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The DEMQOL Bibliography

YVONNE FEENEY, ALICE RUSSELL AND NICOLAS FARINA
CENTRE FOR DEMENTIA STUDIES, BRIGHTON AND SUSSEX MEDICAL
SCHOOL

PREFACE

This document is meant to provide an overview of research studies that has utilised various iterations of the DEMQOL instrument (e.g. DEMQOL, DEMQOL-Proxy, DEMQOL-CH or C-DEMQOL). The hope is that this document can provide an insight in when and how these measures have been used in the past.

Please note:

- This should not be seen as a definitive list of the existing literature.
- It is recommended you access the original publication prior to citing them.
- The use of these measures, and the presence in this document, does not necessarily mean that measures were utilised in accordance with original guidelines or have been formally evaluated.

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ENGLISH LANGUAGE:

Abendstern, M., Davies, K., Poland, F., Chester, H., Clarkson, P., Hughes, J., ... Challis, D. (2019). Reflecting on the research encounter for people in the early stages of dementia: Lessons from an embedded qualitative study. *Dementia*. <https://doi.org/10.1177/1471301219855295>

- *Version: DEMQOL*
- *Procedure: Embedded qualitative study undertaken within a pragmatic randomised controlled trial*
- *Population: 14 dyads; individuals with mild to moderate dementia (aged 50+) and their carer. Participants lived at home independently or with a carer.*

Aguirre, E., Hoare, Z., Streater, A., Spector, A., Woods, B., Hoe, J., & Orrell, M. (2013). Cognitive stimulation therapy (CST) for people with dementia—who benefits most? *International Journal of Geriatric Psychiatry*, 28(3), 284–290. doi:10.1002/gps.3823

- *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.*

Aguirre, E., Kang, S., Hoare, Z., Edwards, R. T., & Orrell, M. (2016). How does the EQ-5D perform when measuring quality of life in dementia against two other dementia-specific outcome measures? *Quality of Life Research*, 25(1), 45-49. doi:10.1007/s11136-015-1065-9

- *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.*

Alford, K., Banerjee, S., Nixon, E., O'Brien, C., Pounds, O., Butler, A., ... Vera, J. H. (2019). Assessment and management of HIV-associated cognitive impairment: Experience from a multidisciplinary memory service for people living with HIV. *Brain Sciences*, 9(2). <https://doi.org/10.3390/brainsci9020037>

- *Version: DEMQOL*
- *Design: Service evaluation*
- *Population: 52 people living with HIV (aged 36-84)*

Ballard, C., Orrell, M., Sun, Y., Moniz-Cook, E., Stafford, J., Whitaker, R., ... Fossey, J. (2017). Impact of antipsychotic review and non-pharmacological intervention on health-related quality of life in people with dementia living in care homes: WHELD—a factorial cluster randomised controlled trial. *International Journal of Geriatric Psychiatry*, 32(10), 1094–1103. <https://doi.org/10.1002/gps.4572>

- *Version: DEMQOL-Proxy*
- *Procedure: Cluster randomised factorial study in 16 UK care homes*
- *Population: 277 care home residents with dementia were randomised into the study.*

Banerjee, S., Hellier, J., Romeo, R., Dewey, M., Knapp, M., Ballard, C., ... Burns, A. (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 Technology Assessment (Winchester, England)*, 17(7), 1–166. doi:10.3310/hta17070

- *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.

Banerjee, S., Smith, S. C., Lamping, D. L., Harwood, R. H., Foley, B., Smith, P., ... Knapp, M. (2006). Quality of life in dementia: more than just cognition. An analysis of associations with quality of life in dementia. *Journal of Neurology, Neurosurgery, and Psychiatry*, 77(2), 146–148. doi:10.1136/jnnp.2005.072983

- **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.

Banerjee, S., Willis, R., Matthews, D., Contell, F., Chan, J., & Murray, J. (2007). Improving the quality of care for mild to moderate dementia: an evaluation of the Croydon Memory Service Model. *International Journal of Geriatric Psychiatry*, 22(8), 782–788. doi:10.1002/gps.1741

- **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.

Borbasi, S., Emmanuel, E., Farrelly, B., & Ashcroft, J. (2011). Report of an evaluation of a Nurse-led Dementia Outreach Service for people with the behavioural and psychological symptoms of dementia living in residential aged care facilities. *Perspectives in Public Health*, 131(3), 124–130. doi:10.1177/1757913911400143

- **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.

Brown, A., Page, T. E., Daley, S., Farina, N., Basset, T., Livingston, G., ... Banerjee, S. (2019). Measuring the quality of life of family carers of people with dementia: development and validation of C-DEMQOL. *Quality of Life Research*, 28(8), 2299–2310. <https://doi.org/10.1007/s11136-019-02186-w>

- **Version:** *DEMQOL-Proxy and C-DEMQOL*
- **Procedure:** *Validation of the C-DEMQOL measure.*
- **Population:** *300 family carers of people with a clinical diagnosis of dementia.*

Brown, H., D'Amico, F., Knapp, M., Orrell, M., Rehill, A., Vale, L., & Robinson, L. (2019). A cost effectiveness analysis of maintenance cognitive stimulation therapy (MCST) for people with dementia: examining the influence of cognitive ability and living arrangements. *Aging and Mental Health*, 23(5), 602–607. <https://doi.org/10.1080/13607863.2018.1442410>

- **Version:** *DEMQOL and DEMQOL-Proxy*
- **Design:** *Secondary analysis (Orrell et al., 2014), cost effectiveness of cognitive stimulation therapy*
- **Population:** *236 participants; individuals with mild-moderate dementia who had completed 7 weeks of CST (14 sessions).*

Brueggen, K., Kasper, E., Ochmann, S., Pfaff, H., Webel, S., Schneider, W., & Teipel, S. (2017). Cognitive Rehabilitation in Alzheimer's Disease: A Controlled Intervention Trial. *Journal of Alzheimer's Disease*, 57(4), 1315–1324.

