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The cost of diagnosis and early support in patients with cognitive decline

Mark Pennington^{1,2}, Manuel Gomes², Theti Chrysanthaki³, Jolijn Hendriks², Raphael Wittenberg⁴, Martin Knapp⁴, Nick Black², Sarah Smith*²

¹King's Health Economics, King's College London, London, UK

²Department of Health Services Research & Policy, London School of Hygiene & Tropical Medicine, London, UK

³School of Health & Medical Sciences, University of Surrey, Guildford, UK

⁴Personal Social Services Research Unit, London School of Economics and Political Science, London UK

*corresponding author

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Address for correspondence:

London School of Hygiene & Tropical Medicine

15-17 Tavistock Place

London WC1H 9SH

Tel: 020 7927 2038

Fax: 020 7927 2701

Email: sarah.smith@lshtm.ac.uk

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Abstract

Objective

Recent research indicates considerable heterogeneity in the provision of memory assessment services (MAS). However, little is known on the extent of variation in the costs of the services MAS provide. We investigated the costs of supporting patients with suspected dementia, including assessment and support over the following six months.

Methods

Clinic costs were estimated on the basis of an organisational survey reporting staff roll, grade and activities. Costs of primary health and social care were estimated from questionnaire data reported by carers of patients at baseline, three and six months after referral.

Results

Mean monthly staff costs at MAS were £73,000. Imaging at assessment cost an additional £3,500 per month. Monthly clinic cost per new patient assessed varied from £320 to £5,400 across clinics. Additional primary health and social care costs of £130-220 a month between baseline and six months were reported by carers. Costs of pharmacological and non-pharmacological treatments reported by carers were small. Informal care costs dwarfed health and social care costs when valued at a modest unit cost. The overall mean cost of supporting a patient for six months varied from £1,600 to £2,500 dependent on assumptions regarding the proportion of MAS intervention and review costs accrued at six months.

Conclusions

There is considerable variation in the intensity and associated costs of services provided by MAS. Further research should ascertain to what extent such variation is associated with differences in patient outcomes.

Introduction

Timely diagnosis of dementia is central to the English Government's strategy to deliver world class dementia care (Department of Health, 2009). Timely diagnosis allows treatment which may slow the progress of the disease and provision of psychosocial support for patients and their family or unpaid carers (hereafter 'carers') (National Institute of Health and Care Excellence, 2016). In England, most people are assessed and diagnosed in Memory Assessment Services (MAS) which also provide or provide access to post-diagnostic support (Hodge & Hailey, 2015). The evolution of MAS in England has been haphazard. Clinical guidelines on their structure and role were not published until 2011 (Doncaster et al. 2011). The resulting plethora of different service models partly reflects the lack of evidence regarding the relative effectiveness of different approaches (Kelly, 2008).

Whilst there is a consensus that MAS improve outcomes, evidence on the relative effectiveness of different models of service delivery is very limited (Melis et al. 2009). In the Netherlands, the AD-EURO study, which randomised 175 patients to support by either a MAS or general practitioner (GP), found no significant difference in health-related quality of life (HRQL) or carer burden (Meeuwssen et al. 2012). The PLASA study randomised 1131 patients to receive either a comprehensive care plan or treatment as usual from their MAS (Nourhashemi et al. 2010). No significant differences in functional decline or ability to undertake daily activities were observed. MAS have been criticised for excessive use of imaging, over-reliance on consultants for diagnosis, and a focus on drug treatment rather than holistic care (Pelosi et al. 2006).

Evidence on the cost of MAS is equally limited. Data from a survey of MAS in England indicated national expenditure of £125million in 2014 (Hodge & Hailey, 2015). A recent UK

study compared the costs of diagnosis and post-diagnostic support in 33 patients attending a MAS and 33 patients diagnosed by their Community Mental Health Team (Rubinsztein et al. 2015). Mean cost for patients attending the MAS (£742 - 2010 GBP) was marginally lower. The increased use of nurses and allied health professionals in place of doctors has been suggested to reduce costs of MAS (Bentley et al. 2014; Page et al. 2008).

A companion paper has reported the results of an extensive organisational survey of 78 MAS in England and found considerable variation in staff numbers, workload, skill-mix and activities (Chrysanthaki et al. 2016). Our aim here was to estimate the cost of diagnosis and initial post-diagnostic services for patients attending a representative sample of MAS across England. Costs of diagnosis are estimated on the basis of staff numbers and activity reported by MAS in the organisational survey, along with costs of primary health and social care following diagnosis estimated from resource use reported by carers.

