Title: Memory Assessment Services and health-related quality of life: one year follow up

Running head: Memory clinics and HRQL: one year follow up

Key words: Dementia; Memory Assessment Services; Memory Clinics; Post-diagnostic interventions; Psychosocial interventions; Anti-dementia drugs; Health-related Quality of Life

Authors: Min Hae PARK PhD[1], Sarah C. SMITH PhD[1], Craig W. RITCHIE MD PhD[2], A.A. Jolijn HENDRIKS PhD[1], Nick BLACK MD [1]

Affiliations: [1] Department of Health Services Research & Policy, London School of Hygiene & Tropical Medicine, 15-17 Tavistock Place, London WC1H 9SH, UK**;** [2] Centre for Dementia Prevention, University of Edinburgh, Edinburgh EH10 5HF, UK

Corresponding author details: Dr Min Hae Park, Department of Health Services Research & Policy, London School of Hygiene & Tropical Medicine, 15-17 Tavistock Place, London WC1H 9SH, UK. Telephone: +44(0)2079272714. Email: minhae.park@lshtm.ac.uk.

Key points:

- There is evidence that patients' health-related quality of life (HRQL) improves in the 6 months after a first appointment at a memory assessment service (MAS), but the sustainability of such benefits is unknown.
- In a large multi-centre study of 702 patients, we show that improvements in HRQL are maintained up to one year after the first appointment.
- The largest improvements are observed in those patients who receive a diagnosis of dementia.

Sponsor: This report is based on independent research commissioned and funded by the NIHR Policy Research Programme (Using Patient Reported Outcome Measures to Assess Quality of Life in Dementia). The views expressed in the publication are those of the author(s) and not necessarily those of the NHS, the NIHR, the Department of Health, 'arms' length bodies or other government departments.

The sponsor had no involvement in the study design, in the collection, analysis and interpretation of data, in the writing of the report or in the decision to submit the report for publication.

Word count: 3482

Number of tables: 5

Supplementary files: 2

ABSTRACT

Objectives: Our group has already demonstrated that patients' health-related quality of life (HRQL) improves in the first 6 months after their first appointment at memory assessment services (MASs), but the sustainability of such gains is unknown. We aimed to describe changes in patients' HRQL at 12 months after their first MAS appointment and to examine associations with patient and MAS characteristics.

Methods: We collected data from 702 patients and 452 lay caregivers at the first appointment and 12 months later. Multivariable linear regression was used to examine the relationships of change in HRQL (self- and proxy-reported) with patients' characteristics and use of post-diagnostic interventions, and multilevel models were used to analyse the relationships of HRQL with MAS characteristics.

Results: In the whole group, self-reported HRQL improved over 12 months (+3.5 points, 95% CI 2.7 to 4.2). Among people diagnosed with dementia, improvement in HRQL was more than double that among those with mild cognitive impairment or no diagnosis. Proxy-reported HRQL improved only in those diagnosed with dementia (+1.2 points, 95% CI 0.2 to 2.2). Changes in HRQL were not associated with any patient characteristics. The only feature of MASs associated with larger improvements in HRQL was the presence of advisory and support staff.

Conclusions: Improvements in HRQL observed at 6 months are maintained up to one year after the first MAS appointment, more so among those who receive a diagnosis of dementia. Continued follow up will determine if the improvement is even longer lasting.

INTRODUCTION

Memory assessment services (MASs) have a central role in dementia care, providing assessment and diagnosis for new referrals, post-diagnostic support, and follow-up.[1-4] The past decade has seen a significant increase in provision of, and investment in, these services.[5]

Despite rapid expansion in service provision, evidence for the benefits of MASs in terms of patient outcomes is limited.[6] It is only recently that robust evaluation of the effectiveness of MASs has emerged. The largest published study of MAS patients to date, which followed up nearly 900 patients from a nationally representative sample of clinics across England, found that patients' health-related quality of life (HRQL) improves in the first six months after their first appointment at a MAS.[7] This finding is consistent with earlier small-scale studies, which suggested that MASs may be beneficial in the initial months after referral.[8,9] However, evidence for patient outcomes beyond six months is currently lacking so the sustainability of such benefits is not known. It is also unknown whether any patient characteristics, use of anti-dementia drugs or psychosocial interventions, or characteristics of the MASs have an impact on outcomes beyond six months.

The aims of this study were: [1] to describe the change in patients' HRQL over the first 12 months after the first MAS appointment; [2] to examine whether patient characteristics are associated with changes in HRQL; [3] to determine if the use of anti-dementia drugs and/or psychosocial interventions is associated with improved HRQL in those patients diagnosed with dementia; and [4] to investigate the extent to which characteristics of MASs are associated with patients' HRQL at 12 months.

