Q6: Can dementia be diagnosed at first or second level care by non-specialist health care providers? What should be the assessment process for the diagnosis of dementia?

Background

The prevalence and incidence of dementia is destined to increase in the developing world in tandem with the ageing population. According to the Alzheimer's disease International (ADI) Delphi consensus study, by 2040, 71% of all people with dementia will be living in developing countries (Ferri et al, 2005). Dementia remains, to a large extent, a hidden problem, particularly in low and middle income countries (LAMIC). Although the symptoms and syndrome are widely recognized, it is considered to be a normal part of ageing, not a medical condition. Most often family members do not seek help, and primary care doctors rarely if ever come across cases. Dementia is an important source of family burden. Thus, there is obvious need to promote help seeking, and to improve the diagnostic skills of clinicians so that they detect more cases. The specific target would be staff at first and second level facility health care providers working in a health centre at peripheral level or at district level in low and middle-income countries.

Will it be possible for a network of non-specialist health care providers to identify probable dementia cases in the community, and in the primary care setting? If so, they could then deliver simple and effective interventions in these settings with supervision and inputs from specialists. This model might work well in most settings if suitably adapted to local resources. It is important to assess the accuracy of clinical evaluations made by non-specialist health care providers by comparing their findings against the gold-standard of a clinical diagnosis by a specialist. It is also important to identify factors or conditions which could improve detection of dementia by first or second level health care providers.

The diagnosis of dementia requires a detailed history and mental state examination. A quick screening test can be useful in primary care as well as in general hospital practice to identify probable cases of dementia, for further clinical investigation. It is important to make a distinction between screening and case-finding. Population screening for dementia is not considered cost-effective even in high income countries. However, in LAMIC identification by community health workers of those with a high probability of dementia might be used to promote help-seeking. Research carried out in developed countries has highlighted the short period of time available for each consultation in primary care, and the need accordingly for brief tools for the identification of possible/ probable dementia; ideally taking five minutes or less to complete; targeted upon those with a higher prior probability of having the disease. This approach will obviously tend to increase the positive predictive value of a test with a given sensitivity and specificity. Screening tools generally involve cognitive testing of the older person or informant interview to obtain a history of decline in intellectual and social or occupational function. Sometimes both approaches are combined in a single test. The ideal test would be sensitive and specific. It should be short, simple and user friendly; and have an unambiguous scoring system. Most studies validating these tests in primary care or community settings were carried out in the UK, Australia and other developed countries. Cultural differences and low levels of education and literacy among those being tested may be limiting factors regarding their generalisability to low resource settings.

Population/Intervention(s)/Comparison/Outcome(s) (PICO)

Population: community-dwelling older people, and older users of primary health care services with probable dementia

Interventions: diagnosis by non-specialist health care provider (e.g. general practitioner, primary care physician etc) by use of an assessment process/ instrument/protocol

Comparison: diagnostic assessment process versus no diagnostic assessment process

Outcomes: the sensitivity and specificity of dementia diagnosis made by non-specialists, among those assessed

diagnostic documentation rates (the proportion of those with dementia in the population covered by the service provider, with a clinical diagnosis of dementia recorded by the primary care provider)

the sensitivity, specificity, positive predictive value and negative predictive value of case-finding procedures for dementia in primary care or community settings

Search strategy

A literature search was conducted to find out studies to answer the objectives. A Pubmed search was made using MeSH terms “Dementia”, “diagnosis” and “primary health care”. The search was limited to items with links to full text, humans and English. Abstracts of 84 references were evaluated for relevance. Available full texts of articles related to the topic were reviewed in detail. Relevant articles from sources including ProQuest database search was also done. All articles underwent detailed evaluation before selecting studies. Apart from this we identified review articles, which looked at the usefulness of screening instruments, which are brief and could be user-friendly in primary care or community settings. We also looked at cross-references and also contacted people working in this area to help us to identify other articles. All these articles were evaluated in detail.