Methods

Study design and inclusion criteria

We recruited 80 MAS at random, selected from the Memory Services Register compiled by the Royal College of Psychiatrists. Each site was expected to recruit 25 patients together with their carers if the patient was accompanied. Two sites subsequently withdrew, five sites were excluded having recruited fewer than six patients, and four sites were excluded after failing to collect outcome data at six months, leaving a final sample of 69. Patients were eligible for the study if they spoke English and were attending the MAS as part of their first assessment. At baseline and 6 month follow up (either at clinic or home visit), carers completed questionnaires on resource use and HRQL, which included EQ-5D-3L-Proxy

(Brooks, 1996) and DEMQOL-proxy (Smith et al. 2007). Resource use was also collected at three months. Patients also completed HRQL questionnaires (EQ-5D and DEMQOL) at baseline and 6 months. The three-month follow-up questionnaires were mailed to carers with a reminder if a response was not received within 4 weeks. All participants were followed up regardless of the diagnosis they received. Data collection commenced in September 2014 and patient recruitment ended in May 2015. An organisational survey was completed by each MAS in March 2015 using a mailed questionnaire to the lead contact with telephone follow-up to maximise response rate (Chrysanthaki et al. 2016).

The study was approved by the National Research Ethics Service Committee London (reference: 14/LO/1146) and the London School of Hygiene & Tropical Medicine ethics committee (reference: 8418).

Questionnaires

Each MAS was asked to provide a list of staff employed in the week the questionnaire was completed, along with their grade, proportion of a full time week they worked and proportion of their time spent in different activities (assessment, interventions and follow-up). The organisational survey also collected data on brain imaging used in assessment and review.

Resource use data were collected from patients' carers at baseline and at three and six month follow-up using a modified version of the Client Services Receipt Inventory (Beecham & Knapp, 2001). The questionnaire asked about resource use in the previous month including: primary health care; social care; unpaid (informal) care; travel time to MAS; social security benefits; personal budgets; drugs prescribed for the patient's cognitive condition; and psychosocial support services relevant to their condition such as cognitive stimulation

therapy (CST). Data on hospital inpatient episodes were not included given the difficulty of establishing whether it was attributable to dementia. We also chose not to collect residential care costs on the assumption that most new patients would be living in their own homes.

Costs

Unit costs for health and social care professionals were derived from national cost sources for the financial year 2013/14 (or inflated to 2013/14 price levels using the Hospital and Community Health Services Index (Curtis, 2014)). Cost of staff employed by MAS including on-costs, qualifications, overheads and capital overheads, were estimated from Curtis (2014), adjusting to reflect Agenda for Change mid-band salaries according to reported staff grade. Imaging costs were taken from NHS reference costs (Department of Health, 2014).

NHS reference costs were used to assess the cost of patients' contacts with: community district nurse; community psychiatric nurse; psychiatrist/neurologist; psychologist, physiotherapist, occupational therapist; dietician; speech and language therapist; Dementia advisor/Admiral Nurse (Department of Health, 2014). Unit costs of contact with GPs, practice nurses, social workers, and mental health team workers were obtained directly from nationally reported costs (Curtis, 2014) or in combination with estimates of contact time of 15 minutes for a practice nurse (Shum et al. 2000), and 20 minutes for a social worker (Davey et al. 2005). Unit costs of social care such as meals on wheels, sitting services and laundry services were derived from national sources (Curtis, 2014) or from an evaluation of befriending services for patients with dementia (Charlesworth et al. 2008).

Drug costs were obtained from the British National Formulary, volume 66

(<http://www.bnf.org/products/bnf-online/>). Unpaid care and travel time to MAS for carers

was costed at £6 per hour based on an opportunity cost assumption, using the national minimum wage for 2013/14. Other travel costs were not included.

Costs of psychosocial support were taken from different sources: CST and befriending services (Curtis, 2014); music/dance therapy (Coulton et al. 2015); animal assisted therapy /art therapy (Uttley et al. 2015); life story work/psycho-education/reminiscence therapy (Woods et al. 2012); social engagement groups/peer support groups (Banerjee et al. 2013); walking groups (Gusi et al. 2008); and Memory Café (Curtis 2014) assuming employment of one mental health nurse and one administrator per five patients.

Statistical analysis

We report estimates of total monthly costs of MAS, and breakdown of costs across assessment, post-diagnosis support and follow-up. We report overall costs and costs per new patient assessed. Allocation of staff costs was undertaken for each staff member on the basis of proportion of time spent in each of: assessment, post-diagnosis support, follow-up, administration, management, audit and research. Costs for administration, management and audit were aggregated and assigned between assessment, post-diagnosis support and follow-up based on relative proportions of time spent on each activity. Costs associated with research were ignored.

We report resource use additional to MAS at baseline, three and six months derived from carer questionnaires and the associated monthly costs. We ignored costs of psychosocial interventions reported by a carer where the relevant MAS reported providing such an intervention as the costs were already included in overall MAS costs. Costs falling on health and personal social services (excluding benefit payments) are summed and reported as costs

of formal care. Societal costs include costs of formal care, informal care and patient travel costs.

Finally, we estimate the cost of assessment and support over six months following the first appointment from a health and personal social services perspective. MAS costs are estimated as the assessment costs (including diagnostic investigations) per new patient and some proportion of the post-diagnosis support and follow-up costs. We had insufficient data to determine the proportion of all interventions and follow-up appointments provided by MAS which are delivered within the first six months and consequently we explored the impact of varying the proportions from 0 – 100%. Additional health and social care costs over the six month period are estimated as three times the monthly cost derived from the carer questionnaires at three months plus three times the monthly cost at six months.