METHODS

Sample

We randomly selected 80 MASs from all 212 clinics in England identified in the Royal College of Psychiatrists national audit.[5] Of these, 73 MASs took part in the study at baseline (2 sites did not participate, 5 sites recruited fewer than 6 patients each and were excluded) and 71 remained in the study at 12-month follow up. The selected MASs were representative of all clinics in England in terms of patient volume, waiting times and accreditation status.[5] Patients referred for a first appointment between September 2014 and April 2015 with sufficient English language to understand the consent process and questionnaires, and their informal caregivers, were eligible for inclusion. Each site was asked to recruit up to 25 consecutive new patients.[10]

Questionnaires were completed by patients (interviewer administered) and their caregivers (self-administered) at the time of the first appointment (before diagnosis) and 12 months later. Additionally at baseline, all 71 MASs completed organisational questionnaires on their structural and process characteristics.[11]

Outcomes

The patient questionnaires at baseline and 12 months included measures of disease-specific (DEMQOL[12]) and generic (EQ-5D-3L[13]) HRQL. DEMQOL is a 28-item instrument with items scored on a four-point response scale, with higher score indicating better HRQL. We used a scoring algorithm based on Rasch Measurement Theory to generate scores,[14] and for analysis the scores were linearly transformed to range from 0 to 100. The EQ-5D-3L has five items, each covering one domain: mobility, self-care, usual activities, pain/discomfort and

anxiety/depression. A summary EQ-5D-3L index score was calculated using value sets derived from a UK general population survey to weight and combine responses.[15] Informal caregivers completed proxy-reported instruments for assessing the disease specific (DEMQOL-Proxy[14]) and generic (EQ-5D-3L proxy[15]) HRQL of the patient.

The primary outcomes in this study were changes in patients' DEMQOL and DEMQOL-Proxy scores between first appointment (baseline) and 12 month follow up. We also included self- and proxy-reported EQ-5D-3L index scores as secondary outcomes.

Patient-level characteristics

Data on patients' socio-demographic characteristics (age; sex; ethnicity; socio-economic status based on patients' residential postcodes and quintiles of the national ranking of Index of Multiple Deprivation IMD scores[16]) were collected at baseline.

At each time point, interviewers extracted data from the patient's case notes on whether the patient had any comorbid conditions from a pre-specified list (heart disease, high blood pressure, problems caused by stroke, leg pain due to poor circulation, lung disease, diabetes, kidney disease, diseases of the nervous system, liver disease, cancer within the last 5 years, depression or arthritis).[17] At baseline, data on cognitive function were extracted and used to derive a three-category cognitive function variable based on tertiles from our own data on the Mini-Mental State Examination (MMSE) score[18]: category 1 (lowest cognitive function) equivalent to MMSE score <24, category 2 MMSE score 24-27, and category 3 (highest cognitive function) MMSE score ≥28. The threshold for the lowest tertile (<24) corresponds to that often used in screening for dementia.[19] At 12-month follow up, interviewers extracted information on patient diagnosis (categorised as: dementia; mild

cognitive impairment MCI; other diagnosis; no diagnosis reached or not thought to have any cognitive impairment).

Informal caregivers provided information on anti-dementia drugs the patient had been prescribed and psychosocial interventions they had received since their first appointment. Respondents were asked to select psychosocial interventions from a predetermined list including cognitive behaviour therapy, music therapy, animal assisted therapies, social engagement groups, walking groups, life story work, peer support groups, befriending services, memory cafes and reminiscence therapy, in addition to providing free-text information on any interventions that were not listed.

MAS characteristics

Structural and process characteristics which varied between MASs were selected for analysis,[11] with dementia policy experts, clinicians, researchers and a lay advisory group involved in the final selection. Structural variables were: skill mix (presence of clinical psychologists, allied health professionals, and advisory and support staff), number of new patients per whole time equivalent (WTE) staff per month, number of new patients seen by the MAS each month, provision of clinical assessments (at first appointment: ECG, neurological examination; at follow up: physical examination, vision/hearing/mobility assessment) and a structural measure of the provision of post-diagnostic psychosocial interventions.

Process characteristics were: waiting time to first appointment (categorised as ≤6 or >6 weeks, the recommended standard[20]), length of first appointment, and number of follow-up

appointments within the first year (categorised as ≤1 or >1, i.e. clinic follow-up complete by 12 months or ongoing).

Statistical analysis

Patient and MAS characteristics were summarised as means and standard deviations (SDs) or percentages. We used chi-squared tests to compare the characteristics of respondents at 12 months with those of non-respondents. Change in each measure of HRQL was assessed using paired t-tests to compare mean scores at baseline and 12 months, for the whole sample of patients and by diagnosis.

We used multivariable linear regression to examine the relationships between patient characteristics and change in HRQL at 12 months, adjusting for all patient characteristics and HRQL score at baseline. Clustering of patients within MASs was taken into account using cluster-robust standard errors. In the sub-group of patients diagnosed with dementia, linear regression was used to assess the relationships between use of anti-dementia drugs and psychosocial interventions and change in HRQL, adjusting for patient characteristics, cognitive function and HRQL at baseline, and in the case of anti-dementia drugs adjusting for psychosocial interventions and vice versa. Due to the clustering of use of psychosocial interventions (differences in use between sites), we adjusted for MAS as a random effect. Results of linear regression models are presented as adjusted differences in HRQL change score with confidence intervals CIs.

Multilevel linear regression models were used to examine the relationships between MAS characteristics and patient HRQL at 12 months. Models included all structural and process characteristics, and were adjusted for patient-level variables and MAS as a random effect.

Analyses were conducted on the full sample of patients, and on the sub-sample of patients diagnosed with dementia. We report results as adjusted differences in HRQL score with confidence intervals.

Due to the large number of tests conducted and associated risk of Type I errors, in the analyses of patient and MAS characteristics we applied the Bonferroni adjustment for multiple testing to *p*-values (family-wise error rate of 0.05 per model divided by the number of tests *k*; in analysis of patient characteristics *k* = 12, in analysis of MAS characteristics *k*=17). Although the risk of missing a possible association (Type II error) is increased, this approach allows a greater degree of certainty about any effects that are observed.[21]

All analyses were conducted using Stata V.14 (StataCorp, College station, Texas, USA).

