

**EVIDEM: ED**

**Patient**

**ID:** \_\_\_\_\_

Based on the NICE & SCIE Audit criteria November 2006 and the Audit support 2009 to accompany NICE clinical guideline 42

<b>Patient ID:</b> <i>(study code- see list)</i>	<b>Date of data extraction:</b>	<b>Date of randomisation</b> (control=TL)/end of training (intervention=TE) <i>(see list):</i>	<b>Data extracted by:</b> PJ 1 I T-B 2 JW 3 _____ 4
<b>Practice ID:</b> <i>(study code- see list)</i>	<b>Patient:</b> Time 1 (anything before randomization/end of training) 1 Time 2 (anything 12 months after randomization/ end of training) 2		<b>Data coded by:</b> PJ 1 I T-B 2 JW 3 _____ 4

<b>1) Gender:</b> M     1         F     2	<b>3) Marital Status:</b> Married/Co-habiting   1             Single 2    Widowed 3		<b>4) Ethnicity:</b>	<b>5) Patient location at Time 1</b> Community     1
<b>2) DOB:</b>	Divorced 4    Separated 5    D/K 88		D/K 88	Care home         2
<b>6) Date registered with current practice:</b> D/K 88		<b>7) Changed practice last 40 months or since original diagnosis if longer</b> Y 1     N 2    D/K 88		
<b>8) Carer details recorded:</b> Yes 1 No 2 D/K 88 N/A 99	<b>9) Gender of carer:</b> M     1         F     2    D/K 88    N/A 99		<b>10) Relationship of person with dementia with carer:</b> D/K 88    N/A 99	
<b>11) Date of Index:</b> (Any dementia related symptom reported by patient/carer/relative and there is evidence of a dementia related response by GP e.g. doing bloods, memory tests etc.) D/K 88    N/A 99		<b>12a) No. of consultations recorded</b> <b>(6 months pre Index → 2 years post Index)</b> D/K 88    N/A 99		
		<b>12b) Time span covered</b> 30 months    .....months    D/K 88    N/A 99		

**13) Symptoms recorded at Index:**

Memory loss 1 Forgettingfulness 2 Behavioural Changes 3 Disorientation 4 Confusion 5 Functional abilities & complex tasks 6 Personality change 7  
Decline in test scores 8 Speech problems 9 Morale, mood, depression 10 Carer's report, concern 11 Cognitive decline, deterioration 12 Global deterioration 13  
Wandering 14 Change in self-care 15 Toileting problems 16 ..... 17  
..... 18 ..... 19 **D/K 88 N/A 99**

**14) Date of Diagnosis:**

(When diagnosis appears in the GP records e.g. from secondary care.)

D/K 88 N/A 99

**15) Months INDEX TO DIAGNOSIS**

D/K 88 N/A 99

**16) Diagnosis made by:**

Primary care 1 Secondary care 2 D/K 88 N/A 99

**17) Diagnosis:**

Senile dementia /Dementia 1 Alzheimer's Disease 2 Vascular dementia 3 Dementia with Lewy Bodies 4 Mixed dementia 5 Mild Cognitive Impairment 6 Other ..... 7 D/K 88 N/A 99

**18) Does this diagnosis change over time?**

Yes 1 No 2 D/K 88 N/A 99

If yes...

**19) Date of new diagnosis:**

**New Diagnosis:** Senile dementia/ Dementia 1 Alzheimer's Disease 2  
Vascular dementia 3 Dementia with Lewy Bodies 4 Mixed dementia 5  
Other 6 .....