Missing data in both MAS-level and patient-level costs were handled with multiple imputation using chained equations (MICE) and 50 imputations (White et al. 2011). Multiple imputation assumes that, conditional on the variables included in the imputation model, the probability of observing the cost data is independent of unobserved values, i.e. data are missing at random. We implemented a multilevel approach to multiple imputation in R (R Core Team, 2013) to recognise the hierarchical structure of the data; patients were clustered within MASs and costs were missing at distinct, patient and MAS levels (van Buuren, 2011). We report mean costs, median costs and associated measures of variance by combining the multiple imputed datasets using Rubin's rules (Rubin, 1987). Descriptive statistics were generated in Stata version 14 (StataCorp, 2015).

Results

Recruitment and response rates

1420 patients from 73 MAS were recruited into the study at baseline of which 1353 were from the 69 MAS included in this analysis. We excluded a further 35 patient who died during the six month follow-up leaving a final sample of 1318 patients. Mean patient age was 78 (range 42-98). Less than 1% of participants were resident in care homes at assessment; 690 (52%) were female and 1235 (94%) were identified as White British; 944 (72%) patients were accompanied by a carer, generally a spouse (571) or child (270); 910 (96%) carers provided resource use data at baseline. Further data on patients is reported elsewhere (Park et al. 2016).

Resource use responses were received from 617 at three months and 586 at six months. At six months, data on diagnosis was available for 825 patients, 441 (53%) diagnosed with dementia, 202 (24%) with mild cognitive impairment, 44 (5%) with other mental health conditions, and the remainder (17%) yet to receive a diagnosis.

Missing data

Missing responses on the carer questionnaire were consistently low (Table 1). Very few patients reported receipt of a personal budget and services purchased with the budget were poorly reported so this resource use was ignored. With regard to the organisational survey, staff employed were reported by 61 (88%) of the 69 MAS and the number of new patients assessed was reported by 68 (99%). However, there was considerable missing data for the allocation of staff time across clinical activity categories.

<Table 1 here>

Resource use by MAS

All MAS employed doctors and nurses but the number of whole time equivalents varied considerably (Table 2). The most common category of employee was nurses. A typical MAS assessed around 50 patients a month but this varied from 10 to 130. Thirty-six (52%) MASs reported using imaging at assessment and 5 (7%) at review.

<Table 2 here>

Resource use reported by carers

The most frequently contacted health care professionals were GPs and nurses, though these contacts may have been unrelated to cognitive function (Table 1). Around 17% of patients reported contact with a psychiatrist or neurologist at both baseline and six month follow-up. Contact with other health care professionals was less than 10% at any follow-up. At baseline, use of drugs for cognitive decline was rare but increased to around a third of patients at three and six months.

Around 16% of respondents reported receiving the services of a cleaner and around 11% received some form of home care support. Around 9% reported contact with a social worker at 3 and 6 months. Use of other forms of social care was low.

At baseline and follow-up use of psychosocial support was rare with the exception of social engagement groups. At six months, most patients (359, 63%) had not received any pharmacological or non-pharmacological intervention in the previous month. (Note: not all patients were diagnosed with dementia).

At baseline 31% of patients reported receiving either personal independence payment, attendance allowance or disability allowance. This increased to 40% by 6 months. Virtually

all patients were receiving informal care at baseline and at each follow-up, around 60 hours at all time points.

Costs

Table 3 reports the monthly costs of MAS after imputation of missing data. These are disaggregated into categories: imaging; assessment; post-diagnostic support; and review (follow-up). Slightly under half of all costs were attributed to assessment. The proportion of MAS resources attributed to post-diagnostic support varied from 4-54% and the proportion attributed to follow-up varied from 6-67%.

<Table 3 here>

Across MAS, total monthly costs attributable to assessment activities varied from £2,138 to £141,156 driven primarily by the number of staff employed. Variation was reduced but still considerable when costs per new patient were calculated. Figure 1 displays the distribution of total monthly MAS cost per new patient assessed (including imaging costs). Costs varied from £317 to £5408. Costs per new patient for 58 (84%) of the MASs were £500 to £3,000.

<Figure 1 here>

Table 4 shows the costs of additional health and social care reported by carers after imputation of missing data and after excluding psychosocial support that may have been provided by MAS. Cost of drugs for cognitive function was small, as was cost of psychosocial support. Societal costs were dominated by informal care. Figure 2 displays the distribution of health and social care costs reported by carers at baseline, three and six months. The increase in mean costs at six months is driven by a general shift to higher expenditure amongst respondents rather than an increase in high cost outliers.

<Table 4 here>

<Figure 2 here>

Table 5 reports estimated mean costs of imaging, diagnosis, post-diagnosis support and follow-up (review) per patient over six months for a patient referred to MAS and including additional health and social care costs reported by carers. Dependent on assumptions regarding accrual of post-diagnosis support and follow-up costs over time, mean costs varied from £1,582 to £2,497. Assuming that 50% of post-diagnosis support activity and 50% of follow-up activity undertaken for all patients is undertaken in the first six months following assessment, mean cost per new patient is £2,039 and median cost is £1,399.