- **Version:** *DEMQOL*
- **Procedure:** *Controlled partial-randomized design*
- **Population:** *16 people with mild Alzheimer's Disease or Mixed dementia living at home.*

Budgett, J., Brown, A., Daley, S., Page, T. E., Banerjee, S., Livingston, G., & Sommerlad, A. (2019). The social functioning in dementia scale (SF-DEM): Exploratory factor analysis and psychometric properties in mild, moderate, and severe dementia. *Alzheimer's and Dementia: Diagnosis, Assessment and Disease Monitoring*, 11, 45–52.
<https://doi.org/10.1016/j.dadm.2018.11.001>

- *Version: DEMQOL-Proxy*
- *Design: Cross-sectional study.*
- *Population: 299 carers of people with dementia.*

Camic, P. M., Williams, C. M., & Meeten, F. (2013). Does a ‘Singing Together Group’ improve the quality of life of people with a dementia and their carers? A pilot evaluation study. *Dementia*, 12(2), 157-176. doi:10.1177/1471301211422761

- *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.*

Charlesworth, G., Burnell, K., Crellin, N., Hoare, Z., Hoe, J., Knapp, M., . . . Orrell, M. (2016). Peer support and reminiscence therapy for people with dementia and their family carers: a factorial pragmatic randomised trial. *J Neurol Neurosurg Psychiatry*, 87(11), 1218-1228. doi:10.1136/jnnp-2016-313736

- *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*

Chua, K. C., Brown, A., Little, R., Matthews, D., Morton, L., Loftus, V., . . . Banerjee, S. (2016). Quality-of-life assessment in dementia: the use of DEMQOL and DEMQOL-Proxy total scores. *Qual Life Res*, 25(12), 3107-3118. doi:10.1007/s11136-016-1343-1

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

Clare, L., Kudlicka, A., Oyebode, J. R., Jones, R. W., Bayer, A., Leroi, I., . . . Woods, B. (2019). Goal-oriented cognitive rehabilitation for early-stage alzheimer's and related dementias: The GREAT RCT. *Health Technology Assessment*, 23(10), 1–244. <https://doi.org/10.3310/hta23100>

- *Version: DEMQOL.*
- *Design: Multicentre two-arm, single-blind pragmatic randomised controlled trial compared cognitive rehabilitation with treatment as usual*
- *Population: 475 people with dementia, diagnosed with Alzheimer's disease, vascular dementia or mixed Alzheimer's disease and vascular dementia. All participants had relatively mild dementia (MMSE \geq 18).*

Clare, L., Kudlicka, A., Oyebode, J. R., Jones, R. W., Bayer, A., Leroi, I., . . . Woods, B. (2019). Individual goal-oriented cognitive rehabilitation to improve everyday functioning for people with early-stage dementia: A multicentre randomised controlled trial (the GREAT trial). *International Journal of Geriatric Psychiatry*, 34(5), 709–721. <https://doi.org/10.1002/gps.5076>

- *Version: DEMQOL.*

- **Design:** *Multicentre two-arm, single-blind pragmatic randomised controlled trial compared cognitive rehabilitation with treatment as usual*
- **Population:** *475 people with dementia, diagnosed with Alzheimer's disease, vascular dementia or mixed Alzheimer's disease and vascular dementia. All participants had relatively mild dementia (MMSE ≥ 18).*

Coe, Á., Martin, M., & Stapleton, T. (2019). Effects of An Occupational Therapy Memory Strategy Education Group Intervention on Irish Older Adults' Self-Management of Everyday Memory Difficulties. *Occupational Therapy in Health Care*, 33(1), 37–63.
<https://doi.org/10.1080/07380577.2018.1543911>

- **Version:** *DEMQOL.*
- **Design:** *A quasi-experimental one -group pre-test post-test prospective clinical study design.*
- **Population:** *47 with subjective memory complaints, MCI or mild dementia (MMSE score ≥ 18)*

Easton, T., Milte, R., Crotty, M., & Ratcliffe, J. (2018). An empirical comparison of the measurement properties of the EQ-5D-5L, DEMQOL-U and DEMQOL-Proxy-U for older people in residential care. *Quality of Life Research*, 27(5), 1283–1294.
<https://doi.org/10.1007/s11136-017-1777-0>

- **Version:** *DEMQOL and DEMQL-Proxy*
- **Design:** *Secondary data analysis using data collected from The INSPIRED study which was a cross-sectional, observational study*
- **Population:** *541 permanent residents of residential aged care facilities*

Evans, N., Carey-Smith, B., & Orpwood, R. (2011). Using smart technology in an enabling way: a review of using technology to support daily life for a tenant with moderate dementia.

