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## **Using Proxies to assess Quality of Life: *A Review of the Issues and Challenges***

Stacey Rand and James Caiels

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Discussion Paper 2899



The Policy Research Unit in Quality and Outcomes of person-centred care (QORU) is a collaboration involving researchers in health and social care from the Universities of Kent, Oxford and the London School of Economics (LSE) funded by the Department of Health.

Our aim is to improve the quality of health and social care of people with long-term conditions through generating high-quality evidence about need, quality and outcomes of person-centred care.

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# 1 Executive summary

## 1.1 Introduction

1. In recent decades, quality of life has been advocated as an indicator to evaluate publicly-funded services and to be used in service planning and delivery.
2. Quality of life is based on an individual's perception of their life. This is influenced by the context (that is, the culture and value system, as well as personal goals or expectations of life). Ideally, quality of life is measured by self-report.
3. A key challenge in quality of life measurement is, therefore, how to measure quality of life of people who are unable to answer on their own behalf, even with additional support or alternative formats.
4. One widely-used method is to collect quality of life data 'by proxy' (that is, a relative, friend or professional has completed questions on behalf of the individual whose quality of life is to be assessed). It is, however, recognised that proxy response is not without methodological challenges or issues.

## 1.2 Aim

5. This literature review aims to scope the literature to identify the methodological challenges and other issues associated with proxy response in the context of self-completion surveys to collect quality of life data for outcomes-based service management, commissioning and policy strategy.

## 1.3 Literature search

6. A literature search of three databases (PsyInfo, PubMed and Social Care Online) was conducted to identify relevant peer-reviewed articles. The title and abstracts of articles published between 2004 and 2014 were searched based on the following key words: 'proxy' or 'proxies'; and 'quality of life'; not 'child' or 'children'.
7. Articles were included if they reported research conducted with adults aged 18 years or older, were available in English language, and were deemed to be relevant to the research topic upon review of the title/abstract and full text.
8. The initial literature search identified 564 articles. After applying the inclusion/exclusion criteria, and review of the title/abstract and full text, 79 articles were included in the literature review.

## 1.4 Discussion

9. The majority of identified studies that compared self-report to proxy-report found that proxies tend to rate quality of life lower than self-report. Some studies, however, have not found any difference or that self-report is higher than proxy-reported quality of life.
10. The size and direction of difference between self-reported and proxy-reported QoL are associated with methodology (specifically, the measurement properties of the

instrument of study and sample size), the balance of objective/subjective attributes in the QoL measure, and the nature and closeness of the relationship between the proxy and the individual.

11. There is also evidence that the difference between self-reported and proxy-reported QoL (inter-rater gap) is associated with various personal characteristics of the proxy or individual. It has been found, for example, that there is a higher level of self- to proxy-report agreement when the health status of the self-respondent is either very good or very poor.
12. Finally, there is some evidence that the cognitive process adopted by the proxy to answer the questions may influence the inter-rater gap. The conceptual framework provided by Pickard and Knight (2005) suggests that there are two proxy perspectives or ways in which the proxy may answer QoL questions on behalf of another individual: (1) the proxy-patient perspective, where the proxy attempts to reconstruct the individual's internal mental state to answer the question; and, (2) the proxy-proxy perspective, where the proxy answers based on their own judgement influenced by their own values, expectations and assumptions. In some studies, the proxy-patient perspective has been found to be closer to self-report than the proxy-proxy perspective. However, the difference between proxy-patient and proxy-proxy perspectives (the intra-proxy gap) has also been found to vary by type of QoL attribute (objective/subjective) and also the characteristics (e.g. the proxy's level of literacy; the duration, intimacy and proximity of the proxy's relationship with self-respondent).

## **1.5 Implications for survey data collection**

13. The literature review identified that a key methodological issue with using proxy respondents is that they are not directly interchangeable with self-report due to the inter-rater gap.
14. Although the evidence suggests that the inter-rater gap is small, the use of proxy respondents in surveys may introduce bias.
15. With cross-sectional survey designs, it is not possible to use experimental design to control for differences in the mix of proxy- and self-respondents.
16. There are various approaches that may be considered: for example, statistical adjustment; exclusion of proxy responses; separate analysis of proxy responses; collection of self- and proxy-response for all respondents with separate analysis.
17. There are limitations for all of these approaches that need to be considered and weighed against each other. If wider inclusion in data collection is a priority, then statistical adjustment may be preferred to the other options, even with its limitations.

## 1.6 Recommendations

18. Four recommendations with regard to the development of a proxy measure may be drawn from the literature review.

- i. The proxy questionnaire should have instructions to explain how the proxy respondent should answer the questions (i.e. from the proxy-patient and/or proxy-proxy perspectives).
- ii. Unless there is a clear justification for one perspective over the other, the development of a proxy measure should consider both the proxy-patient and proxy-proxy perspectives.
- iii. If it is a postal survey, the questionnaire should include some guidance as to who should complete the questionnaire on behalf of the individual (i.e. that the proxy knows the person well and has frequent contact).
- iv. Even if a measure is developed as a proxy tool, it should be noted that proxy-response and self-response are not directly interchangeable. Proxy measures may reduce bias and/or improve face-validity. They do not, however, eliminate the potential for proxy bias, so this would need to be appropriately considered in study design and/or analytical approaches.

## 2 Introduction

In recent decades, there has been considerable interest in the use of self-reported outcome measures, such as quality of life, to evaluate publicly-funded services and inform policy (Bovaird, Loffler 2003). This trend towards outcomes-based management and policy-making aims to reinforce the accountability of public services to people who use their services by focussing the various stakeholders who influence service planning, provision and management on the shared goal of improving service users' quality of life. It also seeks to identify the factors associated with effective publicly-funded services so that 'best practice' can be identified and promoted. Although the political and societal rhetoric associated with the outcomes movement is compelling, there are a number of challenges associated with the measurement, collection and use of outcomes data (Bovaird, Loffler 2003). The aim of this paper is to provide an overview of the issues associated with one particular key measurement challenge: namely, the use of proxy respondents to measure the quality of life of individuals who are not able to answer on their own behalf.

Quality of life is defined as "the individual's perceptions of their position in life in the context of the culture and value system in which they live, and in relationship to their goals, expectations, and standards" (World Health Organization QOL Group 1995). Although some have noted that quality of life may best be measured through a combination of both objective and subjective perspectives (Sloane et al. 2005), many argue that the construct should include subjective components based on individuals' internal perceptions (Stancliffe 1999, Schalock et al. 2002, Cummins, Lau 2005). The standard in the measurement of quality of life is usually, therefore, self-report (Brod et al. 1999, von Essen 2004). A significant challenge is how to ensure that people who experience cognitive or communication difficulties, which may act as a barrier to participation in traditional survey-based data collections, are not systematically excluded. This is a particular issue given that the completion of survey-based quality of life questions is not straightforward; it involves the comprehension of complex abstract concepts, the evaluative judgement between different response options against subjective feelings, preferences and perceptions of life, and the ability to communicate that response.

There are various strategies available to support self-report for individuals with cognitive or communication impairments: for example, user-led action research to ensure that survey questions and administration are tailored to the client population; Easy Read translation; and other visual aids to facilitate communication. Yet, even with support or adaptation of the questionnaire, there may be individuals who are unable to understand, evaluate or respond to questions designed to measure subjective quality of life. In such cases, it is accepted that response by someone else on behalf of the individual ('by proxy') is preferred to systematic exclusion from data collection based on the issues of equity, inclusion and to address concerns about the robustness of analysis due to sample size, missing data and bias (Steel, Geller & Carr 2005, von Essen 2004).



The question of whether or how to use data collected from proxy respondents, either to complement or substitute for self-report (Pickard, Knight 2005), is informed by ethical, practical and measurement considerations: for example, the use of proxies to inform an individual's medical care decisions would involve different considerations to the use of proxy response to inform systems-level or organisational decision-making. It is, therefore, important to note that this literature review has been conducted in the context of work to develop a proxy version of the Adult Social Care Outcomes Toolkit (ASCOT) (Netten et al. 2012) <sup>1</sup>.

In the context of survey-based data collections for outcomes-based management on an aggregate level, such as the collection of ASCOT scores in the Adult Social Care Survey, proxy-report may be used as a substitute for self-report to address issues associated with sample size, sampling bias or missing data and systematic exclusion from 'having a voice' (Steel, Geller & Carr 2005, von Essen 2004). Likewise, however, if quality of life is collected only 'by proxy' for individuals who would have been able to answer on their own behalf, either with a standard survey or other methods (e.g. Easy Read translation, interview etc.), then this would also exclude people from 'having a voice'.

In the ASCS conducted between 2011 and 2013, approximately 8 percent <sup>2</sup> of the responses were by proxy (i.e. without any consultation with the user of social care services). These proxy responses were returned via the standard version of the questionnaire, which is designed to be a self-report survey. The development of a proxy version of the ASCOT aims to provide an improved way of collecting proxy responses to the ASCS, whilst recognising the tension between the potential for wider inclusion and also exclusion (if used inappropriately) inherent in this approach.

## 2.1 Aims

This literature review was conducted as part of the initial phase of development of a proxy version of the ASCOT, although the literature review findings and recommendations aim also to be broadly applicable to proxy measurement of quality of life in the context of survey-based data collections.

The primary aim of this review is to identify the methodological issues associated with using proxy-report of quality of life and, thereby, identify specific issues that should be considered when developing a proxy tool.

