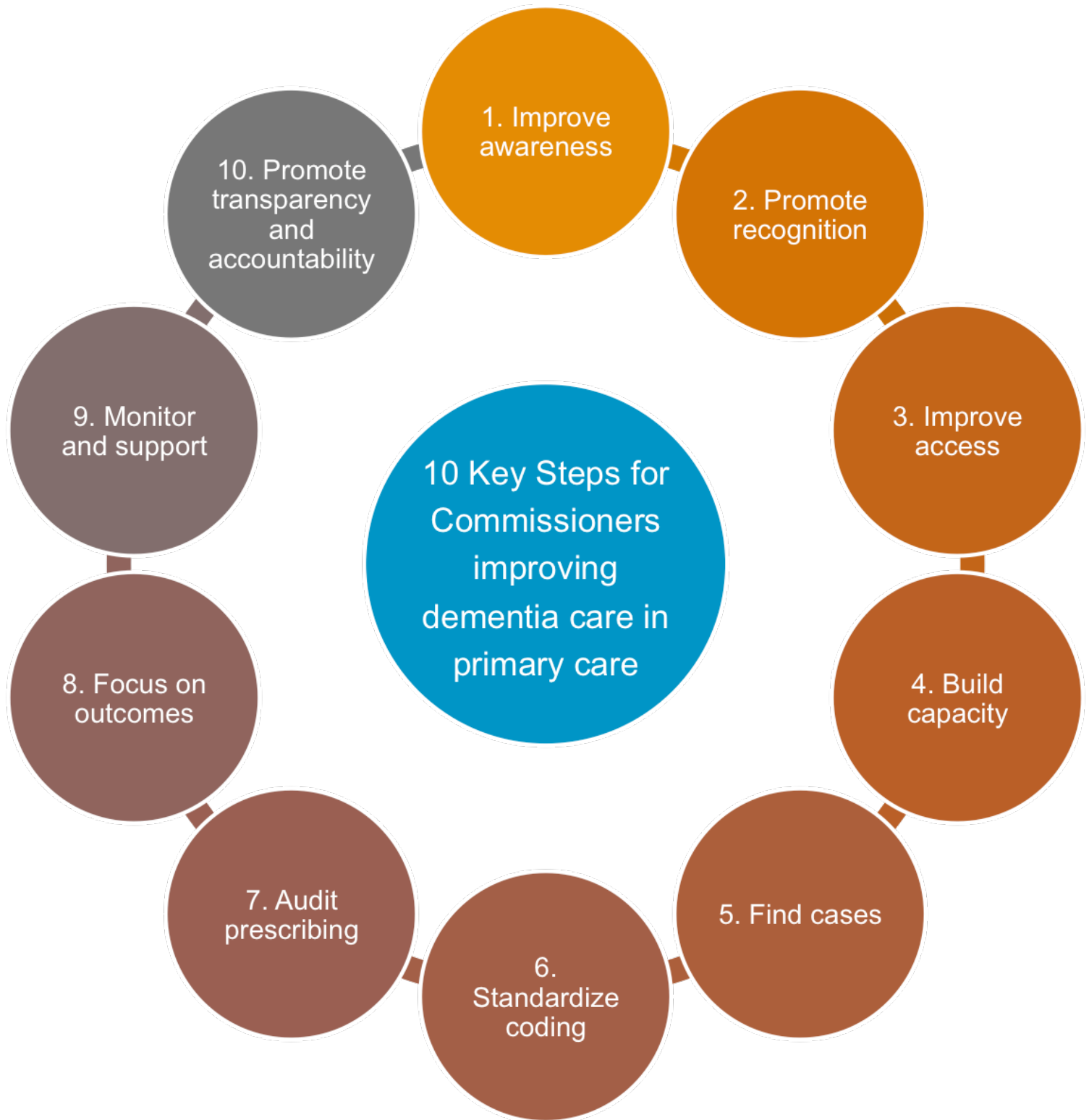
 [Find out more about the NICE Dementia Quality Standards](#) (National Institute for Health and Clinical Excellence, 2010)

Improving diagnosis rates

Diagnosis will be influenced by a number of factors, and multiple actions at different points of the diagnosis pathway.