<Table 5 here>

Discussion

The monthly mean cost of services directly provided by MAS per new patient assessed is estimated to be £1,855. Half of this was attributable to assessment costs of which imaging costs represented about a tenth. Carers reported additional formal care costing £127-224 a month. The combined costs of services provided by MAS and by other formal services over the first six months following assessment ranged from £1582 to £2497, dependent on assumptions regarding the proportion of all post-diagnostic support and follow-up costs accrued at 6 months. The cost of informal care was considerable, despite valuation using a conservative unit cost. There was no evidence that MAS attendance decreased informal care provision. However, the psychological strain of providing such care may have been ameliorated.

There was 17-fold differences in the cost of MAS per patient assessed which arose from variation in staff to patient ratios. Extreme values may have arisen from under-reporting of staff or the number of patients assessed. Nevertheless, it appears that there is marked variation in intensity of MAS activity undertaken to assess and follow-up patients. In contrast, provision of psychosocial support following assessment was limited with most carers reporting that patients received none. Carers may have failed to recognise support such as CST or reminiscence therapy as distinct interventions. It is also possible that the follow-up periods (which collected resource use in the third and sixth months) failed to cover the period of most intense provision of psychosocial support. Variation in case-mix may explain some of the variation in costs across MAS but it is unlikely that case-mix explains the large variation in assessment costs observed. This variation is also not explained by differences in provision of psychosocial support as only a small proportion of patients receive them.

Comparison with previous research

Our estimate of mean monthly staff costs for a MAS of £73,000 is considerably higher than the £46,000 derived from a recent survey (Hodge & Hailey, 2015). These authors reported a mean of 48 new patients assessed per MAS per month, similar to the mean number we observed. Our costs were estimated from staff costs published by the Personal Social Services Research Unit which include elements for training and gaining qualifications, and capital overheads (building construction); these elements account for approximately 20% of the total costs (Curtis 2014). These costs are unlikely to be met from annual MAS budgets and would explain much of the difference between our costs and those reported by the previous survey. The monthly cost of a MAS in Croydon, including capital overheads, has

been estimated at about £71,000 and £1,200 per patient assuming 59 new patients a month (Curtis, 2014).

Our estimates of overall mean cost of supporting a patient for six months including and following initial assessment is higher than the £742 (2010/11 GBP) reported by Rubinzstein et al (2015). That was a small study and appears to have excluded primary care contacts.

Our estimate of assessment costs are higher than the mean overall assessment costs reported for patients in Sweden but are similar to the mean cost of €1,067 for patients referred to specialist services (Jedenius et al. 2010). Cross-country comparisons are hard to interpret, however, given often very different treatment and care systems. Assessment and support costs over 12 months of €38,000 (2005 Euros) have been reported (Wolfs et al. 2009) for patients with dementia in the Netherlands. However, that study included sizeable residential care, day care and secondary care costs which we chose not to include.

Study strengths and limitations

This is the largest and most detailed study to date which has examined the costs of MAS and the interventions provided to patients based on a representative sample of MAS in England. There are several limitations. First, given the size of the study, we could not micro-cost MAS. Instead, we sought to estimate costs based on staff employed. This approach is inevitably less accurate than micro-costing. Second, we were dependent on the quality of reporting by those completing the MAS survey and we cannot be certain that all staff employed were recorded. However, mean WTE observed across MASs closely matched the assumption of 10 WTE per MAS in an English cost-effectiveness analysis (Banerjee and Wittenberg, 2009). Third, we were unable to explore cost variation arising from differences in patient

characteristics. This would have required detailed observation of patient contact with MAS which was impractical in our large sample of MAS.

Fourth, we had some missing data at both MAS and patient level. We applied a principled approach, multiple imputation, to deal with this rather than relying on ad hoc assumptions. We also used a sophisticated multi-level approach to imputation to recognise that the reasons for the missing data at the patient and MAS levels were distinct, and the possible clustering of patients within MAS. Fifth, we relied on questionnaires completed by carers to estimate additional costs of health and social services provided outside MAS. Many of these costs will be attributable wholly or partially to causes other than cognitive impairment. We could not isolate costs attributable to the latter. Asking carers to identify relevant costs risked exacerbating the burden of completing the questionnaire and reducing sensitivity to changes in resource use associated with general health and wellbeing but influenced by MAS. Finally, the data we collected on psychosocial support provided by MASs did not allow us to assess intensity of provision of these services.

Conclusion

The cost to the health and social care sectors of initial assessment and support of patients over the following six months was £1,582 to £2,497, of which approximately half arises from services directly provided by a MAS. The cost of pharmacological treatment is low due to low unit costs. The cost of psychosocial support (non-pharmacological treatment) is modest due to low intensity of use. There is considerable variation in costs across MASs which appears to be due to marked differences in workload per staff member. The impact and cost-effectiveness of assessment and interventions will be reported in subsequent papers.

Conflicts of Interest

None declared.