Inclusion and exclusion criteria

a) All studies which compared the diagnosis of dementia made by a specialist with that of first or second level care provider were included and the data was entered in a study table. Studies which used evaluation of diagnostic capability by using case vignettes were also included and relevant details were tabulated in study tables. Studies which looked at more general “cognitive impairment and used only neuropsychological tests or were not included. Data are extracted

independently by one author and was verified by another author. General guidelines suggested by QUADAS was kept in mind while assessing the quality of studies (Whiting et al, 2003).

b) Review articles or papers which had looked at brief dementia screening instruments for use in primary care and community settings

c) Studies which addressed the issue of dementia case finding by non specialist health workers in low and middle income countries

Narrative description of the studies that went into the analysis

a) A total of nine studies were selected for this review, based on detailed evaluation of 27 studies. Results are summarized in Tables-1 A, B and C. Three categories of studies were identified:

A. Studies specifically validating non-specialist health workers' diagnostic ability, in which non-specialists were asked to consider and report on the likelihood of a dementia diagnosis in a sample of their patients, their judgments then being validated against an independent gold standard diagnosis. The health workers judgment was based upon an index consultation and/ or past knowledge of the patient and case note review. We found three examples of this category of study, in one of which both general practitioners (GP) and practice nurse judgements were compared against a survey gold standard diagnosis. These studies generally report (or permit calculation of) sensitivity, specificity and positive predictive value (PPV) of the non-specialist diagnosis. The studies were conducted in the UK, Germany and the USA.

B. Studies in which the proportion of gold standard cases for which there was formal documentation of dementia diagnoses (or some mention of dementia or cognitive impairment) in primary care practice case note records. We found five examples of such studies, of which one was carried out in the same sample and reported in the same paper as a study in category A. These studies generally only report the documentation rate, which, as the proportion of true cases that are documented, is effectively the sensitivity of case note documentation. The specificity and PPV of documentation could not be estimated in studies that included only known dementia cases.

C. Studies using case vignettes to assess the competence of non-specialist clinicians in dementia diagnosis and management. Two such studies were identified both carried out in Lower Saxony, Germany, using similar designs with an eight year interval between the two studies.

Table 1 – included studies

A. Studies specifically validating primary care health workers' diagnostic ability, based upon an index consultation and/ or past knowledge and case note review								
Study	*Age (years)*	*Setting/ design*	*Non-specialist*	*Gold standard*	*Cases*	*Sensitivity (%)*	*Specificity (%)*	*PPV (%)*

			diagnosis	*diagnosis*	*Diagnosed by Specialist*			
Cooper et al, 1992	>=65	All those consulting in primary care over one month. 24 practices in Mannheim, Germany. GPs were specifically asked to rate the presence and severity of cognitive impairment, using their own records and assessments	GP rating of no impairment/ mild forgetfulness/ mild dementia/ moderate to severe dementia	Independent research diagnosis using CAMDEX criteria	Unweighted 117 Weighted 595	Unweighted 107 (91.5%) Weighted 462 (77.6%) Mild (59.5%) Moderate/ severe (95.3%)	Unweighted 191/223 (85.7%) Weighted 2327/2518 (92.4%)	Unweighted 60.8% Weighted 462/867 (53.3%)
O'Connor et al, 1988	>=75	Primary care practices in Cambridge, UK. GPs were specifically asked to rate participants from a community dementia diagnostic survey for presence of dementia on the basis of recollection and case note review. Sample restricted to those 'known to' the GP	GP ratings of definitely demented/ possibly demented/ not demented made on the basis of recollection and case note review	Independent research diagnosis from community survey, using CAMDEX criteria	208	121 (58%) Mild dementia (50.0%) Moderate (61.2%) Severe (77.8%)	185/236 (78.4%)	Definitely demented 70/81 (86.4%) Possibly demented 51/91 (56.0%)
O'Connor	>=75	Primary care	Practice nurse	Independent	74	64/74 (86.5%)	27/50 (54.0%)	Definitely