Commissioners will need to introduce a number of actions and changes, and use levers at different points within their local health and care systems in order to achieve and sustain improvement in the diagnosis pathway, and to improve the rate of diagnosis for their local population. This Briefing sets out a range of actions and changes which commissioners could use in a strategic and planned way, to ensure that local trajectories for improvement are achieved in diagnosis of rates, and in the quality of local services for people living with dementia and their carers/families.








1. Improve awareness

Improve awareness about dementia.

Establish comprehensive programmes of training and education for general practices. For example,

- ensure access to education and training for GPs and primary health care teams:
 - through deaneries, commission system-wide programmes
 - ensure practices have access to existing training resources
- find out more about training resources, such as
 -  [Dementia Care in Primary Care Toolkit](#) (South West Dementia Partnership, 2012)
 -  [The dementia gateway](#) (Social Care Institute for Excellence, 2010)
 -  [The open dementia e-learning programme](#) (Social Care Institute for Excellence, 2009)
- establish a clinical lead for dementia in every practice
- broker opportunities for general practice clinical leads for dementia to share information, learning and resources, and to network
- commission dementia advisers to work with primary health care teams and provide post-diagnosis support for patients, carers and families
- engage with the local voluntary and community sector to broker support for general practices
- produce and disseminate a regular newsletter about dementia , including community activities and resources for people with dementia and their carers/families
- work with general practice managers to ensure that they are able to access and provide a range of information and resources about dementia for their practice, and on their practice website

Incentives and levers

- Build training targets into primary care contracts.
 - [View the Dementia Care in Primary Care Toolkit](#) (South West Dementia Partnership, 2012)
 - [View the Dementia Workforce Portal](#) (South West Dementia Partnership, 2011)
- Build dementia competencies into primary care contracts.
 - [View the Dementia Competency Framework](#) (South West Dementia Partnership, 2011)
 - [View the Commissioning guidance: Caring, compassionate, skilled – transforming the dementia workforce](#) (South West Dementia Partnership, 2011)
 - [View the Commissioner’s checklist – dementia services and workforce issues](#) (South West Dementia Partnership, 2011)
- Include requirement for a general practice clinical lead for dementia within the primary care contract
- Introduce a CQUIN to specialist dementia services to provide liaison with, and training for general practice primary health care teams.
- Introduce a Local Enhanced Service contract.



2. Promote recognition







- Engage with general practices to promote recognition of dementia among current patients. For example, practices could introduce local protocols to introduce questions about memory functioning in scheduled visits and routine health checks and investigations for people over 65 years. These might include,
 - annual checks for over-65s with long term conditions
 - annual 'flu clinic health questionnaires
 - over -75 health checks
 - adults with Downs Syndrome
 - patients with cardiovascular conditions and stroke
 - patients with Huntingdon's Disease or Parkinson's Disease.
- Encourage general practices to be alert to those cases involving
 - falls
 - older patients failing to attend appointments
 - older patients failing to collect dispensed medications
 - cases where a previous initial assessment for dementia has been undertaken
 - patients in community hospitals
 - references to confusion, depression, problems thinking, reasoning, struggling to follow conversations, forgetfulness, and other changes in mood and cognition.

 [View the Dementia Care in Primary Care Toolkit](#) (South West Dementia Partnership, 2012)



3. Improve access

Improve access to specialist memory services, by better commissioning.