The British Journal of Occupational Therapy, 74(5), 249–253.

doi:10.4276/030802211X13046730116614

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

Ferry, F., Ryan, A., McCauley, C. O., Laird, E. A., Gibson, A., Mulvenna, M. D., ... Curran, K. (2018). Economic costs and health-related quality of life associated with individual specific reminiscence: Results from the InspireD Feasibility Study. *Dementia*. Ulster University, United Kingdom. <https://doi.org/10.1177/1471301218816814>

- *Version: DEMQOL and DEMQOL-Proxy.*
- *Design: Economic analysis of Intervention study*
- *Population: 60 participants; 30 people with mild to moderate dementia and their family carers.*

Forrester-Jones, R., Beecham, J. K., Barnoux, M., Oliver, D., Couch, E., & Bates, C. (2017). People with intellectual disabilities at the end of their lives: The case for specialist care? *Journal of Applied Research in Intellectual Disabilities*, 30(6), 1138–1150. <https://doi.org/10.1111/jar.12412>

- *Version: DEMQOL-Proxy.*
- *Design: Mixed-methods case design.*
- *Population: 9 care home residents with intellectual disabilities (6 with dementia). 14 care staff working in the home.*

Goldberg, S. E., Bradshaw, L. E., Kearney, F. C., Russell, C., Whittamore, K. H., Foster, P. E. R., ... Harwood, R. H. (2013). Care in specialist medical and mental health unit compared

with standard care for older people with cognitive impairment admitted to general hospital: randomised controlled trial (NIHR TEAM trial). *BMJ*, 347, f4132. doi:10.1136/bmj.f4132

- *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.*

Gomes, M., Pennington, M., Black, N., & Smith, S. (2019). Cost-effectiveness analysis of English memory assessment services 2 years after first consultation for patients with dementia. *International Journal of Geriatric Psychiatry*, 34(3), 439–446. <https://doi.org/10.1002/gps.5036>

- *Version: DEMQOL*
- *Design: Service evaluation*
- *Population: 1318 patients with suspected dementia, referred to memory assessment services.*

Gomes, M., Pennington, M., Wittenberg, R., Knapp, M., Black, N., & Smith, S. (2017). Cost-effectiveness of memory assessment services for the diagnosis and early support of patients with dementia in England. *Journal of Health Services Research and Policy*, 22(4), 226–235. <https://doi.org/10.1177/1355819617714816>

- *Version: DEMQOL*
- *Design: Service evaluation*
- *Population: 1318 patients with suspected dementia, referred to memory assessment services.*

Harrison, S. L., Bradley, C., Milte, R., Liu, E., Kouladjian O'Donnell, L., Hilmer, S. N., & Crotty, M. (2018). Psychotropic medications in older people in residential care facilities and associations with quality of life: A cross-sectional study. *BMC Geriatrics*, 18(1).

<https://doi.org/10.1186/s12877-018-0752-0>

- *Version: DEMQOL and DEMQOL-Proxy*
- *Design: Cross-sectional*
- *Population: 541 participants who are long-term permanent residents of old age residential homes.*

Harwood, R. H., van der Wardt, V., Goldberg, S. E., Kearney, F., Logan, P., Hood-Moore, V., ... Orrell, M. (2018). A development study and randomised feasibility trial of a tailored intervention to improve activity and reduce falls in older adults with mild cognitive impairment and mild dementia. *Pilot and Feasibility Studies*, 4(1). [https://doi.org/10.1186/s40814-018-](https://doi.org/10.1186/s40814-018-0239-y)

[0239-y](https://doi.org/10.1186/s40814-018-0239-y)

- *Version: DEMQOL and DEMQOL-Proxy*
- *Design: Feasibility*
- *Population: 60 participants with a diagnosis of mild dementia of MCI*

Hendriks, A. A., Smith, S. C., Chrysanthaki, T., & Black, N. (2017). Reliability and validity of a self-administration version of DEMQOL-Proxy. *Int J Geriatr Psychiatry*. doi:10.1002/gps.4515

- *Version: DEMQOL-Proxy (self-administered)*
- *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.*

Hendriks, A. A. J., Smith, S. C., Chrysanthaki, T., Cano, S. J., & Black, N. (2017). DEMQOL and DEMQOL-Proxy: A Rasch analysis. *Health and Quality of Life Outcomes*, 15(1). <https://doi.org/10.1186/s12955-017-0733-6>

- **Version:** *DEMQOL-Proxy and DEMQOL*
- **Design:** *Psychometric properties and Rasch analysis*
- **Population:** *500 people with suspected dementia.*

Hodgson, N., Gitlin, L. N., & Huang, J. (2014). The influence of sleep disruption and pain perception on indicators of quality of life in individuals living with dementia at home. *Geriatric Nursing*, 35(5), 394-398.

- **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.*

Howard, R., McShane, R., Lindesay, J., Ritchie, C., Baldwin, A., Barber, R., ... Phillips, P. (2012). Donepezil and Memantine for Moderate-to-Severe Alzheimer's Disease. *New England Journal of Medicine*, 366(10), 893–903. doi:10.1056/NEJMoa1106668

- **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.*

Hughes, L. J., Farina, N., Page, T. E., Tabet, N., & Banerjee, S. (2019). Adaptation of the DEMQOL-Proxy for routine use in care homes: A cross-sectional study of the reliability and validity of DEMQOL-CH. *BMJ Open*, 9(8). <https://doi.org/10.1136/bmjopen-2018-028045>

- *Version: DEMQOL-CH*
- *Design: Cross-sectional (Validity and reliability)*
- *Population: 30 Care staff (Phase 1, N=19; Phase 2, N=11)*