Ethical approval

The study protocol 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).

RESULTS

Sample characteristics

Of the 1346 patients and 970 caregivers eligible for follow up, 702 (52%) patients and 452 (47%) caregivers completed questionnaires at 12 months (Supplementary Figure 1). The mean time to follow up was 12.8 months (SD 1.0), with 95% of participants followed up between 10 and 15 months. Participants who were followed up late (>15 months from baseline) were similar to other participants in regards age, sex, ethnicity, deprivation, cognitive function, number of comorbidities, and HRQL at baseline. The only difference was

a higher proportion had an informal caregiver participate at baseline (94% versus 71%, p=0.006).

The characteristics of study participants are summarised in Table 1. Respondents at 12 months were similar to non-respondents in terms of ethnicity, deprivation, comorbidities, HRQL scores at baseline and diagnosis, but were slightly younger (mean age 77.3 versus 78.6 years), more likely to be male (52% versus 44% male) and had higher cognitive function at baseline (31% versus 26% in highest cognitive function category).

[Insert Table 1 here]

By 12 months after the first MAS appointment, 59% (n=405) of patients had received a diagnosis of dementia, and 26% (n=182) had received a diagnosis of mild cognitive impairment (MCI). A few (4%, n=28) had a psychiatric, cerebrovascular (no dementia) or trauma-related diagnosis, and 11% (n=75) had received no diagnosis, some of whom had no evidence of cognitive impairment at baseline.

Change in HRQL over first 12 months

Between baseline and 12 months, self-reported HRQL (DEMQOL) in the whole study population increased by 3.5 points (95% CI 2.7 to 4.3) (effect size: 0.29 SD) (Table 2). While all diagnostic groups demonstrated an increase in HRQL, this increase was larger among those with a diagnosis of dementia (+4.8 points, 95% CI 3.8 to 5.9; effect size: 0.40 SD) than those with MCI (+1.9, 95% CI 0.6 to 3.2; effect size: 0.16 SD) or no diagnosis (+1.6, 95% CI -0.6 to 3.9; effect size: 0.13 SD). No change in self-reported generic HRQL (EQ-5D-3L) was detected.

[Insert Table 2 here]

Although proxy-reported HRQL (DEMQOL-Proxy) for the whole sample did not change over 12 months, the mean score did increase in the sub-group of those with a diagnosis of dementia (+1.2, 95% CI 0.2 to 2.2; effect size 0.13 SD).

There was no change in proxy-reported EQ-5D-3L index score except among those with a diagnosis of MCI in whom it decreased slightly (-0.05, 95% CI -0.1 to -0.008; effect size: 0.17 SD).

Patient characteristics and change in HRQL

Changes in self- and proxy-reported HRQL (DEMQOL and DEMQOL-Proxy) were not associated with any of the patient characteristics in adjusted analyses (Table 3). This was also the case with generic measures of HRQL (self- and proxy-reported EQ-5D-3L index scores; results not presented).

[Insert Table 3 here]

Associations between change in HRQL and interventions in patients with dementia

Of the patients with dementia and data on intervention use (of any kind), 183 (63%) had been prescribed anti-dementia drugs since receiving their diagnosis and 97 (33%) had used psychosocial interventions. Of these, 63 (22%) received both types of intervention. The HRQL of patients with dementia improved regardless of whether or not they received interventions (Table 4). For both anti-dementia drugs and psychosocial interventions the improvements were larger among those using the interventions than those not, though the differences were not statistically significant: the DEMQOL score for those prescribed anti-dementia drugs increased over 12 months by 6.0 points, compared with 3.4 points among those not prescribed these drugs (p-value from Z-test = 0.06); and by 6.6 points among

those using psychosocial interventions compared with 4.3 points among those not (p-value: 0.34). No interaction effect between anti-dementia drugs and psychosocial intervention was detected.

[Insert Table 4 here]

MAS characteristics and patients' HRQL at 12 months

In the whole sample of patients, self-reported HRQL was not associated with any MAS characteristics in the adjusted analysis (Table 5).

[Insert Table 5 here]

Among those participants who received a diagnosis of dementia, only one MAS characteristic was associated with change in HRQL: the presence of advisory and support staff (support workers, social workers, mental health workers, dementia advisers) in the multi-professional team was associated with larger improvement in self-reported HRQL (DEMQOL score +4.3 points, 95% CI 0.9 to 7.8) (Table 5).

MAS characteristics were not associated with changes in proxy-reported HRQL or with self- and proxy-reported generic measures of HRQL in adjusted analyses (results available as Supplementary Table 1). This was true both for the overall sample and among those with a diagnosis of dementia (Supplementary Table 2).

DISCUSSION

Main findings

One year after their first MAS appointment, the majority of patients had received a diagnosis of either dementia or MCI. For the whole sample of patients, the improvements in

self-reported dementia-specific HRQL previously observed at 6 months were still evident at 12 months. We did not find improvements in generic HRQL measured using EQ-5D, but such generic measures often have poor construct validity among people with dementia and the use of condition-specific measures is recommended.[22]

Self-reported improvement in dementia-specific HRQL among those patients diagnosed with dementia was more than twice that among those with MCI or no diagnosis. Although a small improvement in proxy-reported HRQL was observed among those with dementia, this was not apparent in those without a diagnosis of dementia. The improvement among those diagnosed with dementia was greater in those treated with anti-dementia drugs or using psychosocial interventions, though these associations did not reach statistical significance at the 5% level.

