



# General practitioner referrals to memory clinics: are referral criteria delaying the diagnosis of dementia?

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## Introduction

Around 850,000 people are living with dementia in the UK, with an annual cost to society of £26.3 billion, including £4.3 billion in healthcare costs.<sup>1</sup> However, the number thought to have dementia substantially exceeds those with formal diagnoses.

Recognising the need to address this gap, and the importance of recognition of the disease early, Government and the National Health Service (NHS) have made dementia a priority.<sup>2</sup> Resulting policy has targeted primary and secondary care, promoting early identification of patients experiencing symptoms of dementia in primary care and referral for assessment and diagnosis by specialists, usually in dedicated memory clinics.

This has led to an increase in the proportion of those living with dementia with a formal diagnosis from 42% in 2012 to 62% in 2015.<sup>1</sup> Nevertheless, this remains below the Government's target of 75% by 2017,<sup>2</sup> making identification and referral of people with memory problems an area of continued interest.

In this article we examine the process of referral of patients to specialist memory services, describing some of the likely barriers to referral, and questioning whether complex referral criteria may have a negative impact on timely diagnosis.

## Why memory clinics?

The traditional aims of memory clinics have been<sup>3</sup> diagnosis and treatment of dementia, identification and management of other disorders that may contribute to memory problems, research, including evaluation of treatments, and reassurance; a key focus now is on clarification of dementia diagnosis or subtype diagnosis, as well as access to therapies and social support.

The usual UK model is a specialist-led service, often associated with psychogeriatric services, requiring a referral by a general practitioner to access. There are 222 memory clinics in England, each seeing an average of 576 new patients annually, with the number of patients seen increasing by 31% from 2013 to 2014.<sup>4</sup>

Memory clinics are key providers in the drive for 'timely diagnosis'. Benefits of diagnosis include: ending uncertainty, confirming suspicions, increasing understanding, access to support, promoting coping strategies and facilitating planning.<sup>5</sup>

## Barriers to referral

General practitioners, with their long-term relationships with patients, are well placed to recognise and act on signs of dementia early. However, the gradual evolution and varied presentation of dementia, as well as the changing nature of primary care, may make early recognition difficult.<sup>5</sup>

There are few data on the time taken for referral to memory services following first presentation in primary care. Nevertheless, slow recognition of symptoms relating to dementia is considered a significant problem, leading to delay in referral and diagnosis.

Previous studies have categorised possible reasons for this as provider, patient and carer, and system factors.<sup>6</sup> Provider factors include: educational needs, concerns about stigma, 'therapeutic nihilism', lack of suitable assessment tools and discomfort with discussion. Patient and carer factors include: age, marital status, severity, refusal of assessment or treatment, discomfort with possibility and lack of symptom recognition. System factors include: lack of resources including time for assessment, accessible services and specialists, and low reimbursement for care of patients with dementia.

Although their precise interaction is unclear, under-diagnosis of dementia is more likely to be the result of

system factors, including case complexity, time pressure and negative effects of reimbursement systems, than related to physicians' need for training.<sup>5,6</sup>

### Role of primary care

National Institute for Health and Care Excellence guidance<sup>7</sup> proposes a role for general practitioners in diagnosing and monitoring mild cognitive impairment, but it is currently not considered their responsibility to make formal diagnosis of dementia.<sup>8</sup> The expectation is identification of patients suffering from symptoms likely to relate to dementia, exclusion of other medical causes, followed by prompt onward referral to memory services. Once a diagnosis is made, there is a significant role for general practitioners in monitoring of patients, reviewing medication and liaising with specialist, social and support services.

While the NHS has provided incentives, in a 'Dementia Enhanced Service' and the Quality and Outcomes Framework, for proactive approaches to identification of patients with memory problems, population screening for dementia is not currently considered clinically or cost effective.<sup>7,9</sup> Consequently, identification in primary care usually follows patients' or carers' presentation with symptoms, or sometimes clinicians' observations over time.

The exclusion of 'other medical causes' involves establishing that patients are not affected by other conditions which can result in memory symptoms, such as mental health disorders, particularly depression, side effects of medication, medical conditions such as hypothyroidism, diabetes and anaemia, and delirium in acute medical illness.

As a result, routine cognitive scoring to demonstrate existence of a memory problem, as well as batteries of laboratory tests aimed at excluding contributory conditions, have been considered a prerequisite of referrals to memory services.

### Recommendations for assessment and referral

Guidance to inform assessment of patients before referral to memory services can also provide a basis for referral criteria for such services. Of most relevance in here are National Institute for Health and Care Excellence and Scottish Intercollegiate Guidelines Network guidelines on dementia,<sup>7,10</sup> brief advice has also been published by the Royal College of General Practitioners,<sup>11</sup> essentially based on National Institute for Health and Care Excellence guidelines. The key recommendations of these documents in terms of pre-referral assessment are summarised in Table 1.