D/K 88 N/A 99

20) Problem History and co-morbidity

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Other comments:

21) Current medications

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Criterion	Definition	Comments
<b>AT DIAGNOSIS &amp; ASSESSMENT <u>IN PRIMARY CARE</u>: (anything between index and diagnosis)</b>		
<p>22) Was a Dementia Blood Screen performed by the practice?</p> <p>Yes (all) 1</p> <p>No 2</p> <p>Some (tick) 3</p> <p>D/K 88</p> <p>N/A 99</p>	<p>Includes:</p> <p>Urea &amp; Electrolytes (U&amp;E)</p> <p>Calcium (Ca)</p> <p>Glucose (BS)</p> <p>Renal (U&amp;E)</p> <p>Liver function (LFT)</p> <p>Thyroid function tests (TFT)</p> <p>Vitamin B12</p> <p>Folate</p> <p>FBC</p>	<p>If some, which? Tick:</p> <p>Urea &amp; Electrolytes (renal, U&amp;E) <input type="checkbox"/></p> <p>Calcium (Ca) <input type="checkbox"/></p> <p>Glucose (BS) <input type="checkbox"/></p> <p>Liver Function Test (LFT) <input type="checkbox"/></p> <p>Thyroid Function Tests (TFT; TSH, T4, T3) <input type="checkbox"/></p> <p>Vitamin B12 <input type="checkbox"/></p> <p>Folate <input type="checkbox"/></p> <p>Full Blood Count (FBC) <input type="checkbox"/></p>
<p>23) Was Syphilis Serology tested by the practice?</p> <p>Yes 1 No 2 D/K 88 N/A 99</p>	<p>Note: Not recommended in NICE/SCIE guideline</p>	

Criterion	Definition	Comments												
<p>24) Was a Cognitive Function Test performed by the practice?</p> <p>Yes 1 No 2 D/K 88 N/A 99</p>	<p>For example:</p> <p>MMSE</p> <p>6-CIT</p> <p>GPCOG</p> <p>7 minute screen</p> <p>Mini-cog</p> <p>AMTS</p> <p>Other.....</p>	<p>If yes, which:</p> <table data-bbox="868 393 1215 723"> <tr> <td>MMSE (30-items)</td> <td>1</td> </tr> <tr> <td>6-CIT</td> <td>2</td> </tr> <tr> <td>GPCOG</td> <td>3</td> </tr> <tr> <td>7 min screen</td> <td>4</td> </tr> <tr> <td>Minicog</td> <td>5</td> </tr> <tr> <td>AMTS (10-items)</td> <td>6</td> </tr> </table> <p>(sometimes referred to as 10-items MMSE, e.g. MMSE 8/10 is actually an AMTS score)</p> <p>Other..... 7</p>	MMSE (30-items)	1	6-CIT	2	GPCOG	3	7 min screen	4	Minicog	5	AMTS (10-items)	6
MMSE (30-items)	1													
6-CIT	2													
GPCOG	3													
7 min screen	4													
Minicog	5													
AMTS (10-items)	6													
<p>25) Was the Informant History considered by the practice?</p> <p>Yes 1 No 2 D/K 88 N/A 99</p>	<p>Any concerns relevant to dementia mentioned to the GP by nurse, next of kin, friend etc. between index and diagnosis (anyone other than the patient).</p>	<p>If yes, what?</p>												

Criterion	Definition	Comments
<p>26) Was a Referral made by the practice at or after index?</p> <p>Yes 1 No 2 D/K 88 N/A 99</p>	<p>E.g. referral from Primary Care to Old Age Psychiatry, Neurologist, Psychologist etc.</p>	<p>To Whom:</p>
<p>27) Was Depression and/or Psychosis considered by the practice?</p> <p>Yes 1 No 2 D/K 88 N/A 99</p>		
<p>28) Were Carer Concerns recorded by the practice?</p> <p>Yes 1 No 2 D/K 88 N/A 99</p>		<p>If yes, what?</p>
<p>29) Were Behavioural and Psychological Symptoms</p>	<p>For example, aggression, agitation, apathy, anxiety, pacing, wandering, sleep disturbance,</p>	<p>If yes, which?</p>