et al, 1988		practices in Cambridge, UK. Practice nurses were specifically asked to rate participants from a community dementia diagnostic survey for presence of dementia on the basis of recollection and case note review Sample restricted to those 'known to' the practice nurse	ratings of definitely demented/ possibly demented/ not demented made on the basis of recollection and case note review	research diagnosis from community survey, using CAMDEX criteria		Mild (70.1%) Moderate (96.9%) Severe (93.3%)		demented 44/51 (86.3%) Possibly demented 20/36 (55.6%)
Valcour et al, 2000	>=65	Private group practice, Honolulu, Hawaii. 218 ambulatory patients with a recent practice visit. Dementia (according to the gold standard assessment) was ascertained in 18 patients (8.3% of the sample)	Physician completed a form at index consultation, answering the question "Based on this encounter and my previous experience with this patient, in my best opinion, does this patient have dementia?" Response options were	Independent diagnostic work up by specialist physician at home visit. Benson &Cummings criteria and CDR severity	18	6 (33.3%) By dementia severity Mild (9.1%) Moderate (50.0%) Severe (100.0)%	Not reported	Not reported

			"yes," "no," and "unsure."					
B. Studies of primary care documentation of dementia diagnosis								
Study	*Age*	*Setting/ design*	*Primary care documentation of dementia diagnosis*	*Gold-standard diagnosis*	*Cases Diagnosed by Specialist*	*Documentation by primary care service (%)*	*Sensitivity*	*Specificity*
Wilkins et al, 2007	55 (58-103) Mean 80.9(SD=7.7)	411 Community resident older people (Missouri, USA) diagnosed with dementia after referral to a specialist service, and registered with a primary care physician	Any documentation in primary care records or reimbursement records of a diagnosis of dementia	Nurse specialist diagnosis. CERAD protocol for dementia diagnosis, with Clinical Dementia Rating (CDR) severity codings	411	179 (43.6%) Those not diagnosed were more likely to be older, living alone, and to have less severe dementia	Could not be estimated	Could not be estimated
Boustani et al, 2005	>=65	3340 patients from 7 primary care practices in Indianapolis, with at least one primary care attendance in the last two years. 107 cases of dementia identified.	ICD-9 diagnostic codes for dementia or AD in patient records	ICD-10, Expert panel consensus	107	20 (18.7%) Younger age predicted documentation. (Diagnosis documented in only 11.5% of those aged 80 and over (11.5%)	Not reported	Not reported
Olafsdóttir et al, 2000	>=70	A random sample of 350 people recently attending primary care in Sweden. Dementia (according to the	Mention of cognitive impairment or dementia in primary care notes	Independent dementia diagnosed by GP at home visit, using detailed structured	57	15 (26.3%) By dementia severity Mild (24%) Moderate (15%)	100%	100%

		gold standard assessment) was ascertained in 57 patients (16.3% of sample)		neuropsychiatric assessment. DSM III-R criteria		Severe (60%) Greater severity and longer duration predicted documentation		
Valcour et al, 2000	65	Private group practice, Honolulu, Hawaii. 297 ambulatory patients with a recent practice visit. Dementia (according to the gold standard assessment) was ascertained in 26 patients (8.8% of the sample)	Detection based upon search of practice notes for past two years. Precise criteria not specified.	Independent dementia diagnostic work up by specialist physician at home visit. Benson &Cummings criteria and CDR severity	26	9 (34.6%) By dementia severity Mild (21.4%) Moderate (28.6%) Severe (80.0)% Greater severity predicted documentation	Not reported	Not reported
Lopponen et al, 2003	64	1260 elders in the Community, Finland, taking part in longitudinal study. Dementia (according to the gold standard assessment) was ascertained in 112 participants (8.9% of the sample)	Detection based upon search of all available practice records. Two criteria applied – any mention of dementia (dementia documented) and any mention of cognitive/ memory impairment	Independent research diagnoses based upon two phase survey. DSM IV Dementia diagnosis by research physician and geriatrician	112	Documented dementia 54 (48.2%). By dementia severity Mild 33% Moderate 46% Severe 73% Documented dementia or cognitive impairment 76.8%	99.6% 99.2%	93.1% 90.5%

			(cognitive impairment documented)			Mild 66% Moderate 71% Severe 97% Detection was predicted by younger age, female gender and dementia severity		