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<sup>1</sup> ASCOT is a social care-related quality of life measure included in the Adult Social Care Outcomes Framework (ASCOF) (Department of Health 2013, Department of Health 2014). Individual-level ASCOT data are collected annually in the Adult Social Care Survey (ASCS), a postal survey of users of social care services in England. The national ASCS data are publicly reported by the Health and Social Care Information Centre (HSCIC). Local-level data are used by local authorities to inform local management, planning and commissioning of social care support services.

<sup>2</sup> **12.8%** of respondents in care homes and **6.7%** of respondents in the community were answered by proxy.

Alongside this main review question, the following specific questions will be addressed:

1. Do the issues associated with proxy response differ by domain of quality of life? Are there domains that are more or less problematic?
2. Do the issues associated with proxy response differ by survey administration factors, such as administration mode, the characteristics of the proxy, and the type or format of questions?

## **3 Literature search**

### **3.1 Methods**

A database search was conducted for the period 2004 to 2014 to identify peer-reviewed publications on the use of proxy respondents to measure quality of life. The literature search was conducted in the electronic databases PubMed, PsychInfo and Social Care Online using the following search terms for key words in the title/abstract: 'proxy' or 'proxies'; and 'quality of life'; not 'child' or 'children'. The titles and abstracts of the identified articles were reviewed by one researcher (SR) to exclude any articles published before 2004, not available in English, research that involved children or young people under 18 years of age, and articles that were evaluated not to be relevant to the broad research topic of the measurement of quality of life using proxy respondents and/or the specific research questions outlined in section 1.1.

The researcher (SR) then reviewed the full text of each of the remaining identified articles against the inclusion/exclusion criteria, as outlined above, and the research aims outlined in section 1.1. Opinion pieces or purely theoretical articles, such as letters to the editor, commentaries or the presentation of theoretical models without empirical evidence or analysis, were excluded from the formal summary and analysis; however, they may be referred to within the discussion of the issues related to the use of proxy respondents to measure quality of life outlined in this report.

### **3.2 Results**

The literature search is summarised in Figure 1.

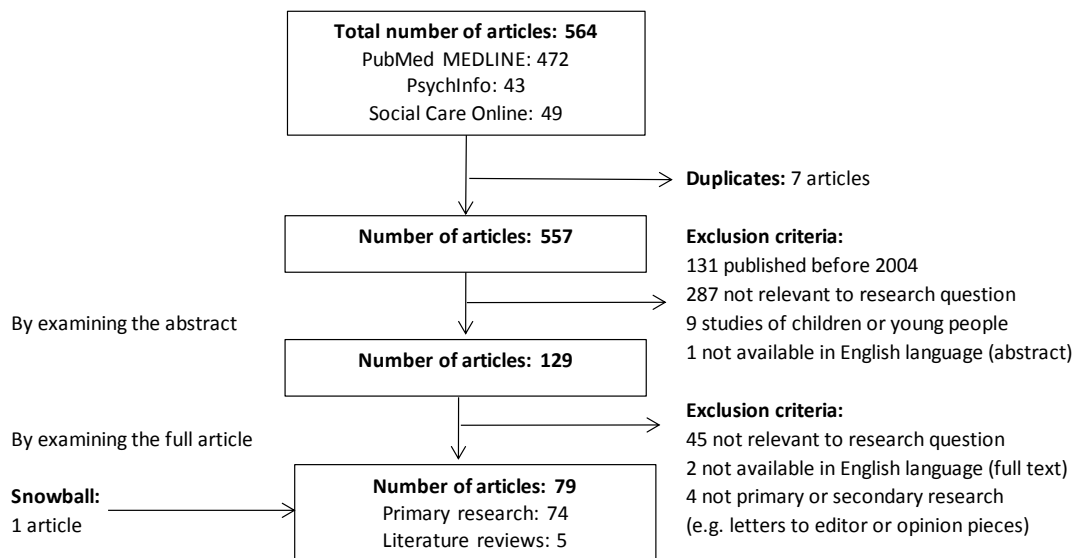
Of the 564 articles initially identified by the literature search, a total of 129 articles were deemed to be potentially relevant to the research question and were reviewed in full. Upon review of the full text, a further 51 articles were rejected based on the inclusion/exclusion criteria. One further relevant article was included based on review of the references cited by these articles. A total of 79 research articles are, therefore, included in this literature review.

The primary research articles are summarised in Table 1. This summary includes the proxy perspective adopted by the respondent based on Pickard and Knight's (2005) conceptual model of proxy response. Proxy respondents may be asked to rate quality of life either as

they think the individual would respond ('proxy-patient' perspective) or based on their own view of the individual's QoL ('proxy-proxy' perspective). The difference in rating of these two perspectives is known as the 'intra-proxy gap'. The inter-rater gap is the difference observed between self-report and the proxy-patient perspective. It has been argued that any attempt to evaluate proxy rating of QoL needs to be aware of these two different proxy perspectives alongside self-report (Pickard, Knight 2005).

The five articles based on systematic literature reviews (Dirven et al. 2013, Hounsome, Orrell & Edwards 2011, Oczkowski, O'Donnell 2010, Shearer et al. 2012, von Essen 2004) are summarised in Table 2.

**Figure 1. Outcomes of the literature search**



**Table 1. Summary of the literature review (primary research)**

Reference	Country	Client group	Sample	Outcome instrument <sup>3</sup>	Type of proxy rating <sup>4</sup>	Key findings
Arlt, S. et al. (2008)	Germany	Dementia	People with dementia (n=100) and family carers (n=97)	EUROHIS-QOL	Proxy-proxy	Family caregivers rate patients' QoL lower than self-report.
Arons, A. et al. (2013)	Netherlands	Dementia	People with dementia and family carers (175 dyads)	EQ-5D; QoL-AD	Proxy-proxy	Proxy rating of QoL was lower than self-rating. Proxy-rated QoL was significantly related to proxy characteristics (e.g. age, financial situation).
Beadle-Brown, J. et al. (2009)	UK	Intellectual disabilities	People with ID and professional/family carers (10 dyads)	LSS	Proxy-patient	There was no significant difference between self- and proxy-rated QoL.
Becchi, A. et al. (2004)	Italy	Schizophrenia	People with schizophrenia (n=292) and family carer (n=154), friend (n=2) or nurse/social worker (n=136)	WHOQOL-100; QoL-P	Proxy-proxy	Proxies rated QoL lower than self-report. There was lower concordance between proxy- and self-rated QoL in psychological compared to physical QoL domains. Family carers had slightly better concordance than non-relatives (i.e. friends or professional carers) in the psychological QoL domain.
Bonham, G. et al. (2004)	USA	Intellectual disabilities	People with intellectual disabilities (n=923) with 18% of responses by proxy rather than self-report	QoLQ	Proxy-patient	Proxy-rated QoL differed from self-reported QoL in seven of the eight QoL domains even after controlling for the characteristics of the person with ID (e.g. cognitive ability or communication impairment).
Brown, P. et al. (2008)	USA	Cancer	People with glioma and family carers (181 dyads)	FACT-Br; POMS-SF; SDS; ESS	Not specified	Proxies underestimated QoL compared to self-report on the SDS at baseline and overestimated QoL at four-month follow-up on the FACT-Br. There were no significant differences between self- and proxy-report on the other QoL measures at baseline or follow-up.
Bruvik, K. et al. (2012)	Norway	Dementia	People with dementia and family carers (230 dyads)	QoL-AD	Proxy-proxy	Proxies rated QoL lower than self-report. The inter-rater gap was smaller for carer-patient dyads who lived together than for dyads who did not. Increased report of neuropsychiatric behaviours associated with dementia was related to lower proxy- (but not self-) rated QoL.

<sup>3</sup> Alzheimer's Disease-Related Quality of Life (**ADRQoL**); Bath Assessment of Subjective Quality of Life in Dementia (**BASQID**); Dementia Quality of Life (**DQoL**); Dementia Quality of Life Questionnaire (D-QoL); Epsom Sleepiness Scale (**ESS**); Functional Assessment of Cancer Therapy-Brain (**FACT-Br**) or Hepatobiliary (**FACT-Hep**) or General (**FACT-G**); Functional Assessment of Multiple Sclerosis (**FAMS**); Health Utilities Index 2 (**HUI2**) or 3 (**HUI3**); Huntingdon's Disease Quality of Life (**HDQoL**); Lifestyle Satisfaction Scale (**LSS**); ICEpop capability measure for Older people (**ICECAP-O**); McGill Quality of Life Questionnaire (**MQoL**); Parkinson's Disease Questionnaire, 8-item (**PDQ-8**) or 13-item (**PDQ-13**); Person-centred Quality of Life (**PQoL**); Personal Outcomes Scale (**POS**); Profiles of Mood States Short Form (**POMS-SF**); Quality of Life-Alzheimer's Disease (**QoL-AD**); Quality of Life in Epilepsy Inventory (**QOLIE-31**); Quality of Life for Proxies (**QoL-P**, which comprises 30 'objective' items from the WHOQOL-100 scale selected for proxy response); Quality of Life Questionnaire (**QoLQ**); Short Form (36) Health Survey (**SF-36**); Stroke and Aphasia Quality of Life Scale (**SAQoL-39**); Quality of Wellbeing Scale (**QWB**); Stroke-Specific Quality of Life Scale (**SS-QoL**); Schedule for the Evaluation of Individualized Quality of Life-Direct Weighting (**SEIQoL-DW**); Symptom Distress Scale (**SDS**); The World Health Organization Disability Assessment Schedule 2.0 (**WHODAS-II**); The World Health Organization Quality of Life, 100 items (**WHOQOL-100**) or BREF (**WHOQOL-BREF**)

<sup>4</sup> See Pickard & Knight, 2005 for discussion of the proxy-proxy and proxy-patient perspective when rating quality of life.