There were no associations between structural characteristics of MASs and outcomes apart from, among those with dementia, the inclusion of advisory and support staff which was associated with larger improvements in self-reported HRQL. None of the process characteristics studied were associated with the outcomes.

Strengths and limitations

This is the largest study of changes in HRQL among people referred to MASs. The selected MASs are representative of all services in England, and at baseline the sample was largely representative of all patients attending them.[10]

The study has four limitations. First, due to the absence of a control arm (of people with suspected dementia who were not referred to MASs), it is not possible to attribute the improvement in HRQL to attending a MAS. As there is a lack of clinical equipoise about the

value of early intervention for dementia, it is not ethical to randomise people to delayed referral, and consequently data on the natural history of HRQL (without any intervention) are not available. However, longitudinal studies assessing HRQL of people with dementia (using dementia-specific measures of HRQL) generally report no mean change in self-reported HRQL and no change or a decline in proxy-reported HRQL over periods of up to three years.[23-29]

Second, the recruitment rate at baseline was 42%, and only half of participants responded at 12 months. Participants recruited into the study at baseline were slightly younger, more likely to be male and had slightly better cognitive function when compared with referrals who did not take part.[10] At follow-up, only three of 12 characteristics differed between respondents and non-respondents, and of those three only cognitive function at baseline was associated with changes in HRQL. However, our analyses and previous studies indicate that better cognitive function at baseline is associated with a decrease in self-reported HRQL,[23] therefore given the higher proportion of respondents with mild impairment (MMSE>27) in our sample, any bias is likely to have led to a slight under- rather than over-estimate of the extent of improvement in self-reported HRQL.

Third, there may have been other patient factors associated with outcomes, which were not fully accounted for in our analyses of intervention use. For example, the presence of contraindications to commonly used anti-dementia drugs.

Fourth, in our analysis of MAS characteristics, some were difficult to standardise across services despite our efforts to verify responses via telephone follow up (e.g. WTE staff levels as individuals worked across multiple services). In addition, some data were based on staff's estimates of typical or mean values (e.g. waiting time).

Comparison with other studies

Data from the same cohort of MAS attendees showed that patients' self-reported HRQL increased by 3.4 points (0.28 SD) over the first 6 months from first appointment.[7] The current study shows that this improvement in HRQL is still evident after 12 months (3.5 points). While the improvement in HRQL at six months had been the same across all diagnostic groups, at 12 months there was a larger improvement among those with dementia. That might suggest that the current design of MASs is only of benefit (as measured in terms of dementia-specific HRQL) to those with MCI for the initial six months. Consistent with other longitudinal studies of people with dementia, we found that changes in HRQL were not associated with patients' socio-demographic characteristics at baseline.[24,26,28,30,31] One study reported declines in HRQL to be associated with the number of comorbidities,[32] but this was in a population of older adults in care homes, who had poorer general health than participants in our study.

Analysis of 6 month data had found that patients with dementia who received anti-dementia drugs reported that their HRQL was improved by 4.6 points on average (compared with 2.2 in the non-treated group).[7] At 12 months this difference was still apparent but was not statistically significant due to the smaller sample size as a result of attrition.

As regards the impact of psychosocial interventions, the negative association detected at 6 months (change in DEMQOL score 2.4 points, compared with 3.8 in non-treated group) was no longer apparent at 12 months. The lack of a negative association at 12 months might indicate that the benefits of psychosocial interventions occur sometime after the initial diagnosis. This would be consistent with some qualitative studies which concluded that in people with early-stage dementia, confronting the challenges of memory loss can lead to

despair and a struggle with acceptance of a diagnosis.[33] In addition, early interactions with professional staff can contribute to feelings of loss of autonomy: in a study of men with early-stage Alzheimer's Disease, the majority of participants described initially perceiving outside help as another symbol of the many losses associated with their diagnosis.[34] The same study described a longer-term and ongoing process of reconstructing a sense of self.

The positive effect of allied health professional staff on HRQL at 6 months[35] was no longer apparent at 12 months. However, this had been replaced by the apparent benefit of advisory and support staff at 12 months which lends weight to the idea that the benefits of different interventions vary over the course of a patient's journey following diagnosis.

Implications

Improvements in HRQL observed in the first 6 months are maintained up to one year after the first MAS appointment, more so among those who receive a diagnosis of dementia. Although this study cannot establish causality, these findings may point to the potential value of early assessment, diagnosis and intervention in people with dementia. The likely value of MAS for people with MCI is less clear, but this may reflect the dementia specific outcomes used in this study. Longer-term follow up is needed to determine the sustainability of any improvements and to establish the cost-utility of MASs. Research to describe the trajectories of HRQL among different groups of patients, for example by type and severity of dementia, and over a greater number of time points could help to identify important transition stages in dementia which may inform the targeting of psychosocial interventions.

ACKNOWLEDGEMENTS: We thank all the participants and researchers who took part in the study.

CONFLICTS OF INTEREST: Authors have no conflicts of interest to declare.