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References

- Banerjee S, Baldwin R, Ballard C, Bentham P, Burns A, Dewey M, Fox G, Hellier J, Holmes C, Katona C, Knapp M. 2013. Study of the use of antidepressants for depression in dementia: the HTA-SADD trial—a multicentre, randomised, double-blind, placebo-controlled trial of the clinical effectiveness and cost-effectiveness of sertraline and mirtazapine. *Health Technol Assess (Winch Eng)* **17**(7).
- Banerjee S, Wittenberg R. Clinical and cost effectiveness of services for early diagnosis and intervention in dementia. 2009. *Int J Geriatr Psychiatry* **24**(7):748-54.
- Beecham J, Knapp M. 2001. Costing psychiatric interventions. In *Measuring Mental Health Needs*. Thornicroft G (eds). London: Gaskell.
- Bentley M, Minstrell M, Bucher H, Morrissey M, Robinson A, Stirling C. 2014. A case study evaluation protocol to assess processes, effectiveness and impact of a nurse practitioner-led memory clinic. *Health* **6**(8). DOI:10.4236/health.2014.68096
- Brooks R. 1996. EuroQol: the current state of play. *Health Policy* **37**(1):53-72.
- Charlesworth G, Shepstone L, Wilson E, Thalanany M, Mugford M, Poland F. 2008. Does befriending by trained lay workers improve psychological well-being and quality of life for carers of people with dementia, and at what cost? A randomised controlled trial. *Health Technol Assess (Winch Eng)* **12**: 4.
- Chrysanthaki T, Fernandes B, Smith S, Black N. 2016. Can memory assessment services (MAS) in England be categorised? A national survey. *J Public Health* (submitted)
- Coulton S, Clift S, Skingley A, Rodriguez J. 2015. Effectiveness and cost-effectiveness of community singing on mental health-related quality of life of older people: randomised controlled trial. *Br J Psychiatry* **207**(3):250-5.
- Curtis L. 2014. Unit costs of health and social care. Canterbury: Personal Social Services Research Unit. Available at: <http://www.pssru.ac.uk/project-pages/unit-costs/2014/> (date last accessed 08/11/16)
- Davey B, Levin E, Iliffe S, Kharicha K. 2005. Integrating health and social care: implications for joint working and community care outcomes for older people. *Journal of Interprofessional Care* **19**(1):22-34.
- Department of Health. 2014. NHS Reference Costs 2013 to 2014. Available at: <https://www.gov.uk/government/publications/nhs-reference-costs-2013-to-2014> (date last accessed 08/11/16)

Doncaster E, McGeorge M, Orrell M. 2011. Developing and implementing quality standards for memory services: The Memory Services National Accreditation Programme (MSNAP). *Aging & mental health* **15**(1):23-33.

Department of Health. 2009. Living well with dementia: A National Dementia Strategy.

Available at:

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/168220/dh_094052.pdf (date last accessed 08/11/16)

Gusi N, Reyes MC, Gonzalez-Guerrero JL, Herrera E, Garcia JM. 2008. Cost-utility of a walking programme for moderately depressed, obese, or overweight elderly women in primary care: a randomised controlled trial. *BMC public health* **8**(1):1.

Hodge S, Hailey E. 2015. Second English National Memory Clinics Audit Report. Royal College of Psychiatry. Available at:

<http://www.rcpsych.ac.uk/pdf/English%20National%20Memory%20Clinics%20Audit%20Report%202014.pdf> (date last accessed 08/11/16)

Jedenius E, Wimo A, Strömqvist J, Jönsson L, Andreasen N. 2010. The cost of diagnosing dementia in a community setting. *Int J Geriatr Psychiatry* **25**(5):476-82.

Kelly C. 2008. Memory clinics. *Psychiatry* **7**(2):61-3.

Meeuwssen EJ, Melis RJ, Van Der Aa GC, Golücke-Willemsse GA, De Leest BJ, Van Raak FH, Schölzel-Dorenbos CJ, Verheijen DC, Verhey FR, Visser MC, Wolfs CA. 2012. Effectiveness of dementia follow-up care by memory clinics or general practitioners: randomised controlled trial. *BMJ* **344**:e3086. doi: 10.1136/bmj.e3086

Melis RJ, Meeuwssen EJ, Parker SG, Rikkert MO. 2009. Are memory clinics effective? The odds are in favour of their benefit, but conclusive evidence is not yet available. *J R Soc Med* **102**(11):456-7.

National Institute of Health and Care Excellence. 2016. NICE guidelines CG42. Dementia: supporting people with dementia and their carers in health and social care. Available at:

<https://www.nice.org.uk/Guidance/cg42> (date last accessed 08/11/16)

Nourhashemi F, Andrieu S, Gillette-Guyonnet S, Giraudeau B, Cantet C, Coley N, Vellas B. 2010. Effectiveness of a specific care plan in patients with Alzheimer's disease: cluster randomised trial (PLASA study). *BMJ*. **340**:c2466. doi: 10.1136/bmj.c2466

Olazarán J, Reisberg B, Clare L, Cruz I, Peña-Casanova J, Del Ser T, Woods B, Beck C, Auer S, Lai C, Spector A. 2010. Nonpharmacological therapies in Alzheimer's disease: a systematic review of efficacy. *Dement Geriatr Cogn Disord* **30**(2):161-78.