Reference	Country	Client group	Sample	Outcome instrument <sup>3</sup>	Type of proxy rating <sup>4</sup>	Key findings
Bryan, S. et al. (2005)	UK	Dementia	Family carers and clinicians of people with dementia (64 triads)	EQ-5D	Not specified	Clinician proxy-reported QoL is higher than family carer proxy-reported QoL. Clinician proxy ratings of the 'observable' EQ-5D dimensions (mobility, self-care) were strongly correlated with ADLs, whereas carer ratings of the less observable QoL domains (usual activities, anxiety/depression) were more strongly associated with the less observable ADL and NPI items. This suggests that these two groups of proxies may be using different criteria to rate proxy QoL.
Buckley, T. et al. (2012)	USA	Dementia	People with dementia and caregivers (246 dyads)	5-point Likert scale	Not specified	Proxies tended to rate QoL lower than self-report. Multiple regression analysis showed that self-report was associated with patient health (comorbidity). Proxy rating was significantly associated with neuropsychiatric symptoms of dementia (NPI). The discrepancy between self and proxy rating was associated with dementia severity (Clinical Dementia Rating score); patients with more severe dementia had lower proxy/self-rating discrepancy than patients with less severe dementia.
Carlozzi, N. et al. (2014)	USA	Huntingdon's Disease	People with HD and family carers (29 dyads)	HD-PRO-TRIAD™	Not specified	Inter-rater agreement was high for all three subscales of the HD-PRO-TRIAD™.
Carpenter, B. et al. (2007)	USA	Dementia	Married couples (n=64) with no dementia (n=31) or mild dementia (n=33)	DQoL; PQoL	Not specified	Moderate agreement between self and proxy ratings were found for both the DQoL and PQoL. There was no significant difference in QoL between couples who had CDR scores of zero (i.e. no dementia) compared to couples where one member had mild dementia.
Claes, C. et al. (2012)	Netherlands	Intellectual disabilities	People with intellectual disabilities and staff and family carers (42 triads)	POS	Proxy-proxy	No significant difference was found between self-rated and family carer-rated QoL. Staff rated QoL significantly lower than people with ID in two domains: interpersonal relations and physical wellbeing. The staff and family proxies also differed significantly in three domains; staff rated interpersonal relations and social inclusion lower than family carers, whereas they rated emotional wellbeing higher than family carers.
Crespo, M. et al. (2012)	Spain	Dementia	People with dementia in residential care (n=102), their relatives (n=184) and staff (n=197)	QoL-AD	Proxy-proxy	Overall self-rated QoL was significantly higher than proxy-rated QoL. Family and staff proxy scores were correlated, but there was poor correlation between proxy- and self-rated QoL.
Crespo, M. et al. (2013)	Spain	Dementia	People with dementia in residential care (n=102), their relatives (n=184) and staff (n=197)	QoL-AD	Proxy-proxy	Multiple regression analysis was used to identify the key predictors of QoL rating by self, staff or family proxy. Depression and cognitive function were the main predictors of self-rated QoL. Predictors of family-rated QoL were resident's functional capacity to carry out activities of daily living (ADL), the family member paying for the nursing home fees, and use of feeding tubes. Predictors of staff-rated QoL were resident's functional capacity to carry out ADLs, cognitive impairment and depression, staff member's work pattern of shifts (rotating vs. permanent) and type of centre administration (public vs. private).
Dinglas, V. D. et al. (2013)	USA	Acute lung injury	People with acute lung injury and next-of-kin (140 dyads)	EQ-5D	Proxy-patient	Self-rating was higher than proxy-rating of retrospective QoL. Proxies tend to rate QoL more moderately rather than at either extreme; proxies underestimated QoL for patients with high QoL and overestimated QoL for patients who rated low QoL.

Reference	Country	Client group	Sample	Outcome instrument <sup>3</sup>	Type of proxy rating <sup>4</sup>	Key findings
Doyle, M. et al. (2007)	Canada	Multiple brain metastases	People with brain metastases and family carers (n=60)	FACT-G; FACE-Br	Not specified	Self-reported and proxy-reported QoL at baseline had low concordance both for overall QoL and in the physical, social, emotional and functional wellbeing subscales.
Edelman, P. et al. (2004)	USA	Dementia	People with dementia and day care staff (n=36 dyads)	QoL-AD; DQoL; ADRQoL	Proxy-proxy	Staff proxies rated QoL lower than self-report. Staff proxy-rated QoL and observational scores (Dementia Care Mapping), but not self-reported QoL, were associated with the person with dementia's cognitive and functional impairment.
Elliott, D. et al. (2006)	Australia	Cardiac surgery	Cardiac surgery patients and their next of kin (n=96 dyads)	SF-36	Not specified	At pre-surgery baseline, there was good agreement between self and proxy ratings in most domains. There was lower correspondence of self and proxy scores at the first follow-up (post-discharge). The highest correspondence was observed for the ratings at the second follow-up, six months post-discharge. Overall, observable and/or physical domains had higher levels of agreement between self and proxy report than non-observable, subjective domains.
Fast, Y. et al. (2009)	USA	Cardiac rehabilitation	Patients in cardiac rehabilitation and their spouses (42 dyads)	SF-36	Not specified	Proxies rated QoL significantly lower than self-report for mental health and vitality at baseline; at six weeks retest, the proxy rating was still significantly lower in these two domains and also in physical functioning. The differences between self and proxy ratings in other subscales (role physical, pain, general health, social functioning, and role emotional) were not statistically significant.
Ferri, C. & Pruchno, R. (2009)	USA	Renal disease	Patients with renal disease and their spouses (315 dyads)	Single item, 5-point Likert scale	Proxy-proxy	Proxy ratings are associated with perceptions of physical health and functioning; this association is not observed for self-report. Both proxies and self-report are associated with mood and subjective health. Proxy rating of QoL is related to the proxy's self-rating of their own QoL.
Fleming, A. et al. (2005)	USA	Parkinson's disease	People with Parkinson's disease and their family carers (64 dyads)	PDQ-13	Proxy-proxy	A (non-significant) trend was observed that proxies rated QoL lower than self-report. Correspondence was highest for the observable domains of mobility and ADLs, and was lowest for the domains of stigma, cognition and communication.
Gabbe, B. J. et al. (2012)	Australia	Traumatic injury	People admitted to trauma centres and family/friend (91%) or healthcare professional (9%) (123 dyads)	EQ-5D	Proxy-patient	There was no significant difference between the mean EQ-5D score rated by self or proxy at 12-months post-injury; however, there was considerable variation in pairwise comparison. Analysis by domain indicates that there was substantial agreement for rating of self-care and mobility, and moderate agreement for usual activities, pain and anxiety/depression.
Giebel, C. et al. (2014)	UK	Dementia	People with dementia and their family or paid carers (122 dyads)	QoL-AD	Proxy-proxy	Proxy-rated quality of life was associated with the person with dementia's performance of activities of daily living (ADLs). In contrast, there was no association between ADLs and self-reported QoL with the exception of continence (mild dementia) and transfer (severe dementia). The person with dementia's mood (depression) and cognitive impairment were associated with proxy-rated, but not self-rated, QoL.

Reference	Country	Client group	Sample	Outcome instrument <sup>3</sup>	Type of proxy rating <sup>4</sup>	Key findings
Giesinger, J. et al. (2009)	Austria	Brain tumours	People with primary brain tumour and their spouse/partner (42 dyads)	EORTC QLQ-C30; QLQ-BN20	Not specified	There was no overall significant difference between self-rated and proxy-rated QoL. The largest discrepancies were observed in the social functioning and dyspnoea domains, where proxy-rated QoL was lower than self-report. There was higher correspondence between self and proxy ratings for physical attributes and functioning than in psychosocial domains (e.g. social functioning, pain).
Gifford, J. et al. (2010)	USA	Acute lung injury	People with acute lung injury and next-of-kin (136 dyads)	SF-36	Proxy-patient	Self-rated retrospective QoL was significantly higher than proxy-rated QoL for seven of the eight SF-36 domains. Proxies tend to rate QoL moderately rather than at either extreme of the scale; therefore, proxies underestimated QoL for patients with high QoL and overestimated QoL for patients who rated low QoL.
Gil, Z. et al. (2004)	Israel	Anterior skull base surgery	People undergoing skull base surgery, their family carers and surgeons (35 triads)	Anterior Skull Base Tumour Questionnaire	Not specified	There was good agreement between self and family carer proxy-rated overall QoL score, as well as in the individual domains of vitality, physical function, role performance and specific symptom but not in the domain for pain. Carers of patients with primary disease showed a trend towards rating QoL lower than self-report, whereas the surgeons overestimated QoL.
Gomez-Gallego, M. et al. (2012)	Spain	Dementia	People with Alzheimer's disease, their primary carer and healthcare staff (102 triads)	QoL-AD	Proxy-patient	Family carer and healthcare staff proxies rated QoL lower than self-report. (There was no significant difference between family carer or staff proxy ratings). Multiple regression analysis identified that depression was the main predictor of self-rated QoL, whereas carer proxy-rated QoL was associated with patient irritability and carer burden. Staff proxy-rated QoL was related to psychotic symptoms and use of neuroleptics.
Graeske, J. et al. (2012)	Germany	Dementia	People with dementia and nursing staff (49 dyads)	QoL-AD	Proxy-proxy	Staff rated overall QoL-AD lower than residents, although staff-rated QoL was higher than self-reported QoL in two domains ('physical health' and 'life as a whole'). Lower staff rating of QoL was found for staff who were not the individual's primary carer compared to nurses who had more frequent contact with the individual.
Graeske, J. et al. (2014)	Germany	Dementia	Nursing staff of people with dementia in residential care (n=133)	ADRQoL; QUALIDEM	Not specified	Proxy-rated QoL (overall and subscales) was associated with both patient-related characteristics (e.g. challenging behaviours, severity of dementia) and nursing staff characteristics (e.g. carer burnout, length of time (years) worked on the ward, number of days worked before current shift, whether rating was completed in leisure time or before/during a shift, and the nurse's life satisfaction).
Gundy, C. & Aaronson, N. (2008)	Netherlands	Cancer	People with cancer and family /friend carers (n=224)	EORTC QLQ-C30	Proxy-proxy & proxy-patient	The EORTC QLQ-30 was completed by self-report and by proxy either from the 'proxy-proxy' or 'patient-proxy' perspective (Pickard & Knight, 2005). Small, significant proxy bias was observed in both proxy conditions. There was no significant difference between the overall ratings of QoL using these two proxy perspectives. Better agreement was observed for the domains 'role' and 'cognitive function' when rated from the proxy-proxy perspective; however, better agreement was found in the 'diarrhoea' scale when rated from the proxy-patient perspective.

