Validity of quality of life measures for routine assessment in residential aged care – results from a feasibility study

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Abstract

Objective: To examine the psychometric performance of four QoL measures (EQ-5D-5L, EQ-HWB(-S), ASCOT and QOL-ACC) in residential aged care using data from a feasibility study that tested how routine QoL measurement could be implemented.

Methods: Residents were eligible to participate if consent was provided for at least one of the following components: (i) the resident self-reporting their QoL; (ii) aged care staff proxy reporting resident's QoL; or (iii) a family member proxy reporting resident's QoL. The EQ-5D-5L was chosen as the primary measure, with a second measure randomly assigned from either the ASCOT, QOL-ACC, or the EQ-HWB. Feasibility, floor-and ceiling effects, convergent validity, known-group validity and inter-rater reliability were examined.

Results: We gathered cross-sectional QoL data from 103 consenting participants through self-report (n=90), staff proxy-report (n=101) and family proxy-report (n=49). Missing values (completely or partially) from residents' self-reported data ranged from 10% (EQ-5D-5L) to 21% (EQ-HWB-S and QOL-ACC). No instrument had floor or ceiling effects. Strong correlations were observed between EQ-5D-5L and QOL-ACC at the instrument-level. The highest level of agreement between residents/staff was observed for the EQ-5D-5L followed by the EQ-HWB-S. The EQ-5D-5L (self and staff-reported) and QOL-ACC (family reported) could discriminate residents by levels of cognitive impairment; most measures could discriminate by level of dependency, though some did not reach statistical significance.

Conclusions: There is evidence supporting the use of EQ-5D-5L as a measure in residential aged care settings. Capturing residents' QoL routinely has the potential to strengthen the monitoring of quality and value of residential aged care.

Funding: EuroQol Research Foundation (150-RA).

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1. Introduction

With the rising demand for residential aged care services (i.e., nursing homes or long-term institutional care),[1] there has been an increased focus on establishing comprehensive indicators of aged care service quality. Yet, quality indicators in many countries to date seem to focus on clinical and functional aspects of care (e.g., pressure injuries, falls),[2] rather than reflecting a person-centred view and users' experiences. Quality of life (QoL), which is broadly defined as an individual's perception of their physical health, psychological state, social relationships and environmental context,[3] is often used as an outcome measure for capturing the patient's voice. However, the routine measurement of QoL to monitor the quality and value of residential aged care is in its infancy.

In Australia, the National Aged Care Mandatory Quality Indicator Program (the QI Program) has recently been expanded from five clinical indicators to an additional six, following inquiries by the Australian Royal Commission into Aged Care Quality and Safety that highlighted many failings in the system. Since 1 April 2023, the Australian Government has mandated the routine collection of QoL in residential aged care, with facilities required to submit the percentage of residents reporting 'good' or 'excellent' QoL (based on sum scores) every quarter using the Quality-of-Life Aged Care Consumers (QOL-ACC) instrument.[4] The QOL-ACC is an older person-specific measure that was co-designed from its inception with older people using aged care services.[5] It is a relatively new measure designed for application in quality assessment and economic evaluation in aged care, and is accompanied by a preference-weighted scoring algorithm that enables the generation of quality-adjusted life years (QALYs) for use in economic evaluation.[6]

Previous reviews found that the EQ-5D, a measure of health-related quality of life (HRQoL), was a commonly used outcome measure in economic evaluation within aged care,[7, 8] and also in assessing QoL in older adults receiving aged care services more generally.[9] It was also recommended for consideration for the expansion of the Australian QI program, alongside the Adult Social Care Outcomes Toolkit (ASCOT) or the ICEpop CAPability measure for Older people (ICECAP-O), which

were found to be applicable measurement tools in the Australian aged care landscape.[10] The EQ-5D has also been found to be the most commonly used generic outcome measure implemented by healthcare organisations to inform improvements in service delivery.[11] Using a generic measure across health and social care offers a consistent measurement approach and enables the evaluation of inter-sectoral interventions. However, it is currently unknown how well the EQ-5D-5L and other QoL measures perform when used within the context of routine assessment of QoL and their relevance to understanding quality and value in residential aged care settings. This study aimed to examine the psychometric performance of QoL measures using data from a feasibility study that intended to implement routine QoL measurement across two residential aged care facilities in Australia, initiated before the national roll-out of the QI program. Quality of life data were obtained from residents directly via staff-led interviews, alongside proxy-reported data from staff and relatives using the EQ-5D-5L measure. While the EQ-5D-5L was chosen as the primary measure, a second measure, randomly assigned from either the ASCOT, QOL-ACC, or the EQ-HWB, was also administered. These four measures were examined in terms of their feasibility, floor-and ceiling effects, convergent validity, known-group validity and inter-rater reliability.

2. Methods

In reporting the findings, we adhere to the COSMIN (COnsensus-based Standards for the selection of health Measurement Instruments) reporting guidelines.[12]

2.1. Sampling and recruitment

All residents who were living in the two selected not-for-profit organisations were eligible to participate if consent was provided. Consent was either obtained from residents directly or their Power of Attorney (PoA) if the resident did not have capacity to consent based on their cognitive ability, determined by the respective facility. Consent could be provided for at least one of the following three components of the study, which included for: (i) the resident to self-report their QoL, (ii) the aged care staff to proxy assess the resident's QoL, or (iii) a relative to proxy assess the resident's QoL. If a resident had no capacity to consent and no PoA, the resident was excluded from

the study. All residents and relatives were provided with a $30 gift card for participating in the study and each facility received $50 per resident assessment. This study was approved by the Monash University Human Research Ethics Committee (Project ID: 32170).

2.2. Data collection process

QoL data were collected electronically (via REDCap) in one facility and using paper-based versions in the second facility, based on facility's preference, between February and August 2023. Both facilities were provided with a password-protected cloud-based Excel spreadsheet that included information about which residents consented to which components of the study as well as the allocated QoL measures. Training was provided to staff involved in the data collection process. On the day of the assessment, staff were instructed to undertake a proxy assessment for the resident before obtaining self-reported assessment from the resident via an interview. This ensured that the staff assessment was unbiased. Staff then conducted the interview with the resident on the same day using the same QoL measures. After the assessment, staff completed a brief evaluation form and noted the interview date in the Excel file, which prompted the research team to call and obtain a proxy report from the nominated relative within a week's time.

2.3. Quality of life measures

The EQ-5D-5L was completed by all residents. It consists of five dimensions (mobility, personal-care, usual activities, anxiety/depression, pain/discomfort) with five response options each (no problems, slight problems, moderate problems, severe problems, extreme problems/unable).[13] The EQ-5D-5L includes a visual analogue scale (EQ VAS), a vertical scale ranging from zero, indicating 'the worst health you can imagine', to 100, representing 'the best health you can imagine'. In this study, the Australian English-language version of the EQ-5D-5L for interviewer administration was used to obtain residents' self-reported QoL. Proxies, including aged care staff and relatives, completed the proxy version 2 of the EQ-5D-5L (i.e., proxy-person perspective). This version prompts the proxy to assess how they believe the resident would rate their own health if able to communicate. All questions

in the EQ-5D-5L refer to your health 'TODAY'. The Australian value set was used to score the EQ-5D-5L measure, with scores ranging from -0.301 to 1, where 1 represents full health.[14]