Page S, Hope K, Bee P, Burns A. 2008. Nurses making a diagnosis of dementia—a potential change in practice? *Int J Geriatr Psychiatry* **23**(1):27-33.

Park MH, Smith SC, Neuberger J, Chrysanthaki T, Hendriks AAJ, Black N. Socio-demographic characteristics, cognitive function and health-related quality of life of patients referred to Memory Assessment Services in England. *Alz Dis & Assoc Dis*. In press.

Pelosi AJ, McNulty SV, Jackson GA. 2006. Role of cholinesterase inhibitors in dementia. *BMJ* **333**;491-493. doi:10.1136/bmj.38945.478160.94

R Core Team. 2013. R: A language and environment for statistical computing. R Foundation for Statistical Computing, Vienna, Austria. URL <http://www.R-project.org/>. (date last accessed 08/11/16)

Rubin DB. 1987. Multiple Imputation for Nonresponse in Surveys. John Wiley. New York.

Rubinsztein JS, van Rensburg MJ, Al-Salihy Z, Girling D, Lafortune L, Radhakrishnan M, Brayne C. 2015. A memory clinic v. traditional community mental health team service: comparison of costs and quality. *BJPsych Bull* **39**(1):6-11.

Shum C, Humphreys A, Wheeler D, Cochrane MA, Clement S. 2000. Nurse management of patients with minor illnesses in general practice: multicentre, randomised controlled trial. *BMJ* **320**(7241):1038-43.

Smith SC, Lamping DL, Banerjee S, Harwood RH, Foley B, Smith P, Cook JC, Murray J, Prince M, Levin E, Mann A. 2007. Development of a new measure of health-related quality of life for people with dementia: DEMQOL. *Psychol Med* **37**(05):737-46.

StataCorp. 2015. Stata Statistical Software: Release 14. College Station, TX: StataCorp LP.

Uttley L, Scope A, Stevenson M, Rawdin A, Buck ET, Sutton A, Stevens J, Kaltenthaler E, Dent-Brown K, Wood C. 2015. Systematic review and economic modelling of the clinical effectiveness and cost-effectiveness of art therapy among people with non-psychotic mental health disorders. *Health Technol Assess (Winch Eng)* **19**: 18.

Van Buuren S. 2011. Multiple imputation of multilevel data. In *Handbook of advanced multilevel analysis*. Hox J, Roberts JK (eds). Routledge, New York.

White IR, Royston P, Wood AM. 2011. Multiple imputation using chained equations: issues and guidance for practice. *Stat Med* **30**(4):377-99.

Wolfs CA, Dirksen CD, Kessels A, Severens JL, Verhey FR. 2009. Economic evaluation of an integrated diagnostic approach for psychogeriatric patients: results of a randomized controlled trial. *Arch Gen Psychiatry* **66**(3):313-23.

Woods RT, Bruce E, Edwards RT, Elvish R, Hoare Z, Hounsborne B, Keady J, Moniz-Cook ED, Orgeta V, Orrell M, Rees J. 2012. REMCARE: reminiscence groups for people with dementia and their family caregivers—effectiveness and cost-effectiveness pragmatic multicentre randomised trial. *Health Technol Assess (Winch Eng)* **16**: 48. doi: 10.3310/hta16480.

Tables

Table 1: Primary health, social care and psychosocial support reported by carers

Resource	Baseline (n = 932)		Follow up			
	Proportion reporting contact (%)	Proportion missing data (%)	3 months (n = 620)		6 months (n = 587)	
			Proportion reporting contact (%)	Proportion missing data (%)	Proportion reporting contact (%)	Proportion missing data (%)
Health care						
General Practitioner	48.1	3.3	36.3	6.0	39.1	2.7
Practice Nurse	26.2	4.3	20.7	6.0	25.1	4.1
District Nurse	8.1	4.9	7.5	6.6	9.4	5.3
Specialist Nurse	1.6	4.2	1.9	5.8	3.1	3.8
Community Mental Health Nurse	10.3	4.1	6.8	6.3	4.6	4.9
Psychiatrist/ neurologist	17.6	3.6	12.2	5.5	17.1	4.6
Psychologist	1.0	4.6	2.8	6.0	2.2	4.3
Physiotherapist	5.6	3.8	5.3	5.5	4.1	4.4
Occupational Therapist	2.7	3.7	5.2	5.2	3.9	3.4
Dietician	1.3	4.3	1.8	5.7	0.3	3.6
Counsellor	0.3	4.0	0.5	6.5	0.0	3.8
SALT	0.7	4.0	0.6	5.8	0.7	3.6
Mental health team worker	3.6	4.2	3.2	6.0	1.7	3.9
Dementia Adviser	1.3	4.6	5.2	5.3	4.6	3.8
Anti-dementia drugs	1.1	11.2	31.6	4.4	33.4	8.4
Social care						
Social worker	4.1	4.1	9.6	5.8	8.4	3.6
Home care	10.5	3.1	9.9	3.9	11.1	3.9
Cleaner	15.8	3.2	13.3	2.9	15.4	3.6
Meals on Wheels	2.3	3.4	2.4	3.9	1.7	3.2
Laundry service	2.5	3.6	2.1	3.6	1.4	4.3
Sitting service	1.4	3.7	1.0	4.1	1.4	3.6
Carer's support worker	2.0	3.7	1.1	4.2	1.5	3.6
Personal assistant	1.2	3.5	1.6	4.1	1.5	3.8
Day care	1.3	3.6	1.0	4.2	1.7	3.6
Psychosocial support						
CST	0.1	3.4	0.6	2.6	2.0	2.6
Music/dance therapy	0.5	3.6	0.5	2.6	1.0	2.7
Animal assisted therapy	0.2	3.6	0.5	2.8	0.2	3.2
Social engagement group	7.1	3.5	6.0	2.6	8.0	3.1
Walking group	0.8	3.6	0.2	2.8	1.0	3.1
Life story work	0.2	4.0	0.3	2.8	0.5	3.2
Peer support group	0.5	3.5	0.3	2.9	1.0	2.9
Befriending service	1.2	3.7	0.6	2.8	1.4	2.9
Memory Café	0.9	3.5	1.6	2.6	3.1	3.4
Psycho-education	0.1	4.1	0.0	2.9	0.0	3.6
Reminiscence therapy	0.3	3.4	1.0	3.1	0.5	3.6
Other	5.8	N/A	7.5	N/A	6.0	N/A