Hurt, C. S., Banerjee, S., Tunnard, C., Whitehead, D. L., Tsolaki, M., Mecocci, P., ... Lovestone, S. (2010). Insight, cognition and quality of life in Alzheimer's disease. *Journal of Neurology, Neurosurgery & Psychiatry*, 81(3), 331–336. doi:10.1136/jnnp.2009.184598

- *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.*

Jones, R. W., Romeo, R., Trigg, R., Knapp, M., Sato, A., King, D., . . . Lacey, L. (2015). Dependence in Alzheimer's disease and service use costs, quality of life, and caregiver burden: The DADE study. *Alzheimer's & Dementia*, 11(3), 280-290. doi:http://dx.doi.org/10.1016/j.jalz.2014.03.001

- *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.*

Kinnunen, K. M., Rapaport, P., Webster, L., Barber, J., Kyle, S. D., Hallam, B., ... Livingston, G. (2018). A manual-based intervention for carers of people with dementia and sleep disturbances: An acceptability and feasibility RCT. *Health Technology Assessment*, 22(71), I–408. <https://doi.org/10.3310/hta22710>

- *Version: DEMQOL-Proxy*
- *Procedure: Single-blind, randomised, parallel-group feasibility trial.*
- *Population: 62 people with dementia and sleep disturbances, and their primary carer.*

Knapp, M., King, D., Romeo, R., Adams, J., Baldwin, A., Ballard, C., ... Howard, R. (2017). Cost-effectiveness of donepezil and memantine in moderate to severe Alzheimer's disease (the DOMINO-AD trial). *International Journal of Geriatric Psychiatry*, 32(12), 1205–1216. <https://doi.org/10.1002/gps.4583>

- *Version: DEMQOL-Proxy*
- *Procedure: 52-week multicentre, double-blind, placebo-controlled trial*
- *Population: 295 community-dwelling patients with moderate to severe Alzheimer's disease already receiving donepezil.*

Laybourne, A., Livingston, G., Cousins, S., Rapaport, P., Lambe, K., La Frenais, F., ... Cooper, C. (2019). Carer coping and resident agitation as predictors of quality of life in care home residents living with dementia: Managing Agitation and Raising Quality of Life (MARQUE) English national care home prospective cohort study. *International Journal of Geriatric Psychiatry*, 34(1), 106–113. <https://doi.org/10.1002/gps.4994>

- *Version: DEMQOL and DEMQOL-Proxy*
- *Design: Prospective cohort study*
- *Population 1,483 care home residents with a diagnosis of dementia, and their carers (n=1,566)*

Livingston, G., Barber, J. A., Kinnunen, K. M., Webster, L., Kyle, S. D., Cooper, C., ... Rapaport, P. (2019). DREAMS-START (Dementia RELATED Manual for Sleep; STRategies for Relatives) for people with dementia and sleep disturbances: A single-blind feasibility and acceptability randomized controlled trial. *International Psychogeriatrics*, 31(2), 251–265. <https://doi.org/10.1017/S1041610218000753>

- *Version: DEMQOL-Proxy*
- *Design: Parallel-group, single blind randomised controlled trial, feasibility and acceptability*
- *Population: 62 participants with dementia and sleep disturbances (and their family carers)*

Livingston, G., Barber, J., Marston, L., Rapaport, P., Livingston, D., Cousins, S., ... Cooper, C. (2017). Prevalence of and associations with agitation in residents with dementia living in care homes: MARQUE cross-sectional study. *BJPsych Open*, 3(4), 171–178. <https://doi.org/10.1192/bjpo.bp.117.005181>

- *Version: DEMQOL-Proxy and DEMQOL*
- *Design: Cross-sectional*
- *Population: 1,489 care home residents with dementia*

Livingston, G., Barber, J., Marston, L., Stringer, A., Panca, M., Hunter, R., ... Rapaport, P. (2019). Clinical and cost-effectiveness of the Managing Agitation and Raising Quality of Life (MARQUE) intervention for agitation in people with dementia in care homes: a single-blind, cluster-randomised controlled trial. *The Lancet Psychiatry*, 6(4), 293–304. [https://doi.org/10.1016/S2215-0366\(19\)30045-8](https://doi.org/10.1016/S2215-0366(19)30045-8)

- *Version: DEMQOL-Proxy*
- *Design: Parallel-group, cluster-randomised controlled trial*

- **Population:** 318 care home residents with dementia, and care staff (n=354).

Longden, E., Davis, P., Carroll, J., Billington, J., & Kinderman, P. (2016). An evaluation of shared reading groups for adults living with dementia: preliminary findings. *Journal of Public Mental Health, 15*(2), 75-82. doi:10.1108/JPMH-06-2015-0023

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

Low, L.-F., Brodaty, H., Goodenough, B., Spitzer, P., Bell, J.-P., Fleming, R., ... Chenoweth, L. (2013). The Sydney Multisite Intervention of LaughterBosses and ElderClowns (SMILE) study: cluster randomised trial of humour therapy in nursing homes. *BMJ Open, 3*(1), e002072. doi:10.1136/bmjopen-2012-002072

- **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.

Mhaoláin, A. M. N., Gallagher, D., Crosby, L., Ryan, D., Lacey, L., Coen, R. F., ... Lawlor, B. (2012). Frailty and Quality of Life for People With Alzheimer's Dementia and Mild Cognitive Impairment. *American Journal of Alzheimer's Disease and Other Dementias, 27*(1), 48–54. doi:10.1177/1533317511435661

- **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.