Reference	Country	Client group	Sample	Outcome instrument <sup>3</sup>	Type of proxy rating <sup>4</sup>	Key findings
Hilari, K. et al. (2007)	UK	Post-stroke aphasia	People with chronic aphasia and family carers (50 dyads)	SAQOL-39	Proxy-patient	Proxies rated QoL lower than people with aphasia post-stroke. The agreement between self and proxy rating varied by domain from excellent (physical domain) to good (psychosocial and communication domains) to moderate (energy domain). The characteristics of the person with aphasia and proxy (including carer strain) were not associated with the discrepancy between self and proxy report.
Hocaoglu, M. et al. (2012)	UK	Huntingdon's Disease	People with HD and family carers (105 dyads)	HDQoL	Proxy-proxy	There was excellent agreement between self and proxy rating of QoL on the summary scale. However, proxies tended to rate QoL higher than self-report on the specific hopes and worries subscale, whereas proxies tended to rate QoL lower than self-report on the cognitive and physical/functional subscales. Across all patient groups (by severity of disease), there was better self/proxy agreement for 'objective' (e.g. physical) than subjective subscales.
Hoe, J. et al. (2007)	UK	Dementia	People with dementia and their family or paid carers (191 dyads)	QoL-AD	Proxy-proxy	Family or paid carers rated quality of life lower than self-report by people with dementia. In multiple regression analysis, higher levels of dependency and neuropsychiatric symptoms (e.g. apathy & irritability) in the person with dementia were significant predictors of lower QoL rated by proxy; however, these factors did not reach significance as predictors of self-reported QoL.
Huang, H. et al. (2009)	Taiwan	Dementia	People with dementia and family carers (120 dyads)	QoL-AD	Proxy-proxy	Agreement between self and proxy rating of quality of life was low, with carer proxy rating QoL lower than self-report. Agreement was higher in observable domains (e.g. physical items) than in non-observable domains (e.g. memory, family relationship). The self/proxy rating discrepancy was associated with behaviours associated with dementia, the carers' perceived distress associated with challenging behaviour, the carers' overall quality of life, and the quality of the carer-care recipient relationship.
Hung, M. et al. (2010)	Taiwan	Patients with prolonged medical ventilation	55 patients assigned to patient-family carer dyads (n=53) and/or patient-nurse dyads (n=42)	EQ-5D	Proxy-patient	The overall rating of EQ-5D by proxy (family carer or nurse) is not significantly different from self-report, although there is a trend that family carers rate QoL lower than self-report. Observable dimensions (mobility, self-care, usual activities) have higher levels of agreement than subjective dimensions (pain, anxiety/depression). Family carers had higher agreement with self-report in the non-observable domains compared to nurse-proxy rating of QoL.
Hung, S. et al (2007)	USA	Stroke	People who have had a stroke and family carers (95 dyads)	HUI3	Proxy-proxy	Family carer proxies with depressive symptoms underestimated pain, but not other domains of QoL. Carers with higher self-rating of pain overestimated the pain experienced by the patient.
Jones, A. & Feeny, D. (2005)	Canada	Hip fracture	Older adults who have had a hip fracture and their family carers (245 dyads)	HUI2, HUI3	Not specified	Self/proxy agreement on the overall HUI score was good at baseline and improved to excellent at six months. There were some differences by domain, with higher levels of agreement between proxy and self-rated scores in the 'observable' domains (ambulation and mobility).



Reference	Country	Client group	Sample	Outcome instrument <sup>3</sup>	Type of proxy rating <sup>4</sup>	Key findings
Jones, J. et al. (2011)	Canada	Cancer	People with cancer, their family carers and doctors (167 triads with n=149 and n=113 remaining in the study at 3 and 6 day follow-up)	MQOL	Not specified	Proxies reported lower QoL compared to patient self-report across all domains except for 'support'. Agreement between self and proxy report was highest for the 'existential' and 'support' subscales and lowest for 'psychological' and 'physical' (symptoms) subscales. Family carers had better agreement with self-report compared to physicians on the support subscale, whereas Physicians' rating of physical symptoms was closer to self-report. The agreement between patient and proxy report increased between days 3 and 6. There was better self/proxy agreement for patients who reported greater symptom burden and cognitive difficulties.
Jonsson, L. et al. (2006)	Sweden, Denmark, Norway and Finland	Dementia	People with Alzheimer's disease and their primary caregiver (208 dyads completed baseline, 6 and 12 month follow-up)	EQ-5D; QoL-AD	Not specified	Self-reported QoL was higher than proxy report in all five EQ-5D domains, as well as on the overall EQ-5D utility and QoL-AD scores. There was poor agreement between self and proxy ratings for self-care, usual activities and anxiety/depression, and moderate agreement for the mobility and pain domains.
Kane, R. et al. (2005)	USA	Nursing home residents	Residents of nursing homes, their family carers and staff (1,326 resident-staff dyads and 989 resident-family carer dyads)	10-domain QoL measure	Not specified	Staff proxies rated privacy, meaningful activity, enjoyment, functional competence, security and autonomy higher than self-report, but comfort lower than self-report. By contrast, family carers overestimated privacy, dignity and autonomy but underestimated comfort, functional competence, meaningful activity and security. Self/proxy agreement was associated with cognitive impairment with the highest agreement in the least and most impaired groups.
Kim, E. et al. (2010)	Korea	Schizophrenia or bipolar disorder	People with schizophrenia or bipolar disorder and their family carers (131 dyads)	WHOQOL-BREF; SF-36	Not specified	A high level of agreement between self/proxy reports was observed for both instruments. The mean score by proxies was lower than self-report, and this reached significance in some domains (e.g. psychological domain of the WHOQOL-BREF in the schizophrenia group, physical function subscale of the SF-36 in both groups).
Kunz, S. (2010)	Germany	Dementia	People with mild/moderate dementia and their family carers (333 dyads)	EQ-5D	Proxy-patient	Proxies rated QoL significantly lower than self-report. The highest agreement between self and proxy report was observed in the EQ-5D self-care domain, and the lowest agreement was in the anxiety/depression domain. Higher inter-rater reliability was observed where the person with dementia had better ADL performance and the carer reported lower care-related burden.
Lewis, C. et al. (2014)	Germany	Parkinson's disease	People with Parkinson's disease and their family carers (28 dyads)	PDQ-13	Not specified	There was no significant difference at baseline between self and proxy report. However, at one year follow-up, family carers rated quality of life lower than self-report overall, as well as on the subscales of communication and cognition.
Makai, P. et al. (2014)	Germany	Dementia	Care staff acting as proxies for people with dementia (n=95)	ICECAP-O	Not specified	Female proxies and those who had more than two years' work experience rated QoL higher than male proxies or those with less than two years' work experience.
Makai, P. et al. (2012)	Netherlands	Dementia	Care staff or family carers acting as proxies for people with dementia (n=122 with n=56 with two proxies)	ICECAP-O	Proxy-patient	Nursing and family proxy scores were not significantly correlated, with the exception of the 'control' domain.

