# Can memory assessment services (MAS) in England be categorised? A national survey

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## Abstract

### Background

The effectiveness and efficiency of memory assessment services (MASs) is unknown. Our aim was to determine if a typology can be constructed, based on shared structural and process characteristics, as a basis for a non-randomised evaluation of their effectiveness and cost-effectiveness.

### Methods

Survey of random sample of 73 MASs in 2015; comparison of characteristics and investigation of inter-correlation.

### Results

It was not possible to group characteristics to form the basis of a typology of MASs. However, there was considerable variation in staff numbers (20-fold), new patients per WTE staff (20-fold), skill-mix and the nurse:doctor ratio (1-10).

The operational performance also varied: first appointments (50-120 minutes); time for first follow-up (2-12 weeks); frequency of follow-up in first year (1-5). These differences were not associated with the number of new patients per WTE staff or the accreditation status of the MAS.

Post diagnosis, all MASs provided pharmacological treatment but the availability of non-pharmacological support varied, with half providing none or only one intervention while others providing four or more.

### Conclusions

In the absence of any clear typology, evaluation of MASs will need to focus on the impact of individual structural and process characteristics on outcomes.

**Keywords:** Memory assessment services; memory clinics; staffing; workload

## Introduction

In England, the 2009 National Dementia Strategy [1] advocated an increase in dementia diagnostic rates, a policy reinforced by the Prime Minister’s Challenge on Dementia in 2012. [2] This was to be achieved by increasing the number of referrals to a Memory Assessment Service (MAS), ambulatory clinics that provide an integrated multi-professional approach and frequently referred to as memory clinics. [3] First established in the early 1980s in England, their number increased in the 1990s with the availability of new drugs for Alzheimer's disease and by 2013 there were 214. [4] Their activities include: diagnostic assessment of new referrals; provision of post-diagnosis support (both pharmacological and non-pharmacological); and follow-up. [1, 4-7]

Although attempts have been made to standardise the services provided [8-12], there is known to be variation in aspects of the structure (staffing levels, skill-mix) and the processes of care (waiting times, length of consultations, diagnostic tests, treatments, post diagnosis support). [4, 13] An attempt to standardise through accreditation was initiated in 2009 but this scheme does not provide information on individual MAS to permit comparisons of structure or processes. [14] Considerable resources are allocated to MASs (around £125m in 2014) but little is known about their effectiveness and cost-utility. As it is not feasible to delay referral of people with memory problems, a comparison of MAS with no intervention is not possible. However, it would be possible to compare different types of MAS to establish their relative cost-effectiveness. The best way to do this would be to create a typology of MASs based on shared structural and process characteristics.

Using a large, randomly selected sample of MASs, our aims were: to describe the variation in structural and process characteristics of MAS; to explore any associations between the characteristics; and to determine if a typology of MASs based on shared characteristics can be identified.

## Methods

### *Sample*

In February 2014, 80 MASs were randomly selected (using a random number generator) from those identified from a Memory Services Register, the Memory Services National Accreditation Programme [14], a web search and Community Mental Health Teams. Two subsequently dropped out and five were later excluded from the analysis (as in the subsequent prospective cohort study they each recruited fewer than six patients), leaving a final sample of 73 (about a third of all MASs). Ethical approval was not required.

### *Questionnaire development and survey method*

A questionnaire to be completed by each MAS was developed based on existing questionnaires [4, 5, 9, 15], the accreditation programme [14], discussion with MAS staff, and the involvement of five experienced doctors. It covered four aspects: structural characteristics (year established, governance, organisational context (speciality setting, stand alone, one-stop service, single point of access), catchment population, number of staff and whole-time equivalent (WTE), number by profession, allocation of time to different activities, clinic frequency, research and audit activities); first appointments (waiting time, location, length of appointment, clinical assessments, existing diagnosis, provision of diagnosis); post-diagnosis support (pharmacological and non-pharmacological interventions, assistive technology provision, referral to other providers); and follow-up appointments (time of first follow-up, frequency, length of consultation, clinical assessments). The draft questionnaire was piloted in three MASs which resulted in some minor changes to improve face validity.The questionnaire also collected cost data to enable a comparison of the costs of different types of MAS (based on organisational characteristics) to be made. This will enable the relative cost-effectiveness of different types of MAS to be determined. Given that, it would be inappropriate to include the cost of a MAS in determining the typology as cost would appear on both sides of the comparison.