In addition to the EQ-5D-5L, a second measure was randomly assigned from either the QOL-ACC, ASCOT, or the EQ-HWB. The QOL-ACC was chosen as it is an older person-specific QoL measure used in the Quality Indicator program in Australia. It includes five dimensions (independence, mobility, pain management, emotional wellbeing, social connection, and activities) with five response levels each.[5] Both the interviewer-led and the proxy-version of the QOL-ACC were used in this study. The recently developed Australian value set was used to score the QOL-ACC.[6] The ASCOT is a measure of a person's social-care related QoL, consisting of eight domains (personal comfort and cleanliness, personal safety, food and drink, occupation, control over daily life, social participation, home cleanliness and comfort, and dignity) with four levels (ideal state, no needs, some needs, and high needs).[15] The SCT-4 version was used for residents' self-report, while the proxy version was used for proxy assessment, which asks proxies to rate the resident's QoL from both perspectives, the proxy-proxy and proxy-person perspective.[16] ASCOT data were scored using the UK value set, as Australia scores are not available.[15] Finally, the EQ-HWB was administered, a 25-item measure that was developed by the EuroQol to measure health and wellbeing in 'the last 7 days'.[17] The self-report version was used for interviews with residents, whereas the proxy version 2 (i.e., proxy-person perspective) was used for proxy assessment. A level sum score was created for the 25-item EQ-HWB, with scores ranging from 25-125, where higher scores represent better QoL (i.e., negatively worded items were reversed). Additionally, the UK pilot value set was used to derive the EQ-HWB short version (EQ-HWB-S), which is a preference-weighted measure.[18]

2.4. Statistical analyses

All paper-based collected data from one facility were entered electronically and merged with the RECap data from the second facility to facilitate analyses in STATA v.17. Descriptive statistics were used to analyse the quantitative data, using percentages for categorical data and means (standard deviation, SD) for continuous data. Feasibility was assessed in terms of missing values, differentiating between partial missingness (i.e., one or a few items not completed) and complete missingness (i.e.,

all items of the respective measure not completed). Floor or ceiling effects were considered to be present if more than 15% of respondents reported the lowest or highest possible QoL, respectively, by exploring the profiles of the four measures. Convergent validity was only examined for the EQ-5D-5L by formulating a priori hypotheses about the expected relationship with the other three measures based on previous literature. While strong a correlation was hypothesised between the EQ-5D-5L and EQ-HWB-S,[19] only a weak correlation was expected with the ASCOT[20] and a moderate correlation with the QOL-ACC based on previous evidence.[21] Correlations were explored at the instrument level using Pearson correlation. The size of correlation coefficients was interpreted as negligible (0.00 to 0.30), weak (>0.30 to 0.50), moderate (>0.50 to 0.70) and strong (>0.70 to 0.90). Known-group validity was tested based on the instruments' ability to discriminate between residents based on their cognitive functioning and level of dependence, and residents' latest assessments which were provided by the facilities. A one-way analysis-of-variance (ANOVA) was calculated and adjusted for multiple comparison using Scheffe. Effect sizes were calculated based on Cohen's Delta (d), which were classified as small (d = 0.2), medium (d = 0.5), and large (d ≥ 0.8).[22] Cognitive functioning was measured using the Psychogeriatric Assessment Scale – Cognitive (PAS-Cog), which ranges from 0-21 with higher scores indicating greater severity.[23] Of the 101 residents for whom the PAS-Cog score was available, 14% had no impairment (0<4), 38% mild impairment (4<10), 19% moderate impairment (10<16), and 25% had severe impairment (16-21). Two equally sized groups were created to indicate either no or mild impairment (0-9) or mild to moderate impairment (10-21). The Collin Modified Barthel Index of Activities of Daily Living was used to measure residents' level of dependency across ten areas (e.g., feeding, toilet use). Scores range from 0-20, with lower scores indicating increased disability.[24] Two equally sized groups were created for the known-group validity (group 1: 0-7; group 2: 8-20). Finally, inter-rater reliability was examined using two-way random effects intra-class correlation (ICC) coefficient for the index scores, with scores interpreted as poor reliability (<0.5), moderate reliability (0.5-0.75), good reliability (0.75-0.9) and excellent reliability (>0.9).[25] Agreement was also explored at the dimension level using weighted Kappa statistic, which takes the ordering of the ordinal data into account. Linear pre-recorded weights for agreement were used in Stata using the command *wgt(w)*. Agreement based on Kappa scores was interpreted as: 0 =

none; 0.01 ≤ 0.20 = poor, 0.21 to ≤ 0.40 = fair, 0.41 to ≤ 0.60 = moderate, 0.61 to ≤ 0.80 = good, and 0.81 to 1.00 = very good.[26]

3. Results

Of the 103 participants who consented, we gathered QoL data through self-report (EQ-5D-5L=90, ASCOT=31, QOL-ACC=33, EQ-HWB=24), staff proxy-report (EQ-5D-5L=101, ASCOT=35, QOL-ACC=37, EQ-HWB=30) and family proxy-report (EQ-5D-5L=49, ASCOT=18, QOL-ACC=15, EQ-HWB=16). Due to an administration error, multiple assessments were conducted for some residents for certain QoL measures (i.e., seven self-reports and seven staff proxy-reports). Appendix 1 illustrates the consent and data collection process.

Table 1 shows the descriptive statistics for the QoL measures, highlighting that for both self- and proxy-reported scores, utility scores were lowest when using the EQ-5D-5L (self: 0.57, staff: 0.5, family: 0.37), followed by EQ-HWB-S (self: 0.68, staff: 0.60, family: 0.50), QOL-ACC (self: 0.69, staff: 0.66, family: 0.46) and ASCOT (self: 0.83, staff: 0.86-0.87, family: 0.57-0.64). Additionally, residents' self-reported scores were higher than proxy scores, with family members reporting lower scores than staff across all measures, including EQ VAS and EQ-HWB.

The highest occurrence of missing values, whether partial or complete, was noted in the residents' self-reported QoL, predominantly as partial omissions for specific items rather than complete missingness (see Table 2). While partial missingness was highest (25%) for the EQ-HWB (25-items), the highest proportion for complete missingness was observed for the QOL-ACC (15%). The EQ-5D-5L exhibited the fewest missing values among all measures. Proxy responses by staff and family members were generally complete across measures (except for the ASCOT proxy-person perspective), with the highest proportion of partial missingness observed for the EQ-HWB. Appendices 2-5 provide graphical representations of the missing values by the items of the respective measures. Table 2 further shows that none of the instruments had floor or ceiling effects. Although 14% of staff and 10% of residents reported the highest response level across all ASCOT items, these proportions were below the 15% threshold used to detect ceiling effects.

In terms of convergent validity of the EQ-5D-5L, Table 3 shows the correlation analysis results. Although a strong correlation was hypothesised between the EQ-5D-5L and EQ-HWB-S, this was only confirmed for staff proxy reported scores (r = 0.67), with weak correlations noted for residents' self-report (r = 0.44) and family proxy-report (r = 0.38). In contrast, despite hypothesising a moderate correlation with the QOL-ACC, strong correlations were observed for staff (r = 0.75) and family proxy-reports (r = 0.82), with moderate correlations among residents (r = 0.62). As hypothesised, no or only weak correlations were observed between the EQ-5D-5L and the ASCOT.

Inter-rater reliability statistics, based on ICC, are shown in Table 4, indicating a greater level of agreement between residents and staff than between residents and family members, or staff and family members across all measures. Excellent reliability between staff and resident was observed for the EQ-5D-5L (ICC=0.96), with good reliability noted when using the EQ-HWB (ICC=0.89), EQ-HWB-S (ICC=0.86), QOL-ACC (ICC=0.85) and EQ VAS (ICC=0.77). While good reliability was also observed between resident/family and staff/family using the EQ-5D-5L, QOL-ACC, EQ-HWB and EQ-HWB-S, poor reliability was noted for the ASCOT and EQ VAS. Weighted Kappa agreement statistics in Appendix 6 further show that agreement was good to very good for observable domains of QoL, such as mobility, personal care, activities, compared with emotional wellbeing or feelings.

