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# **Head-to-head comparison of the psychometric properties of three carer-related preference-based instruments**

## **Authors:**

Nikki McCaffrey, PhD (corresponding author)

Deakin University, Geelong, Deakin Health Economics, Institute for Health Transformation,  
School of Health and Social Development, Victoria, Australia

[nikki.mccaffrey@deakin.edu.au](mailto:nikki.mccaffrey@deakin.edu.au)

Phone 03 924 68767, mobile 04 4726 1668, fax 03 924 46261

Jessica Bucholc, BHealth Promotion & Nursing

Deakin University, Geelong, Deakin Health Economics, Institute for Health Transformation,  
School of Health and Social Development, Victoria, Australia

Stacey Rand, MA (Cantab)

Personal Social Services Research Unit (PSSRU), Cornwallis Building, University of Kent,  
Canterbury, United Kingdom

Renske Hoefman, PhD

The Netherlands Institute for Social Research (SCP), The Hague, The Netherlands

Anna Ugalde, PhD

Deakin University, Geelong, Quality and Patient Safety, Institute for Health Transformation,  
School of Nursing and Midwifery Victoria, Australia

Anne Muldowney, M Social Policy

Carers Victoria, 1/37 Albert St, Footscray, Victoria, Australia

Cathrine Mihalopoulos, PhD

Deakin University, Geelong, Deakin Health Economics, Institute for Health Transformation,  
School of Health and Social Development, Victoria, Australia

Lidia Engel, PhD

Deakin University, Geelong, Deakin Health Economics, Institute for Health Transformation,  
School of Health and Social Development, Victoria, Australia

**Funding:** This research was supported by a grant awarded by the Faculty of Health, Deakin University. The Faculty had no role in the study design, data analysis or writing of the report.

**Competing interests:** The authors have no competing interests to declare.

**Ethics approval:** The survey was approved by the Deakin University Faculty of Health, Human Ethics Advisory Group, Burwood, Australia (reference number HEAG-H 91\_2018) and through the Carers Victoria's Carer Participation in Research process. Informed consent was obtained from all participants before completing the survey.

**Precis:** This study compares the psychometric properties of three carer-related, preference-based instruments, the ASCOT-Carer, CarerQol and CES using data from an informal carer survey in Australia.

**Acknowledgements:** The authors are indebted to the carers who participated in this research and warmly thank the members of Deakin Health Economics and the Faculty of Health who tested the pilot survey. Many thanks to Lana Dogan and Jessica Merganovski, Carers Victoria for their assistance with recruiting participants to the study.

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## **Abstract**

**Objectives:** To compare the psychometric properties of the Adult Social Care Outcomes Toolkit for carers (ASCOT-Carer), the Carer Experience Scale (CES), and the Care-related Quality of Life (CarerQol) to inform the choice of instrument in future studies.

**Methods:** Data were derived from a 2018 online survey of informal carers in Australia. Reliability was assessed via internal consistency (Cronbach alpha,  $\alpha$ ) and test-retest reliability (intra-class correlation coefficient, ICC) for respondents who self-reported no change in their quality of life as a carer over two weeks. Convergent validity was evaluated via pre-determined hypotheses about associations (Spearman's rank correlation) with existing, validated measures. Discriminative validity was assessed based on the ability of the carer-related scores to distinguish between different informal care situations (Mann Whitney U, Kruskal-Wallis one way analysis of variance).

**Results:** Data from 500 carers were analysed. The ASCOT-Carer demonstrated a higher degree of internal consistency, possibly due to a uni-dimensional structure, and test-retest reliability than the CarerQol and CES ( $\alpha=0.87, 0.65, 0.59$ ; ICC 0.87, 0.67, 0.81 respectively). All three instruments exhibited convergent validity and detected statistically significant associations between carer-related scores and different informal care situations, except for the CarerQol-7D and sole carer status.

**Conclusions:** The ASCOT-Carer, CarerQol and CES performed reasonably well psychometrically; the ASCOT-Carer exhibited the best psychometric properties overall in this sample of Australian informal carers. Findings should be used in conjunction with consideration of research goals, carer population, targeted carer-related constructs and prevailing perspective of the economic evaluation to inform choice of instrument in future studies.

## Highlights

*What is already known about the topic?*

- Three preference-based instruments specific for informal carers, the ASCOT-Carer, the CarerQol and the CES, have been developed to capture the impact of providing informal care, caring experience and social care-related quality of life respectively.

*What does the paper add to existing knowledge?*

- This cross-sectional study provides quantitative evidence supporting the measurement properties of the carer-related instruments in a population of informal carers in Australia.

*What insights does the paper provide for informing health care-related decision making?*

- The ASCOT-Carer, CarerQol and CES are promising measures for evaluating strategies targeting carer-related quality of life. This paper provides further insights into differences between the instruments to inform future choice.

## **Introduction**

The impacts and value of informal care are enormous and often hidden. In this context, an informal carer is a person who provides regular, ongoing assistance to a person with chronic, progressive or life-limiting illness, usually without receiving payment for the care they provide and could include family members, friends or neighbours (1). International estimates of the value of informal care as a percentage of gross domestic product, range from 0.3% (France) to 7.4% (UK) (2) compared with an average government spend of 7-8% on aged care and 6% on health in Organisation for Economic Co-operation and Development (OECD) countries (3). In Australia, approximately 1 in 10 people in the community provide unpaid care (4) with estimated annual contributions to health and social care costs at A\$60 billion (2). Although caring for a person can be fulfilling and some carers have a positive experience (5), evidence has shown that informal caring can lead to distress, deterioration of carer physical and mental health, and reduced ability to undertake paid work and participate in society (6-10).