Reference	Country	Client group	Sample	Outcome instrument <sup>3</sup>	Type of proxy rating <sup>4</sup>	Key findings
Martinez-Martin, P. et al. (2004)	Spain	Parkinson's disease	People with Parkinson's disease and their family carers (64 dyads)	EQ-5D; PDQ-8	Not specified	Agreement between self and proxy rating of the EQ-5D was substantial for mobility and pain, and moderate for the other three domains. The difference in score was not significant for the EQ-5D domains, with the exception of 'usual activities', where the proxy-rated QoL as lower than self-rating. The inter-rater agreement for the PDQ-8 was substantial for all domains except for 'concentration'. There was substantial agreement for the 'observable' domains of getting around in public, dressing etc., as well as also non-observable domains, such as embarrassment in public.
McPhail, S., et al (2008)	Australia	Older adults	Older adults in rehabilitation and their physicians (n=150 proxy-patient reports; n=130 proxy-proxy reports)	EQ-5D	Proxy-proxy & proxy-patient	Proxy rating of QoL using the proxy-patient perspective (at all cognitive levels) had good agreement with self-report at discharge from hospital. However, there was only moderate agreement between self-report and proxy-report using the proxy-proxy perspective; the proxies rated QoL lower than self-report for older adults with impaired cognition, although there was better self/proxy agreement for older adults with less impaired cognition.
Milne, D. et al. (2006)	Australia	Cancer	People with advanced cancer and their family carers (51 dyads) at baseline (t1) and 12 week follow-up (t2)	EORTC QLQ-C30	Not specified	Family carer proxies rate QoL lower than self-report. There was higher self/proxy agreement at the 12-week follow-up than at baseline. Self/proxy rating agreement varied by domain. The lowest agreement was observed in the emotional domain. Significant differences in self/proxy rating were also found in the physical (t1 & t2), global QoL (t1), and cognitive (t2) domains.
Moyle, W. et al. (2012)	Australia	Dementia	People with dementia, their family carers and care staff (58 triads)	QoL-AD	Proxy-proxy	Quality of life was rated lower by family carer or care staff proxies compared to self-report. Limitations in daily activities were associated with lower proxy-rated QoL (especially ratings by care staff proxies) but not with self-reported QoL.
Muus, I. et al. (2009)	Denmark	Stroke	People who have had a stroke and their family carer or care staff proxies (143 dyads)	SS-QoL	Not specified	Proxies reported significantly better QoL in two domains (overall QoL, social) than self-report. In cases where the proxy was co-resident (n=98), there was a significant difference only in the social domain, with proxies rating QoL higher than self-report. Among proxies who were not co-resident (n=45), proxies rated QoL lower than self-report in the family role domain.
Naglie, G. et al. (2006)	Canada	Dementia	People with dementia and their family carers (60 dyads)	QWM; HUI3; EQ-5D	Not specified	Proxy-reported quality of life was lower than self-report for all three measures. The largest discrepancy between self and proxy report was observed for the HUI3. Unlike the EQ-5D and QWB, the HUI3 contains a number of cognitive items that were rated significantly lower by proxies than self-report.
Pearcy, R. et al. (2008)	UK/Ireland	Prostate cancer	People with adenocarcinoma, their partners and urologists (25 triads)	SEIQoL-DW; FACT-P	Proxy-proxy	There was no significant difference between self and partner proxy-rated QoL, nor in the selection of priority QoL domains for the SEIQoL-DW. Physicians reported lower QoL than self-report and were poor judges of the individual's QoL priorities.
Pickard, A. et al. (2004)	Canada	Stroke	People who have had a stroke and their family carers (124 dyads) at baseline and 6 month follow-up	EQ-5D; HUI3	Proxy-patient	At baseline, there were no significant differences between proxy and self-report EQ-5D score, whereas at six-month follow-up proxies reported significantly more problems than self-report in the domains of self-care, pain and anxiety/depression. There was good agreement at both baseline and six-month follow-up between self and proxy rating of the HUI3, with the exception of hearing (proxies tended to underestimate difficulties) and cognition (proxies rated more impairment than self-report).

Reference	Country	Client group	Sample	Outcome instrument <sup>3</sup>	Type of proxy rating <sup>4</sup>	Key findings
Pickard, A. et al. (2009)	USA	Prostate cancer	People with prostate cancer and their informal carers (87 dyads)	EQ-5D; EORTC QLQ-C30	Proxy-proxy & proxy-patient	Self-reported QoL was higher than both proxy perspectives (proxy-proxy, proxy-patient). The proxy-patient perspective was closer to self-report than the proxy-proxy perspective. The intra-proxy gap was associated with the proxy relationship (spouse or not) and proxy gender for two domains (role functioning, health literacy for physical functioning).
Ramos-Remus, C. et al. (2014)	Mexico	SLE, RA, SA <sup>5</sup>	People with SLE, RA or AS and their family carers (291 dyads)	WHODAS-II	Proxy-proxy	Proxies underestimate QoL compared to self-report. The social interaction and cognitive ability domains had a high proportion of disagreement (either under- or overestimation).
Rebollo, P. et al. (2004)	Spain	Renal disease	Dialysis patients, their family carers, nurse and physician (222 tetrads)	EQ-5D; Karnofsky Scale	Not specified	Agreement between self-report and proxy-report was moderate to good (KS) or fair to moderate (EQ-5D). The level of agreement was highest for family carer proxies, then nurses, and lowest for doctors. The EQ-5D VAS scores by nurse and doctor proxies were significantly higher than self-report, although the difference is only small in both cases. The characteristics of the proxy (e.g. carer burden, mental and physical subscales of the SF-36, patient comorbidity, and physician's age and experience) were found to be associated with the difference between self/proxy-report, with different factors affecting the ratings of the three different groups of proxies.
Schiffczyk, C. et al. (2011)	Germany	Dementia	People with dementia and their family carers (212 dyads)	QoL-AD	Proxy-patient	Self-report and proxy-patient rating of the QoL-AD were similar. Proxy-rated QoL was associated with patient self-rated depression, carer self-rated QoL, and carer proxy-rated neuropsychiatric symptoms of the patient.
Schiffczyk, C. et al. (2010)	Germany	Dementia	People with dementia and co-resident family carers (137 dyads)	EQ-5D	Not specified	The difference between self and proxy rating of QoL is correlated with dementia severity, with lower proxy rating of QoL and greater self/proxy discrepancy associated with more severe dementia. Proxy-rated QoL is associated with cognitive and behavioural symptoms of dementia, mood and the proxy's cognitive ability; proxies with higher self-rated depression and higher semantic fluency rate the person with dementia's QoL lower than proxies with low depression score or lower cognitive ability.
Schmidt, S. et al. (2010)	Germany, UK, Spain, Turkey, Czech Republic, Brazil	Intellectual disabilities	People with intellectual disability (n=614) and their family and/or professional carers (n=874)	WHOQOL-BREF	Not specified	People with intellectual disabilities rate their QoL higher than proxies, except for two items in the physical domain. There were some differences in agreement between self- and proxy-report by country. Greater knowledge of the person with ID was associated with a smaller discrepancy between self- and proxy-report across all domains.
Scocco, P. et al. (2006)	Italy	Older adults	Older adults and their informal or professional carers (138 dyads)	WHOQOL-100; QoL-P	Not specified	Older adults reported significantly higher QoL than proxies in the physical, independence and psychological domains.
Sheehan, B. et al. (2012)	UK	Dementia	People with dementia and their family carers (109 dyads)	QoL-AD; EQ-5D	Not specified	People with dementia (PwD) rated their QoL higher than proxies on the QoL-AD and EQ-5D. Proxies rated QoL higher for people with lower impairments in daily activities (EQ-5D only) and less severe dementia (QoL-AD, EQ-5D). Lower PwD self-reported QoL was associated with carer stress (EQ-5D), or PwD depression, impairment in daily activities and proxy psychiatric symptoms rated on the GHQ-12 (QoL-AD).

<sup>5</sup> Systemic lupus erythematosus, rheumatoid arthritis & ankylosing spondylitis.

Reference	Country	Client group	Sample	Outcome instrument <sup>3</sup>	Type of proxy rating <sup>4</sup>	Key findings
Sloane, P. et al. (2005)	USA	Dementia	People with dementia in residential care and staff proxies (421 dyads)	QoL-AD; QoL-D	Not specified	Agreement between self and proxy rating of QoL was low. Proxies rated QoL lower than self-report. Observational measures of QoL correlated more closely to proxy than self-report.
Steel, J. et al. (2005)	USA	Cancer	People with hepatocellular carcinoma, family carers and oncologist (82 triads at baseline, 32 triads at 3-month follow-up and 16 triads at 6-month follow-up)	FACT-Hep	Not specified	Proxies consistently rated QoL lower than self-report, with the exception of physicians' rating of QoL at six-month follow-up, which was higher than self-report. At baseline, self and family carer proxy report of QoL were consistent for all domains (e.g. physical, social, family, functional wellbeing) except for emotional wellbeing. By contrast, patient and physician report were only consistent for physical wellbeing. Family and physician proxies were only consistent on physical and emotional wellbeing.
Steinmann, D. et al. (2013)	Germany	Cancer	People with brain metastases and family carers (baseline, 141 dyads; 3-month follow-up, 65 dyads)	EORTC (self-report); DEGRO brain module (proxy)	Proxy-proxy	Correlation of self and proxy report on overlapping questions in the EORTC and DBM was higher for physical symptoms (e.g. fatigue, nausea and headache) than for emotional function. The correlation increased between baseline and 3-month follow-up, especially for emotional functioning. Correlations were higher for spousal compared to non-spousal proxies.
Stineman, M. et al. (2004)	USA	n/a	People who completed the US National Health Interview Survey (NHIS)	Four QoL items <sup>6</sup>	Not specified	The study found case-mix differences between self and proxy respondents: for example, proxy respondents were more likely to be on behalf of a young, married male, high school graduate with a household income of more than \$20,000, who experiences fewer difficulties with physical, psychological or sensory functioning and self-care activities. An analysis of case-mix adjusted QoL found that differences between self and proxy response were no longer significant. Adjustment based on socio-economic factors alone explained much of the difference, although functional differences also contributed.
Tang, S. (2006)	Taiwan	Cancer	People with cancer and family carers (114 dyads)	MQOL; SDS	Not specified	The agreement between self- and proxy-rated responses on the MQOL was fair. Family carers rated spiritual wellbeing significantly lower than self-report, whereas they overestimated physical wellbeing compared to self-report. On the SDS, there was a high level of concordance between self- and proxy-report with the exception of the pain domain, where family carers overestimated pain compared to self-report.
Trigg, R. et al. (2011)	UK	Dementia	People with dementia and their family carers (69 dyads)	BASQID (patient); ADRQoL (proxy)	Not specified	There was a weak, non-significant correlation between proxy-rated QoL on the ADRQoL and self-rated QoL on the BASQID.

<sup>6</sup> Four dichotomous (Yes/No) items: poor health; disability; ≥20 visits to doctor over the past year; remaining in bed for more than half a day over the previous 30 days.