Stoppe et al, 1994	-	145 GPs and 14 Neuropsychiatrists were assessed for diagnostic ability by using case vignettes. Lower Saxony Germany (Year 1993)	Assigning a diagnosis for case 2 vignettes	Under diagnosis of dementia, more evident when symptoms are mild
Maeck et al, 2008		122 family Lower Saxony Germany (Year 2001)	Assigning a diagnosis for 2 case vignettes	Guideline adherence remained low. Dementia was considered more often in year 2001 than 1993

References for the studies described in the table above:

1. Cooper B, Bickel H, Schaufele M (1992). The ability of general practitioners to detect dementia and cognitive impairment in their elderly patients: a study in Mannheim. *International Journal of Geriatric Psychiatry,* 7:591-8.
2. O'Connor DW et al (1988). Do general practitioners miss dementia in elderly patients? *British Medical Journal*, 297:1107-10.
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7. Lopponen M et al. (2003). Diagnosing cognitive impairment and dementia in primary care- a more active approach is needed. *Age and Aging*, 32:606-12.

8. Stoppe G et al (1994). Diagnosis of dementia in primary care: results of a representative survey in Lower Saxony, Germany. *European Archives of Psychiatry and Clinical Neuroscience,* 244:278-83.

9. Maeck L et al (2008). Dementia Diagnostics in Primary Care: A Representative 8-Year Follow-Up Study in Lower Saxony, Germany. *Dementia and Geriatric Cognitive Disorders,* 25:127-34.

The case vignette studies came from Lower Saxony in Germany and the first study done in 1993 found under-diagnosis of dementia diagnosis by family physicians when compared to neuropsychiatrists (See study 5 in Table-1).The other study (Study 6 of Table-1) noted low adherence to guidelines in the assessment and management of dementia by family physicians in the same locality in year 2001.

b) The instruments were evaluated in terms of their quality as dementia screening measures, cognitive assessment, informant based assessment, and case finding by non specialist health care providers in LAMICs.

A. Screening Instruments for diagnosis of Dementia in Primary Care

Selective screening of those for whom there is a prior index of suspicion can be carried out either by cognitive testing, or informant report of cognitive and functional decline, alone or in combination. The Mini-Mental State Examination (MMSE) is the most widely used cognitive screen, and adapted versions have been normed for use in many LAMIC. However, it takes 10 minutes to complete and is prone to educational and cultural bias.

We identified four review articles providing information regarding potentially useful dementia screening instruments. These reviews identified three instruments: General Practitioner Assessment of Cognition (GPCOG); Memory Impairment Screen (MIS) and Mini Cog that were most suitable for routine dementia screening in general practice. They each took less than five minutes to administer, and were validated in community or general practice samples with validity coefficients at least as favourable as for the MMSE. However, none of these assessments has been validated in LAMIC. The Vellore Screening Instrument for Dementia was recently developed and validated in hospital and community settings in south India (Stanley et al, 2009). With 10 cognitive test

items and 10 informant items, it is fairly brief, taking around 5 minutes to administer each section. For the purpose of this evidence profile, the following four instruments were thus evaluated and compared with each other (See Table-2).

- General Practitioner Assessment of Cognition(GPCOG)
- Memory Impairment Screen(MIS)
- Mini Cog
- Vellore Screening Instrument for Dementia (VSID).

There are many factors which are important in making fair assessments of cognitive functions in older people. It is possible to have a positive screen purely due to bias which discriminates against people who are illiterate and are from a different socio-cultural background .We looked at factors like educational and cultural bias, the setting of the study, prevalence of dementia (%) in the study sample, reported sensitivity, specificity positive and negative predictive values. Use of pencil /paper tests, assessment of multiple cognitive domains and use of Informant section were also looked at. Two reviews independently considered the GPCOG, Mini cog and MIS as potentially useful instrument for diagnosis of dementia by general practitioners, mainly because of the brevity, ease of administration, acceptability and psychometric properties (Brodaty et al, 2006; Milne et al, 2008) .However GPCOG has educational bias whereas MIsS assess only the domain of memory. All except VSID needs either clock drawing test or require reading ability which are indeed not suitable for assessment of illiterate older people. All these instruments needs further testing to prove efficacy in diverse cultural settings as well as in populations with high rates of illiteracy and low education.