International guidelines on conducting economic evaluations typically recommend including informal carer costs and benefits (11-13) to inform clinicians, funders and policy-makers on the value for money of healthcare interventions. Despite this, few economic evaluations include informal care, possibly due to the difficulties associated with measuring costs and outcomes in patients and carers, methodological challenges such as double counting, interdependencies in preferences between informal carers and care recipients, valuing the impact of informal care and the prevailing perspective of the analysis (14-19). Economic evaluations that do include carer impacts, generally cost informal carers' time input but rarely include carer outcomes (15). The inclusion of informal care costs and effects in such

evaluations can have a substantial impact on inferences about the cost-effectiveness of the strategy under consideration (11, 19).

As a response to these concerns, new preference-based instruments specific for carers have been developed in the UK and the Netherlands, including the Adult Social Care Outcomes Toolkit for Carers (ASCOT-Carer) (20), the Carer Experience Scale (CES) (21) and the Care-related Quality of Life (CarerQoL) (22). It is important to ensure that any new instrument is psychometrically sound, i.e. should measure the concept/s it was designed to capture (content validity); display theoretically meaningful relationships with other measures (construct validity); reproduce the same results in similar circumstances (test-retest reliability for stability); pick up differences in observed outcomes over time when present (responsiveness); and be appropriately designed for the target population (feasibility) (23).

The ASCOT-Carer, CarerQoL and CES are instruments designed for economic evaluation of the impact of interventions on carers beyond health. All three measures are designed to measure care-related QoL with nuanced differences in the concepts captured. The ASCOT-Carer measures social-care related QoL (SCRQoL) and has emerging evidence of construct validity and feasibility (20, 24). In the UK, social care refers to community-based services such as home care and day centres, and residential or nursing care. English preference weights have been recently calculated (25). In comparison, the CarerQoL and CES capture the problems and positive experiences of caring respectively, with evidence of feasibility, construct validity and test-retest reliability for the former and construct validity for the latter (22, 24, 26-29). Whilst CarerQoL preference weights have been calculated for Australia, Germany, the Netherlands, Sweden, United Kingdom and United States (16, 30), CES preference weights are currently available for the UK population only (21).

There is limited information to guide the choice of carer-related instrument for economic evaluations (17). Recently, Rand and colleagues directly compared the ASCOT-Carer and CES in a sample of carers of adults who used long-term care support in England (N=387), with evidence of construct validity. The instruments largely captured separate constructs of SCRQoL (ASCOT-Carer) and carer experience (CES), demonstrating overlap in relation to the domains of activities outside caring and social support (24). A head-to-head comparison of the CarerQoL and CES suggested both instruments validly assess the effect of caring in end-of-life care (27). To date, no study has empirically compared the psychometric properties of all three instruments to further inform instrument selection. Further, despite international recommendations to empirically evaluate the validity of patient-reported outcome measures in populations living in different countries (31-33), comparative assessment of carer-related preference-based measures has not been undertaken in Australia (34).

The aim of this study is to address this knowledge gap by investigating and comparing the psychometric properties of the ASCOT-Carer, CarerQoL and CES in accordance with the COnsensus-based Standards for the selection of health status Measurement Instruments (COSMIN) checklist on evaluating measurement properties (32). The findings will inform instrument choice when conducting economic evaluations of health and social care strategies, which include carer outcomes, leading to improved measurement of the impact of caring and better informed clinical, funding and policy decisions.

## **Methods**

A web-based survey was developed, piloted, and administered between June and September 2018 to a sample of informal carers recruited through Carers Victoria, a state-wide not-for-profit organisation representing and providing support to carers to improve their health, wellbeing, capacity and resilience (35). The main aim of the survey was to compare the psychometric properties of the three instruments.

## ***Participants***

### ***Eligibility criteria***

Persons aged  $\geq 18$  years, self-identified as a primary, informal carer who were Australian residents and able to read the study questionnaires were invited to participate in an on-line survey between June and September 2018. The survey web link was included in the *Voice: Carers Victoria* ebulletin and a direct email invitation was sent to all carers registered with Carers Victoria who had previously given permission to Carers Victoria to be contacted about possibly taking part in research. Informed consent was obtained from all participants before completing the survey and a \$10 gift voucher was provided to all respondents as an acknowledgement of the carers' contributions.

### ***Sample size***

Recommendations on validation study sample sizes range from 2-20 participants per questionnaire item and a minimum of 300 respondents (36). Consequently, a target sample size of 500 informal carers was considered sufficient, accounting for potential missing data.

Ethical approval to conduct the survey was granted by the Deakin University Faculty of Health, Human Ethics Advisory Group, Burwood, Australia (reference number HEAG-H 91\_2018).