Criterion	Definition	Comments
<p>related to the Dementia (BPSD) recorded by the practice (apart from depression)?</p> <p>Yes 1 No 2 D/K 88 N/A 99</p>	<p>repetitive speech and behavior etc.</p>	<p>If yes, what action was taken?</p>
<p>30) Was information given by the practice to either the carer or patient or both, on:</p>		
<p>a) Signs and symptoms?</p> <p>Yes 1 No 2 D/K 88 N/A 99</p>	<p>See BPSD list in Q 29 but also memory loss and change in abilities.</p>	
<p>b) Course and prognosis?</p> <p>Yes 1 No 2 D/K 88 N/A 99</p>		
<p>c) Treatments?</p> <p>Yes 1 No 2 D/K 88 N/A 99</p>		
<p>d) Local care and support services?</p>		

Criterion	Definition	Comments
Yes 1 No 2 D/K 88 N/A 99		
e) Support groups? Yes 1 No 2 D/K 88 N/A 99		
f) Sources of financial and legal advice and advocacy? Yes 1 No 2 D/K 88 N/A 99	E.g. the Alzheimer's Society, Age Concern/Age UK, Citizen's Advice Bureau, DISC etc.	
g) Medico-legal issues? Yes 1 No 2 D/K 88 N/A 99	Includes driving, advance directives, capacity of patients to make health care decisions...	
h) Local information sources, including libraries and voluntary organizations? Yes 1 No 2 D/K 88 N/A 99		

Criterion	Definition	Comments
<p>31) Has the patient been offered Anti-Dementia Medication (cholinesterase inhibitors)?</p> <p>Yes 1 No 2 D/K 88 N/A 99</p>	<p>E.g. by secondary care and prescribed by either secondary or primary care.</p>	<p>Which?</p> <p>If no, what reason?</p>
<p>32) Was a Medication Review conducted around the time of the Index case and during assessment, e.g. to identify any drugs that may impair/improve cognitive functioning (added, stopped, changed)?</p>	<p>For example:</p> <p>Aspirin</p> <p>Risperidone, Sulpiride, (Thioridazine)</p> <p>Benzodiazepines (e.g. Temazepam, Diazepam, nitrazepam, Triazolam,</p>	

Criterion	Definition	Comments
Yes 1 No 2 Not clear 3 D/K 88 N/A 99	Zopiclone) Anticholinergic drugs (e.g. Procyclidine, Biperiden, HCL, Benztropine)	
33) Was the patient referred for a CT/MRI scan by the GP? Yes 1 No 2 D/K 88 N/A 99		
<b><u>DURING MANAGEMENT IN PRIMARY CARE:</u></b>		
34) Since diagnosis, has Anti- Psychotic Medication been	(E.g. Risperidone, Aripiprazone, Haloperidol,	If yes, which?

Criterion	Definition	Comments
<p>prescribed by the GP?</p> <p>Yes 1 No 2 D/K 88 N/A 99</p>	<p>Olanzapine etc.)</p>	<p>If yes, why?</p>
<p>35) Consent and Capacity:</p> <p>a) Does the health record show evidence of continuing valid consent from the patient, or that the provisions of the Mental Capacity Act have been followed if the person lacks capacity?</p> <p>Yes 1 No 2 D/K 88 N/A 99</p>	<p>Read Codes E000 senile dementia and E001 presenile dementia should be used to identify patients.</p> <p>The health record should include notes of a discussion about consent with the patient, including how understanding was checked and that the patient continues to consent over</p>	<p>If yes, what does it say?</p>

Criterion	Definition	Comments
<p>b) Is there evidence of recall, reasoning, decision making and if relevant, agreement from next of kin?</p> <p>Yes 1 No 2 D/K 88 N/A 99</p>	<p>time. If appropriate, the record should include notes of a decision-specific test to establish whether the person had the capacity to give valid consent.</p> <p>The patient should be asked to sign the record to note that they understand and give consent.</p>	
<p>36) Is there a Care Plan evident?</p>	<p>E.g. there is a care plan scanned into the medical records or there is a</p>	