### Evidence supporting recommendations

Careful history-taking is emphasised by each of the guidelines, and the Scottish Intercollegiate Guidelines Network<sup>12</sup> highlights evidence that subjective memory complaints should be taken seriously: they are important in some as the earliest stage of the syndrome and may even be associated with biomarker changes found in Alzheimer's disease.<sup>13</sup>

Mental state examination is another important part of history-taking, with recommendation that depression be considered in patients presenting with memory problems supported by evidence of a complex relationship between depression and dementia.

Evidence for brief cognitive tests in screening patients with memory problems remains mixed, and although the Scottish Intercollegiate Guidelines Network recommends use of the Mini Mental State Examination specifically, the National Institute for Health and Care Excellence comments on of the shortcomings of these, particularly the Mini Mental State Examination, advising against reliance on published 'cut-offs'. Nevertheless, use of these tests may be of value in reducing inappropriate referrals.<sup>14</sup>

Both National Institute for Health and Care Excellence and Scottish Intercollegiate Guidelines Network guidelines state that little evidence supports routine laboratory investigations or imaging before referral, with the Scottish Intercollegiate Guidelines Network highlighting that 'reversible causes' of dementia such as hypothyroidism, vitamin B12 deficiency and intracerebral pathologies are uncommon and rarely detected by routine investigations.<sup>15</sup> The National Institute for Health and Care Excellence therefore bases its recommendation for blood screening on review of other guidelines, and a consensus statement from the Royal College of Psychiatrists.

### Referral criteria in practice

Referral criteria are often considered necessary to keep a check on demand, while ensuring that referrals are 'appropriate' in terms of being likely to benefit from specialist referral. We have often found memory clinic referral criteria to be complex and time-consuming, contributing to long consultations and multiple visits for patients in primary care. Investigating these locally, we obtained information on the referral criteria of seven London memory clinics. These showed considerable variation (Table 2), with some requirements for laboratory testing in excess of both National Institute for Health and Care Excellence guidelines and thresholds for incentive payments under the Quality and Outcomes Framework.

Only two services had a requirement for cognitive screening, while four required routine mid-stream

**Table 1.** Summary of guideline recommendations on pre-referral assessment in suspected dementia.

	National Institute for Health and Care Excellence	Scottish Intercollegiate Guidelines Network	RCGP
	Dementia: the NICE-SCIE guideline on supporting people with dementia and their carers in health and social care	Management of patients with dementia: a national clinical guideline	Dementia: diagnosis and early intervention in primary care
History	<ul style="list-style-type: none"> <li>Onset, progression, pattern of memory problems</li> <li>Past medical and psychiatric history, family history</li> <li>Collateral history (with standardised instruments such as IQCODE and BADL)</li> </ul>	As for the National Institute for Health and Care Excellence plus: <ul style="list-style-type: none"> <li>Take subjective memory complaints seriously, especially in educated people</li> <li>Consider possibility of depression as part of assessment</li> </ul>	<ul style="list-style-type: none"> <li>Short- and long-term loss, duration</li> <li>Associated symptoms: mood, sleep, personality changes, self-care</li> <li>Change in functional abilities: work, driving, finances and household tasks</li> <li>Past medical and psychiatric history, including vascular risk factors</li> </ul>
Cognitive testing	MMSE, GPCOG, 6CIT, 7-min screen, clock drawing test	MMSE	MMSE, GPCOG, 6CIT, MiniCOG
Examination	Basic neurological examination: to exclude disorders which can present with memory problems as well as focal neurological signs and motor features such as Parkinsonism	Not specified: physical investigations selected on clinical grounds according to history and clinical circumstances	Physical examination, not further specified
Laboratory blood tests	FBC, U + E, calcium, glucose, LFT, TFT, B12, folate (syphilis serology or HIV not routinely tested unless indicated by specific risk factors or clinical presentation)	Good practice to screen for co-existing medical conditions and potential causes of dementia at first presentation but physical investigations should be selected on the basis of clinical history and examination rather than completed routinely	FBC, ESR, U + E, LFT, TFT, glucose, calcium, B12 and folate
Other investigations	<ul style="list-style-type: none"> <li>MSU if delirium possible</li> <li>CXR or ECG if indicated by clinical presentation</li> <li>MRI or CT scanning for exclusion of intracerebral lesion and to inform subtype diagnosis (not specified whether this should take place in primary care)</li> </ul>	Selected on basis of clinical history and examination <ul style="list-style-type: none"> <li>MRI or CT scanning for exclusion of intracerebral lesion and to inform subtype diagnosis (not specified whether this should take place in primary care)</li> </ul>	<ul style="list-style-type: none"> <li>CXR and ECG may be helpful</li> <li>MRI or CT scanning to inform subtype diagnosis (not specified whether this should take place in primary care)</li> </ul>

urine testing. One clinic expected physical examination, with elements of this specified as ‘pulse, blood pressure, cardiac and chest exam’; neurological examination was not mentioned. Two services had no specific referral criteria.

