STUDIES USING THE DEMQOL

This document is meant to highlight the available literature surrounding the DEMQOL and DEMQOL-Proxy. This should not be seen as a comprehensive list. Please note, the studies listed in this document only reflect those that have utilised the DEMQOL or DEMQOL-Proxy measure. The use of the measure, and the presence in this document, does not necessarily mean that measures were utilised in accordance with original guidelines.

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CONTENTS

English Language: ........................................................................................................2

Other Languages:........................................................................................................13

Chinese .........................................................................................................................13

Russian .........................................................................................................................13

German.........................................................................................................................14

Spanish .........................................................................................................................15
ENGLISH LANGUAGE:


- **Version:** DEMQOL & DEMQOL-Proxy.
- **Procedure:** Measured DEMQOL pre and post 7 week CST intervention.
- **Population:** 272 participants; individuals with dementia and their carer, 50% community dwelling and 50% care home residents.


- **Versions:** DEMQOL and DEMQOL-Proxy
- **Procedure:** Compared the EQ-5D with the DEMQOL and both proxies with each other
- **Population:** 272 participants with mild to moderate dementia.


- **Version:** DEMQOL & DEMQOL-Proxy
- **Procedure:** Measured DEMQOL at baseline, 13 weeks and 39 weeks in three groups; placebo, sertraline and mirtazapine.
- **Population:** 326 individuals diagnosed with probable Alzheimer’s disease and depression.

- **Version:** DEMQOL-Proxy
- **Procedure:** Measured DEMQOL and other measures in a cross-sectional study (e.g. NPI, MMSE) to calculate their associations with DEMQOL.
- **Population:** 200 participants; individuals with a diagnosis of dementia and their carer.


- **Version:** DEMQOL and DEMQOL-Proxy
- **Procedure:** Measured DEMQOL at baseline and at 6 month follow up.
- **Population:** 247 service users of the memory service over an 18-month period.


- **Version:** Amended version of the DEMQOL system
- **Procedure:** Measured DEMQOL at baseline, immediately following the intervention and at 3-6 months following baseline.
- **Population:** 320 participants; residential aged care facilities staff.
28th February 2017


- **Version**: DEMQOL and DEMQOL-Proxy.
- **Procedure**: Measured DEMQOL pre, post and 10-weeks following ‘Singing Together Group’ intervention.
- **Population**: 10 participants over 65 years with dementia or MCI and their family carers.


- **Version**: DEMQOL and DEMQOL-Proxy.
- **Procedure**: Measures administered pre-randomisation at baseline, 5 months and 12 months during intervention.
- **Population**: 289 people with dementia and their family carers.


- **Version**: DEMQOL and DEMQOL-Proxy
- **Procedure**: Measures completed at memory assessment service
- **Population**: 868 community-dwelling people with dementia and 909 informants


- **Version**: DEMQOL.
28th February 2017

- **Procedure:** Measured DEMQOL 4 times throughout the 12 months of the study.
- **Population:** 1 participant with mild-moderate dementia living in sheltered housing.


- **Version:** DEMQOL and DEMQOL-Proxy.
- **Procedure:** Measured DEMQOL at baseline and 90 days following randomisation to either standard care or a specialist unit.
- **Population:** 600 participants over 65 years, identified as being ‘confused’ on admittance to hospital.


- **Version:** DEMQOL-Proxy
- **Procedure:** DEMQOL-Proxy was self-administered to establish the reliability and validity of self-administering this measure
- **Population:** 173 informal carers of memory assessment service users.


- **Version:** DEMQOL-Proxy
- **Procedure:** Cross-sectional study investigating the relationship between perception of pain, sleep quality and DEMQOL-Proxy.
- **Population:** 88 participants with dementia and their family caregivers.