Milte, R., Ratcliffe, J., Bradley, C., Shulver, W., & Crotty, M. (2019). Evaluating the quality of care received in long-term care facilities from a consumer perspective: Development and construct validity of the Consumer Choice Index - Six Dimension instrument. *Ageing and Society*, 39(1), 138–160. <https://doi.org/10.1017/S0144686X17000861>

- **Version:** DEMQOL and DEMQOL-Proxy (only subset of items used)
- **Procedure:** Development of the Consumer Choice Index–Six Dimension instrument. This study was nested in a large cross-sectional, observational study (INSPIRED)
- **Population:** 68 older residents who have been living in a care home for 12 months, not receiving palliative care, alongside family carers (N=185).

Mulhern, B., Rowen, D., Brazier, J., Smith, S., Romeo, R., Tait, R., ... Banerjee, S. (2013). Development of DEMQOL-U and DEMQOL-PROXY-U: generation of preference-based indices from DEMQOL and DEMQOL-PROXY for use in economic evaluation. *Health Technology Assessment (Winchester, England)*, 17(5), 1–140. doi:10.3310/hta17050

- **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.

Mulhern, B., Smith, S. C., Rowen, D., Brazier, J. E., Knapp, M., Lamping, D. L., ... Banerjee, S. (2012). Improving the measurement of QALYs in dementia: developing patient- and carer-

reported health state classification systems using Rasch analysis. *Value in Health: The Journal of the International Society for Pharmacoeconomics and Outcomes Research*, 15(2), 323–333. doi:10.1016/j.jval.2011.09.006

- **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.

Orgeta V., Leung P., Yates L., Kang S., Hoare Z., Henderson C,,... Orrell M. (2015). Individual cognitive stimulation therapy for dementia: a clinical effectiveness and cost-effectiveness pragmatic, multicentre, randomised controlled trial. *Health Technology Assessment* 25(1). doi:10.3310/hta19640

- **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

Orrell, M., Aguirre, E., Spector, A., Hoare, Z., Woods, R. T., Streater, A., ... Russell, I. (2014). Maintenance cognitive stimulation therapy for dementia: single-blind, multicentre, pragmatic randomised controlled trial. *The British Journal of Psychiatry*, Advance online publication. doi:10.1192/bjp.bp.113.137414

- **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).

- Orrell, M., Yates, L., Leung, P., Kang, S., Hoare, Z., Whitaker, C., ... Orgeta, V. (2017). The impact of individual Cognitive Stimulation Therapy (iCST) on cognition, quality of life, caregiver health, and family relationships in dementia: A randomised controlled trial. *PLoS Medicine*, 14(3). <https://doi.org/10.1371/journal.pmed.1002269>
- *Version: DEMQOL*
- *Procedure: Single-blind, pragmatic randomised controlled trial (RCT)*
- *Population: 356 people with mild to moderate dementia and their carers.*

Park, M. H., Black, N., Ritchie, C. W., Hendriks, A. A., & Smith, S. C. (2017). Is the effectiveness of memory assessment services associated with their structural and process characteristics? *Int J Geriatr Psychiatry*. doi:10.1002/gps.4675

- *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*

Park, M. H., Smith, S. C., Hendriks, A. A. J., & Black, N. (2019). Caregiver burden and quality of life 2 years after attendance at a memory clinic. *International Journal of Geriatric Psychiatry*, 34(5), 647–656. <https://doi.org/10.1002/gps.5060>

- *Versions: DEMQOL and DEMQOL-Proxy*
- *Design: Longitudinal study (24 months)*
- *Population: 187 memory assessment service users (out of n=1020 at baseline), and 653 informal carer provided longitudinal data (out of n=1020 at baseline).*

Park, M. H., Smith, S. C., Ritchie, C. W., Hendriks, A. A. J., & Black, N. (2018). Memory assessment services and health-related quality of life: 1-year follow-up. *International Journal of Geriatric Psychiatry*, 33(9), 1220–1228. <https://doi.org/10.1002/gps.4913>

- *Versions: DEMQOL and DEMQOL-Proxy*
- *Design: Longitudinal study (12 months)*
- *Population: 702 memory assessment services users and 452 informal carers.*

Pennington, M., Gomes, M., Chrysanthaki, T., Hendriks, J., Wittenberg, R., Knapp, M., ... Smith, S. (2018). The cost of diagnosis and early support in patients with cognitive decline. *International Journal of Geriatric Psychiatry*, 33(1), 5–13. <https://doi.org/10.1002/gps.4641>

- *Versions: DEMQOL and DEMQOL-Proxy*
- *Design: Observational study, cost analysis*
- *Population: 69 memory assessment services users*

Perales, J., Cosco, T. D., Stephan, B. C., Fleming, J., Martin, S., Haro, J. M., ... The CC75C Study. (2014). Health-related quality of life in the Cambridge City over-75s Cohort (CC75C): development of a dementia-specific scale and descriptive analyses. *BMC Geriatrics*, 14(1), 18. doi:10.1186/1471-2318-14-18

- *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.*

Ratcliffe, J., Flint, T., Easton, T., Killington, M., Cameron, I., Davies, O., . . . Crotty, M. (2017). An Empirical Comparison of the EQ-5D-5L, DEMQOL-U and DEMQOL-Proxy-U in a Post-