With regard to known-group validity, none of the measures, except for self-reported and staff-reported EQ-5D-5L as well as the family-reported QOL-ACC, could discriminate residents by levels of cognitive impairment based on the PAS-Cog (see Table 5). In terms of the level of assistance required using the Barthel Index, all measures produced lower scores with increasing level of disability; however, the significance level for all three self- and proxy-reported scores was not reached for some measures, except for the EQ-5D-5L and QOL-ACC. Effect sizes were also small or medium for most of the comparisons (Table 6).

4. Discussion

This study explored the psychometric performance of four QoL measures simultaneously in residential aged care using residents' self-reported and proxy reported QoL data. Overall, our findings

indicate that the primary measure employed in this study, the EQ-5D-5L, has good psychometric performance in this setting, demonstrating few missing values, no floor or ceiling effects, good convergent validity, acceptable known-group validity, and good to excellent inter-rater reliability. These findings broadly confirm a previous study examining the feasibility and validity of the EQ-5D-5L proxy version of nursing home residents in Singapore.[27] Similar to our study, incomplete EQ-5D-5L proxy assessments by nurses were relatively small (2.6%), the study did not report floor or ceiling effects, and the EQ-5D-5L was able to discriminate between residents with varying communication abilities and physical functions. However, as highlighted in a recent systematic review, there is still limited evidence regarding the use of EQ-5D proxy assessments in residential aged care facilities, emphasising the need for further validation studies.[28]

Findings for the three other measures used in our study (i.e., ASCOT, QOL-ACC and EQ-HWB) were mixed and results need to be interpreted carefully due to small samples. Overall, all measures exhibited good acceptability in relation to the number of missing values, which were predominantly related to specific items rather than affecting the entirety of the questionnaire. While the exact reasons for missingness are unclear, our previous qualitative study, examining the perceptions of residents towards the four QoL measures, indicated issues with some measures related to comprehension and difficulty selecting a response level due to double-barrelled and ambiguous items, which could explain some of the quantitative findings.[29] While none of the measures showed any floor effects, the highest ceiling effect was found for the ASCOT. Compared to other measures, which measure HRQoL and wellbeing, the ASCOT focuses on SCRQoL, with items related to quality of care, such as ‘food and drink’ or ‘home cleanliness and comfort’. It is likely that the staff proxy assessments on these questions represent a potential response bias, where 14% of staff reported the best state for the ASCOT. However, it is noteworthy that also 10% of residents reported the best state on the ASCOT. This could indicate high levels of satisfaction, but could indicate fear of repercussions if negative responses are given, resulting in more positive responding to the ASCOT questions, especially to questions related to food and drink, safety and cleanliness.[29] Only one previous study explored ceiling effects of the ASCOT, showing that it was negatively skewed with a possible ceiling effect at the

upper end of the scale in adults with long-term physical, sensory and mental health conditions.[30] More evidence within the residential aged care setting is needed and further guidelines in ensuring responses are free of bias, which is a general issue regardless of the measure.

When interpreting results from the known-group validity analysis for the EQ-HWB, QOL-ACC and ASCOT, special caution should be exercised given the small sample sizes within certain groups. Results have shown that only the EQ-5D-5L (self and staff-reported) and QOL-ACC (family-reported) could discriminate by level of cognitive impairment. These findings align with a recent systematic review, showing that only seven out of 17 studies that explored the relationship between EQ-5D (-3L and -5L) and cognition detected a positive significant relationship (i.e., greater cognitive impairment would be associated with lower EQ-5D scores), with three of these studies having a sample size greater than 300.[31] Although the non-significant results observed in our study could be driven by sample size, a previous study has found that non-cognitive factors affect self-reported or proxy-reported QoL ratings in people with dementia, such as awareness of diseases or depressive symptoms.[32] In contrast, most measures could discriminate by level of dependency, even though not all could reach statistical significance. These findings were anticipated by measures that contain health-related aspects of QoL, such as the EQ-5D-5L, EQ-HWB and QOL-ACC.[31]

When examining the utility scores, our study further showed that self-reported scores were higher (i.e., indicating better QoL) than proxy-reported scores, which is consistent with previous literature in residential aged care using the EQ-5D-5L[33] and QOL-ACC measures.[34] Additionally, family proxy reports were found to be lower (i.e., indicating worse QoL) in our study than staff proxy reports, which has also been previously reported in the literature.[35-37] One possible explanation is that family proxies tend to assess the resident's QoL in relation to their past self before moving into aged care or having dementia, while staff may draw comparisons with other residents under their care.[36] It is also possible that residents have adapted to their circumstances in residential aged care, which may not have been noticed by family members, especially if visits were infrequent. Further, compared with previous studies where proxy ratings tended to correlate more strongly with each other than they did with the residents' scores,[35, 36] our inter-rater reliability results indicated better agreement between

staff and residents than between staff and family members or between residents and family members. Although staff members were instructed to perform the proxy assessment prior to interviewing the resident about their QoL, it is possible that the presence and behaviour of the staff member conducting the interview may have influenced residents' responses, resulting in an interviewer effect bias. While this could have been avoided if the research team would have obtained QoL assessments from residents, it is crucial to recognise that this study's goal was to introduce routine QoL measurement within the respective facility, where interviewer-led assessments were inevitable. Additionally, interviewer-facilitated completion is also recommended by the present Australian QI program if residents cannot independently complete the QoL measure themselves.[4] The slightly lower agreement between residents and family members could potentially stem from delays in contacting families after residents have provided their self-reports. However, it is also possible that family members do not always visit residents frequently enough to be able to proxy report their QoL.

We also found that inter-rater reliability between the three different raters was better for the EQ-5D-5L than for other measures. Compared to the other measures, the EQ-5D-5L has fewer dimensions (hence, less to disagree on) and focuses on health-related aspects of QoL, which may be easier for proxies to assess than broader aspects of wellbeing or social-related QoL. Additionally, we found a better agreement for observable domains of QoL, such as mobility (EQ-5D-5L, EQ-HWB, QOL-ACC), personal care (EQ-5D-5L and EQ-HWB), activities (EQ-5D-5L, EQ-HWB, QOL-ACC), compared with emotional wellbeing (QOL-ACC) or feelings and cognition (EQ-HWB), which is in line with previous evidence.[38] While moderate agreement between resident and staff was found for the ASCOT measure, generally the agreement on the item level was poor. To our knowledge, no previous study has examined the inter-rater reliability between self-reported and proxy-reported scores using the ASCOT, where the reasons for the poor agreement remain unknown.

Limitations

Given the cross-sectional nature of the study, we were unable to explore responsiveness to change or test-retest reliability. We could only explore convergent validity of the EQ-5D-5L given that no head-to-head comparison data were available for the other three measures. While our intention was to

ascertain the average time required to administer each measure to the resident, inaccurate and inadequate estimates, which included the entire interview process duration, hindered our ability to determine the average completion time. We also had limited information about residents' characteristics, which prevented us from undertaking further known group validity analyses and describing the sample sufficiently. Pas-Cog and Barthel Index of Activities of Daily Living data were not available for all residents, resulting in small samples. Further, some PoAs declined participation for residents who had complex health needs or insufficient English proficiency, affecting generalisability of our findings. The unavailability of translated versions for some instruments and the absence of an interpreter also meant that we could not fully explore the appropriateness of these measures among culturally or linguistically diverse individuals. The fact that the two aged care facilities for this study were selected using a convenience sampling approach and that both were not-for-profit organisations from the same provider, potentially limits the transferability of our findings to private or government-owned facilities. The final limitation of our study relates to the small sample size, which is of particular concern for results reported for the second randomly assigned measure. Although we reported findings using the available data for transparency, caution should be exercised when interpreting these results. Finally, all analyses conducted in this study were based on instruments' specific value sets and we acknowledge that the use of value sets is more relevant within the context of conducting an economic evaluation rather than quality assessment.