- **Version:** DEMQOL-Proxy.
- **Procedure:** Measured DEMQOL 52 weeks after randomisation to one of four treatment groups; (1) continue donepezil, (2) stop donepezil, (3) stop donepezil and take memantine and (4) continue donepezil and take memantine.
- **Population:** 295 community-dwelling participants with moderate-severe dementia, receiving donepezil for at least 3 months and their caregivers.


- **Version:** DEMQOL and DEMQOL-Proxy.
- **Procedure:** Measured DEMQOL to investigate the relationship between insight and HRQL in dementia.
- **Population:** 256 participants with Alzheimer’s disease recruited and their carers.


- **Version:** DEMQOL and DEMQOL-Proxy
- **Procedure:** Cross-sectional study which utilised the DEMQOL and DEMQOL-Proxy to investigate the relationship between HRQL and dependency.
- **Population:** 249 participants, both community-dwelling and institutionalised, with Alzheimer’s disease and a knowledgeable informant.

- **Version**: DEMQOL-Proxy
- **Procedure**: 6 month interventional study, whereby measures were completed monthly
- **Population**: 31 care home residents with mild to moderate dementia


- **Version**: DEMQOL and DEMQOL-Proxy.
- **Procedure**: Measured DEMQOL pre, post and 13 weeks following a humour therapy intervention in two groups; (1) treatment and (2) control group.
- **Population**: 398 participants; residents of nursing homes that cater for dementia.


- **Version**: DEMQOL-Proxy.
- **Procedure**: Measured DEMQOL and frailty in two groups; (1) milder cognitive impairment and (2) moderate-severe cognitive impairment, to investigate relationship between frailty and HRQL.
- **Population**: 115 participants; community dwelling individuals with Alzheimer’s disease or MCI and their carers.

- **Version:** DEMQOL-U and DEMQOL-Proxy-U.
- **Procedure:** Produced two dementia-specific preference-based measures for use in economic evaluation; DEMQOL-U and DEMQOL-Proxy-U.
- **Population:** 1327 participants in stage 1; individuals with mild-moderate dementia and their carers, 742 participants in stage 2; general population, individuals with mild dementia and their carers.


- **Version:** DEMQOL and DEMQOL-Proxy.
- **Procedure:** Developed a health state classification system based on DEMQOL system.
- **Population:** 1327 participants; individuals with mild to moderate dementia and their carers.


- **Version:** DEMQOL and DEMQOL-Proxy.
- **Procedure:** Measured DEMQOL and DEMQOL-Proxy at baseline, 13 weeks and 26 weeks.
- **Population:** 356 dyads of individuals with dementia and their family carers.

- **Version**: DEMQOL and DEMQOL-Proxy.
- **Procedure**: Measured DEMQOL at baseline, immediately before, 3 months following and 6 months following randomisation into either the (1) maintenance CST group (24 weeks) or (2) treatment as usual group.
- **Population**: 236 participants; individuals with mild-moderate dementia who had completed 7 weeks of CST (14 sessions).


- **Versions**: DEMQOL and DEMQOL-Proxy
- **Procedure**: Both measures were used at baseline and 6 month follow up to assess change in quality of life
- **Population**: 785 memory assessment service users and 511 informal carers


- **Version**: DEMQOL domains mapped onto retrospective data to produce amended version.
- **Procedure**: Measured DEMQOL and other constructs to investigate associations with HRQL.
- **Population**: 110 participants; individuals with mild-moderate dementia, over 80 years, living in the community or a care home.

- **Versions:** DEMQOL-U and DEMQOL Proxy-U
- **Procedure:** Measures were administered at baseline and 4 weeks and compared to the EQ-5D to establish suitability of the measures with elderly people, regardless of cognitive ability
- **Population:** 240 elderly participants in residential care, recovering from hip fracture surgery.