Hospitalisation Population of Frail Older People Living in Residential Aged Care. *Appl Health Econ Health Policy*. doi:10.1007/s40258-016-0293-7

- *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.*

Regan, B., & Wells, Y. (2018). Effectiveness of the maximising cognition (MAXCOG) information resource for clients with mild cognitive impairment and their families. *Australasian Journal on Ageing*, 37(1), E29–E32. <https://doi.org/10.1111/ajag.12479>

- *Versions: DEMQOL and DEMQOL-Proxy*
- *Design: Non-randomised controlled trial*
- *Population: 80 people with mild cognitive impairment or early dementia, and their family carers.*

Robertson, S., Cooper, C., Hoe, J., Lord, K., Rapaport, P., Marston, L., ... & Livingston, G. (2020). Comparing proxy rated quality of life of people living with dementia in care homes. *Psychological medicine*, 50(1), 86-95.

- *Versions: DEMQOL*
- *Procedure: Mixed-methods design, is nested in the Managing Agitation and Raising Quality of Life (MARQUE) national care home survey in England.*
- *Population: 1056 people with dementia living in care homes (alongside paid or unpaid carers).*

Romeo, R., Knapp, M., Salverda, S., Orrell, M., Fossey, J., & Ballard, C. (2017). The cost of care homes for people with dementia in England: a modelling approach. *Int J Geriatr Psychiatry*. doi:10.1002/gps.4637

- *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*

Romeo, R., Zala, D., Knapp, M., Orrell, M., Fossey, J., & Ballard, C. (2019). Improving the quality of life of care home residents with dementia: Cost-effectiveness of an optimized intervention for residents with clinically significant agitation in dementia. *Alzheimer's and Dementia*, 15(2), 282–291. <https://doi.org/10.1016/j.jalz.2018.08.010>

- **Versions:** *DEMQOL-Proxy*
- **Procedure:** *Cost-effectiveness analysis within a cluster-randomized factorial study*
- **Population:** *549 care home residents with clinically significant agitation in dementia.*

Rowen, D., Mulhern, B., Banerjee, S., Hout, B. van, Young, T. A., Knapp, M., ... Brazier, J. E. (2012). Estimating preference-based single index measures for dementia using DEMQOL and DEMQOL-Proxy. *Value in Health: The Journal of the International Society for Pharmacoeconomics and Outcomes Research*, 15(2), 346–356. doi:10.1016/j.jval.2011.10.016

- **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.*

Rowen, D., Mulhern, B., Banerjee, S., Tait, R., Watchurst, C., Smith, S. C., ... & Brazier, J. E. (2014). Comparison of general population, patient, and carer utility values for dementia health states. *Medical Decision Making*, 35, 68-80. doi: 10.1177/0272989X14557178.

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

Schulz, R., Cook, T. B., Beach, S. R., Lingler, J. H., Martire, L. M., Monin, J. K., & Czaja, S. J. (2013). Magnitude and Causes of Bias Among Family Caregivers Rating Alzheimer Disease Patients. *The American Journal of Geriatric Psychiatry*, 21(1), 14–25. doi:10.1016/j.jagp.2012.10.002

- *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.*

Schulz, R., Monin, J. K., Czaja, S. J., Lingler, J. H., Beach, S. R., Martire, L. M., ... Cook, T. B. (2010). Measuring the Experience and Perception of Suffering. *The Gerontologist*, 50(6), 774–784. doi:10.1093/geront/gnq033

- *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.*

Sheaff, R., Sherriff, I., & Hennessy, C. H. (2018). Evaluating a dementia learning community: Exploratory study and research implications. *BMC Health Services Research*, 18(1). <https://doi.org/10.1186/s12913-018-2894-3>

- *Version: DEMQOL.*
- *Procedure: Controlled mixed methods realistic evaluation*
- *Population: 246 care home residents*

Shi, G., Liu, C., Li, Q., Zhu, H., & Wang, L. (2012). Influence of acupuncture on cognitive function and markers of oxidative DNA damage in patients with vascular dementia. *Journal of Traditional Chinese Medicine = Chung I Tsa Chih Ying Wen Pan / Sponsored by All-China Association of Traditional Chinese Medicine, Academy of Traditional Chinese Medicine*, 32(2), 199–202.

- *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.*

Stites, S. D., Harkins, K., Rubright, J. D., & Karlawish, J. (2018). Relationships between cognitive complaints and quality of life in older adults with mild cognitive impairment, mild Alzheimer disease dementia, and normal cognition. *Alzheimer Disease and Associated Disorders*, 32(4), 276–283. <https://doi.org/10.1097/WAD.0000000000000262>

- *Version: DEMQOL.*
- *Design: Cross-sectional*
- *Population: 259 older adults with normal cognition, Mild Cognitive Impairment, and Alzheimer's Disease.*

Stites, S. D., Karlawish, J., Harkins, K., Rubright, J. D., & Wolk, D. (2017). Awareness of Mild Cognitive Impairment and Mild Alzheimer's Disease Dementia Diagnoses Associated with Lower Self-Ratings of Quality of Life in Older Adults. *Journals of Gerontology - Series B Psychological Sciences and Social Sciences*, 72(6), 974–985. <https://doi.org/10.1093/geronb/gbx100>

- *Version: DEMQOL.*

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- **Design:** *Cross-sectional*
- **Population:** *259 older adults with normal cognition, Mild Cognitive Impairment, and Alzheimer's Disease.*

Tanajewski, L., Franklin, M., Gkountouras, G., Berdunov, V., Harwood, R. H., Goldberg, S. E., ... Elliott, R. A. (2015). Economic Evaluation of a General Hospital Unit for Older People with Delirium and Dementia (TEAM Randomised Controlled Trial). *PLoS One*, *10*(12), e0140662. doi:10.1371/journal.pone.0140662

- **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.*

Trigg, R., Jones, R. W., Knapp, M., King, D., & Lacey, L. A. (2014). 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*.