- Calculate capacity and resource requirements using national Dementia Commissioning Pack cost benefits tool and commissioning specification for memory services.
 -  [View the national Dementia Commissioning Pack](#) (Department of Health, 2010)
 -  [View the national Dementia Commissioning Pack Cost Benefits Tool for Memory Assessment Services](#) (Department of Health, 2010)
- Working with people using services, design local memory service pathway and referral protocols.
 -  [View the Map of Medicine for Dementia assessment](#) (Map of Medicine, 2010)
 -  [View the Map of Medicine for Dementia management](#) (Map of Medicine, 2010)
- Commission memory assessment services sufficient to meet estimated local demand.
 -  [View the South West Dementia Partnership Commissioning Guidance – memory services](#) (South West Dementia Partnership, 2011)
- Ensure memory services are compliant with NICE standards, and positive practice. Build standards into memory service contracts.
 -  [View the Guidance and Standards for Diagnosing Dementia](#) (South West Dementia Partnership, 2012)

Incentives and levers

- Build into memory service contracts:
 - targets for assessment,
 - standards for the transfer of diagnosis data to primary care
 - the capture of feedback from people using services.
- Audit and monitor activity and delivery of memory assessment targets in-year.
- Introduce CQUIN to specialist memory services to provide liaison with, and training for general practice primary health care teams.

4. Build capacity

- Commission dementia advice and support for primary care and community health services to deliver a range of possible functions, including:
 - initial screening
 - advice for GPs and primary health care teams
 - pre- and post-diagnosis information and support for people with dementia and their carers/families
 - maintenance of dementia register and dementia review records (QOF DEM1, DEM2)
 - signposting to community resources
 - education for carers/families
 - provision of a consistent point of contact for people with dementia and their carers/families
 - case management and care co-ordination
 - link with memory services, specialist dementia services, social services, voluntary and community resources
 - patient and carer advocacy.



[View An evaluation of dementia support worker roles](#) (South West Dementia Partnership, 2011)

Incentives and levers:



[Q3 2011/12 local authorities have received £10m non-recurring funding to improve early diagnosis and interventions.](#)

5. Standardize coding

- Recommend that general practices and memory services standardise Read coding for diagnoses of dementia.

Recommended QOF read codes

- **F110** Alzheimer's Disease
- **F111** Pick's Disease (front temporal dementia)
- **Eu01** Vascular dementia
- **Eu025** Lewy Body Dementia
- **Eu023** Dementia in Parkinson's disease
- **E00** Senile and pre senile organic psychotic conditions, and for advanced dementia (not being referred for memory assessment)
- **Eu01** 'Mixed Dementia'

Associated QOF read codes

Consider checking any patients with the following codes:

- **1B1A** Memory loss symptom
- **1B1A0** Temporary loss of memory
- **Eu057** Mild cognitive disorder

6. Find cases

Consider general practices' patients who are in care homes, and in the community.


- Where dementia is established,
 - Has a diagnosis been recorded and captured on the General Practice dementia register?
 - Are these patients benefitting from regular health checks, and reviews of medication?
 - What training about dementia are care home staff receiving?
 - Are staff in the care home able to manage behaviours that challenge, offering alternatives to prescribing antipsychotics?
 - Are inspections highlighting any concerns? What action is being taken by the local authority and health commissioners?

 [Find out more about the care home Dementia Quality Mark](#) (South West Dementia Partnership, 2010)



Incentives and levers

- Ensure general practices are providing general medical services for patients with dementia living at home, and in care homes. These should include,
 - personalised care plans
 - regular health checks
 - regular medication reviews
 - advice and support for staff in managing behaviours that challenge
 - diagnosis, where dementia is established
 - advance plans to avert unnecessary admissions to hospital
 - plans for care toward the end of life.

 - Commission community pharmacists to undertake regular medication reviews of patients in primary care and in care homes, and advise general practitioners of possible diagnoses being 'missed'.
-  [View the national Call 2 Action for the reduction of prescribing of antipsychotics for people with dementia](#) (Dementia Action Alliance and NHS Institute for Innovation and Improvement, 2011)
- Introduce a CQUIN to specialist dementia services to provide in-reach services and training for care home staff.