Conclusion

This is the first study to explore the psychometric performance of four QoL measures simultaneously in residential aged care using self-reported and proxy-reported data. The EQ-5D-5L demonstrated good performance in this setting, although the performance of other measures needs to be interpreted carefully due to small samples. Our research indicates that the EQ-5D-5L could be considered as a candidate measure for implementation in the aged care sector. Using such a brief and generic measure has potential advantages in allowing consistent measurement of outcomes across health and social care, and evaluating interventions that involve an interface between the two sectors. However, further similar studies are needed to establish sufficient evidence.

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Table 1: Descriptive statistics of QoL measures

Measures	Respondent	Sample (n)	Mean (SD)
EQ-5D-5L	Staff proxy	100	0.5 (0.35)
	Family proxy	42	0.37 (0.36)
	Resident	81	0.57 (0.35)
QOL-ACC	Staff proxy	37	0.66 (0.21)
	Family proxy	13	0.46 (0.35)
	Resident	26	0.69 (0.19)
ASCOT	Staff proxy-proxy	32	0.86 (0.13)
	Staff proxy-person	28	0.87 (0.11)
	Family proxy-proxy	17	0.64 (0.22)
	Family proxy-person	16	0.57 (0.22)
	Resident	27	0.83 (0.17)
EQ-HWB-S	Staff proxy	28	0.60 (0.23)
	Family proxy	13	0.50 (0.25)
	Resident	19	0.68 (0.24)
EQ-VAS	Staff proxy	100	66.53 (20.00)
	Family proxy	48	51.98 (26.02)
	Resident	79	65.59 (20.05)
EQ-HWB	Staff proxy	25	95.92 (12.68)
	Family proxy	13	86 (20.75)
	Resident	16	97.81 (15.66)

Table 2: Missing values and floor/ceiling effects results, N (%)

	EQ-5D-5L	EQ VAS	QOL-ACC	EQ-HWB	EQ-HWB-S	ASCOT (proxy-proxy)	ASCOT (proxy-person)
Missing values - Staff	**N=101**	**N=101**	**N=37**	**N=30**	**N=30**	**N=35**	**N=35**
Completely missing	1 (1%)	1 (1%)	0	0	0	0	2 (6%)
Partially missing	0	0	0	5 (17%)	2 (7%)	3 (9%)	5 (14%)
Missing values - Family	**N=49**	**N=49**	**N=15**	**N=16**	**N=16**	**N=18**	**N=18**
Completely missing	0	1 (2%)	0	0	0	0	0
Partially missing	7 (14%)	0	2 (13%)	3 (19%)	3 (19%)	1 (6%)	2 (11%)
Missing values - Resident	**N=90**	**N=90**	**N=33**	**N=24**	**N=24**	**N=31**	**N=31**
Completely missing	7 (8%)	11 (12%)	5 (15%)	1 (4%)	1 (4%)	1 (3%)	1 (3%)
Partially missing	2 (2%)	0	2 (6%)	7 (29%)	4 (17%)	3 (10%)	3 (10%)
Best state (ceiling effect)							
Staff	3 (3%)	1 (1%)	2 (5%)	0	0	4 (11%)	5 (14%)
Family	0	1 (2%)	0	1 (6%)	1 (6%)	0	0
Resident	6 (7%)	3 (3%)	1 (3%)	2 (8%)	2 (8%)	3 (10%)	3 (10%)
Worst state (floor effect)							
Staff	0	0	0	0	0	0	0
Family	0	1 (2%)	0	0	0	0	0
Resident	0	0	0	0	0	0	0

Table 3: Correlation analysis results

	EQ-5D-5L staff	**EQ-5D-5L family**	**EQ-5D-5L resident**
EQ-5D-5L staff	1.00	0.8177***	0.9144***
EQ-5D-5L family	0.8177***	1.00	0.8257***
EQ-5D-5L resident	0.9144***	0.8257***	1.00
QOL-ACC staff	**0.7486*** **	0.8811***	0.7607***
QOL-ACC family	0.7976**	**0.8156** **	0.6397*
QOL-ACC resident	0.5654**	0.8892**	**0.6245*** **
EQ-HWB-S staff	**0.6659*** **	0.3504	0.4906
EQ-HWB-S family	0.4054	**0.3816**	0.3152
EQ-HWB-S resident	0.4895	0.3497	**0.4428**
ASCOT staff proxy-person	**0.4823** **	0.3007	0.5063**
ASCOT staff proxy-proxy	**0.4328** *	0.1583	0.4623*
ASCOT family proxy-person	-0.0389	**0.2051**	-0.3153
ASCOT family proxy-proxy	0.1243	**0.5206** *	-0.044
ASCOT resident	0.0016	0.1428	**0.0998**
EQ VAS staff	**0.2131** *	0.21	0.2615*
EQ VAS family	0.260	**0.5216*** **	0.0805
EQ VAS resident	0.4187***	0.4772**	**0.4476*** **
EQ-HWB staff	**0.4925** *	0.47	0.35
EQ-HWB family	0.51	**0.33**	0.34
EQ-HWB resident	0.5141*	0.743*	**0.45**

* indicates p-value < 0.05, ** indicate p-value < 0.01, *** indicate p-value < 0.001.
A-priori hypothesised relationships examined for convergent validity of the EQ-5D-5L are in bold.

Table 4: Inter-rater reliability results

	Resident/staff			Resident/family			Staff/family		
	N	**ICC**	**95% CI**	**N**	**ICC**	**95% CI**	**N**	**ICC**	**95% CI**
EQ-5D-5L	78	0.96	(0.93, 0.97)	34	0.84	(0.35, 94)	42	0.86	(0.58, 0.94)
QOL-ACC	26	0.85	(0.67, 0.93)	9	0.74	(0.04, 0.94)	13	0.8	(0.36, 0.94)
ASCOT proxy-proxy	26	0.54	(0.02, 0.79)	11	-1	(-4.2, 0.42)	16	-0.29	(-1.31, 0.44)
ASCOT proxy-person	23	0.59	(0.09, 0.82)	11	-0.72	(-2.85, 0.47)	15	-0.02	(-0.38, 0.43)
EQ-HWB-S	18	0.86	(0.63, 0.95)	10	0.8	(-0.17, 0.96)	11	0.75	(0.13, 0.93)
EQ-HWB	16	0.89	(0.70, 0.96)	7	0.71	(-0.43, 0.95)	10	0.81	(0.31, 0.95)
EQ VAS	76	0.77	(0.63, 0.85)	36	0.08	(-0.64, 0.50)	48	0.23	(-0.21, 0.54)

Table 5: Known-group validity – Psychogeriatric Assessment Scale – cognitive (PAS-Cog)