The questionnaire was sent by email in March 2015 to each MAS. Contact with the sites enabled queries to be answered and reminders were sent to non-respondents. Respondents were asked to report on their actual rather than their intended performance. Missing data (particularly on governance and organisational context) was sought by telephone.

### *Data management*

Extreme values were identified and the originating site contacted for clarification. Attempts were made to obtain missing items and clarify invalid responses. Several variables were recoded in the following ways.

Six continuous variables (year of establishment, number of new patients, waiting times, length of consultations, frequency of follow-up, number of staff) were re-coded as categorical variables, dividing ranges of data into tertiles or quartiles.

Respondents used a diverse range of terms to describe the occupations of staff employed. In collaboration with a specialist dementia nurse, all terms were assigned to one of six categories: doctors; nurses; psychologists; allied health professionals (occupational therapists; speech therapists; pharmacists); administrators; and advisory and support staff (Appendix 1).

Types of non-pharmacological post-diagnosis support were assigned to one of the six categories: assistance with adjustment to diagnosis; help with stress, anxiety and depression; help for families and carers; help improving and maintaining cognitive function; assistance maintaining quality of life; and help for couples' and families' relationships and communication. [16] (Appendix 2). In addition, we created a seventh category - help with physical health.

Three derived continuous variables were created: staff workload (number of new patients per WTE staff per month); WTE nurse:doctor ratio; and length of initial consultation regardless of location.

### *Analysis*

Simple descriptive analyses identified variables that showed variation across MASs. Prior to any potential grouping of variables, associations between variables were investigated. Pearson correlation coefficients of 0.10 - 0.35 were deemed weak, 0.35 - 0.60 moderate, and above 0.60 strong. [17] If clear patterns of an underlying typology were apparent, multi-variate analysis (such as cluster analysis) would be used.

## Results

### *Survey response*

All 73 MAS responded with over 93% completeness for most variables. Information on a few variables was either not available (respondents were not able to assign staff time to different activities; catchment populations could not be defined), or was not reported consistently because of differences in interpretation (frequency of clinics, single point of access, stand-alone). These were, therefore, not considered in the analysis.

Only 65 MASs supplied data on number of staff of which 42 (59%) supplied accurate data on the WTE number of staff. The latter sites had a mean of 12.80 staff and a mean WTE of 9.02. Given that their mean number was similar to that of the other 23 MASs for which such information were not available, the WTE number was estimated for the latter based on 70.5% (9.02/12.80) of their staff number.

### *Structural characteristics*

MASs were similar in several respects. The medical specialty location of all but one MAS was psychiatry. All employed doctors (predominantly psychiatrists but some geriatricians and a few neurologists), nurses and administrators. While 27% provided a 'one-stop service' in which all diagnostic and treatment activities were provided during a single appointment, the majority needed to refer patients to other services (usually within the same hospitals) for certain assessments. Most MASs provided education and training for their staff (78%) and their staff had contributed to research (85%) and audit (79%) during the preceding year.

In contrast, MASs varied considerably in several characteristics (Table 1). First, while over a third had recently been established (within past five years), 19% had been in existence for at least 15 years. Second, only a quarter had been accredited. Third, the overall WTE number of staff ranged from 1.2 to 26.7. (Figure 1A) This partly reflected variation in the numbers of doctors, nurses and administrators, but was also due to whether they employed psychologists, allied health professionals and advisory and support staff.

The mean WTE number of staff was 9.9 (SD 6.0) made up of 1.7 doctors, 3.6 nurses, 1.9 administrators, 0.8 psychologists, 0.9 AHPs and 1.0 advisory & support staff. The staff-mix varied - while the mean nurse:doctor ratio was 3.4 (SD 3.8), it varied from less than 1.0 to 20.0 (Figure 1B).

The variation in staffing levels was not necessarily reflected in differences in the number of first appointments which ranged from 1 to 20 (Figure 1C) per WTE staff member per month (mean 6.4; SD 3.6)

*New patients*

All MASs accepted new patients of all ages. Most (75%) operated a 'single point of access' for referrals (ie Trusts that managed more than one MAS allocated referrals to each constituent service). The source of referrals were general practitioners (for 73% of MASs), acute hospitals (62%) and mental health teams (56%). The mean number of new patients per month was 48.2 (SD 26.5) with most MASs (85%) seeing fewer than 75 (Table 1; Figure 1D).