- **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.*
- **Population:** *145 participants with possible/probable Alzheimer's disease and their carers.*

van der Wardt, V., Burton, J. K., Conroy, S., Welsh, T., Logan, P., Taggar, J., ... Gladman, J. (2018). Withdrawal of antihypertensive therapy in people with dementia: Feasibility study. *Pilot and Feasibility Studies*, *4*(1). <https://doi.org/10.1186/s40814-017-0221-0>

- *Version: DEMQOL and DEMQOL-Proxy (English versions, assumed for some).*
- *Procedure: A cohort study comprising medication withdrawal, home blood pressure monitoring and an interview sub-study was undertaken.*
- *Design: Feasibility of a randomised controlled withdrawal trial.*
- *Population: 29 people with dementia treated for hypertension*

Windle, G., Joling, K. J., Howson-Griffiths, T., Woods, B., Jones, C. H., Van De Ven, P. M., ... Parkinson, C. (2018). The impact of a visual arts program on quality of life, communication, and well-being of people living with dementia: A mixed-methods longitudinal investigation. *International Psychogeriatrics*, 30(3), 409–423. <https://doi.org/10.1017/S1041610217002162>

- *Version: DEMQOL and DEMQOL-Proxy (English versions, assumed for some).*
- *Design: Mixed-methods longitudinal study*
- *Population: 125 people with mild to severe dementia*

OTHER LANGUAGES:

Chinese

Shi, G. X., Li, Q. Q., Yang, B. F., Liu, Y., Guan, L. P., Wu, M. M., . . . Liu, C. Z. (2015). Acupuncture for Vascular Dementia: A Pragmatic Randomized Clinical Trial. *Scientific World Journal*, 2015, 161439. doi:10.1155/2015/161439

- *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

Gavrilova, S. I., Ferri, C. P., Mikhaylova, N., Sokolova, O., Banerjee, S., & Prince, M. (2009). Helping carers to care—The 10/66 dementia research group’s randomized control trial of a caregiver intervention in Russia. *International Journal of Geriatric Psychiatry*, 24(4), 347–354. doi:10.1002/gps.2126

- **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.

Herrschaft, H., Nacu, A., Likhachev, S., Sholomov, I., Hoerr, R., & Schlaefke, S. (2012). Ginkgo biloba extract EGb 761® in dementia with neuropsychiatric features: A randomised, placebo-controlled trial to confirm the efficacy and safety of a daily dose of 240 mg. *Journal of Psychiatric Research*, 46(6), 716–723. doi:10.1016/j.jpsychires.2012.03.003

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

Ihl, R., Bachinskaya, N., Korczyn, A. D., Vakhapova, V., Tribanek, M., Hoerr, R., & Napryeyenko, O. (2011). Efficacy and safety of a once-daily formulation of Ginkgo biloba extract EGb 761 in dementia with neuropsychiatric features: a randomized controlled trial. *International Journal of Geriatric Psychiatry*, 26(11), 1186–1194. doi:10.1002/gps.2662

- **Version:** DEMQOL-Proxy (Russian version).
- **Procedure:** Measured DEMQOL at baseline, 12 weeks and 24 weeks in a (1) Treatment (Ginkgo 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.

Ihl, R., Tribanek, M., & Bachinskaya, N. (2010). Baseline neuropsychiatric symptoms are effect modifiers in Ginkgo biloba extract (EGb 761®) treatment of dementia with neuropsychiatric features. Retrospective data analyses of a randomized controlled trial. *Journal of the Neurological Sciences*, 299(1–2), 184–187. doi:10.1016/j.jns.2010.08.033

- **Version:** DEMQOL-Proxy (Russian version).
- **Procedure:** Measured DEMQOL at baseline, 12 weeks and 24 weeks in a (1) Treatment (Ginkgo 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

Berwig, M., Leicht, H., & Gertz, H. J. (2009). Critical evaluation of self-rated quality of life in mild cognitive impairment and Alzheimer's disease — Further evidence for the impact of anosognosia and global cognitive impairment. *JNHA - The Journal of Nutrition, Health and Aging*, 13(3), 226–230. doi:10.1007/s12603-009-0063-4

- **Version:** DEMQOL and DEMQOL-Proxy (German versions).
- **Procedure:** Measured DEMQOL in individuals with (1) MCI or (2) Alzheimer's disease.
- **Population:** 27 participants with Alzheimer's disease or MCI and their caregivers.