General practitioners may often not meet referral criteria,<sup>16</sup> and criticism has been directed at them in

this context, with a NHS England report on memory services<sup>17</sup> commenting on ‘poor quality referrals’ and ‘inadequate completeness’, with lack of screening blood tests an example.

Current financial and workload pressures on primary care are well recognised, and these pressures can affect clinicians’ adherence to guidelines.<sup>18</sup> It is

Table 2. Comparison of referral criteria for nine London memory clinics.

	Memory clinic								
	1	2	3	4	5	6	7	8	9
Referral criteria									
Referral form	Y	Y	Y	Y	N	N	Y	N	N
Age restriction	N	N	N	N	*	>65	N	N	N
Memory screening	N	N	Test or description	Mini COG/MST	*	*	N	N	N
Blood tests									
National Institute for Health and Care Excellence	Y	Y	Y	Y	*	*	Y	N	N/A
Others	Lipids, HbA1c, VDRL	GGT, ESR, lipids, CRP, syphilis/HIV	Bone profile, cholesterol	ESR, cholesterol	*	*	Fasting glucose, ESR, CRP	N	N/A
Timeframe	<6 months	<3 months	N	N	*	*	N	N	N/A
MSU	Y	Y	Y	Y	*	*	Y	N	N
CXR	N	N	If available	N	*	*	N	N	N
ECG	N	If available	If available	N	*	*	N	N	N
Other criteria	Any recent/past imaging	Subjective memory problems; functional change >6 months; carer's report of change; no previous diagnosis of dementia	Physical examination in past 6 weeks: pulse, BP, cardiac and chest. Hx, social hx, effect on carer; home care/social service details	GP encounter record	*	*	Details of hospital admission in past 6/12	Blood if available/infection excluded. Referral letter to general MH triage	Referral by letter to MH Trust
Exclusions	N	Behavioural problem, suicidal ideation, psychotic behaviour, crisis situation from carer's perspective	N	N	*	*	N	N	N

\* Information not available

likely clinicians will have difficulty assessing patients with memory problems in strict accordance with guidance within a 10-min consultation; in our experience a significant proportion of available consultation time can be taken up in carrying out just one of the brief cognitive tests. Furthermore, older patients, for whom this may be most relevant, often suffer from multiple health problems, leading to further demands on consultation time.

### Alternative approaches

While requiring specialists to establish subtype, the National Institute for Health and Care Excellence suggests that diagnosis of dementia may 'often be appropriately made in primary care'. A primary care led process,<sup>12</sup> perhaps staffed by practice nurses carrying out assessments according to protocols, may speed up diagnosis while reducing pressure on general practitioners and specialists.

It may also be appropriate to allow people with memory concerns direct access to memory clinics:<sup>19</sup> NHS policy documents<sup>8,20</sup> suggest that there may be a place for more open referral processes and that memory services should consider accepting referrals directly from sources other than primary care, including hospitals, social services, and patients and carers themselves.

While this may risk 'opening the floodgates' to secondary care, evidence of the small numbers of patients excluded by screening investigations<sup>15</sup> would suggest that this is unlikely. Furthermore, patient self-referral based on subjective memory complaints may result in more appropriate referrals than current 'screening' activities carried out by professionals.

### Conclusions

The pathway from early identification in primary care of symptoms suspicious of dementia to secondary care assessment is crucial to patients receiving a timely diagnosis. On a background of current workload pressures on primary care, complex criteria involving multiple investigations are likely to provide a significant disincentive for referral.

With a lack of evidence for pre-referral investigations in the diagnosis of dementia, and clear variation in current requirements of memory clinics, there seems little justification for referral criteria in this context, certainly where involving laboratory testing. Brief cognitive testing may aid initial assessment, and it will remain important for referring clinicians to be alert to the possibility of reversible conditions, but their rarity as causes of memory symptoms means that this should not be allowed to delay referral for memory assessment.

Streamlining referral criteria is likely to be beneficial, but alternative approaches also have much to recommend them. Primary care led memory clinics may offer a practical solution, while the importance of subjective memory complaints in the diagnosis of dementia provides a strong argument for allowing self-referrals.

With a significant proportion of those likely to be suffering from dementia remaining undiagnosed, a system that discourages or delays referral is highly counterproductive; urgent review of this area is necessary to establish a system that effectively supports patients and clinicians in early diagnosis, treatment and prevention.

### Declarations

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