## ***Measures***

### ***Carer-related preference based instruments***

#### ***Adult Social Care Outcomes Toolkit for Carers (ASCOT-Carer)***

The ASCOT-Carer, developed in the UK, is a preference-based measure of carers' SCRQoL and includes seven domains; control over daily life, occupation, social participation and involvement, personal safety, self-care, time and space to be yourself and feeling supported

and encouraged (20). Focus groups and interviews with care managers and carers were used to inform the content of the ASCOT-Carer. The English scoring algorithm, based on general population preferences was used to calculate the preference weight and ranges from 0 (worst QoL) to 1 (best QoL) (20, 25).

#### *Care-related Quality of Life (CarerQol)*

The CarerQol, developed in the Netherlands, measures care-related QOL with two components; the CarerQol-7D (subjective burden) and the CarerQol-VAS (wellbeing) (22, 27). The CarerQol-7D has seven dimensions; fulfilment, support, relational problems, mental health problems, problems combining daily activities with care, financial problems and physical health problems. A review of eight popular burden measures informed the content of the Carer-Qol and a survey of carers was used to identify any missing domains (22). Scoring algorithms based on general population preferences for six countries are available to calculate an overall score ranging from 0 (worst informal care situation) to 100 (best informal care situation) (16, 30). The UK rather than the Australian scoring algorithm was used to calculate the preference weights to be consistent with the ASCOT-Carer and CES scoring in this comparative study. The CarerQol-VAS measures the happiness of carers on a horizontal visual analogue scale (VAS) ranging from 0 (completely unhappy) to completely happy (10) (27).

#### *Carer Experience Scale (CES)*

The CES, developed in the UK has six dimensions; activities outside caring, support from family and friends (social support), assistance from organizations and the government (institutional support), fulfilment from caring, control over the caring and getting on with the care recipient (21). The descriptive system of the CES was developed from a meta-ethnography of qualitative studies on caring and semi-structured interviews with carers. The

UK scoring algorithm, based on the preferences of carers of older people, was used to calculate the preference weights which can range from 0 to 100, representing the worst or best caring experience respectively (37).

### ***Negative & positive aspects of caring***

#### ***Caregiver Reaction Assessment (CRA)***

The CRA instrument is a well-validated, non-preference based instrument measuring negative and positive impacts of caring with 24 items across five domains; impact on schedule (5 items), finances (3 items), family support (5 items), health (4 items) and esteem (7 items) (38, 39). Each item consists of a five-point Likert scale, ranging from strongly disagree to strongly agree (scored 1-5 respectively). Although the CRA does not generate a total score, subscale scores are calculated from the average item scores and range from one to five. Higher scores on the esteem subscale represent more positive effects of caring, whereas higher scores on the other subscales suggest greater negative effects (40, 41). The subscale scores enable the exploration of correlations between discrete impacts of caring and domains within the carer-related instrument measuring related constructs, facilitating evaluation of convergent validity.

### ***Health-related quality of life***

Two HrQoL questionnaires, commonly used in economic evaluations were included in the survey to enable comparison of the informal carers' health with the general population for assessing generalisability and to evaluate the convergent validity of the three carer-related, preference-based instruments.

#### ***EQ-5D-5L***

The EQ-5D is a widely applied, validated, generic, preference-based instrument measuring health status (34, 42). The recently developed five response level version (no problems;

slight; moderate; severe; and extreme problems) has five dimensions; mobility, personal care, usual activities, pain/discomfort, anxiety/depression was used (43). The UK scoring algorithm based on public preferences was used to convert the health states into a utility weight (44) as an Australian scoring algorithm is not yet available for the 5L. Potential values range from -0.281 to 1 (44, 45).

#### *Assessment of Quality of Life 8 dimensions (AQoL-8D)*

The AQoL-8D is a validated preference-based instrument measuring HrQoL and was developed in Australia, particularly to address the limited coverage of broader psychosocial domains of QoL which is a characteristic of other generic preference-based measures such as the EQ-5D (46-50). The AQoL-8D instrument contains 35 items across eight dimensions; independent living, pain, senses, mental health, happiness, coping, relationships and self-worth. A scoring algorithm based on Australian public preferences, including people with mental health problems is used to convert the health states into a utility weight (51). The Australian value set was used to calculate index scores. Potential values range from -0.09 to 1 (52).

#### *Survey*

The survey was powered by Qualtrics® and piloted amongst the investigator team, a convenience sample of informal carers and members of Deakin Health Economics and the Faculty of Health (N=21) to develop appropriate accessible wording, ensure understanding of the tasks and maximise completion rates.

Participants were asked to complete information about the care situation (primary carer status, sole carer status, sharing household, care duration, intensity of caring, number of activities), together with characteristics of the carer (age, gender, health status, relationship to care recipient, educational attainment, employment, household income) and care recipient (age,

gender, educational attainment, number of co-morbidities) to capture variables potentially influencing carer-related QoL and to facilitate evaluation of the generalisability of the results. Second, respondents were asked to complete the three carer-related, preference-based questionnaires (ASCOT-Carer, CarerQoL, CES), the CRA and the two HrQoL instruments (EQ-5D-5L, AQoL-8D). Random allocation of the ordering of the carer-related instruments in the survey was used to minimise potential ordering effects (53). Next, respondents were asked to complete a structured questionnaire on the positive and negative impacts of caring (CRA) and finally, respondents were asked to consent to a follow-up survey containing the carer-related instruments and HrQoL questionnaires only, with one additional anchor question, “In the last two weeks, has your quality of life as a carer changed?”, to enable assessment of the test-retest reliability of the instruments under investigation (see ‘Analysis’ for further details) (54). Consenting participants were sent the follow-up survey via email after approximately 14 days, considered a long enough interval to forget previous responses (55). Weekly reminders were sent to non-completers up to 6 weeks post-completion of the baseline survey.