Table-2 Brief Screening Instruments for diagnosis of Dementia in Primary Care

	GPCOG	**MINICOG**	**MIS**	**VSID Hospital**	**VSID Community**
Source of information	Brodaty et al, 2006	Brodaty et al, 2006	Brodaty et al, 2006	Stanley et al, 2009	Stanley et al, 2009
Includes informant section?	Yes	No	No	Yes	Yes
Time Taken in minutes	4.5	2-4	4	8-10	8-10

Pencil /paper test	Yes	Yes	Yes	No	No
Educational Bias	Yes	No	No	No	No
Cultural bias	Yes (informant section)	No	No		
Assessment of multiple cognitive domains	Yes	Yes	No	Yes	Yes
Validated in LAMC	No	No	No	Yes	Yes
Setting	GP	Community	Community	Hospital	Community
Diagnostic criteria	Clinical/CAMDEX DSM IV	DSMIII-R/ NINCDS-ADRDA	DSMIII-R/ NINCDS-ADRDA	DSM IV	DSM IV
Prevalence of Dementia(%)	29	6	10	20.0	3.0
Sensitivity (%)	85	76	80	83.9	66.7
Specificity (%)	86	89	96	96.5	95.3
PPV(%)	71	34	70	85.8	30.5
NPV(%)	93	98	98	96.0	98.9
Misclassification Rate	14	12	5.6		

The Community Screening Instrument for Dementia (CSI D)(Milne et al, 2008) is by far the most extensively validated dementia screening assessment, across a variety of LAMIC. It combines culture and education-fair cognitive testing of the participant and an informant interview into a single predictive algorithm. It consists of a 32 item cognitive test (20 minutes) and a 26 item informant interview, enquiring after the participant's daily functioning and general health (15 minutes). It was from the outset intended to be used across cultures with the minimum of necessary adaptation. It was developed and first validated among Cree American Indians (Milne et al, 2008; Jacob et al, 2007), further validated and used in population-based research (The NIA US-Nigeria Study) among Nigerians in Ibadan and African-Americans in Indianapolis (Shen et al, 2006), and has also been validated among white Canadians in Winnipeg, and in Jamaica (Hall et al, 2000). The addition of the informant interview significantly improved upon the predictive power of the CSI 'D' cognitive test component in Ibadan, Winnipeg and Jamaica (Hall et al, 2000). The CSI D test score distributions among those with dementia and controls, and the degree of discrimination provided were remarkably consistent across these five very different cultural settings (Hall et al, 2000). CSI D was further validated in the community with 2885 persons

aged 60 and over recruited in 25 centres in India, China and South East Asia, Latin America and the Caribbean and Africa; 729 people with dementia, and three groups free of dementia; 702 with depression, 694 with high education and 760 with low education in LMIC in Latin America, India, China and Nigeria, as part of the 10/66 Dementia Diagnosis Protocol. The psychometric properties from this validation study, for criterion validation against the gold standard diagnosis of DSM IV dementia are summarized in the table below.

		AUROC	**Sensitivity**	**Specificity**	
				High education	Low education
Cognitive score	**All centres**	**91 (90-92)**	**92**	**94**	**75**
	India	93 (91-95)	96	95	76
	China + SE Asia	95 (92-97)	90	100	85
	Latin America	90 (88-92)	90	93	73
Informant score	**All centres**	**94 (93-95)**	**-**	**Not reported**	**-**
	India	97 (95-98)	**-**	**Not reported**	**-**
	China + SE Asia	95 (92-97)	**-**	**Not reported**	**-**
	Latin America	93 (91-94)	**-**	**Not reported**	**-**
Discriminant	**All centres**	**96 (95-96)**	**95**	**96**	**91**
Function score	India	97 (96-99)	96	99	98
	China + SE Asia	97 (95-98)	97	98	98
	Latin America	94 (93-96)	96	95	87

B Case finding abilities of health workers

Identification, in the community, of cases of probable dementia by community health workers

Three studies carried out in India and Brazil has reported on the effectiveness of case identification in the community by community healthcare workers. The essence of the method is that the healthcare workers are given one half to one day of training on the typical presenting features of dementia, and are then asked to nominate possible cases, based on their knowledge of older people and their living circumstances in households with which they have had contact. The idea for this approach originated from the observation, in south India, that few primary healthcare doctors had encountered cases of dementia due to limited help-seeking, but community health workers (Anganwadi's) although not responsible for elder care, seemed to be aware of many possible cases.