References

1. Lindesay J, Marudkar M, van Diepen E, Wilcock G. The second Leicester survey of memory clinics in the British Isles. *International journal of geriatric psychiatry.* 2002;17(1):41-47.
2. Kelly C. Memory clinics. *Psychiatry and Clinical Neurosciences.* 2007;7:61-63.
3. Jolley D, Moniz-Cook E. Memory clinics in context. *Indian Journal of Psychiatry* 2009;51(Suppl1):S70-S76.
4. Department of Health. *Living well with dementia: a national dementia strategy.* London, Crown Copyright: Department of Health; 9 February 2009 2009.
5. Royal College of Psychiatrists & NHS England. *Second English National Memory Clinics Audit Report.* London: Royal College of Psychiatrists;2015.
6. Banerjee S. A narrative review of evidence for the provision of memory services. *International psychogeriatrics / IPA.* 2015;27(10):1583-1592.
7. Park MH, Smith SC, Chrysanthaki T, et al. Change in health-related quality of life after referral to Memory Assessment Services. *Alzheimer disease and associated disorders.* 2017;DOI: 10.1097/WAD.0000000000000190.
8. Banerjee S, Willis R, Matthews D, Contell F, Chan J, Murray J. Improving the quality of care for mild to moderate dementia: an evaluation of the Croydon Memory Service Model. *International journal of geriatric psychiatry.* 2007;22(8):782-788.
9. Melis RJ, Meeuwsen EJ, Parker SG, Olde Rikkert MG. Are memory clinics effective? The odds are in favour of their benefit, but conclusive evidence is not yet available. *Journal of the Royal Society of Medicine.* 2009;102(11):456-457.
10. Park MH, Smith SC, Neuburger J, Chrysanthaki T, Hendriks AAJ, Black N. Sociodemographic characteristics, cognitive function, and health-related quality of life of patients referred to Memory Assessment Services in England *Alzheimer disease and associated disorders.* 2016;DOI: 10.1097/WAD.0000000000000166.

11. Chrysanthaki T, Fernandes B, Smith S, Black N. Variation in provision and practice in memory assessment services (MAS) in England. *J Public Health.* 2017; doi: 10.1093/pubmed/fdx018.

12. Smith SC, Lamping DL, Banerjee S, et al. Measurement of health-related quality of life for people with dementia: development of a new instrument (DEMQOL) and an evaluation of current methodology. *Health Technology Assessment.* 2005;9(10):1-93, iii-iv.

13. EuroQol Group. *EQ-5D-3L Health Questionnaire: English version for the UK.* 1990.

14. Smith SC, Hendriks AAJ, Chrysanthaki T, Cano SJ, Black N. How can we interpret proxy reports of HRQL when it is no longer possible to obtain a self-report? ISOQOL 22nd Annual Conference; 2015; Vancouver, Canada.

15. EuroQol Group. *User Guide: Basic information on how to use EQ-5D.* Rotterdam: EuroQol Research Foundation;2015.

16. Department for Communities and Local Government. *English Indices of Deprivation 2010.* 2011.

17. Chard J, Kuczawski M, Black N, van der Meulen J. Outcomes of elective surgery undertaken in independent sector treatment centres and NHS providers in England: audit of patient outcomes in surgery. *BMJ.* 2011;343.

18. Folstein MF, Folstein SE, McHugh PR. "Mini-mental state". A practical method for grading the cognitive state of patients for the clinician. *Journal of psychiatric research.* 1975;12(3):189-198.

19. Tombaugh TN, McIntyre NJ. The mini-mental state examination: a comprehensive review. *Journal of the American Geriatrics Society.* 1992;40(9):922-935.

20. Royal College of Psychiatrists. *Memory Services National Accreditation Programme (MSNAP): Standards for Memory Services. Fifth Edition.* 2016.

21. Armstrong RA. When to use the Bonferroni correction. *Ophthalmic and Physiological Optics.* 2014;34(5):502-508.

22. Ara R, Duarte A, Harnan S, et al. *Supporting the routine collection of patient reported outcome measures in the National Clinical Audits for assessing cost-effectiveness. Work Package 1: What patient reported outcome measures should be used in the 13 health conditions specified in the 2013/14 National Clinical Audit programme? Economic Evaluation of Health and Social Care Interventions Policy Research Unit. Research Report RR0029.* 2015.

23. Beerens HC, Zwakhalen SMG, Verbeek H, et al. Change in quality of life of people with dementia recently admitted to long-term care facilities. *Journal of Advanced Nursing.* 2015;71(6):1435-1447.

24. Clare L, Woods RT, Nelis SM, et al. Trajectories of quality of life in early-stage dementia: individual variations and predictors of change. *International journal of geriatric psychiatry.* 2014;29(6):616-623.

25. Conde-Sala JL, Turro-Garriga O, Garre-Olmo J, Vilalta-Franch J, Lopez-Pousa S. Discrepancies regarding the quality of life of patients with Alzheimer's disease: a three-year longitudinal study. *Journal of Alzheimer's disease : JAD.* 2014;39(3):511-525.

26. Hoe J, Hancock G, Livingston G, Woods B, Challis D, Orrell M. Changes in the Quality of Life of People with Dementia Living in Care Homes. *Alzheimer disease and associated disorders.* 2009;23(3):285-290.

27. Selwood A, Thorgrimsen L, Orrell M. Quality of life in dementia--a one-year follow-up study. *International journal of geriatric psychiatry.* 2005;20(3):232-237.