Participants were given the opportunity to complete the survey over multiple sessions and no forced entry was applied.

### *Analyses*

Participant and care recipient characteristics and responses were analysed using descriptive analysis and where applicable compared with national Survey of Disability, Ageing and Carers (SDAC) data to explore generalisability (56). The SDAC is a comprehensive, population-based survey of people who care for those who have a disability, long term health condition, or are aged 65 and older in rural and urban Australia. The survey includes demographic and socio-economic characteristics and is conducted by the Australian Bureau of Statistics (56). The participant mean EQ-5D-5L and AQoL-8D scores were also compared

with Australian general population scores to investigate any differences in health status (45, 57).

### *Psychometric analyses*

Content validity was explored using qualitative and quantitative approaches and will be reported separately. The focus of feasibility and internal consistency was the descriptive systems. For all other analyses, preference weights were also taken into account.

### *Feasibility*

The completion rates of each carer-related, preference-based instrument were examined to assess feasibility. Item completion rates were compared with the Kruskal-Wallis one way analysis of variance tests (58) and were expected to be similar based on previous validation studies and comparable number of domains (26, 28, 59).

### *Ceiling/ floor effects*

Floor and ceiling effects were examined for each instrument, defined as  $\geq 15\%$  of the sample with extreme scores (60). Based on previous validation studies, none of the instruments were expected to exhibit floor or ceiling effects (20, 26, 61).

### *Reliability*

Internal consistency was assessed with Cronbach alpha ( $\alpha$ ) and a threshold of 0.70 (62). Test-retest reliability was evaluated using an intra-class correlation coefficient (two-way mixed model with absolute agreement (63)) for consistency of at least 0.70 (55) in respondents who reported no change in their wellbeing and caring experience between baseline and follow up when answering the question, “In the last two weeks, has your quality of life as a carer changed?” (55). The baseline and follow up survey were administered two weeks’ apart. This time period was considered short enough to assume care-related quality of life would not have changed. The anchor question was included in the survey to enhance this approach.

The instruments were expected to have similar reliability given the comparable number of domains (55).

#### *Convergent validity*

Convergent validity was evaluated by investigating *a priori* hypothesised relationships between the carer-related index scores and the AQoL-8D, EQ-5D-5L and CRA subscale scores, based on a review of the literature on the carer-related instruments (26-29, 59) and investigators' experience, using the Multitrait-Multimethod Matrix (Spearman's rank correlation) (64). Correlations were interpreted according to Cohen's guidelines, i.e. 'strong' ( $\geq 0.51$ ), 'moderate' (0.31-0.50), 'weak' (0.11-0.30) and 'none' (0-0.10) (65). The three carer-related instruments were expected to be strongly correlated with each other, whereas the carer-related instruments were anticipated to be weak to moderately correlated with the QoL measures.

#### *Discriminative validity*

The abilities of the carer-related index scores to reflect known or expected differences in the informal care situation were evaluated to assess discriminative validity. *A priori* hypotheses were generated for associations with consistent supportive evidence from previous validation studies (26-29, 59). Positive associations (higher carer-related QoL) were anticipated between carer-related scores and relationship (more remote), sole carer status (no), multiple care recipients (no), sharing the household (no), care duration (less time in the caring role), intensity of caring (less hours caring per week), and number of supported activities (greater number of activities undertaken). As total scores were non-normally distributed (Kolmogorov-Smirnov test, *p-value* < 0.05), differences between subgroups were assessed using the non-parametric Mann Whitney *U* test (two groups) and Kruskal-Wallis one way analysis of variance (multiple groups) and a threshold *p-value* of 0.05. Effect sizes were

calculated and interpreted as follows: eta squared based on the Kruskal-Wallis H-statistic ‘weak’ 0.01-0.059, ‘moderate’ 0.06-0.139, ‘strong’  $\geq 0.14$ ; Cohen’s  $r$  based on the  $z$  value for the Mann-Whitney U ‘weak’ 0.11-0.30, ‘moderate’ 0.31-0.50, ‘strong’  $\geq 0.50$  (66, 67).

The sensitivities of the carer-related instruments for detecting differences between distinct carer groups stratified by the hours of care provided per week (<20, 20-29, 30-39,  $\geq 40$  hours) were assessed in *post-hoc* analysis. This ‘anchor’ was chosen based on relevance and strength of association with the carer-related scores (54, 68). Differences among carer groups were tested with Dunn’s pairwise test and the p-value adjusted using the Bonferroni correction (69).

Statistical analyses were conducted within IBM SPSS Statistics for Windows, Version 25 (IBM Corp., Armonk, NY) and pairwise deletion was used for all statistical analyses.

## **Results**

### ***Descriptives***

In total, 500 informal carers participated in the survey. Table 1 summarises the sociodemographic characteristics and caring situation of the informal carers and care recipients in the study sample.

[*Insert Table 1*]

Among the 500 respondents, 79% were females, 21% were aged  $\geq 65$  years of age, and just over half were the only person providing informal care (54%). About a third (32%) of respondents were caring for a parent (32%) or child (31%). Most respondents (74%) had been fulfilling the caring role for over two years and most commonly, provided more than 40 hours of care per week (43%).