SALT – Speech and Language Therapist; CST – Cognitive Stimulation Therapy

Table 2: MAS staffing levels and patient throughput

	Missing	Mean	Median	Range
WTE doctors	8	1.77	1.40	0.1-8
WTE nurses	8	3.81	2.82	0.6-10.35
WTE psychologists	8	0.91	0.71	0-5.49
WTE allied health professionals	8	0.81	0.71	0-3.6
WTE advice & support workers	8	0.94	0.71	0-7.05
WTE administrators	8	1.85	1.41	0-5.83
Patients assessed per month	1	48.28	45	10-130

WTE – whole time equivalent

Table 3: Costs associated with MAS

	Mean (£)	SD (£)	Median (£)	IQR (£)
Monthly costs of a MAS				
Imaging	3,482	4,645	1,844	5,316
Assessment *	33,697	27,348	26,684	26,793
Post diagnosis support*	17,833	14,784	14,415	12,403
Follow-up*	21,193	16,154	18,133	21,569
Total	76,206	46,921	66,866	48,319
Monthly cost per new patient				
Assessment (including imaging)*	898	755	740	741
Post diagnosis support*	427	355	360	376
Follow-up*	531	497	383	503
Total	1,855	1,221	1,574	1,436

*costs include a proportion of administration, management and audit costs

Note: mean costs per patient assessed are means of ratios and hence do not equate to ratios of the mean costs and the mean number of new patients assessed.

Table 4: Cost of care and services received outside MAS reported by carers over previous one month at baseline and follow-up

	Baseline (£)			3 month follow-up (£)			6 month follow-up (£)		
	Mean	Median	Range	Mean	Median	Range	Mean	Median	Range
Health care	60	0	0 - 6,906	30	0	0 - 551	59	2	0 - 894
Social care	69	0	0 - 3,360	92	0	0 - 5,428	154	0	0 - 7,200
Psychosocial support	11	0	0 - 1,372	4	0	0 - 336	11	0	0 - 672
Social security benefits	125	0	0 - 609	130	0	0 - 609	166	12	0 - 609
Informal care	1,493	1,415	0 - 4,032	1,527	1,344	0 - 3,984	1,621	1,344	0 - 4,032
Total cost of formal care	141	1	0 - 10,471	127	1	0 - 6,086	224	19	0 - 8,016
Total societal cost	1,637	1,565	0 - 13,162	1,658	1,362	0 - 8,792	1,847	1,462	0 - 10,699

Table 5 Mean (SD) of projected costs of diagnosis and support per patient for patients attending MAS over six months from assessment (£).

		Proportion of all post-diagnostic support costs accrued at six months				
		0%	25%	50%	75%	100%
Proportion of all follow-up costs accrued at six months	0%	1,582 (2,571)	1,689 (2,602)	1,796 (2,635)	1,904 (2,672)	2,011 (2,710)
	25%	1,703 (2,590)	1,811 (2,622)	1,918 (2,656)	2,025 (2,692)	2,132 (2,732)
	50%	1,825 (2,615)	1,932 (2,646)	2,039 (2,681)	2,147 (2,718)	2,254 (2,758)
	75%	1,946 (2,644)	2,054 (2,676)	2,161 (2,711)	2,268 (2,748)	2,375 (2,788)
	100%	2,068 (2,678)	2,175 (2,710)	2,282 (2,745)	2,390 (2,783)	2,497 (2,823)

Median and Interquartile range available from the authors on request.