Reference	Country	Client group	Sample	Outcome instrument <sup>3</sup>	Type of proxy rating <sup>4</sup>	Key findings
Tripoliti, E. et al. (2007)	UK	Multiple sclerosis	People with MS and their family carers (40 dyads)	FAMS	Not specified	Proxy-rated QoL was lower than self-report, although there was considerable variation in the data. Further analysis highlighted that proxies of clients with high self-reported QoL tended to underestimate QoL, whereas proxies of clients with low self-reported QoL tended to overestimate QoL. The observable domain of mobility had higher levels of agreement between self and proxy-rating than non-observable domains (e.g. fatigue, thinking and social wellbeing).
Whynes, D. et al. (2013)	16 countries (including UK)	Stroke	People with stroke (n=1026) or family carers (n=462)	EQ-5D	Not specified	There was a non-significant trend for family carer proxies to be more likely to report some problems with usual activities, pain and anxiety/depression, and less likely to report severe problems for usual activities, compared to self-report.
Williams, L. et al. (2006)	USA	Post-stroke depression	People with post-stroke depression and family carers in contact with the person at least 3 days/week (225 dyads)	SS-QOL	Not specified	Proxies rated overall QoL lower than self-report. The average score on the Thinking, Mood and Energy domains had the greatest disparity, although there were significant differences between mean proxy and self-rated QoL in all seven domains (t-test, p<0.05). There was higher agreement between patient/proxy pairs where the patient had higher depression scores and the carer reported lower caregiving burden. The agreement between self-rated and proxy scores was only fair to moderate, with the highest agreement in Physical Functioning and the lowest agreement in Thinking and Role Function.
Yeaman, P. et al. (2013)	USA	Dementia	People with dementia and their family carer (10 dyads)	QoL-AD	Proxy-proxy	Proxy rated QoL was significantly lower than self-report in four of the 13 QoL-AD domains (physical health, memory, ability to do chores, money).
Zhao, H. et al. (2012)	France	Dementia	People with Alzheimer's disease and their family carers (122 dyads)	QoL-AD	Proxy-proxy	Proxy respondents significantly underestimate QoL in all domains except for 'self-esteem', which was overestimated, and 'mood', 'living situation' and 'friends', where there was no significant self/proxy difference. A larger discrepancy between self- and proxy-rating was associated with lower levels of cognitive decline, greater difficulty with IADLs and more reported neuropsychiatric symptoms in the person with Alzheimer's disease, as well as higher levels of carer burden.
Zimmermann, F. & M. Endermann (2008)	Germany	Intellectual disabilities (mild) with epilepsy	People with mild ID / epilepsy and their formal carers (36 dyads)	QOLIE-31	Proxy-proxy	Proxy-rated QoL was significantly lower than self-report for overall QOLIE-31 score and in the following domains: social functioning, seizure worry, emotional wellbeing and cognitive functioning. The difference between self/proxy rating was smaller (and not statistically different) in the more observable domains (e.g. health, fatigue).
Zucchella, C. et al. (2014)	Italy	Dementia	People with Alzheimer's disease and their family carers (135 dyads)	QoL-AD	Proxy-proxy	Carer proxy-reported QoL was significantly lower than self-reported QoL overall and on all items except for 'marriage' (not significant). Self-reported QoL was associated with difficulties with everyday activities and patient depression, whereas proxy report was associated with mood and behavioural disturbances. Regression analysis identified that a smaller discrepancy between self and proxy report was associated with higher levels of depression in the person with Alzheimer's disease, fewer ADL difficulties, fewer neuropsychiatric symptoms, and lower levels of carer burden or depression.

**Table 2. Summary of the Literature Review (literature reviews)**

Reference	Literature review topic	Client group	Review methods	Key findings
Dirven, L. et al. (2013)	HRQoL measurement in clinical trials: methodological issues	Brain tumour	Narrative review	The use of proxy ratings is discussed as one of the issues associated with HRQoL measurement in clinical trials. The discussion draws on five articles identified in the search conducted for this paper (Milne et al. 2006, Brown et al. 2008, Gundy et al. 2008, McPhail et al. 2008, Giesinger et al. 2009) plus six additional articles to highlight the issues of: only low-moderate agreement between patients and proxies; the tendency for proxies to underestimate quality of life; the level of disagreement increases with symptom severity or cognitive impairment and is also associated with characteristics of the proxy (e.g. type of proxy, depression and carer burden).
Hounsom, N. et al. (2011)	Use of EQ-5D as an outcome measure	Dementia	Systematic review; between 1999 and 2009	21 studies were identified, with some overlap with the search presented in this paper (Bryan et al. 2005, Naglie et al. 2006, Jonsson et al. 2006, Hoe et al. 2007). The findings indicate that many people with moderate/severe dementia are not able to complete the EQ-5D in its standard format without support. Patients with dementia report significantly higher EQ-5D domain scores and VAS compared to proxy ratings by professional and family carers. There was some agreement for the 'observable' domains (mobility, self-care), but not for the non-observable domains (pain, anxiety/depression). Proxy and self-understanding of the 'usual activities' domain varied considerably. These discrepancies are not associated with the PwD's MMSE score, which indicates that the discrepancy is not simply attributable to cognitive impairment. Patients' rating of their HRQoL related to anxiety/depression, but not severity of dementia, whereas proxy rating was strongly associated with rating of dementia severity and behavioural symptoms. The review also reports research that found the level of agreement between family carer and healthcare professional ratings are particularly poor for less observable dimensions (pain, anxiety/depression).
Oczkowski, C. & O'Donnell, M. (2010)	Reliability of proxy respondents	Stroke	Systematic review; between 1969 and 2008	The literature search identified 13 studies that (with one exception) used intra-class correlation coefficients (ICC) or k statistic to evaluate proxy-/self-agreement on rating of ADLs (n=5) or QoL (n=9). (The review includes three articles also identified in the literature search presented in this article (Pickard et al. 2004, Williams et al. 2006, Hilari et al. 2007)). The agreement on ADLs was moderate to excellent (0.61-0.91) and moderate to substantial for QoL (0.41-0.80). Key factors associated with low proxy-/self-agreement were the type of question (objective/subjective) and stroke severity. Proxy-/self-agreement was also higher beyond the acute stroke period.
Shearer, J. et al. (2012)	Health state values for economic evaluation of treatments	Alzheimer's disease	Systematic review; between 2000 and 2011	A systematic review of the literature identified 12 studies that reported preference-based health state values to support economic analysis of treatments of AD. (The review includes three articles also identified in the literature search presented in this article (Jonsson et al. 2006, Naglie et al. 2006, Kunz 2010)). The identified instruments from these studies were: EQ-5D; HUI 2/3; Quality of Well-being Scale. In studies that included both proxy and self-report (n=5), proxies rated health states lower than self-report. Carers with higher reported subjective burden tended to rate proxy QoL as lower than carers with lower subjective burden. Interestingly, people with AD also rated their ability to complete daily activity as higher than proxy report, and often did not perceive or report any disability (e.g. 41% of EQ-5D scores were at ceiling).
Von Essen, L. (2004)	Factors associated with self/proxy agreement	n/a	Narrative review with systematic methods; between 1994 and 2004	A review of the literature on proxy rating identified the following key themes: (1) How the accuracy of proxy ratings is determined (2); the tendency for proxies to underestimate QoL compared to self-report; and (3) factors associated with this discrepancy. The authors identify the following factors associated with self/proxy discrepancy: methodological factors (e.g. sample size); inclusion of observable and/or non-observable domains; who is the proxy and/or frequency of contact between patient and proxy; and characteristics of the proxy and patient (e.g. carer burden or psychosocial health, level of patient impaired functioning, or stage of disease with associated adaptation or coping by the patient).

## 4 Discussion

### 4.1 Comparison of self- and proxy-reported quality of life

Many studies that compare self- to proxy-report (see Box 1) have found that proxies rate quality of life lower than self-report. This 'proxy bias' is a weak effect that has been observed in studies of various client groups, including people with **dementia** (Edelman, Fulton & Kuhn 2004, Sloane et al. 2005, Jonsson et al. 2006, Naglie et al. 2006, Hoe et al. 2007, Arlt et al. 2008, Huang et al. 2009, Kunz 2010, Schiffczyk et al. 2010, Bruvik et al. 2012, Crespo et al. 2012, Gomez-Gallego, Gomez-Amor & Gomez-Garcia 2012, Graeske et al. 2012, Moyle et al. 2012, Sheehan et al. 2012, Zhao et al. 2012, Arons et al. 2013, Yeaman et al. 2013, Zucchella et al. 2014), **cancer** (Steel, Geller & Carr 2005, Milne et al. 2006, Jones et al. 2011), **stroke** (Williams et al. 2006, Hilari, Byng 2009, Whyntes et al. 2013), **cardiac surgery or rehabilitation** (Elliott, Lazarus & Leeder 2006, Fast, Steinke & Wright 2009), **intellectual disability** (Zimmermann, Endermann 2008, Claes et al. 2009, Schmidt et al. 2010), **acute lung injury** (Gifford et al. 2010, Dinglas et al. 2013), **Parkinson's disease** (Fleming et al. 2005), **schizophrenia or bipolar disorder** (Becchi et al. 2004, Kim et al. 2010), **autoimmune disease** (Ramos-Remus et al. 2014), **older adults** (Scocco, Fantoni & Caon 2006) and **renal disease** (Ferri, Pruchno 2009).