The survey participants were of a similar age to the national estimate (mean age, 52 vs 54 years respectively) and both groups tended to share the household with their care recipient (80% vs 79% respectively) (56). However, the study sample had a higher proportion of females (79% vs 72%) and adult carers of parents (32% vs 26%) and children (31% vs 27%). Fewer survey respondents were in the workforce (51% vs 71% respectively).

Consistent with previous evidence, the study sample reported poorer HrQoL than the Australian general population (70-72). The mean total EQ-5D-5L and AQoL-8D scores were 0.76 (95% CI 0.74, 0.78) and 0.60 (95% CI 0.59, 0.62), respectively compared (Table 2) with Australian population norms of 0.91 (95% CI 0.90, 0.91) and 0.86 (95% CI 0.85, 0.87).

[*Insert Table 2*]

### ***Feasibility***

Virtually all respondents completed the carer-related questionnaires (ASCOT-Carer 99.5 %, CarerQoL-7D 99.7%, CES 98.9%) and all of the questionnaire items (ASCOT-Carer 99.5 %, CarerQoL-7D 98.1%, CES 98.9%). There were no statistically significant differences in completion rates between the three carer-related instruments (Kruskal-Wallis H 2.91, *p-value* = 0.09). Note, due to technical issues just after launching the on-line survey, some participants were not given the opportunity to complete the carer-related questionnaires (ASCOT-Carer n=115, CarerQoL-7D n=141, CES n=121).

### ***Ceiling/ floor effects***

None of the carer-related instruments demonstrated ceiling or floor effects (Table 3). The distributions of the carer-related scores are presented in Appendix 1.

[*Insert Table 3*]

### ***Reliability***

The Cronbach alpha for the ASCOT-Carer exceeded the recommended 0.70 threshold ( $\alpha=0.87$ ), whereas the CarerQoL-7D and CES values were lower ( $\alpha=0.65$  and  $\alpha=0.59$  respectively). Intra-class correlations for the ASCOT-Carer and CES exceeded the recommended threshold of 0.70 (ICC 0.87 and 0.81 respectively), whilst the ICC for the CarerQoL-7D was just below the threshold (ICC 0.67) (Table 3).

### ***Convergent validity***

As expected, the carer-related scores were strongly correlated with each other (Table 4). Spearman's rank correlations between the carer-related scores and the AQoL-8D, EQ-5D-5L and CRA subscale scores were in the anticipated directions except for the CRA subscale "Finances", and generally stronger than anticipated.

[Insert Table 4]

### ***Discriminative validity***

Table 5 summarises the associations between the carer-related scores and informal care situation groups.

[Insert Table 5]

All of the carer-related instruments detected statistically significant associations between carer-related scores and known or expected differences in the informal care situations, except for the CarerQoL-7D and sole carer status. Generally, the ASCOT-Carer detected stronger effect sizes than the CarerQoL-7D and CES.

Higher carer-related scores were associated with lower hours of care provided per week for the ASCOT-Carer (Kruskal-Wallis H 91.99,  $p$ -value <0.001), CarerQoL-7D (Kruskal-Wallis H 19.27,  $p$ -value <0.001) and CES (Kruskal-Wallis H 53.41,  $p$ -value <0.001) (Table 5). There was very strong evidence of a difference in mean ASCOT-Carer scores between informal carers who provide <20 hours and 30-39 hours ( $p$ -value <0.001), <20 hours and  $\geq$ 40 hours ( $p$ -

*value* <0.001), 20-29 hours and  $\geq$ 40 hours (*p-value* <0.001), and 30-39 hours and  $\geq$ 40 hours (*p-value* < 0.01). Whilst higher CarerQol-7D scores were also associated with lower hours of care provided per week, a statistically significant difference was evident only for informal carers who provided 20-29 hours and  $\geq$ 40 hours (*p-value* <0.03) and <20 hours and  $\geq$ 40 hours (*p-value* <0.001). Finally, there was a statistically significant difference in CES scores between informal carers who provided <20 hours and  $\geq$ 40 hours (*p-value* <0.001), 20-29 hours and  $\geq$ 40 hours (*p-value* <0.001) and 30-39 hours and  $\geq$ 40 hours (*p-value* < 0.05).

## **Discussion**

This is the first study internationally to directly compare the psychometric properties of three carer-related preference-based instruments, the ASCOT-Carer, CarerQol and CES administered to a population of heterogeneous, informal carers. In line with previous studies, each instrument exhibits some degree of validity, reliability and feasibility in measuring carer-related outcomes (22, 24, 26-29, 73, 74). All of the instruments demonstrated good discriminative validity, with larger effect sizes for the ASCOT-Carer, and the ASCOT-Carer exhibited good internal consistency *and* test-retest reliability. Overall, whilst all of the instruments performed reasonably well, the ASCOT-Carer demonstrated better psychometric properties in this sample of informal carers in Australia.

The instruments appear to be feasible measures of carer outcomes; item response rates were high with a full range of responses and there was no evidence of floor or ceiling effects or notable differences between the instruments.

The ASCOT-Carer demonstrated good reliability with strongly related items and the CarerQol-7D and CES exhibited weaker but acceptable reliability (75), consistent with previous evidence (73). These differences may reflect a uni-dimensional structure of the

ASCOT-Carer (20). The ASCOT-Carer and CES also showed good test-retest reliability, whereas the CarerQoL-7D demonstrated more moderate results.