Diagnosis of dementia

In the original study carried out in rural Kerala, south India, local community health workers were asked to identify possible cases of dementia from the community they served. The community health workers identified 51 out of 1979 over 60 year old residents (a prevalence of 2.6%) as suspected cases of dementia. Diagnoses were then verified by a senior local psychiatrist; 33 met DSM-IV criteria for dementia. The majority of confirmed cases were of the Alzheimer's disease sub-type. Most "non-cases" were found to be suffering from other major psychiatric disorders, with substantial unmet need. The positive predictive value of the community health workers informal screening was 64.7%. Negative predictive value, sensitivity and specificity could not be assessed (Shaji et al, 2002).

In a study carried out in Piraju, a Brazilian town, 25 community health workers were trained to identify dementia cases among 2,222 people aged 65 and older. After the training, the community health workers identified 72 residents (a prevalence of 3.2%) as suspected cases of dementia. Diagnoses were then verified by a senior local psychiatrist; 45 met DSM-IV criteria for dementia. Most of the confirmed cases met clinical criteria for Alzheimer's disease and vascular dementia. The positive predictive value of the community health workers informal screening was 62.5%. Negative predictive value, sensitivity and specificity could not be assessed (Ramos-Cerqueira et al, 2005).

A study carried out by Jacob et al, 2007 evaluated the sensitivity, specificity and predictive values of the diagnosis of dementia made by trained community health workers. A total of 1000 subjects over the age of 65 years were recruited for the study. The community health workers identified nine older people as having dementia. This was compared against an education adjusted diagnosis of dementia made in accordance with the 10／66 dementia research group protocol. The sensitivity and specificity of the community health worker diagnosis was 3.8% and 99.4% respectively. The false positive rate and positive predictive values were 55.6% and 44.4%, respectively. The false negative rate and negative predictive value were 10.3% and 89.7% respectively. Similar values were obtained against a DSM IV diagnosis. Subjects with dementia who were correctly diagnosed by the community health workers and those whose condition was missed did not differ significantly on socio-demographic and clinical variables.

Table-3 Dementia case finding by trained community health workers

	Thrissur ,India	**Piraju ,Brazil**	**Vellore, India**
Source	Shaji et al, 2002	Ramos-Cerqueira et al. 2005	Jacob et al. 2007
Diagnostic Criteria	DSM IV	DSM IV	DSM IV
Setting	community	community	Community
Age group	More than 60 yrs	More than 65 yrs	More than 65 yrs

Diagnosis of dementia

Total number	1979	2222	991
Prevalence of dementia according to health worker identification	1.6 %	2%	0.8%
'Cases' reported by health workers	51	72	8
True Positives	33	45	1
Sensitivity	Could not be estimated	Could not be estimated	12.5%
Specificity	Could not be estimated	Could not be estimated	99.2%
PPV	64.7%	62.5 %	11.1%
NPV	-	-	88.9 %
Tested in LAMIC Settings	Yes	Yes	Yes

Narrative conclusion

a) Dementia diagnosis, in principle be made at first or second level care by non-specialist health care providers. However, the evidence supporting this comes from high income countries where health care services are probably more sensitive to the needs of older people with disabling conditions like dementia. These findings cannot be generalized to low and middle income countries, where the context is likely to be very different, specifically:

1) fewer health professionals per capita, hence shorter consultation times;

2) less training and education regarding old age medicine, dementia diagnosis and care; and

3) less incentive to make a diagnosis of dementia, with few available referral, treatment or long-term care options, and a focus on the detection and treatment of acute 'curable' conditions.