Figures

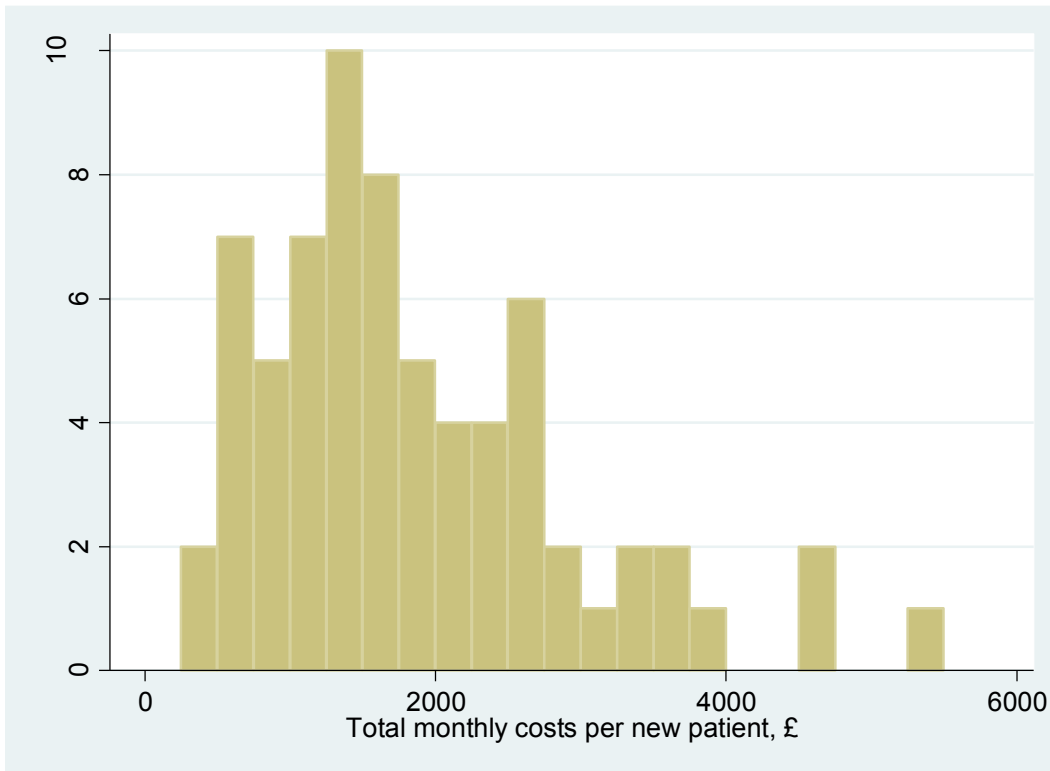


Figure 1. Distribution of total monthly costs per new patient assessed across clinics

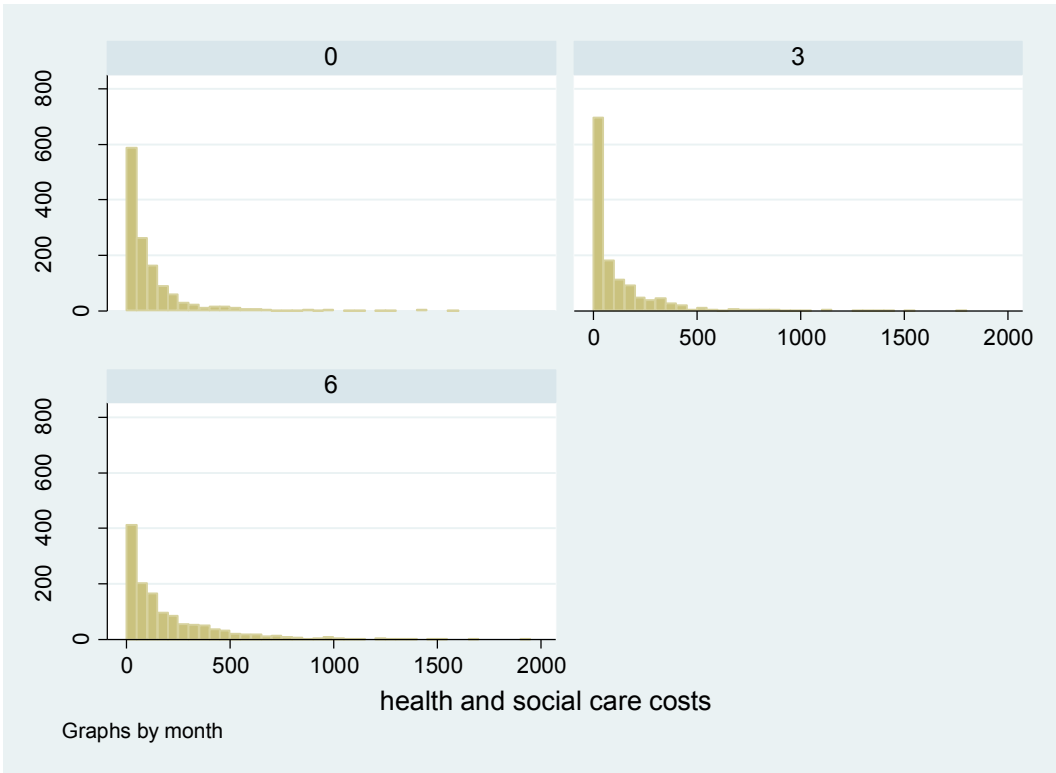


Figure 2. The distribution of health and social care costs reported by carers at baseline, three and six months (plots truncated at £2,000)