Criterion	Definition	Comments
Yes 1 No 2 D/K 88 N/A 99	<p>mention of a care plan being followed/adhered to.</p> <p>A care plan could also be a letter from secondary care if specified as such.</p>	
<p>37) Is there evidence that Behavioural and Psychological Symptoms have been addressed and managed?</p> <p>Yes 1 No 2 D/K 88 N/A 99</p>	<p>These may cover the patient's:</p> <ul style="list-style-type: none"> <li>-physical health</li> <li>-depression</li> <li>-possible undetected pain or discomfort</li> <li>-side effects of medication</li> <li>-physical environmental factors</li> <li>-individual biography (e.g. beliefs, spiritual and</li> </ul>	

Criterion	Definition	Comments
	cultural identity) -psychosocial factors -specific behavioural and functional analysis conducted by trained professionals in conjunction with family carers and care workers.	
38) Is there mention of the following in <u>primary care</u> :		
a) Advance statements?  Yes 1 No 2 D/K 88 N/A 99	A written statement, drawn up and signed when the person is well, which sets	



Criterion	Definition	Comments
	<p>out how s/he would prefer to be treated (or not treated) if s/he were to become ill in the future.</p>	
<p>b) Living will? Yes 1 No 2 D/K 88 N/A 99</p>	<p>A living will is one form of advance directive, leaving instructions for treatment.</p>	
<p>c) Lasting power of attorney? Yes 1 No 2 D/K 88 N/A 99</p>	<p>An authorization to act on someone else's behalf in a legal or business matter.</p>	
<p>d) Preferred Priorities (previously 'Preferred Place' of Care?) Yes 1 No 2 D/K 88 N/A 99</p>	<p>An example of Advance Care Planning; A document for writing down wishes and preferences of care.</p>	

Criterion	Definition	Comments
	<p>This means that everyone involved in the care of someone knows what they want and how they wish to be cared for. It is also called an '<i>Advanced Care Plan</i>'.</p>	
<p>e) Direct payments / Personal budgets?</p> <p>Yes 1 No 2 D/K 88 N/A 99</p>	<p>Cash payments made to individuals who have been assessed as needing services, in lieu of social service provisions.</p>	
<p>39) Is there a mention of the patient's Functional Abilities/ADLs or the use of measures of Global</p>	<p>Functional ability refers to the ability to conduct activities of daily living (ADL) such as eating,</p>	

Criterion	Definition	Comments
<p>Assessments?</p> <p>Yes 1 No 2 D/K 88 N/A 99</p>	<p>dressing and bathing.</p>	
<p>40) Is there a mention of discussions with a main carer about what <b>their own needs</b> are and whether their needs are being met?</p> <p>Yes 1 No 2 D/K 88 N/A 99</p>		
<p>41) Was information given by the practice to either the carer or patient or both, during management period on:</p>		
<p>a) Local care and support</p>		

Criterion	Definition	Comments
services? Yes 1 No 2 D/K 88 N/A 99		
b) Support groups? Yes 1 No 2 D/K 88 N/A 99		
c) Sources of financial and legal advice and advocacy? Yes 1 No 2 D/K 88 N/A 99	E.g. the Alzheimer's Society, Age Concern/Age UK, Citizen's Advice Bureau, DISC etc.	
d) Medico-legal issues? Yes 1 No 2 D/K 88 N/A 99	Includes driving, advance directives, capacity of patients to make health care decisions...	
e) Local information sources, including libraries and voluntary organizations?		

Criterion	Definition	Comments
Yes 1 No 2 D/K 88 N/A 99		
42 a) How many formal Dementia Annual Reviews have been conducted in the last 12 months (prior to randomization/ end of training)?	Any mentioning of a 'Dementia Review'.	No:..... D/K 88 N/A 99
42 b) How many Opportunistic Dementia Reviews have been conducted in the last 12 months (prior to randomization/ end of training)?	Any mentioning of issues around dementia and related problems in any consultation. E.g. patient attends for other conditions such as diabetes and during consultation the doctor deals with dementia related issues in addition. This	No:..... D/K 88 N/A 99

<b>Criterion</b>	<b>Definition</b>	<b>Comments</b>
	should be clearly documented.	