28. Sheehan B, Lall R, Gage H, Holland C, Katz J, Mitchell K. A 12-month follow-up study of people with dementia referred to general hospital liaison psychiatry services. *Age and ageing.* 2013;42(6):786-790.

29. Trigg R, Jones RW, Knapp M, King D, Lacey LA, Groups D-I. The relationship between changes in quality of life outcomes and progression of Alzheimer's disease: results from the dependence in AD in England 2 longitudinal study. *International journal of geriatric psychiatry.* 2015;30(4):400-408.

30. Mjørud M, Røsvik J, Rokstad AMM, Kirkevold M, Engedal K. Variables Associated with Change in Quality of Life among Persons with Dementia in Nursing Homes: A 10 Months Follow-Up Study. *PLoS ONE.* 2014;9(12):e115248.

31. Missotten P, Ylieff M, Di Notte D, et al. Quality of life in dementia: a 2-year follow-up study. *International journal of geriatric psychiatry.* 2007;22(12):1201-1207.

32. Castro-Monteiro E, Forjaz MJ, Ayala A, et al. Change and predictors of quality of life in institutionalized older adults with dementia. *Quality of life research : an international journal of quality of life aspects of treatment, care and rehabilitation.* 2014;23(9):2595-2601.

33. Steeman E, De Casterlé BD, Godderis J, Grypdonck M. Living with early-stage dementia: a review of qualitative studies. *Journal of Advanced Nursing.* 2006;54(6):722-738.

34. Pearce A, Clare L, Pistrang N. Managing Sense of Self. *Dementia.* 2002;1(2):173-192.

35. Park MH, Black N, Ritchie CW, Hendriks AAJ, Smith SC. Is the effectiveness of Memory Assessment Services associated with their structural and process characteristics? *Int J Geriatric Psychiatry.* 2017;DOI: 10.1002/gps.4675.

Table 1: Characteristics of respondents and non-respondents at 12 months

Patient characteristic	Respondents	Non-respondents	p-value from χ^2 test
Mean age (years)	77.3 (SD 8.3)	78.6 (SD 8.5)	0.004 *
% female	340 (48.4%)	389 (55.7%)	0.007 *
Black, Asian or minority ethnic (BAME)	33 (4.7%)	38 (5.5%)	0.530
Missing	4	4	
Deprivation quintile			
1 – least deprived	186 (26.8%)	161 (23.4%)	0.079
2	163 (23.5%)	134 (19.5%)	
3	129 (18.6%)	148 (21.5%)	
4	123 (17.7%)	129 (18.8%)	
5 – most deprived	93 (13.4%)	115 (16.7%)	
Missing	8	12	
Cognitive function at baseline			
Lowest MMSE<24	205 (37.1%)	256 (46.8%)	0.005 *
MMSE 24-27	175 (31.7%)	150 (27.4%)	
Highest MMSE >27	173 (31.3%)	141 (25.8%)	
Missing	149	152	
Number of comorbidities at baseline			
None	149 (21.3%)	162 (23.2%)	0.420
1	199 (28.4%)	172 (24.6%)	
2	157 (22.4%)	167 (23.9%)	
3 or more	195 (27.9%)	197 (28.2%)	
Missing	2	1	
Companion in study at baseline	509 (72.5%)	498 (71.2%)	0.599
Diagnosis at 12 months			
Dementia	405 (58.7%)	N/A	N/A
MCI	182 (26.4%)	N/A	
Other	28 (4.0%)	N/A	
No diagnosis took place	75 (10.9%)	N/A	
Missing	12	N/A	
Patient HRQL at baseline			
EQ-5D-3L Index (self report)	0.71 (SD 0.28)	0.71 (SD 0.27)	0.845
EQ-5D-3L Index (proxy report)	0.62 (SD 0.30)	0.60 (SD 0.30)	0.396
DEMQOL (equated score, standardised)	65.5 (SD 12.2)	64.5 (SD 12.1)	0.132
DEMQOL-Proxy (equated score, standardised)	57.0 (SD 9.2)	55.9 (SD 9.8)	0.053

HRQL – health-related quality of life; MCI – mild cognitive impairment; MMSE – Mini Mental State Examination; * - indicates statistically significant difference at 5% level.

Table 2: Change in patient health-related quality of life, in all participants and by diagnosis at 12 months

	Score at baseline Mean (SD)	Score at 12 months (Mean SD)	Mean change (95% CI)
DEMQOL equated score (n=694)	65.5 (12.2)	69.0 (13.2)	**3.5 (2.7 to 4.3)**
Dementia (n=397)	66.1 (12.5)	71.0 (13.7)	**4.8 (3.8 to 5.9)**
MCI (n=182)	66.5 (11.5)	68.4 (12.4)	**1.9 (0.6 to 3.2)**
No diagnosis (n=75)	62.8 (12.3)	64.4 (10.7)	1.6 (-0.6 to 3.9)
EQ-5D-3L index score (n=681)	0.71 (0.28)	0.72 (0.29)	0.01 (-.005 to .03)
Dementia (n=392)	0.74 (0.25)	0.75 (0.3)	0.01 (-.02 to .04)
MCI (n=176)	0.70 (0.29)	0.72 (0.29)	0.02 (-.02 to .05)
No diagnosis (n=74)	0.64 (0.30)	0.67 (0.30)	0.03 (-.03 to 0.1)
DEMQOL-Proxy equated score (n=447)	57.2 (9.0)	57.9 (10.7)	0.7 (-0.1 to 1.5)
Dementia (n=286)	55.9 (8.7)	57.0 (10.8)	**1.2 (0.1 to 2.2)**
MCI (n=107)	59.9 (9.0)	58.9 (10.0)	-1.1 (-2.7 to 0.6)
No diagnosis (n=36)	60.6 (9.0)	62.7 (11.8)	2.1 (-1.2 to 5.3)
EQ-5D-3L Proxy index score (n=416)	0.63 (0.30)	0.60 (0.31)	-0.03 (-.05 to .006)
Dementia (n=264)	0.62 (0.30)	0.59 (0.31)	-0.03 (-.06 to .005)
MCI (n=101)	0.67 (0.28)	0.62 (0.29)	**-0.05 (-0.1 to -.008)**
No diagnosis (n=33)	0.58 (0.34)	0.56 (0.34)	-0.02 (-0.1 to .07)