Berwig, M., Leicht, H., Hartwig, K., & Gertz, H. J. (2011). Self-rated quality of life in mild cognitive impairment and Alzheimer's disease: The problem of affective distortion. *GeroPsych:*

The Journal of Gerontopsychology and Geriatric Psychiatry, 24(1), 45–51.

doi:<http://dx.doi.org/10.1024/1662-9647/a000029>

- *Version: DEMQOL and DEMQOL-Proxy (German amended version).*
- *Procedure: Measured DEMQOL and mood state in individuals with (1) MCI or (2) Alzheimer's disease.*
- *Population: 30 participants with Alzheimer's disease or MCI and their caregivers.*

Ochmann, S., Dyrba, M., Grothe, M. J., Kasper, E., Webel, S., Hauenstein, K., & Teipel, S. J. (2017). Does Functional Connectivity Provide a Marker for Cognitive Rehabilitation Effects in Alzheimer's Disease? An Interventional Study. *Journal of Alzheimer's Disease*, 57(4), 1303–1313. <https://doi.org/10.3233/JAD-160773>

- *Version: DEMQOL (German version, assumed).*
- *Procedure: Intervention*

Population: 30 patients with a clinical diagnosis of probable or possible AD.

Schwab, C. G. G., Dichter, M. N., & Berwig, M. (2018). Item distribution, internal consistency, and structural validity of the German version of the DEMQOL and DEMQOL-proxy. *BMC Geriatrics*, 18(1). <https://doi.org/10.1186/s12877-018-0930-0>

- *Version: DEMQOL and DEMQOL-Proxy (German versions).*
- *Procedure: Psychometric properties of the DEMQOL and DEMQOL-Proxy*
- *Population: 201 outpatients with mild form of Alzheimer's disease and their caregivers.*

Spanish

De Jesus Llibre-Rodriguez, J., Valhuerdi-Cepero, A., López-Medina, A. M., Noriega-Fernández, L., Porto-Álvarez, R., Guerra-Hernández, M. A., ... Marcheco-Teruel, B. (2017). Cuba's aging and Alzheimer longitudinal study. *MEDICC Review*, 19(1), 31–35.

- *Version: DEMQOL (Spanish version, assumed).*
- *Design: Longitudinal prospective cohort study*

- **Population:** 2944 participants aged ≥ 65 years

Gomez-Gallego, M., Gomez-Garcia, J., & Ato-Lozano, E. (2015). Addressing the bias problem in the assessment of the quality of life of patients with dementia: Determinants of the accuracy and precision of the proxy ratings. *The Journal of Nutrition, Health & Aging*, 19(3), 365-372. doi:10.1007/s12603-014-0564-7

- **Version:** DEMQOL and DEMQOL-Proxy (Spanish versions).
- **Procedure:** Utilised DEMQOL and DEMQOL-Proxy to establish the degree of discrepancy between the measures and explored contribution factors.
- **Population:** 138 participants with Alzheimer's disease and their informal carers.

Guerra, M., Ferri, C. P., Fonseca, M., Banerjee, S., & Prince, M. (2011). Helping carers to care: the 10/66 dementia research group's randomized control trial of a caregiver intervention in Peru. *Revista Brasileira de Psiquiatria*, 33(1), 47–54. doi:10.1590/S1516-44462010005000017

- **Version:** DEMQOL (Spanish version).
- **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.

Lucas-Carrasco, R., Lamping, D. L., Banerjee, S., Rejas, J., Smith, S. C., & Gómez-Benito, J. (2010). Validation of the Spanish version of the DEMQOL system. *International Psychogeriatrics*, 22(04), 589–597. doi:10.1017/S1041610210000207

- **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.

Lucas-Carrasco, R., Skevington, S. M., Gómez-Benito, J., Rejas, J., & March, J. (2011). Using the WHOQOL-BREF in persons with dementia: a validation study. *Alzheimer Disease and Associated Disorders*, 25(4), 345–351. doi:10.1097/WAD.0b013e31820bc98b

- *Version: DEMQOL (Spanish versions).*
- *Procedure: Psychometric testing and validation of Spanish WHOQOL-BREF system.*
- *Population: 104 participants with mild-moderate dementia.*

Japanese

Niikawa, H., Kawano, Y., Yamanaka, K., Okamura, T., Inagaki, H., Ito, K., & Awata, S. (2019). Reliability and validity of the Japanese version of a self-report (DEMQOL) and carer proxy (DEMQOL-PROXY) measure of health-related quality of life in people with dementia. *Geriatrics and Gerontology International*, 19(6), 487–491. <https://doi.org/10.1111/ggi.13646>

- *Version: DEMQOL and DEMQOL-Proxy (Japanese versions).*
- *Procedure: Validation and reliability study*
- *Population: 87 people with dementia and their carers.*

Italian

Raggi, A., Tasca, D., Lupica Capra, P. M. D., Panerai, S., Neri, W., & Ferri, R. (2017). Health-related quality of life in community dwelling patients with mild-to-moderate Alzheimer's disease. *European Geriatric Medicine*, 8(2), 158–163. <https://doi.org/10.1016/j.eurger.2017.01.008>

- *Version: DEMQOL and DEMQOL-Proxy (Italian versions, assumed).*
- *Procedure: Cross-sectional*
- *Population: 90 community-dwelling people with mild to moderate Alzheimer's Disease and their carer.*

Welsh

Windle, G., Joling, K. J., Howson-Griffiths, T., Woods, B., Jones, C. H., Van De Ven, P. M., ... Parkinson, C. (2018). The impact of a visual arts program on quality of life, communication, and well-being of people living with dementia: A mixed-methods longitudinal investigation. *International Psychogeriatrics*, 30(3), 409–423. <https://doi.org/10.1017/S1041610217002162>

- *Version: DEMQOL and DEMQOL-Proxy (Welsh versions, assumed for some).*
- *Procedure: Mixed-methods longitudinal study*
- *Population: 125 people with mild to severe dementia*