PAS	N	Mean (SD)	p value (ES)	N	Mean (SD)	p value (ES)	N	Mean (SD)	p value (ES)
	EQ-5D-5L resident			**EQ-5D-5L staff**			**EQ-5D-5L family**		
No or mild impairment	52	0.62 (0.32)	0.07 (0.44)	52	0.58 (0.34)	0.02 (0.50)	22	0.45 (0.36)	0.12 (0.49)
Moderate or severe impairment	27	0.47 (0.37)		45	0.41 (0.35)		20	0.28 (0.34)	
	QOL-ACC resident			**QOL-ACC staff**			**QOL-ACC family**		
No or mild impairment	21	0.69 (0.19)	0.86 (0.09)	22	0.70 (0.21)	0.17 (0.47)	6	0.68 (0.27)	0.04 (1.33)
Moderate or severe impairment	5	0.67 (0.19)		15	0.60 (0.21)		7	0.28 (0.32)	
	EQ-HWB-S resident			**EQ-HWB-S staff**			**EQ-HWB-S family**		
No or mild impairment	13	0.67 (0.25)	0.90 (-0.06)	13	0.59 (0.29)	0.97 (-0.02)	9	0.48 (0.28)	0.70 (-0.24)
Moderate or severe impairment	6	0.69 (0.24)		14	0.60 (0.18)		4	0.54 (0.21)	
	ASCOT resident			**ASCOT staff proxy-proxy**			**ASCOT family proxy-proxy**		
No or mild impairment	14	0.86 (0.16)	0.37 (0.36)	16	0.90 (0.13)	0.13 (0.56)	8	0.65 (0.21)	0.77 (0.14)
Moderate or severe impairment	11	0.80 (0.20)		15	0.82 (0.13)		9	0.62 (0.24)	
	ASCOT resident			**ASCOT staff proxy-person**			**ASCOT family proxy-person**		
No or mild impairment	14	0.86 (0.16)	0.37 (0.36)	14	0.90 (0.13)	0.27 (0.44)	7	0.57 (0.26)	0.96 (0.03)
Moderate or severe impairment	11	0.80 (0.20)		13	0.85 (0.09)		9	0.56 (0.20)	
	EQ VAS resident			**EQ VAS staff**			**EQ VAS family**		
No or mild impairment	52	65.62 (20.08)	0.84 (-0.05)	52	63.87 (18.89)	0.11 (-0.33)	22	53.91 (26.62)	0.64 (0.14)
Moderate or severe impairment	25	66.6 (19.81)		45	70.27 (20.23)		26	50.35 (25.92)	
	EQ-HWB resident			**EQ-HWB staff**			**EQ-HWB family**		
No or mild impairment	11	98.45 (15.71)	0.82 (0.13)	11	96.27 (13.17)	0.87 (0.07)	9	86.33 (24.09)	0.94 (0.05)
Moderate or severe impairment	5	96.4 (17.31)		13	95.38 (13.28)		4	85.25 (13.15)	

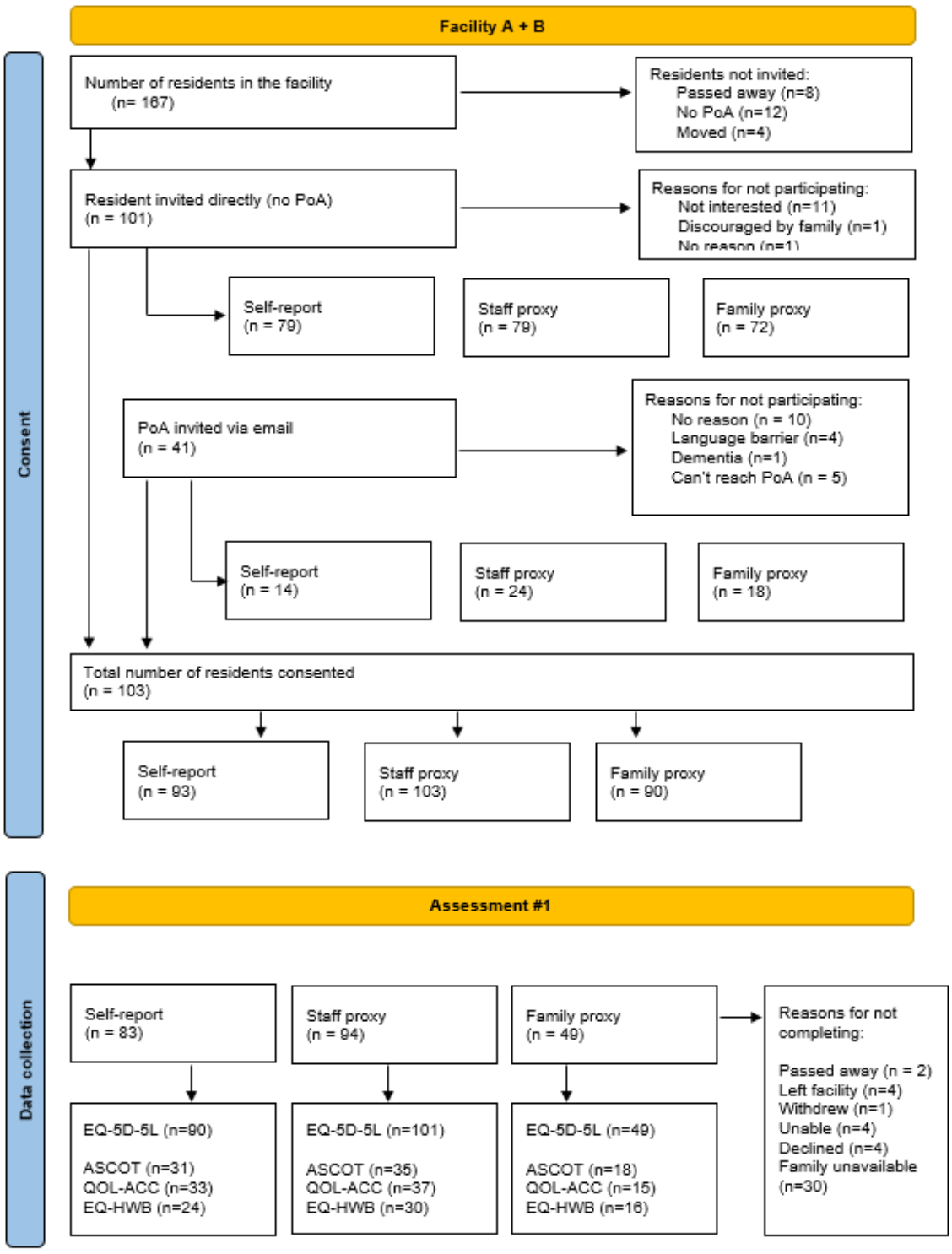
ES: Effect size (Cohen's Delta).

Table 6: Known-group validity – Collin Modified Barthel Index of Activities of Daily Living