- **Versions:** DEMQOL and DEMQOL-Proxy
- **Procedure:** The measures were utilised to see if QOL was associated with cost of care, among many other explanatory variables
- **Population:** 277 care or nursing home residents with dementia


- **Version:** DEMQOL and DEMQOL-Proxy.
- **Procedure:** Produced preference-based single index measures; DEMQOL-U and DEMQOL-Proxy-U.
- **Population:** 593 participants; members of the general population.

- **Version:** DEMQOL-U and DEMQOL-Proxy-U.
- **Population:** 155 general population, 71 patients with mild dementia and 71 carers.


- **Version:** DEMQOL and DEMQOL-Proxy.
- **Procedure:** Measured DEMQOL at baseline and at 12 month follow up in two groups; (1) individuals with dementia or (2) carers to investigate caregiver-patient discrepancies.
- **Population:** 105 participants with probable Alzheimer’s disease and their carers.


- **Version:** DEMQOL.
- **Procedure:** Measured DEMQOL in three different patient-carer groups to explore the perception of suffering; (1) Dementia, (2) Osteoarthritis and (3) Dementia in African American/Hispanic individuals.
- **Population:** 279 participants and their carers.

Version: DEMQOL.

Procedure: Measured DEMQOL pre-, post- and 4 weeks following a 6 week acupuncture intervention.

Population: 16 participants aged 50-80 years with a diagnosis of Vascular dementia.


Version: DEMQOL-Proxy

Procedure: DEMQOL-Proxy completed at follow-up for participants lacking an EQ-5D score

Population: 600 ‘confused’ patients admitted for acute hospital health care.


Version: DEMQOL and DEMQOL-Proxy.

Procedure: Measured DEMQOL and DEMQOL-Proxy at baseline and at 18 months to assess the relationship between disease severity and changes in quality of life.

OTHER LANGUAGES:

**Chinese**

- **Version**: DEMQOL and DEMQOL-Proxy
- **Procedure**: DEMQOL and Proxy were administered at baseline, after 6 weeks treatment and 4 weeks post-treatment
- **Population**: 68 participants with Vascular Dementia

**Russian**

- **Version**: DEMQOL (Russian version).
- **Procedure**: Measured DEMQOL at baseline and 6 months in two groups: (1) Caregiver education and training intervention group and (2) Treatment as usual group.
- **Population**: 60 participants; family caregivers of individuals over 65, with dementia.


- **Version**: DEMQOL-Proxy (Russian version).
- **Procedure**: Measured DEMQOL at baseline and 24 weeks in a (1) Treatment (Gingko Biloba) group and (2) Placebo group.
- **Population**: 410 participants; outpatients with mild-moderate dementia and their carers.

- **Version:** DEMQOL-Proxy (Russian version).
- **Procedure:** Measured DEMQOL at baseline, 12 weeks and 24 weeks in a (1) Treatment (Gingko Biloba) group and (2) Placebo group.
- **Population:** 404 participants; individuals with Alzheimer’s disease, Vascular dementia or Alzheimer’s disease with vascular components exhibiting neuropsychiatric symptoms, and their carers.


- **Version:** DEMQOL-Proxy (Russian version).
- **Procedure:** Measured DEMQOL at baseline, 12 weeks and 24 weeks in a (1) Treatment (Gingko Biloba) group and (2) Placebo group.
- **Population:** 404 participants; individuals with Alzheimer's disease, Vascular dementia or Alzheimer’s disease with vascular components exhibiting neuropsychiatric symptoms, and their carers.

**German**


Spanish

Procedure: Measured DEMQOL at baseline and at 6 months in the (1) caregiver intervention group and (2) control group.

Population: 58 participants; individuals with dementia over 65 and their carers.


Version: DEMQOL and DEMQOL-Proxy (Spanish versions).

Procedure: Psychometric testing and validation of Spanish DEMQOL system.

Population: 119 participants; individuals with dementia and their carers.


Version: DEMQOL (Spanish versions).

Procedure: Psychometric testing and validation of Spanish WHOQOL-BREF system.

Population: 104 participants with mild-moderate dementia.