Generally, the carer-related scores were moderately or highly correlated with the CRA subscale scores (except for self-esteem) supporting convergent validity. The ASCOT-Carer and CarerQoL-7D had stronger associations with impact on schedule, finances and health subscales and the CES was most strongly associated with family support, although differences between instruments were relatively small.

The moderate correlation of the carer-related scores with the EQ-5D-5L is consistent with previously reported results (24) and likely reflects the broader constructs covered by the carer-related instruments which include some overlapping aspects of health. Stronger correlations were displayed with the AQoL-8D scores, likely due to the relatively greater psychosocial content and the relationship between psychosocial health and carer-related QoL (49, 71).

The ASCOT-Carer scores were most strongly correlated with the CES scores, suggesting greater overlap between the underlying constructs of these instruments than with the CarerQoL-7D. The content varies between each carer-related instrument with a small degree of evident domain overlap; 'daily activities' and 'support' only are captured by all measures.

The ASCOT-Carer and the CarerQoL include other domains, such as self-care and financial problems, unique to these instruments. There are nuanced differences in the concepts captured; the ASCOT-Carer measures social care-related QoL, i.e. aspects of carers' QoL that may be influenced by social care services and support and the CES captures carer experience more broadly, whereas the CarerQoL measures carer burden (22, 24).

The ASCOT-Carer exhibited the greatest ability to discriminate between carer subgroups based on the intensity of caring provided and differences in ASCOT-Carer scores were most strongly associated with differences in the informal carer situation such as sole carer status, potentially related to the more socially-orientated aspects of this instrument.

Although there is a modest body of evidence on the feasibility, validity and reliability of the ASCOT-Carer, CarerQol and CES carer-related preference-based instruments, more research is needed to evaluate the responsiveness of the measures to changes over time. Further, clearer guidance on how to incorporate “spillover” effects from providing informal carer in economic evaluations is needed (76), particularly given the challenges of overlap between the health-related and carer-related instruments.

As all of the instruments performed reasonably well, the choice of whether to use the ASCOT-Carer, CarerQol or CES in future studies largely depends on the research question/s. For example, the CES captures broad aspects of carers’ experiences and may be more suited to evaluations of interventions targeting the relationship between the informal carer and care recipient (21, 24). The ASCOT-Carer measures SCRQoL and would likely be a better choice when personal safety is an important dimension (20). The CarerQol includes physical and mental health dimensions, suggesting this instrument is better suited to evaluations of interventions for anxiety or depression (22).

A strength of this study is the direct comparison of three carer-related preference-based instruments in a heterogeneous group of informal carers, facilitating generalisability of the results to all carers providing informal care. Previous studies have focused on specific informal carer populations or investigated only one or two of the instruments. However, whilst some carer demographic characteristics were consistent with population estimates, female carers, carers who were children or parents of the care recipient and carers out of the workforce were overrepresented. Further, most participants (74%) had been fulfilling their role for more than two years, so the findings may not accurately reflect the experiences of carers new to the role. Only 8% (n=38) of respondents had been providing care for up to six months. Despite this, numbers were sufficient to compare carer-related scores between informal carers who had been fulfilling their role for more or less than two years for the three

instruments. There are many non-preference based measures of carer burden and needs which could have been used to evaluate convergent validity but there is currently no known gold standard (77). However, the CRA was well-developed, is well-validated, includes both negative and positive impacts of caring and was recommended as a measure of burden in a review of self-report instruments developed to measure the burden, needs and quality of life of informal caregivers (77). Test-retest analysis was based on change from baseline to week two, considered a short enough period for stable conditions based on previous research (28). The anchor question was devised by the research team and may not accurately reflect stable care-related quality of life. This approach to evaluating test-retest reliability was considered superior to simply *assuming* care-related quality of life did not change in the two week time period. Whilst some respondents completing the survey to receive the \$10 gift voucher may not have been providing regular, ongoing assistance to a person with chronic, progressive or life-limiting illness, most, if not all respondents should be informal carers as participants were only recruited through Carers Victoria. Finally, the preference weights will have influenced test-retest reliability and convergent and discriminative validity and this should be taken into account when comparing the findings with other psychometric validation studies.

## **Conclusions**

Whilst the ASCOT-Carer, CarerQoI and CES performed reasonably well psychometrically, the ASCOT-Carer exhibited the best psychometric properties overall in this sample of informal carers in Australia. When choosing which carer-related instrument to administer in future studies, careful consideration of the research question, distinct theoretical frameworks underpinning the instruments and diverse domains, prevailing perspective of the economic evaluation, and population and health and social-care decision making context should also be considered alongside evidence of psychometric properties.