MCI – mild cognitive impairment. Numbers in **bold** indicate statistically significant difference between baseline and 12 month scores, $p<0.05$.

Table 3: Change in self- and proxy-reported health-related quality of life by patient characteristics

Patient characteristics	DEMQOL				DEMQOL-Proxy			
	N	Change (SD) in score over 12 months	Adjusted difference in change * (95% CI with Bonferroni correction) (n=670)	P-value	N	Change (SD) in score over 12 months	Adjusted difference in change * (95% CI with Bonferroni correction) (n=435)	P-value
Ages (years)								
<75	231	4.0 (10.0)	Reference		142	1.2 (8.7)	Reference	
75-79	158	3.4 (10.8)	-0.7 (-3.6 to 2.2)	0.46	111	0.7 (8.4)	-0.7 (-3.8 to 2.3)	0.48
80-84	163	2.5 (9.6)	-1.0 (-4.0 to 1.9)	0.30	105	-0.7 (8.5)	-1.6 (-5.3 to 2.1)	0.21
≥85	142	3.8 (11.9)	0.2 (-3.4 to 3.8)	0.86	89	1.6 (10.0)	-0.3 (-4.1 to 3.5)	0.82
Sex								
Male	359	2.7 (9.9)	Reference		259	0.8 (9.0)	Reference	
Female	335	4.3 (11.0)	1.9 (-0.2 to 4.0)	0.01	188	0.6 (8.6)	-0.7 (-3.7 to 2.2)	0.45
Ethnicity								
White/White British	658	3.6 (10.5)	Reference		431	0.6 (8.8)	Reference	
Other ethnicity	33	2.5 (11.8)	-1.9 (-6.7 to 2.9)	0.24	16	4.6 (10.4)	3.2 (-4.2 to 10.7)	0.20
Deprivation								
1 – least deprived	182	2.2 (9.6)	Reference		130	0.2 (7.7)	Reference	
2	161	3.9 (10.4)	0.9 (-2.9 to 4.6)	0.50	105	0.01 (7.6)	-0.5 (-3.9 to 2.9)	0.63
3	129	4.0 (10.9)	1.2 (-1.5 to 3.9)	0.20	81	1.0 (8.9)	1.0 (-3.0 to 5.0)	0.46
4	122	4.1 (10.6)	0.8 (-1.8 to 3.5)	0.35	71	2.0 (10.7)	1.4 (-3.1 to 5.9)	0.37
5 – most deprived	92	3.3 (11.3)	1.0 (-2.8 to 4.9)	0.43	54	0.7 (10.8)	-0.4 (-4.4 to 3.6)	0.78
Number of comorbidities								
None	148	3.3 (11.3)	Reference		89	0.7 (9.5)	Reference	
1	198	3.7 (11.1)	0.4 (-2.8 to 3.5)	0.74	129	0.9 (8.3)	-0.4 (-4.2 to 3.3)	0.72
2	155	3.8 (10.6)	0.5 (-3.3 to 4.3)	0.69	107	-0.2 (9.3)	-0.7 (-4.7 to 3.2)	0.58
3 or more	192	3.2 (9.1)	-0.8 (-4.3 to 2.7)	0.48	122	1.4 (8.6)	-0.1 (-3.8 to 3.6)	0.91

* Adjusted for age, sex, ethnicity, deprivation, number of comorbidities, diagnosis, HRQL score at baseline and clustering by clinic. Bonferroni-corrected 95% confidence intervals (family-wise error rate of 0.05 for each model divided by number of tests, p=0.004).

Table 4: Change in health-related quality of life at 12 months among patients with dementia diagnosis, by post-diagnostic interventions received (random effects model)

	DEMQOL				DEMQOL-Proxy			
	N	**Change (SD) in equated score over 12 months**	**Adjusted difference in change * (95% CI)**	**P-value**	**N**	**Change (SD) in equated score over 12 months**	**Adjusted difference in change * (95% CI)**	**P-value**
Anti-dementia drugs								
No	107	3.4 (12.1)	Reference		102	0.7 (9.1)	Reference	
Yes	183	6.0 (10.5)	3.7 (-0.1 to 7.5)	0.06	179	1.4 (8.5)	1.2 (-1.3 to 3.8)	0.34
Psychosocial interventions								
No	198	4.3 (11.2)	Reference		192	0.6 (8.6)	Reference	
Yes	97	6.6 (11.1)	1.4 (-1.5 to 4.3)	0.34	93	2.0 (8.8)	1.6 (-1.0 to 4.1)	0.22