	N	Mean (SD)	p value (ES)	N	Mean (SD)	p value (ES)	N	Mean (SD)	p value (ES)
	EQ-5D-5L resident			**EQ-5D-5L staff**			**EQ-5D-5L family**		
BI 0-7	33	0.33 (0.28)	<0.001 (0.44)	51	0.30 (0.29)	<0.001 (0.50)	19	0.10 (0.26)	<0.001 (0.49)
BI 8-20	41	0.78 (0.34)		42	0.77 (0.24)		21	0.63 (0.22)	
	QOL-ACC resident			**QOL-ACC staff**			**QOL-ACC family**		
BI 0-7	14	0.64 (0.19)	0.03 (0.09)	23	0.59 (0.21)	<0.001 (0.47)	8	0.26 (0.29)	0.01 (1.33)
BI 8-20	10	0.80 (0.13)		12	0.83 (0.12)		4	0.80 (0.13)	
	EQ-HWB-S resident			**EQ-HWB-S staff**			**EQ-HWB-S family**		
BI 0-7	6	0.60 (0.24)	0.07 (-0.06)	14	0.50 (0.22)	0.01 (-0.02)	5	0.51 (0.20)	0.86 (-0.24)
BI 8-20	10	0.81 (0.18)		10	0.76 (0.19)		7	0.54 (0.28)	
	ASCOT resident			**ASCOT staff proxy-proxy**			**ASCOT staff proxy-person**		
BI 0-7	9	0.75 (0.22)	0.07 (0.36)	13	0.82 (0.14)	0.11 (0.56)	9	0.61 (0.24)	0.68 (0.14)
BI 8-20	16	0.88 (0.13)		18	0.89 (0.13)		8	0.66 (0.21)	
	ASCOT resident			**ASCOT family proxy-proxy**			**ASCOT family proxy-person**		
BI 0-7	9	0.75 (0.22)	0.07 (0.36)	10	0.80 (0.14)	0.01 (0.44)	8	0.58 (0.22)	0.86 (0.03)
BI 8-20	16	0.88 (0.13)		17	0.92 (0.06)		8	0.56 (0.24)	
	EQ VAS resident			**EQ VAS staff**			**EQ VAS family**		
BI 0-7	31	62.45 (19.68)	0.12 (-0.05)	51	66.84 (20.04)	0.67 (-0.33)	24	47.5 (26.01)	0.21 (0.14)
BI 8-20	41	69.76 (19.00)		42	68.60 (19.32)		22	57.27 (25.45)	
	EQ-HWB resident			**EQ-HWB staff**			**EQ-HWB family**		
BI 0-7	5	90.2 (18.10)	0.11 (0.13)	12	92.08 (10.92)	0.05 (0.07)	5	86.2 (11.58)	0.73 (0.05)
BI 8-20	9	104.56 (13.18)		10	102.6 (13.18)		7	90.43 (24.04)	

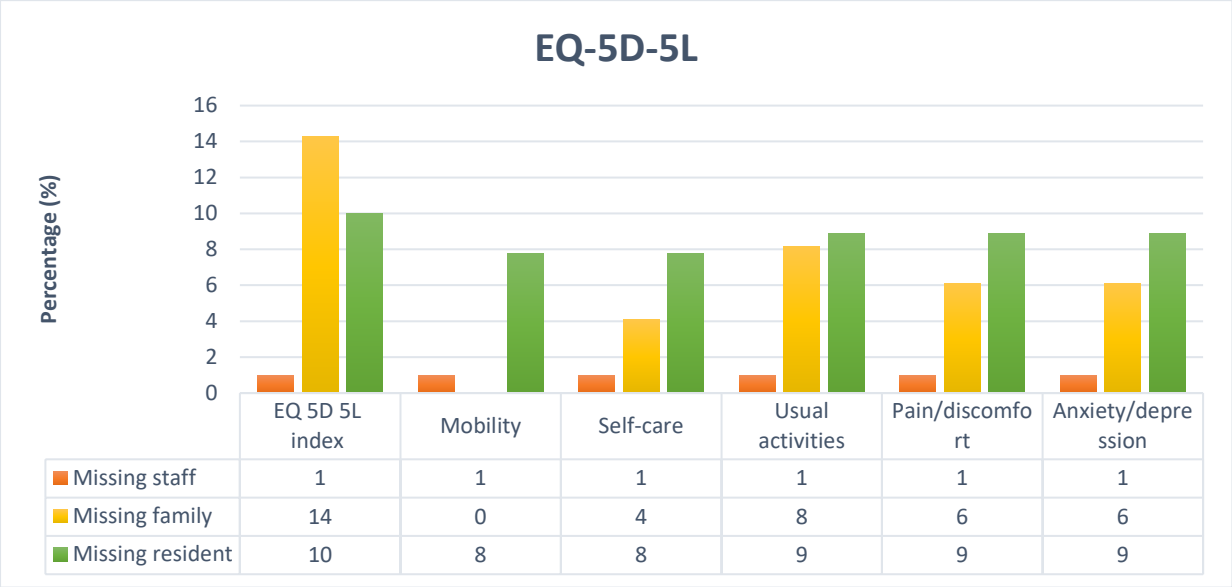
BI: Barthel Index; Scores range from 0-20, with lower scores indicating increased disability. ES: Effect size (Cohen's Delta).

Appendix 1: Flowchart depicting the consent and data collection process.



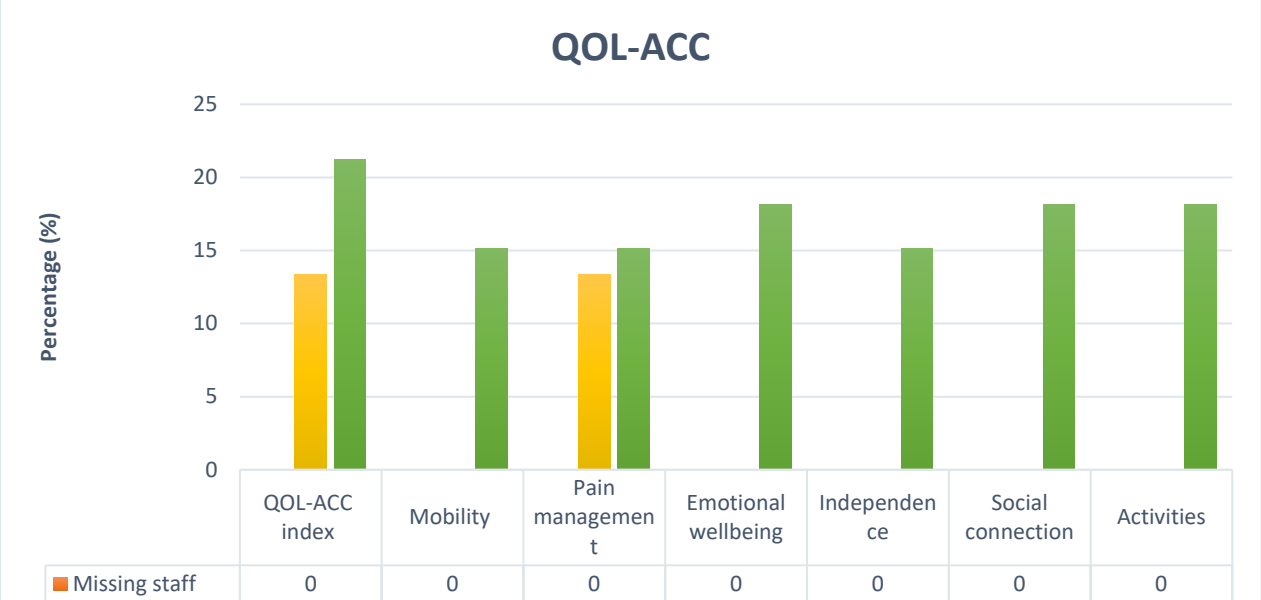
Note: Multiple assessments were obtained for 7 self-reports and 7 staff proxy-reports.