**Table 1 Sociodemographic characteristics and caring situation of the informal carers and care recipients**

Characteristic	n (%)
<b>Informal carer</b>	
Age in years, mean (SD) (n=482)	52 (14)
Gender, female (n=497)	393 (79)
Education attainment (n=496)	
Year 11 or below	87 (17)
Year 12	44 (9)
Certificate/ Diploma	137 (27)
Undergraduate	131 (26)
Postgraduate	90 (18)
Other	7 (1)
Employment (n=498)	
Employed (full-time, part-time, casual, self-employed)	253 (51)
Retired, housework duties including carer tasks	229 (46)
Student, unemployed or other	16 (3)
Country of birth (n=494)	
Australia	401 (80)
Language spoken at home, English (n=498)	478 (96)

Marital status (n=493)	
Single	39 (8)
Married or de-facto	371 (74)
Divorced, separated or widowed	83 (17)
Annual household income (n=438)	
<\$52,000	203 (41)
\$52,000 - \$129,999	175 (35)
\$130,000 or more	50 (10)
<b>Care recipient</b>	
Age, mean (SD) (n=469)	45 (27)
Gender, female (n=497)	202 (40)
Medical condition (n=495)	
Temporary disease or disability	35 (7)
Chronic disease or disability	226 (45)
Dementia or memory problems	110 (22)
Mental health problems	168 (34)
Intellectual or developmental disability	166 (33)
Problems due to aging	88 (18)
Terminal illness	25 (5)
Neurological	17 (3)

Other	33 (6)
Number of medical conditions, mean (SD) (n=495)	1.65 (0.88)
<b>Caring situation</b>	
Relationship to the care recipient (n=495)	
Partner	126 (25)
Child	161 (32)
Parent	157 (31)
Another family member, friend or neighbour	51 (10)
Sole carer, yes (n=493)	269 (54)
Support more than one care recipient, yes (n=496)	131 (26)
Sharing household with care recipient, yes (n=494)	402 (80)
Duration of care (n=497)	
≤24 months	127 (25)
>24 months	370 (74)
Hours of care per week (n=488)	
<20 hours	100 (20)
20 – 29 hours	112 (22)
30 – 39 hours	59 (12)
≥40 hours	217 (43)
Tasks (n=496)	

Household activities	406 (81)
Personal care	451 (90)
Practical support	463 (92)

ASCOT-Carer = Adult Social Care Outcomes Toolkit for Carers; CarerQol = Care-related Quality of Life; CES = Carer Experience Scale; SD = standard deviation

**Table 2 Descriptive statistics for the survey instruments**

	<b>n</b>	<b>mean</b>	<b>SD</b>	<b>Min</b>	<b>Max</b>
CRA Self-esteem *	473	3.724	0.607	1.710	5.000
CRA Schedule <sup>#</sup>	475	3.717	0.816	1.000	5.000
CRA Family <sup>#</sup>	476	2.900	0.947	1.000	5.000
CRA Financial <sup>#</sup>	474	3.156	0.970	1.000	5.000
CRA Health <sup>#</sup>	474	3.185	0.861	1.000	5.000
AQoL-8D*	469	0.604	0.196	0.104	0.991
EQ-5D-5L*	476	0.756	0.194	-0.050	1.000
ASCOT-Carer*	383	0.625	0.241	0.022	0.999
CarerQol*	358	57.666	22.419	0.000	98.800
CES*	375	60.496	20.328	10.140	100.000

AQoL-8D = Assessment of Quality of Life 8 dimensions; ASCOT-Carer = Adult Social Care Outcomes Toolkit for Carers; CarerQol = Care-related Quality of Life; CES = Carer Experience Scale; CRA = Caregiver Reaction Assessment; SD = standard deviation; \* higher scores represent better outcomes; # higher scores represent more negative effects;

**Table 3 Proportion of respondents scoring minimum/ maximum values and reliability**

<b>Carer-related instrument</b>	<b>No of domains</b>	<b>% min value (n)</b>	<b>%max value (n)</b>	<b>Cronbach <math>\alpha^*</math></b>	<b>ICC (95% CI)<sup>##</sup></b>
ASCOT-Carer (N=383)	7	0 (0)	1.6 (8)	<b>0.87</b>	<b>0.87</b> (0.80, 0.91)
CarerQol-7D (N=358)	7	0.4 (2)	0.2 (1)	0.65	0.67 (0.48, 0.77)
CES (N=375)	6	0 (0)	1.6 (8)	0.59	<b>0.81</b> (0.73, 0.87)

ASCOT-Carer = Adult Social Care Outcomes Toolkit for Carers; CarerQol = Care-related Quality of Life; CES = Carer Experience Scale; \* values  $\geq 0.70$  threshold are highlighted in bold; # sample sizes for ICC, ASCOT-Carer n=105, CarerQol-7D n=94, CES n=104

**Table 4 Pre-defined hypotheses about associations between carer-related, AQoL-8D, EQ-5D-5L and CRA scores and correlations\***

<b>Instrument</b>	<b>ASCOT-Carer</b>	<b>CarerQol-7D</b>	<b>CES</b>
ASCOT-Carer		Strong + <i>0.54</i>	Strong + <i>0.71</i>
CarerQol	Strong + <i>0.54</i>		Strong + <i>0.45</i>
CES	Strong + <i>0.71</i>	Strong + <i>0.45</i>	
<b>Caregiver Reaction Assessment</b>			
Schedule	Mod – <i>-0.65</i>	Weak – <i>-0.51</i>	Weak – <i>-0.47</i>
Finances	None <i>-0.45</i>	Weak + <i>-0.47</i>	None <i>-0.37</i>
Family support	Weak – <i>-0.39</i>	Weak – <i>-0.38</i>	Weak – <i>-0.44</i>
Health	Weak – <i>-0.68</i>	Weak – <i>-0.66</i>	Weak – <i>-0.50</i>
Self-esteem	None <i>0.09</i>	Weak + <i>0.27</i>	Weak + <i>0.24</i>
AQoL-8D	Mod +	Mod +	Mod +