Diagnosis of dementia

In high income countries, the evidence suggests that primary care physicians and nurses can, in principle, make a dementia diagnosis with reasonable accuracy, using their knowledge of the patient, available case note information, and their own routine assessments in the limited time available during a typical consultation. When specifically requested to consider and report on the probability of dementia non-specialist clinicians in Germany and the UK correctly identified more than half, and up to 87% of true cases, while performance in a US private clinic was somewhat worse. PPVs for cases identified by the non-specialists in these studies ranged from 53.3% to 86.4%. However, routine detection and documentation of dementia diagnoses is much worse than this, ranging from 18.7% to 48.2% with a median value from six studies of 39.1%. The probability of a documented diagnosis is mainly determined by dementia severity, although younger age and frequency of consultation also predict documentation. The discrepancy between what non-specialists could, and do in practice achieve is explained partly by limited help-seeking. It may also be that non-specialists either do not attend to dementia, or do not bother to confirm and record the diagnosis when the possibility occurs to them. The availability of evidence-based treatment guidelines is likely to enhance both help-seeking and health professional efforts to detect cases. Most of the available research evidence is more than 10 years old, and more research is needed, in high income countries as well as in LAMIC to monitor trends regarding diagnostic efficacy and documentation.

b) Even targeted screening of those perceived as being at higher risk requires the use of very brief screening assessments. Expert opinion in high income countries has converged on five minutes as the upper limit for the duration of such a test, ruling out most available assessments. Average consultation times in LAMIC non-specialist settings are likely to be even briefer. A test suitable for application in LAMIC should also be culturally appropriate and capable off being administered to those with low levels of education and/ or who are illiterate, without undue bias. A large body of research suggests that screening assessments based on informant report are not prone to educational bias, in contrast to those based on cognitive assessment, which, to a greater or lesser extent, are all influenced by education independent of dementia status. The validity of informant interview screening tests compares well with that of those based on cognitive testing (Shaji et al, 2002). It is important have a reliable informant to complete these assessments, and this resource may be more readily available in LAMIC than in the urbanized developed world.

Bearing these criteria in mind, existing research evidence does not support the validity of any specific assessment tool for use by non-specialists in LAMIC settings. The three tools that have been found to be brief enough, and at least as valid as the longer MMSE (GPCOG; MIS; and Mini Cog) have only been validated in high income countries. Inspection of the content of these assessments reveals that none of them is suitable for use in low education LAMIC settings. MIS requires reading ability, and GPCOG and MiniCog include clock drawing tasks. The level of adaptation required to make them suitable would, in effect, be equivalent to the development of a new assessment. The recently developed Vellore Screening Instrument for Dementia seems promising, but with 10 cognitive test items and 10 informant items is probably slightly too long for routine use. Furthermore, its only community validation to date was on a sample of only 101 participants, of whom only three were found to have dementia, according to the gold standard. The CSI D has been demonstrated to be both culture- and relatively education-fair, and to have excellent psychometric properties with regard to detection of dementia in community-based validation studies across a very large number of LAMIC settings. However, with 32 cognitive items, and 26 informant items, and requiring around 30 minutes to

administer, it is far too long for routine use in primary care. It could, however, be shortened and the revised version tested specifically in those settings. Adoption of a simple scoring method will also add to its value as a primary care screening assessment.

The community case finding method developed by the 10/66 dementia Research Group in Thrissur (Shaji et al, 2002) is a feasible and arguably cost-effective approach to identifying probable cases of dementia in the community with a high prior probability (around two-thirds) of meeting the case criteria for dementia. This on the one hand addresses the problem of limited awareness and limited help-seeking by family members and on the other provides practice-based clinicians with a high probability at risk group for targeted screening. The half day training protocol for the community health workers has been manualised. Health workers make use of their existing knowledge regarding older people in the community, supplemented where necessary by further interaction with the families and carers. Feedback regarding the accuracy of case identification, and follow up of identified cases will help to sharpen their skills and maintain motivation. They can and should be encouraged to play a significant role in offering guidance and support to the family engaged in dementia care.