Appendix 2: Missing values (%) for the EQ-5D-5L



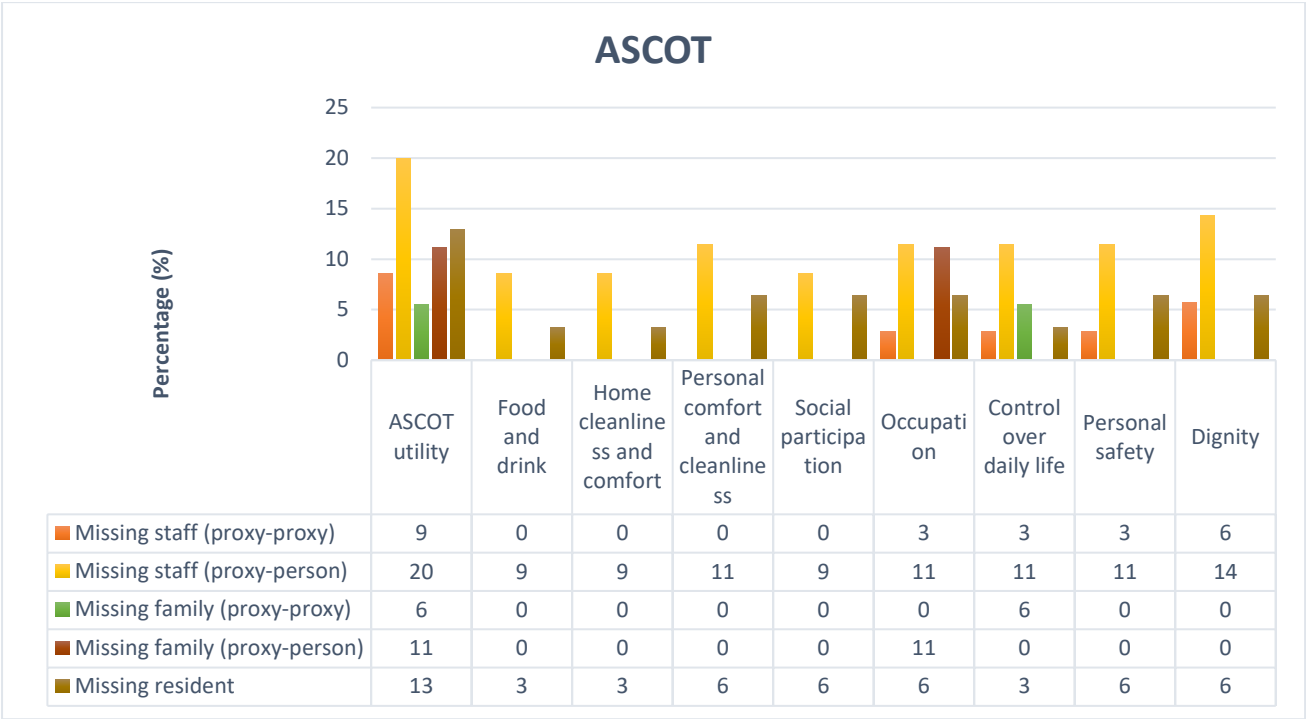
	EQ 5D 5L index	Mobility	Self-care	Usual activities	Pain/discomfort	Anxiety/depression
Missing staff	1	1	1	1	1	1
Missing family	14	0	4	8	6	6
Missing resident	10	8	8	9	9	9

Appendix 3: Missing values (%) for the QOL-ACC



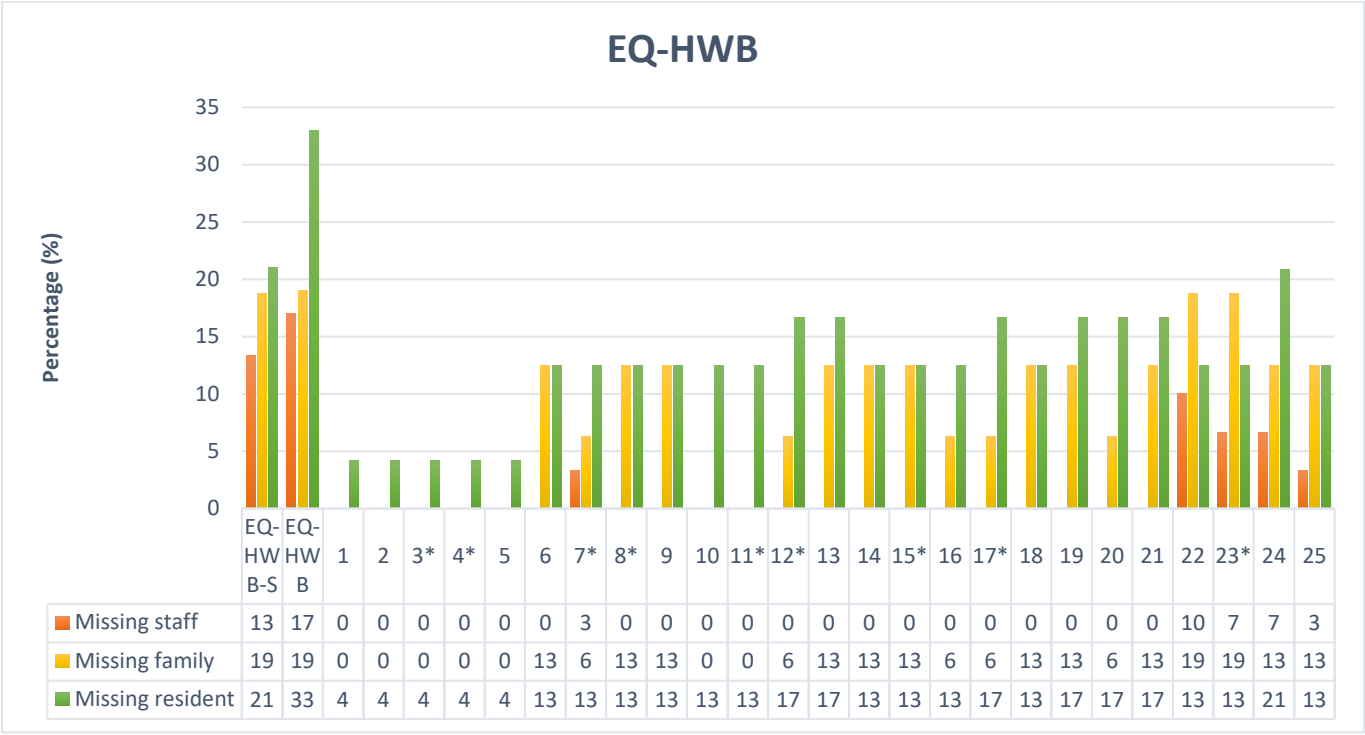
	QOL-ACC index	Mobility	Pain management	Emotional wellbeing	Independence	Social connection	Activities
Missing staff	0	0	0	0	0	0	0
Missing family	13	0	13	0	0	0	0
Missing resident	21	15	15	18	15	18	18

Appendix 4: Missing values (%) for the ASCOT



	ASCOT utility	Food and drink	Home cleanliness and comfort	Personal comfort and cleanliness	Social participation	Occupation	Control over daily life	Personal safety	Dignity
Missing staff (proxy-proxy)	9	0	0	0	0	3	3	3	6
Missing staff (proxy-person)	20	9	9	11	9	11	11	11	14
Missing family (proxy-proxy)	6	0	0	0	0	0	6	0	0
Missing family (proxy-person)	11	0	0	0	0	11	0	0	0
Missing resident	13	3	3	6	6	6	3	6	6

Appendix 5: Missing values (%) for the EQ-HWB



	EQ-HWB-S	EQ-HWB	1	2	3*	4*	5	6	7*	8*	9	10	11*	12*	13	14	15*	16	17*	18	19	20	21	22	23*	24	25
Missing staff	13	17	0	0	0	0	0	0	3	0	0	0	0	0	0	0	0	0	0	0	0	0	0	10	7	7	3
Missing family	19	19	0	0	0	0	0	13	6	13	13	0	0	6	13	13	13	6	6	13	13	6	13	19	19	13	13
Missing resident	21	33	4	4	4	4	4	13	13	13	13	13	13	17	17	13	13	13	17	13	17	17	17	13	13	21	13

Items included in the EQ-HWB-S. 1. Seeing; 2. Hearing; 3. Getting Around 4. Day to Day*; 5. Washing; 6. Sleep; 7. Exhaustion*; 8. Lonely*; 9. Support; 10. Memory; 11. Concentration*; 12. Anxious*; 13. Unsafe; 14. Frustrated; 15. Depressed*; 15. 16. Looking forward; 17. Control*; 18. Cope; 19. Accepted; 20. Felt Good; 21. Do Things; 22. Pain Frequency; 23. Pain Severity*; 24. Discomfort Frequency; 25. Discomfort Severity