	<b>0.68</b>	<b>0.61</b>	<b>0.62</b>
EQ-5D-5L	Weak + <b>0.52</b>	Weak + <i>0.44</i>	Weak + <i>0.44</i>

AQoL-8D = Assessment of Quality of Life 8 dimensions; ASCOT-Carer = Adult Social Care Outcomes Toolkit for Carers; CarerQoL = Care-related Quality of Life; CES = Carer Experience Scale; correlations were interpreted according to Cohen’s guidelines, i.e. ‘strong’ ( $\geq 0.51$ ), ‘moderate’ (0.31-0.50), ‘weak’ (0.11-0.30) and ‘none’ (0-0.10). Strong correlations are bolded; \* all Spearman’s rank correlations were statistically significant ( $p$ -value < 0.001) except CRA self-esteem and the ASCOT-Carer score. “+” = positive direction, “-” = negative direction;

**Table 5 Mean carer-related index scores by informal caring situation**

Characteristic	Instruments					
	ASCOT-Carer		CarerQol-7D		CES	
	n	Mean (SD)	n	Mean (SD)	n	Mean (SD)
Relationship (N=495)						
Partner	96	0.60 (0.23)	91	59.11 (20.61)	95	59.20 (19.03)
Parent	126	0.67 (0.24)	122	59.09 (20.57)	124	63.90 (20.56)
Child	123	0.56 (0.23)	111	54.42 (23.66)	117	56.43 (20.65)
Another family member	20	0.73 (0.21)	17	74.98 (22.06)	21	61.62 (20.76)
Friend or neighbour	14	0.84 (0.21)	14	67.26 (20.98)	15	73.64 (12.57)
Total	379	KW 32.08*** EF 0.07	355	KW 17.62*** EF 0.04	372	KW 17.64*** EF 0.04
Only carer (N=493)						

Yes	217	0.57 (0.24)	200	57.43 (21.62)	214	56.77 (19.71)
No	163	0.70 (0.22)	156	60.23 (22.53)	159	65.91 (20.39)
Total	380	Z -4.81*** EF -0.25	356	Z -1.50 EF -0.08	373	Z -4.71*** EF -0.24
Support more than one care recipient (N=496)						
Yes	104	0.55 (0.25)	97	52.95 (25.42)	103	55.12 (21.59)
No	278	0.65 (0.23)	260	60.63 (20.17)	271	62.77 (19.71)
Total	382	Z -3.53*** EF -0.18	357	Z -2.61** EF -0.14	374	Z -2.83** EF -0.15
Sharing household (N=494)						
Yes	307	0.59 (0.24)	291	56.49 (22.01)	302	58.61 (20.59)
No	71	0.77 (0.20)	63	67.65 (19.55)	69	70.64 (16.84)
Total	378	Z -5.61*** EF -0.29	354	Z -3.62*** EF -0.19	371	Z -4.47*** EF -0.23
Duration fulfilling carer role (N=497)						

≤24 months	95	0.82 (0.16)	90	64.88 (17.40)	92	76.82 (15.57)
>24 months	287	0.56 (0.22)	267	56.85 (23.00)	282	55.37 (19.13)
Total	382	<b>Z -9.83*** EF -0.59</b>	357	Z -2.90* EF -0.15	374	Z -9.02*** EF -0.47
Hours of care per week (N=488)						
<20 hours	84	0.76 (0.20)	76	65.76 (20.12)	80	68.01 (18.32)
20 – 29 hours	84	0.73 (0.20)	77	62.31 (18.75)	80	69.45 (18.51)
30 – 39 hours	47	0.64 (0.24)	43	58.05 (23.09)	46	60.67 (22.69)
≥40 hours	162	0.50 (0.21)	156	53.16 (22.72)	162	52.61 (18.68)
Total	377	<b>KW 91.99*** EF 0.23</b>	352	KW 19.27*** EF 0.04	368	KW 53.41*** EF 0.13
Number of tasks (N=496)						
1	30	0.74 (0.21)	21	68.11 (21.01)	25	70.27 (16.50)
2	68	0.77 (0.21)	64	65.93 (18.21)	69	69.92 (14.70)

3	284	0.58 (0.23)	272	56.14 (22.38)	280	57.43 (21.07)
Total	382	<b>KW 46.93*** EF 0.11</b>	357	<b>KW 13.88*** EF 0.03</b>	374	<b>KW 27.06*** EF 0.06</b>

ASCOT-Carer = Adult Social Care Outcomes Toolkit for Carers; CarerQoI = Care-related Quality of Life; CES = Carer Experience Scale; EF = effect size; KW = Kruskal-Wallis H test; \* p-value  $\leq 0.05$ ; \*\* p-value  $\leq 0.01$ ; \*\*\* p-value  $\leq 0.001$ ; Kruskal-Wallis H effect size ‘weak’ 0.01-0.059, ‘moderate’ 0.06-0.139, ‘strong’  $\geq 0.14$ ; Mann-Whitney U effect size ‘weak’ 0.11-0.30, ‘moderate’ 0.31-0.50, ‘strong’  $\geq 0.5$ . **Bolded** results indicate a strong effect size.

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