A small number of studies have, however, found no significant difference between self- and proxy-report (Gabbe et al. 2012, Hung et al. 2010, Beadle-Brown, Murphy & DiTerlizzi 2009, Schiffczyk et al. 2011) or that proxies overestimate overall quality of life compared to self-assessment (Muus, Petzold & Ringsberg 2009). Rather than 'bias' to underestimate QoL, there may be an underlying tendency for proxies to rate quality of life more moderately than self-report (that is, there is a bias towards moderate responses, and away from either extreme of very good or very poor quality of life) (Dinglas et al. 2013, Tripoliti et al. 2007). The observation of an 'underestimation' bias may be due to the positive cognitive bias in self-reported quality of life. While proxies tend to rate QoL at the centre, there is a negatively skewed distribution of self-report QoL scores with the average at the upper end of the scale. Therefore, the average proxy-rated QoL will be lower than self-rated QoL.

The size and direction of the discrepancy between self- and proxy-rating of quality of life has been found to be affected by various factors: for example, study design and methodology; the balance of observable or non-observable QoL attributes in the measurement instrument; the type and proximity of the relationship between the proxy and self-respondent; the characteristics of the proxy; the characteristics of the self-respondent; and the instructions for how proxies are to rate quality of life. The evidence for the influence of these factors on the discrepancy between proxy- and self-reported quality of life will be summarised, before considering the implications for the conceptualisation and measurement of proxy-rated quality of life.

### Box 1. Comparison of self- and proxy-reported quality of life

The reliability of proxy report is typically determined in the literature by comparison between self-report and proxy-report. This comparison may be made at the:

1. **Individual level** using correlation analysis to indicate the extent to which proxy rating agrees with self-rating of QoL. This is usually assessed using the Pearson correlation coefficient, weighted Kappa statistic, or the intra-class correlation coefficient.
2. **Group level** using comparison of mean scores with effect sizes to indicate both the direction and size of any systematic bias between self- and proxy-reporting (Von Essen, 2004).

The underlying assumption of these analyses is that self-report is an 'accurate' standard against which proxy-report may be assessed to give an indication of reliability. It is unclear whether this assumption is justified and it may be more accurate to describe proxy-report as a separate source of information to self-report.

Furthermore, such comparisons may only be made when an individual is able to answer on their own behalf. Proxy measurement is primarily designed for use in situations where this is not possible, which presents an important methodological issue. Some studies aim to address this issue by comparing self- and proxy-agreement across different levels of functional ability, in order to extrapolate the findings beyond what is measurable to those people who would not be able to respond on their own behalf (von Essen 2004).

#### 4.1.1 Methodological considerations

Self-proxy agreement may be affected by limitations in the study design or methodology (von Essen 2004). The internal validity of the quality of life instrument may affect the degree of self-proxy concordance. Since the correlation between two scores may not exceed the square root of the product of the scores' internal consistency (Nunnally, Bernstein 1994), any study of an instrument with low internal consistency will not find high levels of self-proxy agreement using correlation analysis. The level of agreement may also be affected by the range, variability and skewness of the outcome variable: for example, low agreement between proxy- and self-report may be due to low variability (Sneeuw et al. 1997). Finally, it has been found that studies with fewer than approximately 50 proxy-self pairs typically have lower levels of agreement than studies of larger samples (Sneeuw, Sprangers & Aaronson 2002). This finding should be considered when interpreting the findings of the thirteen studies identified by the literature search in this report with a sample of fewer than 50 dyads (Edelman, Fulton & Kuhn 2004, Gil et al. 2004, Tripoliti et al. 2007, Pearcy et al. 2008, Zimmermann, Endermann 2008, Beadle-Brown, Murphy & Di 2009, Fast, Steinke & Wright 2009, Giesinger et al. 2009, Claes, et 2012, Graeske et al. 2012, Arons et al. 2013, Yeaman et al. 2013, Carlozzi et al. 2014, Lewis et al. 2014).



### 4.1.2 Quality of life domains

The studies identified in this literature review included a number of different quality of life instruments. Whereas some instruments are designed to measure general quality of life (e.g. WHOQOL-BREF), others are designed to capture general (e.g. EQ-5D, SF-36) or condition-related (e.g. FACT-Br) health-related quality of life. Some of the general quality of life instruments are designed for use in certain populations, such as people with Alzheimer’s disease (e.g. QoL-AD, ADRQoL, DQoL) or older adults (e.g. ICECAP-O). The domains in these quality of life instruments vary according to the measurement construct of interest (see Table 3). There is evidence that the degree of agreement between proxy and self-report depends, in part, on the domains of quality of life being assessed, with a higher degree of correspondence between self- and proxy-ratings of objective, externally-observable domains than for subjective domains (von Essen 2004).

**Table 3. Quality of life domains by QoL instrument**

<b>Instrument</b>	<b>Target group</b>	<b>Quality of life attributes</b>
EORTC QLQ-30 <sup>7</sup>	Cancer	Five <i>functional</i> scales (physical, role, cognitive, emotional, and social) and three <i>symptom</i> scales (fatigue, pain, and nausea/vomiting), a <i>global health status / QoL</i> scale and items to rate specific symptoms of financial difficulties associated with the disease
EQ-5D <sup>8</sup>	Generic	<i>Everyday activities; mobility; personal care; pain/discomfort; anxiety/depression</i>
FACT-Br <sup>9 10</sup>	Brain tumour	<i>Physical; social/family; emotional; functional; concerns relevant to patients with brain tumour</i>
HUI3 <sup>11</sup>	Generic	<i>Vision; hearing, speech; ambulation; dexterity; emotion; cognition; pain</i>
ICECAP-O <sup>12</sup>	Older adults	<i>Attachment</i> (love and friendship); <i>Security</i> (thinking about the future without concern); <i>Role</i> (doing things that make you feel valued); <i>Enjoyment</i> (enjoyment and pleasure); <i>Control</i> (independence)
PDQ-39 <sup>13</sup>	Parkinson’s disease	<i>Mobility; activities of daily living; emotional wellbeing; stigma; social support; cognition; communication; bodily discomfort</i>

<sup>7</sup> Aaronson NK, Ahmedzai S, Bergman B, Bullinger M, Cull A, Duez NJ, Filiberti A, Flechtner H, Fleishman SB, de Haes JC. 1993. The European Organization for Research and Treatment of Cancer QLQ30: a quality-of-life instrument for use in international clinical trials in oncology. *Journal of National Cancer Institute*, 85(5):365-76.

<sup>8</sup> EuroQol. EQ-5D. Available from: <http://www.euroqol.org/>. [Accessed 19 January, 2015].

<sup>9</sup> Cella DF, Tulsky DS, Gray G, et al. 1993. The Functional Assessment of Cancer Therapy scale: development and validation of the general measure. *Journal of Clinical Oncology* 11:570-579.

<sup>10</sup> Weitzner MA, Meyers CA, Gelke CK, et al. 1995. The Functional Assessment of Cancer Therapy (FACT) scale: Development of a brain subscale and revalidation of the general version (FACT-G) in patients with primary brain tumors. *Cancer* 75(5):1151-1161.

<sup>11</sup> Health Utilities Inc. HUI3. Available from: <http://www.healthutilities.com/>. [Accessed 21 January, 2015].

<sup>12</sup> ICECAP. ICECAP-O. Available from <http://www.birmingham.ac.uk/research/activity/mds/projects/HaPS/HE/ICECAP/ICECAP-O/index.aspx>. [Accessed 21 January, 2015].

<sup>13</sup> Jenkinson C, Fitzpatrick R, Peto V, Greenhall R, Hyman N. The Parkinson’s disease Questionnaire (PDQ-39): development and validation of a Parkinson’s disease summary index score. *Age & Ageing* 1997;26:353–357.

Instrument	Target group	Quality of life attributes
QoL-AD <sup>14</sup>	Alzheimer's disease	<i>Physical health; energy; mood; living situation; memory; family; marriage; friends; self as a whole; ability to do chores around the household; ability to do things for fun; money; life as a whole</i>
SF-36 <sup>15</sup>	Generic	<i>Physical functioning; role limitations due to physical health; role limitations due to emotional problems; energy/fatigue; emotional well-being; social functioning; pain; general health</i>
WHOQOL-BREF <sup>16</sup>	Generic	<i>Physical health; psychological health; social relationships; environment</i>

The literature review identified a number of studies that compared self- and proxy-ratings of the five QoL attributes in the EQ-5D. A systematic review of the literature between 1999 and 2009 of studies using the EQ-5D with proxy report in people with dementia found that proxy-self agreement was higher for the observable (*mobility, self-care*) than non-observable attributes (*pain, anxiety/depression*) with variable findings for *usual activities* (Hounscome, Orrell & Edwards 2011) <sup>17</sup>. Some studies have found a significant discrepancy between patient and proxy rating of *usual activities*, or that both patients and proxies find the term 'usual' ambiguous since it is unclear whether, for example, this includes paid employment or other specific activities (Coucill et al. 2001, Selai et al. 2001, cited in Hounscome, Orrell & Edwards, 2011).

Other studies of proxy-reported quality of life for people with dementia identified in this literature review also find higher proxy/patient agreement for observable compared to non-observable EQ-5D domains (Kunz 2010, Pickard et al. 2004). This finding has also been observed in studies of other patient groups: for example, the agreement between self- and proxy-ratings in people with traumatic brain injury and their family or professional carers was higher for the objective than the subjective EQ-5D domains with moderate agreement for *usual activities* (Gabbe et al. 2012); family or nursing staff proxies of people on prolonged ventilation had poor-moderate agreement with self-report on the objective domains and *usual activities*, while the subjective domains of pain and anxiety/depression had poor agreement (Hung et al. 2010); and a study of patients with prostate cancer and their informal carers found greater agreement on the observable domains (*mobility, self-care*) than for *usual activities, pain* or *anxiety/depression* (Pickard et al. 2004).

