Appendix 1

**This appendix was part of the submitted manuscript and has been peer reviewed.
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Quality of life measures in INSPIRED

Quality of life utility measures

The quality of life measure used in this analysis is the EQ-5D-5L. The EQ-5D-5L is a preference based quality of life measure that is widely used in economic evaluations and is most commonly used in research in residential aged care (Bulamu, Kaambwa, & Ratcliffe, 2015). This is the main outcome measure as it is used as a standard within health economics to enable comparison across different health conditions. The EQ-5D-5L covers five dimensions influencing health-related quality of life: Mobility, Self-Care, Usual Activities, Pain/Discomfort, and Anxiety/Depression. The ED5D5L has been shown to have generally good reliability and validity in populations with dementia (Hounsome, Orrell, & Edwards, 2011).

There are limitations of using proxy assessment for quality of life, particularly studies indicate that agreement between ratings given by proxies and people with dementia themselves can be poor (Orgeta et al 2015, Coucill et al 2001), however in order to capture quality of life of those with more severe dementia proxy rating is the only option. Other studies have found good agreement particularly using the EQ-5D in people with vascular cognitive impairment and family member proxies (Hounsome et al 2011).

A commonly used dementia-specific measure is the DEMQOL (self-reported) and the DEM-QOL Proxy (completed by a proxy on behalf of the participant). DEMQOL-Utility scores are based on five different dimensions (positive emotion, negative emotion, memory, relationships and loneliness), while DEMQOL-Proxy-Utility scores are based on four dimensions (positive emotion, negative emotion, memory and appearance). These measures were also used within the INSPIRED study, however not all participants had dementia (in standard models of care 55% of participants had a dementia diagnosis, 79% had a dementia diagnosis or a PAS-Cog score of ≥5). Those within the INSPIRED study population without cognitive impairment are likely to be in residential care due to physical activity limitations, thus it was considered most appropriate to use a quality of life measure that captures both cognitive and physical functioning, as discussed in a published paper on this topic conducted in this population.(Easton, Milte, Crotty, & Ratcliffe, 2018) The EQ-5D-5L captures physical function (mobility, self-care and usual activities) more appropriately than the DEMQOL utility measures for those without dementia.

In addition, the EQ-5D-5L could be used in the entire study population, allowing those with higher cognitive function to self-assess their quality of life yet still capturing the quality of life of those with poorer cognition by the use of proxy respondents. It was considered important for people living with dementia to self-complete questionnaires, particularly of quality of life, whenever possible. There is a current movement towards meeting the needs and preferences of people with dementia and involving them in decisions about their lives and care. Within Australia this is exemplified by the philosophy of the Alzheimer's Australia's National Dementia Consumer Network, i.e. 'Nothing about us, without us'. (Alzheimer's Australia 2017, World Health Organization and Alzheimer's Disease International 2012) This, is in addition to the limitations of using proxy ratings as discussed above indicate that the DEMQOL and DEMQOL-Proxy were less appropriate measures for capturing quality of life than the EQ-5D-5L within this study. Ie, the EQ-5D-5L best captures participant views of the study population considering those in aged care for both cognitive and physical dependencies and also enables comparison to other studies within residential aged care and other disease areas.

Dementia-specific quality of life study outcomes

The DEMQOL was used in 311 participants within the study. With this measure those residing in a clustered model of care had a higher quality of life (adjusted utility difference 0.049, 95%CI 0.038 to 0.137, P=0.27) which did not reach statistical significance; however the power was reduced. With the DEMQOL-Proxy residents of a clustered model of care also had a higher quality of life that did not reach statistical significance (adjusted utility difference 0.037, 95%CI -0.013 to 0.087). The DEMQOL and DEM-QOL proxy could not be combined to obtain a single utility measure capturing self-rated QOL where possible and proxy rated where self-completion was not possible (Easton et al 2018). These data are shown below in Table S2.1.

Table S2.1 Dementia-specific quality of life measures for residents living in a clustered domestic model or a standard Australian model of care, adjusted for potential confounding factors*

Consequences	Adjusted means (95% CI)		Difference (clustered-standard care) (95%CI)		P value~
	Homelike	Traditional	Unadjusted	Adjusted	
Quality of Life – DEM-QOL Proxy	0.734(0.681,0.781)	0.697(0.667, 0.728)	-0.0005(-0.031, 0.030)	0.037 (-0.013,0.087)	0.14
Quality of Life – DEMQOL (n = 311)	0.877(0.794 0.960)	0.828(0.784, 0.872)	0.035(-0.022,0.091)	0.049(-0.038,0.137)	0.27

*Adjusted for age, gender, PAS-Cog, Modified Barthel Index, frequency of social interactions, number of co-morbidities, regional location, facility size (No. beds), staff training and direct care hours

NOTE: not all residents in standard models of care had dementia.

Proxy respondent rates

Within the INSPIRED study, there were significantly more proxy responses for those living in a clustered model of care as below:

Characteristic	Clustered domestic model of care (n=120)	Standard model of care (n=421)
Proxy responses, n (%)	114 (95.0)	277 (65.8)*

* p<0.05

In general, in those studies that have found a difference, proxies been found to give poorer ratings of quality of life than the people with dementia themselves self-completing (Coucill et al 2001, Hounsome et al 2011, Kunz et al 2010). The proportion of proxy responses was significantly higher in the clustered models of care – this would indicate that relatively the quality of life in the clustered models of care may be underestimated and that the estimate of a higher quality of life of residents in the clustered model may be conservative.

References

Alzheimer's Australia (2017). Introducing dementia alliance international.   Retrieved from https://www.fightdementia.org.au/dementia-news/issue-04/introducing-dementia-alliance-international.

Bulamu, N. B., Kaambwa, B., & Ratcliffe, J. (2015). A systematic review of instruments for measuring outcomes in economic evaluation within aged care. *Health and Quality of Life Outcomes, 13*(1), 179. doi:10.1186/s12955-015-0372-8

Coucill W, Bryan S, Bentham P, Buckley A, Laight A: EQ-5D in patients with dementia- an investigation of inter-rater agreement. Medical Care 2001, 39:760-771.

Davis JC, Hsiung GY, Bryan S, Jacova C, Jacova P, Munkacsy M, Cheung W, Lee P, Liu-Ambrose T: Agreement between Patient and Proxy Assessments of Quality of Life among Older Adults with Vascular Cognitive Impairment Using the EQ-5D-3L and ICECAP-O. PLoS One 2016, 11:e0153878.

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. *Qual Life Res*. doi:10.1007/s11136-017-1777-0

Hounsome, N., Orrell, M., & Edwards, R. T. (2011). EQ-5D as a quality of life measure in people with dementia and their carers: evidence and key issues. *Value Health, 14*(2), 390-399. doi:10.1016/j.jval.2010.08.002

Kunz S: Psychometric properties of the EQ-5D in a study of people with mild to moderate dementia. Quality of Life Research 2010, 19:425-434.

Orgeta V, Edwards RT, Hounsome B, Orrell M, Woods B: The use of the EQ-5D as a measure of health-related quality of life in people with dementia and their carers. Quality of Life Research 2015, 24:315-324.

Sterne, J. A. C., White, I. R., Carlin, J. B., Spratt, M., Royston, P., Kenward, M. G., . . . Carpenter, J. R. (2009). Multiple imputation for missing data in epidemiological and clinical research: potential and pitfalls. *BMJ, 338*. doi:10.1136/bmj.b2393

World Health Organization and Alzheimer's Disease International. (2012). *Dementia: a public health priority*. Available from: http://www.who.int/mental_health/publications/dementia_report_2012/en/