In most aspects, initial assessments at the first appointment do not vary between MASs. Most services (87%) offer patients the option of the first appointment being held either in the clinic or in the patient's home. Initial assessments almost always include history taking and review, cognitive function tests, physical examination (88%), blood and urine tests (85%), assessment of vision, hearing and mobility (80%), CT scans (67%), risk assessment (97%) and social needs assessment (84%).

Variation between MASs does occur in the timing and length of first appointments and the type of examination provided (Table 1). While the majority of services (73%) manage to see all referrals within six weeks, the waiting time for a few (7%) is over 12 weeks. The mean length of the first appointment was 86.5 minutes (SD 32.0) but varied between MASs from 50 to 120 minutes (plus one MAS in which visits lasted 300 minutes as it included conducting a brain scan) (Figure 1E). Most services conduct a physical examination but only 42% include a neurological examination (usually conducted by a psychiatrist rather than a neurologist) and 62% an ECG.

*Post-diagnosis support*

Most MASs provide pharmacological treatments (anti-dementia drugs 99%; other drugs 76%), signposting to other services (96%) and education and support for patients and carers (86%). Most also provide advice as to where else relevant services are provided. In contrast, financial and legal advice is not so widely provided by MASs (63%).

MASs vary in the number of non-pharmacological interventions provided (Table 2) with 21% providing none while 20% provided four or more. The types of interventions most frequently provided aim to help families and carers (57% of MASs). Improving cognitive function (eg cognitive stimulation therapy, memory groups, mindfulness).

was available in 36% of MASs but the five other categories were provided by only 16-26% MASs.

The provision of a post-diagnosis disclosure programme (60%) and the provision of assistive technologies (eg digital devices) (52%) was also not universally available.

*Follow-up*

The ways patients are assessed at follow-up appointments did not vary much between MASs as regards cognitive function tests (78%), history taking and review (81%), risk assessment (85%) and social needs assessment (74%). Physical examination and clinical investigations were not routinely conducted.

However, MASs varied considerably in the schedule of appointments (Table 4). While 36% of services saw patients within four weeks, 36% left it for over 8 weeks (Figure 1F). When they were seen, the length of the appointment ranged from 20 to 90 minutes:  34% of services provided less than half an hour while 33% provided over 45 minutes. MASs also varied in the number of times they saw a patient after their initial visit in the first year – 11% provided no follow-up appointment, 11% saw them only once, while 26% saw them at least three times.

*Associations between structural characteristics and processes*

The associations between all variables that showed considerable variation between MASs (shown in Tables 1 & 2) were investigated to see if there were any groupings that could form the basis of a typology. Eight variables (year established, psychologists employed, nurse:doctor ratio, waiting time for first appointment, post-diagnosis disclosure programme, number of types of post-diagnosis support, provision of assistive technology, number of follow-up appointments in first year) had no or only a weak association with all other variables and were not considered further. The correlation coefficients (r) for the remaining 12 variables are shown in Table 3. There was one strong association and 11 moderate associations observed. The four main areas of association are described below.

### MAS size (number WTE staff)

Larger services (higher WTE numbers of staff) were associated with a higher likelihood of including AHPs (r = 0.433) and advisory and support staff (r = 0.485). The only association with processes was that larger MAS provided longer first appointments (r = 0.394) and the latter was associated with longer follow-up appointments (r = 0.459).

### New patients per WTE staff

Although larger MASs were associated with higher numbers of new patients (r = 0.433), the number of new patients per WTE staff were lower (r = -0.436). Despite this, lower workloads were not associated with patients having shorter waiting times or longer first appointments. It is partly explained by fewer new patients per WTE staff being associated with more AHPs (r = 0.416) and advisory and support staff (r = 0.656) who may be less involved in managing initial appointments and focus more on follow-up attendances.

### Staffing and clinic activities

While the overall staffing level and workload did not appear to have any impact on the way patients were assessed or managed (including post-diagnosis support), the skill-mix of the team was associated with some differences. Services with AHPs are less likely to undertake an ECG (r = -0.355) which in turn was associated with a lower likelihood of a neurological assessment at the first appointment (r = 0.481). This may indicate that some MASs are less medical in their orientation and culture.

### Accreditation

Services that had been accredited did not differ significantly regarding their number of staff, workload, waiting times, lengths and frequency of appointments, and clinical activities. The only way that accredited MASs differed was that they did not follow-up patients as soon after the first appointment (r = 0.353).