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From evidence to recommendations

Factor	Explanation
Narrative summary of the evidence base	a) Of nine studies reviewed only three directly tested the ability of non-specialists to diagnose dementia, and each of these was conducted in high income primary care settings. Relatively high sensitivity and positive predictive values were achieved when non-specialists were specifically requested to consider a dementia diagnosis, applying their own reviews and assessment procedures in the context of routine care. However, six studies of documentation of dementia diagnosis indicated that in practice routine detection and documentation of dementia diagnoses ranges from 18.7% to 48.2% of true dementia cases with a median value from six studies of 39.1%. Low help seeking, low clinician attention to the possibility of dementia, and low recording of diagnoses may explain the discrepancy. Documentation of dementia diagnosis is predicted by the severity of dementia, the frequency of consultation and younger age of the person with dementia. b) Four dementia screening tests were identified; brief enough to be viable for routine use in primary care settings. Only one (VSID) was developed and tested in a LAMIC. The other three

	were each validated in high income country settings, and found to be at least as valid as the longer Mini Mental State Examination. Unfortunately none of them is suitable for administration in low education LAMIC settings. The VSID, with 10 cognitive and ten informant items is perhaps a little too long, and the only community validation was on too small a sample (with only three cases of dementia) to be able to draw any conclusions regarding its validity. Nevertheless, its hospital validation was promising, and it does not contain cognitive items that require reading ability, arithmetic ability or performance of pen and paper tasks. More research is required specifically to validate the VSID and other suitable cognitive and informant assessments in primary care in LAMIC. The widely validated Community Screening instrument for Dementia is similarly devoid of such educationally biased tasks, and includes a culture- and education fair informant assessment. It would need abbreviation to make it suitable for screening in primary care. Screening instruments based exclusively or partly on Informant assessments may be less affected by educational and cultural bias, and may help to frame the presenting problem from the perspective of family carers. The available evidence supports the validity of informant-based assessments in screening for dementia diagnosis. The community case finding method developed by the 10/66 dementia Research Group in Thrissur is a feasible and approach to identify probable cases of dementia in the community with a high prior probability (around two-thirds) of meeting the case criteria for dementia. This on the one hand addresses the problem of limited awareness and limited help seeking by family members, and on the other provides practice-based clinicians with a high probability at risk group for targeted screening.
Summary of the quality of evidence	Moderate quality evidence
Balance of benefits versus	Although the symptoms of dementia are widely recognized, it is considered to be a normal part of ageing, not a medical condition. It carries a physical and psychosocial burden. Thus it is

harms	important to diagnose at first opportunity and manage dementia, in order to improve the quality of life of both patient and carer. The evidence is mainly from high income country settings with limited generalisability to LAMIC settings. Evidence from high income countries suggests that dementia diagnosis, properly conveyed, tends to reduce levels of depression and anxiety in the diagnosed person. The main risks are those associated with misdiagnosis, particularly misidentifying acute or sub-acute delirium as dementia, and failing to treat the underlying causes.
Values and preferences including any variability and human rights issues	Dementia remains, to a large extent, a hidden problem in the developing world. Families rarely seek health care or contact medical services for symptoms suggestive of dementia and health professional are not aware of patients with dementia living in the community. Dementia nevertheless represents a considerable burden for families and carers. Diagnosis would not be helpful in the absence of accessible evidence-based programmes of continuing care and support for people diagnosed and their families and carers.
Costs and resource use and any other relevant feasibility issues	Suitable brief primary care based case finding and assessment processes or instruments need to be identified and validated for each setting. Non-specialist health care providers at the first or second level of care would benefit from brief training in the formal diagnosis and management of dementia, and some degree of ongoing supervision from specialists in the field. The details of the training programme should take into consideration the needs and skills of the care providers.
Final recommendation(s) Non-specialist health care providers should seek to identify possible cases of dementia in the primary health care setting and in the community after appropriate training and awareness raising. Brief informant assessment and cognitive tests should be used to assist in confirming these cases. For a formal dementia diagnosis, a more detailed history, medical review and mental state examination should be carried out to exclude other common causes of cognitive impairment and decline. Training should be provided to non-specialist health care providers to diagnose dementia at first or second level health care.	

Strength of recommendation: STRONG
Any additional remarks Studies designed to test the validity of brief dementia screening assessments administered by non-specialists in primary care; Studies formally assessing the diagnostic ability of trained non-specialist clinicians; Studies monitoring trends in the documentation of dementia diagnoses in primary care, and their accuracy.

Update of the literature search – June 2012

In June 2012 the literature search for this scoping question was updated. No new systematic reviews were found to be relevant.