7. Audit prescribing

Anti-dementia drugs

Are people with an early diagnosis of dementia being prescribed anti-dementia drugs in line with NICE guidance?

- With your medicines management lead, review data on the prescribing of anti-dementia drugs, by general practice and secondary care provider in order to
 - highlight any outliers, and agree action to address this;
 - correlate prescribing data with information on general practice dementia registers.
- Introduce an audit of prescribing of anti-dementia drugs to establish that standards are in line with NICE guidance.



[View Donepezil, galantamine, rivastigmine and memantine for the treatment of Alzheimer's disease. Technology Appraisal 217.](#) (National Institute for Health and Clinical Excellence, 2011)

Anti-psychotic prescribing

- With your medicines management lead, review data on the prescribing of antipsychotic drugs for people with dementia by secondary mental health services, acute and community hospitals, and in primary care in order to,
 - highlight any outliers, and agree action to address this;
 - correlate prescribing data with information on general practice dementia registers.
- Introduce an audit of prescribing of antipsychotic drugs to establish that standards are in line with NICE guidance.
- Ensure staff working with people with dementia are trained in the use of alternatives to prescribing antipsychotic medication.



[View Optimising treatment and care for people with behavioural and psychological symptoms of dementia: A best practice guide for health and social care professionals.](#) (Alzheimer's Society, 2011)



[View the national Call 2 Action for the reduction of prescribing of antipsychotics for people with dementia](#) (Dementia Action Alliance and NHS Institute for Innovation and Improvement, 2011)

8. Focus on outcomes

- Ensure that improving diagnosis and interventions for people with dementia, and their carers/families, are integral to local plans to deliver the NHS Outcomes Framework 2012/13 (Department of Health, 2011).



[View the NHS Outcomes Framework 2012/13](#) (Department of Health, 2011)

- Seek, and listen to the experience of people using services, to inform commissioning and service improvement.

Incentives and levers:



[Q3 2011/12 local authorities have received £10m non-recurring funding to improve early diagnosis and interventions.](#)

- NHS Operating Framework 2012/13:
 - compliance with NICE Quality Standards for Dementia
 - improvements in the quality of general practice and community services
 - improved diagnosis rates
 - local dementia plans published
 - support for carers.




[View the NHS Operating Framework 2012/13](#) (Department of Health, 2011)




9. Monitor and support

- Monitor and support improvement.
- Review dementia diagnosis rates by general practice to identify outliers
 - Establish why some practices have higher rates of diagnosis. How are they achieving this?
 - Target those practices where diagnosis rates are lower than expected. What are the impediments?


 [View general practice Quality and Outcomes Framework \(QOF\) figures](#)


 [View Quality and Outcomes Framework guidance for GMS contract 2011/12](#) (NHS Employers and British Medical Association, 2011)


 [View the Dementia Practice Prevalence Calculator](#) (South West Dementia Partnership, 2011)


- Work with outlying practices to develop general practice action plans to improve recognition and rates of diagnosis.

 [View the Dementia Workforce development portal](#). This includes:

 [Dementia learning and education pathway](#) (South West Dementia Partnership, 2011)

 [Dementia Competency Framework](#) (South West Dementia Partnership, 2011)

 [Commissioning guidance: Caring, compassionate, skilled – transforming the dementia workforce](#) (South West Dementia Partnership, 2011)