Appendix 6: Weighted Kappa agreement statistics by measure

	Resident/ staff		Resident/ family		Staff/ family	
EQ-5D-5L	**Weighted Kappa**	**95% CI**	**Weighted Kappa**	**95% CI**	**Weighted Kappa**	**95% CI**
Mobility	0.809	(0.765; 0.825)	0.599	(0.567; 0.725)	0.562	(0.501; 0.582)
Personal care	0.735	(0.702; 0.780)	0.677	(0.521; 0.778)	0.688	(0.634; 0.777)
Usual activities	0.698	(0.624; 0.757)	0.461	(0.379; 0.627)	0.404	(0.326; 0.516)
Pain/discomfort	0.599	(0.497; 0.652)	0.302	(0.168; 0.386)	0.347	(0.174; 0.462)
Anxiety/depression	0.571	(0.528; 0.5930	0.186	(0.102; 0.329)	0.336	(0.252; 0.462)
QOL-ACC						
Mobility	0.692	(0.535; 0.737)	0.555	(0.118; 0.604)	0.553	(0.284; 0.690)
Pain management	0.691	(0.517; 0.786)	-0.163	(-0.455; 0.000)	0.071	(-0.240; 0.315)
Emotional wellbeing	0.375	(0.138; 0.677)	0.054	(-0.250; 0.2.4)	0.192	(-0.000; 0.252)
Independence	0.452	(0.231; 0.541)	0.089	(-0.200; 0.585)	0.521	(0.270; 0.609)
Social connection	0.531	(0.408; 0.685)	0.330	(0.027; 0.506)	0.279	(0.183; 0.519)
Activities	0.619	(0.580; 0.683)	0.241	(-0.286; 0.291)	0.104	(-0.141; 0.46)
EQ-HWB-S						
1. Seeing	0.171	(0.063; 0.258)	0.175	(-0.008; 0.228)	0.084	(0.030; 0.233)
2. Hearing	0.319	(0.219; 0.379)	0.075	(-0.005; 0.563)	0.469	(0.300; 0.647)
3. Getting Around*	0.649	(0.628; 0.765)	0.311	(0.092; 0591)	0.171	(-0.013; 0.341)
4. Day to Day*	0.539	(0.428; 0.636)	0.528	(0.359; 0.619)	0.085	(-0.296; 0.412)
5. Personal care	0.512	(0.397; 0.596)	0.466	(0.125; 0.627)	0.392	(-0.203; 0.617)
6. Sleep	0.512	(0.332; 0.640)	-0.100	(-0.176; 0.000)	-0.047	(-0.023; -0.043)
7. Exhaustion*	0.451	(0.370; 0.455)	0.214	(0.067; 0.231)	0.319	(0.061; 0.495)
8. Lonely*	0.403	(0.301; 0.627)	0.105	(0.027; 0.265)	0.015	(-0.122; 0.282)
9. Support	0.212	(0.097; 0.286)	0.016	(0.000; 0.167)	0.043	(-0.061; 0.313)
10. Memory	0.689	(0.590; 0.921)	0.214	(-0.061; 0.424)	0.332	(0.126; 0.540)
11. Concentration*	0.423	(0.292; 0.544)	0.154	(-0.088; 0.485)	0.308	(0.190; 0.539)
12. Anxious*	0.198	(0.158; 0.331)	0.24	(0.069; 0.490)	0.063	(-0.069; 0.286)
13. Unsafe	0.529	(0.525; 0.633)	0.180	(-0.035; 0.297)	0.195	(-0.290; 0.679)
14. Frustrated	0.477	(0.279; 0.533)	0.259	(0.146; 0.344)	0.217	(-0.024; 0.561)

15. Depressed*	0.429	(0.263; 0.489)	0.101	(0.017; 0.294)	0.108	(0.000; 0.234)
16. Looking forward	0.427	(0.322; 0.555)	0.192	(0.070; 0.537)	0.243	(0.413; 0.446)
17. Control*	0.254	(0.047; 0.489)	-0.010	(-0.093; 0.354)	0.329	(0.192; 0.538)
18. Cope	0.548	(0.444; 0.846)	0.459	(0.211; 0.758)	0.255	(0.154; 0.625)
19. Accepted	0.266	(-0.033; 0.462)	0.649	(-0.111; 1.000)	0.179	(0.082; 0.276)
20. Felt Good	0.511	(0.362; 0.670)	0.211	(-0.046; 0.365)	0.238	(0.040; 0.352)
21. Do Things	0.459	(0.305; 0.660)	0.430	(0.186; 0.789)	0.140	(-0.051; 0.400)
22. Pain Frequency	0.488	(0.290; 0.656)	0.494	(0.173; 0.563)	0.275	(-0.238; 0.511)
23. Pain Severity*	0.537	(0.532; 0.667)	0.333	(0.217; 0.462)	0.200	(-0.077; 0.432)
24. Discomfort Frequency	0.682	(0.497; 0.846)	0.234	(-0.444; 0.571)	0.183	(-0.066; 0.186)
25. Discomfort Severity	0.487	(0.380; 0.656)	0.407	(0.222; 0.537)	0.250	(-0.011; 0.631)
ASCOT proxy-proxy						
Food and drink	0.565	(0.260; 0.870)	0.231	(-0.408; 0.869)	0.064	(0.004; 0.0111)
Home cleanliness	0.250	(-0.118; 0.618)	-0.136	(-0.653; 0.380)	-0.288	(-0.484; -0.081)
Personal cleanliness	0.182	(-0.199; 0.562)	0.447	(0.008; 0.885)	0.111	(-0.363; 0.585)
Social participation	0.302	(0.171; 0.367)	-0.018	(-0.313; 0.207)	0.242	(0.205; 0.435)
Occupation	0.318	(0.271; 0.568)	0	(-0.250; 0.152)	0.191	(-0.083; 0.415)
Control	0.281	(0.079; 0.417)	0.071	(-0.138; 0.092)	-0.118	(-0.231; -0.068)
Personal safety	0.361	(-0.138; 0.565)	-0.105	(-0.286; 0)	-0.174	(-0.250; -0.102)
Dignity	0.221	(-0.063; 0.309)	0.023	(-0.103; 0.379)	0.068	(-0.010; 0.106)
ASCOT proxy-person						
Food and drink	0.372	(0.105; 0.639)	0.130	(-0.466; 0.726)	0.208	(0.049; 0.257)
Home cleanliness	0.368	(0.014; 0.723)	0	(-0.518; 0.518)	-0.050	(-0.360; 0.167)
Personal cleanliness	0.261	(-0.104; 0.625)	0.253	(-0.211; 0.717)	0.242	(0.125; 0.314)
Social participation	0.335	(0.224; 0.481)	0.019	(-0.039; 0.244)	0.147	(0.072; 0.278)
Occupation	0.288	(0.119; 0.552)	-0.011	(-0.222; 0.137)	0.071	(-0.057; 0.234)
Control	0.458	(0.355; 0.622)	0.133	(-0.154; 0.444)	-0.092	(-0.289; 0.063)
Personal safety	-0.045	(-0.092; 0.00)	-0.105	(-0.207; -0.091)	-0.097	(-0.211; 0.00)
Dignity	0.354	(0.224; 0.416)	0.046	(-0.175; 0.137)	-0.007	(-0.213; 0.189)

*Items included in the EQ-HWB-S.