* Adjusted for age, sex, ethnicity, deprivation, number of comorbidities, cognitive function, HRQL score at baseline and clinic as a random effect

Table 5: Differences in mean patient health-related quality of life scores at 12 months by MAS characteristics, in all participants and those with diagnosed dementia

MAS characteristics	Adjusted mean difference in patient HRQL score (95% CI with Bonferroni correction) and p-value							
	All participants				Participants with diagnosed dementia			
Structural characteristics	**DEMQOL (n=655)**		**DEMQOL-Proxy (n=417)**		**DEMQOL (n=381)**		**DEMQOL-Proxy (n=267)**	
Psychologists	-0.3 (-3.6 to 2.9)	0.76	-1.4 (-5.2 to 2.4)	0.29	-0.9 (-5.3 to 3.5)	0.55	-0.6 (-4.6 to 3.4)	0.65
Allied Health Professionals	1.3 (-2.4 to 5.0)	0.30	0.3 (-4.5 to 5.0)	0.86	0.7 (-3.4 to 4.8)	0.62	0.8 (04.7 to 6.2)	0.68
Advisory & Support staff	2.2 (-1.1 to 5.5)	0.04	2.7 (-1.4 to 6.7)	0.05	**4.3 (0.9 to 7.8) ***	<0.001	2.0 (-3.0 to 7.1)	0.23
New patients per WTE staff per month (Reference: 1-3)								
4-6	1.5 (-2.1 to 5.0)	0.21	1.9 (-3.1 to 6.8)	0.26	1.5 (-2.9 to 5.8)	0.32	1.2 (-4.3 to 6.8)	0.51
7 or more	0.07 (-3.6 to 3.8)	0.96	2.7 (-1.9 to 7.4)	0.08	1.2 (-3.3 to 5.6)	0.44	3.0 (-2.4 to 8.5)	0.10
New patients seen per month (Reference: <25)								
25-49	0.6 (-3.1 to 4.3)	0.64	0.3 (-4.4 to 5.0)	0.86	0.2 (-5.1 to 5.5)	0.92	-0.5 (-6.5 to 5.5)	0.81
50-74	-0.1 (-4.1 to 3.8)	0.93	-0.7 (-6.1 to 4.6)	0.69	-1.0 (-6.1 to 4.1)	0.56	-2.5 (-9.3 to 4.4)	0.29
75 or more	0.2 (-4.4 to 4.8)	0.89	-1.0 (-6.0 to 4.1)	0.58	-1.4 (-7.1 to 4.4)	0.47	-1.8 (-8.0 to 4.5)	0.40
ECG offered at first appointment	0.4 (-3.2 to 4.0)	0.74	0.07 (-3.7 to 3.8)	0.96	0.3 (-4.0 to 4.6)	0.85	2.4 (-1.7 to 6.4)	0.08
Neurological examination offered at first appointment	-1.1 (-4.8 to 2.5)	0.36	0.7 (-3.2 to 4.6)	0.57	-1.1 (-5.7 to 3.5)	0.47	-0.4 (-4.8 to 4.1)	0.81
Physical examination offered at follow up	-0.08 (-4.0 to 3.9)	0.95	-2.1 (-7.6 to 3.3)	0.25	-0.4 (-4.7 to 3.9)	0.79	-1.7 (-8.3 to 5.0)	0.46
Vision/hearing/mobility assessment offered at follow up	-0.6 (-4.0 to 2.7)	0.93	2.0 (-3.0 to 7.1)	0.23	-0.3 (-4.9 to 4.2)	0.83	1.3 (-5.3 to 7.8)	0.56
Provision of psychosocial support	-0.6 (-4.0 to 2.7)	0.58	1.9 (-2.8 to 6.6)	0.23	0.05 (-3.7 to 3.8)	0.97	1.2 (-3.4 to 5.8)	0.45
Process characteristics								
Waiting time to first appointment >6 weeks	-1.2 (-4.4 to 2.0)	0.26	-2.3 (-7.4 to 2.8)	0.18	-1.5 (-5.4 to 2.4)	0.26	0.008 (-6.4 to 6.4)	0.99
Length of first appointment (Reference: ≤60 mins)								
61-90 mins	-0.4 (-3.2 to 2.4)	0.68	-0.7 (-4.5 to 3.1)	0.58	-1.3 (-4.8 to 2.1)	0.35	-0.3 (-5.1 to 4.5)	0.85
>90 mins	1.1 (-2.3 to 4.5)	0.35	-0.5 (-5.1 to 4.2)	0.76	2.3 (-1.8 to 6.4)	0.10	-0.9 (-6.4 to 4.5)	0.61

Two or more follow up appointments (Reference: ≤1)	1.3 (-2.1 to 4.6)	0.26	-2.2 (-7.1 to 2.7)	0.18	1.7 (-1.9 to 5.3)	0.16	-0.6 (-6.6 to 5.5)	0.77

ECG – electrocardiogram; MAS – memory assessment service; WTE – whole time equivalent. Adjusted differences and Bonferroni-corrected 95% confidence intervals (family-wise error rate of 0.05 for each model divided by number of tests, p=0.003). Higher score indicates better health-related quality of life, HRQL. Adjusted for all structural and process characteristics, HRQL score at baseline, patient age, sex, ethnicity, deprivation, comorbidity, diagnosis and MAS as a random effect. * Statistically significant at family-wise error rate <0.05.