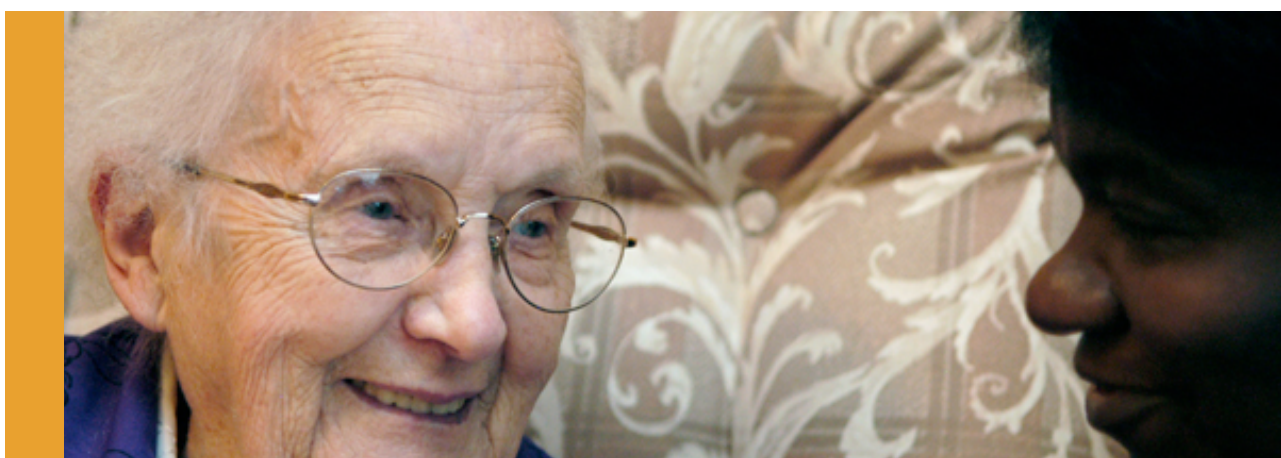
 [Commissioner's checklist – dementia services and workforce issues](#) (South West Dementia Partnership, 2011)

 [View the Dementia Care in Primary Care Toolkit](#) (South West Dementia Partnership, 2012)

10. Promote transparency and accountability

- Ensure that Clinical Commissioning Groups have identified leads for dementia, receive regular updates on progress with delivering national and local priorities, and any unmet needs.
- Work with a local multi-stake holder Dementia Strategy implementation group to design and implement an Early Diagnosis and Interventions Action Plan. Ensure this group is able to reflect the needs, priorities and preferences of people living with dementia, and their carers/families.
- Publish your Dementia Action Plan, including progress with delivery of trajectories to improve rate of diagnosis.
- Engage with Health and Wellbeing Boards and local HealthWatch to ensure that needs of people with dementia are reflected in the Joint Strategic Needs Assessment, local priorities and commissioning strategies.
- Engage with the Dementia Action Alliance to support your local Dementia Alliance to promote awareness; to assure that the rights of people with dementia and people who support them are protected; and to assure that their wellbeing is promoted.

 [Find out more about the Dementia Action Alliance](#)



Appendix 1: References

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South West Dementia Partnership (2011) [Dementia Quality Mark: Operating Framework](#). South West Dementia Partnership, Bridgwater.

South West Dementia Partnership (2011) [Guidance on the Commissioning of Memory Assessment Services](#). South West Dementia Partnership, Bridgwater.

Appendix 2: Useful websites

[AgeUK](#)

The Age UK Group works to improve later life for everyone by providing life-enhancing services and vital support.

[Alzheimer's Society](#)

Alzheimer's Society is a membership organisation, which works to improve the quality of life of people affected by dementia in England, Wales and Northern Ireland.

[ATdementia](#)

Supports people to consider areas of daily living where they may experience difficulties and offers advice and information on technologies and other strategies that may be helpful.

[Carers UK](#)

Carers UK is a charity set up to help the millions of people who care for family or friends.

[Dementia Action Alliance](#)

Over 40 organisations committed to transforming the quality of life of people living with dementia in the UK and the millions of people who care for them.

[Department of Health Dementia Portal](#)

This website follows the implementation of the National Dementia Strategy. It offers information to anyone with an interest in improving services for people with dementia.

[Horsemouth](#)

Horsemouth is a website where people with questions can ask people with relevant personal experiences for advice.

[Social Care Institute for Excellence Dementia Gateway](#)

A set of web based resources focused on supporting people with dementia, their carers and staff working in dementia services.