## Discussion

### *Main finding of this study*

Although MASs differ in many structural and process characteristics, no distinct groupings of shared characteristics exists that could form the basis of a typology. Thus evaluations of the effectiveness and cost-effectiveness of these services need to focus on single characteristics that show considerable variation (plus the possibility of deriving some composite variables based on combinations of two or more). Our analysis indicated that a wide range of characteristics deserve consideration.

Staffing levels vary 20-fold which is only partly reflected in the number of first appointments. Thus the workload (as measured by new patients per WTE staff) also varies 20-fold. Some of the variation in staffing levels arise because some MASs are more likely to include AHPs, psychologists or advisory & support staff.

Although all MASs provide post-diagnosis pharmacological treatment, there is variation in the provision of non-pharmacological support, with half providing none or only one type of intervention while others provide four or more. The latter are more likely to employ AHPs, suggesting a greater emphasis on the psycho-social component of their work

While three-quarters of MASs see new patients within six weeks, others have average waits of over 12 weeks. And once seen, the mean length of initial appointments vary 2-fold (50-120 minutes). Variation is also seen in follow-up care: some provide none and, of those that do, the average time to the first follow-up appointment varies from two to 30 weeks; the frequency of appointments in the first year varies from one to five; and the length of follow-up appointments varies 5-fold (20-100 minutes). Such differences between MASs are not explained by variation in staff workload.

MASs that had been accredited (26%) did not stand out as being different as regards structural or process characteristics from those that had not been accredited. The only difference was unexpected – accredited MAS did not see their patients for follow-up so soon after the first appointment.

### *What is already known on this topic*

Previous research studies have usually been limited to describing a single MAS, not providing any insight into the extent of variation in structures and processes. [18-21] However, the two national audits conducted in 2012 and 2014 [4, 13] provided some evidence of variation but did not investigate associations between characteristics. While the lack of an agreed operational definition of the role and function of MASs was recognised early on by many clinicians in this field and has sparked the development of the national accreditation programme [14], no attempt has previously been made to quantify the way MASs vary in practice.

### *What this study adds*

Although no typology has been revealed to underpin evaluative studies, this study has identified a wide range of characteristics that vary sufficiently to form the basis of comparative analyses (i.e. natural experiments). This will allow the comparison of ways of assessing patients and different post diagnosis interventions to establish which ones result in the greatest benefit. This will permit clearer evidence-based guidance for MASs to be drawn up. Equally, if there are no discernible differences in outcomes between different MASs, then the most efficient patient-centred approach needs to be adopted to maximise the benefits to the public.

The characteristics that could be investigated are: workload (new patients per WTE staff); nurse:doctor ratio; waiting time for first appointment; length of first appointment; number and types of PDS interventions provided; follow-up (frequency of appointments or time to first follow-up appointment). To evaluate these characteristics, their impact on patients’ and carers’ health related quality of life needs to be assessed. These are currently being studied in a cohort of patients attending the MASs included in this study. [22] In addition, the cost of MASs and the cost implications for patients is being determined so that the cost-benefit of these services can be evaluated.

We have also developed and provided a glossary of terms for staff posts that allow classification into six categories (Appendix 1) and, similarly, for the plethora of terms used to describe psycho-social interventions (Appendix 2). These should be of help in introducing some standardisation of terminology in this field of research.

### *Limitations of this study*

There were five potential limitations. The first concerned data collection. Attempts to collect accurate data on aspects of the governance and the organisational context of services were unsuccessful. This was because of the lack of an established and widely agreed terminology among MAS staff as regards types of services defined in terms of ‘single point of access' and 'stand-alone service'. The development of clear definitions and a meaningful classification is needed. [23] The other limitation of data collection was the lack of data on the allocation of staff time to different activities as this is not routinely collected and varies according to workload and staff availability.

The second limitation was that the grade or experience of staff could not be taken into account in the analyses of workload. Third, we limited the study to distinct MASs so did not consider the assessment of people that takes place within primary care as part of routine services. [19- 21, 24, 25]

Fourth, inevitably our search for a typology was limited to the variables we collected. Their selection was based on expert clinical advice and on practical considerations as to feasibility given the use of a mailed questionnaire (rather than site visits and interviews). It is possible that consideration of other variables might reveal a typology.

Finally, as with any study that relies on self-reporting, there is some uncertainty about the validity of the data. Phone discussions with all MAS sought to detect any inaccuracies but we cannot be sure all such errors were detected.

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