The finding that there is higher agreement on objective compared to subjective attributes has been replicated in studies using quality of life measures other than the EQ-5D. The Stroke and Aphasia Quality of Life Scale (SAQOL-39), for example, has high proxy/self-rating agreement for the *physical health* domain, moderate agreement for the *psychosocial* and

<sup>14</sup> Logsdon RG, Gibbons LE, McCurry SM, Teri L. 1999. Quality of life in Alzheimer's disease: patient and caregiver reports. *Journal of Mental Health and Aging* 5, 21–32.

<sup>15</sup> Medical Outcomes Trust. SF-36. Available from: <http://www.sf-36.org/>. [Accessed 21 January, 2015].

<sup>16</sup> World Health Organization. WHOQOL-BREF. Available from: [http://www.who.int/substance\\_abuse/research\\_tools/whoqolbref/en/](http://www.who.int/substance_abuse/research_tools/whoqolbref/en/). [Accessed 21 January, 2015].

<sup>17</sup> Three of the eleven studies identified in Hounscome et al.'s (2011) review that draw on both self- and proxy-report overlap with the literature search conducted for this literature review (Naglie et al. 2006, Jonsson et al. 2006, Bryan et al. 2005).

*communication* domains, and lowest agreement for the subjective domain of the level of *energy* experienced by the person with aphasia (Hilari, Owen & Farrelly 2007). Cardiac surgery patients and their next of kin had highest concordance on the *physical* domain of the SF-36, which has an external, observable element, and lowest concordance on the subjective experience of *energy/fatigue*, *emotional wellbeing* and *emotional role functioning* domains (Elliott, Lazarus & Leeder 2006). The highest level of agreement was found for the *mobility* domain of the Functional Assessment of Multiple Sclerosis (FAMS) questionnaire with low agreement for *role function*, *thinking and fatigue* (Tripoliti et al. 2007). Family carers had better concordance with self-report of the observable domains of *functional dependency* and *symptom distress* rated on the Symptom Distress Scale (SDS) than the subjective *psychological*, *social* and *spiritual concerns* of the patient from the McGill Quality of Life Questionnaire (MQOL) (Tang 2006). The rating of *mobility* and *activities of daily living* by people with Parkinson's disease and family carers had higher agreement (ICC>0.6) than non-observable domains of the PDQ-39, such as experience of *stigma*, *cognition* and *communication* (ICC<0.4) (Fleming et al. 2005).

Similarly, the rating by people with brain tumour and their spouse or partner proxies had low agreement on the EORTC-QLQ domains of *social functioning* and *pain*, whereas the observable *physical* domain had the highest level agreement (Giesinger et al. 2009). Family proxy rating of the EORTC-QLQ also tended to agree more with self-report for *physical* compared to psychosocial domains in a study of people with advanced cancer (Milne et al. 2006). The subjective domains of *social interaction* and *cognitive ability* had higher levels of discrepancy than other domains in the WHODAS-II for people with autoimmune disease (Ramos-Remus et al. 2014). People with schizophrenia and their family, friend, nurse or social worker proxies had better agreement on physical than psychological domains of the WHOQOL-BREF (Becchi et al. 2004). Higher agreement between family proxies and self-report was found for physical quality of life attributes compared to non-observable, subjective domains on the Huntingdon's disease health-related quality of life questionnaire (HDQoL) (Hocaoglu, Gaffan & Ho 2012), the quality of life in Alzheimer's disease scale (QoL-AD) (Huang et al. 2009), the stroke-specific quality of life questionnaire (Williams 2006), the quality of life in epilepsy inventory (QOLIE-31) (Zimmermann, Endermann 2008) and the Health Utilities Index (HUI) (Jones, Feeny 2005, Pickard et al. 2004).

It is not only the degree of agreement that varies by quality of life attribute, but also whether quality of life tends to be under- or over-reported by proxies. In a study of the QoL-AD rated by people with Alzheimer's disease and their family carers, it was found that proxies rated quality of life lower than self-report in all domains except for *self-esteem*, which was overestimated, and *mood*, *living situation* and *friends*, where there was no significant difference between self- and proxy-report (Zhao et al. 2012). Family member carers rated the QOL-AD domains lower than self-report for all domains except for *yourself overall* and *the people who work here*, which were rated significantly higher than self-report. A similar pattern was observed with staff proxies, with higher rating than self-report

for *yourself overall* and *living situation* (Crespo et al. 2012). Therefore, the overall level of agreement on a composite quality of life scale may be, at least in part, affected by the domains included in the scale due to both the degree of agreement and the direction of the tendency for proxies to rate quality of life differently from self-report (i.e. over- or under-estimation).

Some findings indicate that the effect of type of domain (objective/subjective) may be influenced by the sample characteristics and/or the degree of intimacy, proximity and quality of communication between the individual and their proxy. A study of people with Parkinson's disease and their family carers in Spain found moderate to good agreement for all five domains; *mobility* (objective) and *pain* (subjective) domains had the highest concordance (Martinez-Martin et al. 2004). The authors suggest that this finding may be due to the high level of social interaction between the individual and their proxy in the sample. Likewise, proxy- and self-rating discrepancy on the psychological aspects of QoL has been found to be smaller for relatives compared to non-relatives, and this has been hypothesised to be due to a greater degree of intimacy among relatives (Becchi et al. 2004). Furthermore, low agreement on the observable physical domains of the WHOQOL-BREF found in a study of people with intellectual disabilities and their family or staff proxies has been suggested to be due to the lower relevance of physical domains to people with intellectual disabilities compared to samples that focus on people with physical health conditions (Schmidt et al. 2010). The literature, therefore, suggests that there may be an interaction between the objective/subjective nature of the quality of life domain and other factors, such as the frequency or quality of interaction between proxy and patient or the relevance of the QoL attribute to the experience and life situation of the study sample.

#### **4.1.3 Proxy relationship to self-respondent**

Most of the studies identified in the literature search collected proxy-reported quality of life from relatives, professional care or support staff (e.g. care or nursing assistants, social workers) or health care professionals (e.g. nurses or clinicians). One study drew on data collected from trained observers alongside staff proxy rating of QoL (Edelman, Fulton & Kuhn 2004). Proxy respondents were usually selected on the basis of intimate knowledge of the individual, or their professional capacity or skills to make judgements on another person's behalf. The literature suggests that ratings by different types of proxy may not be equivalent or interchangeable. Unlike family proxies who tend to underestimate quality of life, clinicians and nurses have been found to overestimate overall quality of life compared to self-report in some studies (Gil et al. 2004, Graeske et al. 2012) while they underreport in others (Pearcy et al. 2008). In studies that directly compare different proxies' rating of QoL, the correlation between family and staff proxy ratings is modest (Kane et al. 2005) and there is higher self-proxy agreement for family members compared to professional health or care staff proxies (Steel, Geller & Carr 2005, Becchi et al. 2004, Gil et al. 2004), particularly in subjective domains (Hung et al. 2007, Claes, et 2012, Jones et al. 2011). Physicians have lower overall agreement with self-report than nurses or family carers, and tend to

overestimate overall QoL (VAS) and *anxiety/depression*, yet underestimate *pain* on the EQ-5D (Rebollo et al. 2004).

There is evidence that observable health or care-related characteristics, such as activities of daily living, symptoms or behaviours, predict more of the variance in QoL for professional carers compared to family carers (Crespo, Hornillos & de Quiros 2013). Clinicians' rating of observable domains has higher construct validity and agreement with self-report than informal carer proxy rating; this finding is reversed for subjective QoL domains (Bryan et al. 2005). This suggests that differences between staff and relative proxy ratings may be a product of different perspectives or criteria for making proxy ratings; specifically, that professional carers rely more heavily on observable factors to make their ratings than either self-report or family proxy ratings. This tentative hypothesis is supported by the finding that there was no significant difference between staff proxy rating of QoL and observational ratings of quality of life (Edelman, Fulton & Kuhn 2004).

Some studies, however, have found no difference between family and staff proxy rating of quality of life (Schmidt et al. 2010, Crespo et al. 2012, Gomez-Gallego, Gomez-Amor & Gomez-Garcia 2012). Rather than only through a systematic difference in perspective by proxy type (family or staff), the evidence suggests that the difference in QoL ratings may also be partly explained by differences in the proximity, intimacy and frequency of contact between the proxy and the individual. Higher frequency contact between the proxy and patient is associated with higher correspondence of self- and nurse proxy-rated QoL (Graeske et al. 2012). Spousal or co-resident family carer-rated QoL has higher agreement with self-report than ratings by non-spousal caregivers or those who do not live with the person (Stineman et al. 2004). The discrepancy between (mainly spousal) family carer proxy-rated quality of life and self-report was found to decrease over the 12-week period following diagnosis of advanced cancer (Milne et al. 2006), and the level of agreement between self- and family proxy-report of QoL has been found to improve after hospital discharge compared to pre-surgery and at hospital discharge (Elliott, Lazarus & Leeder 2006); this change over time has been hypothesised to be associated with the increased proximity and contact between the individual and proxy in the post-discharge or diagnosis period. Finally, a study of the care-related quality of life measure, ICECAP-O, administered in a residential care setting found that nursing staff proxies with a high level of interaction with the care recipient rate QoL closer to self-report than family proxies with less frequent contact (Makai et al. 2012). The literature, therefore, suggests that ideally the chosen proxy respondent should have frequent contact with the individual that allows the proxy insight into the individual's situation, experiences and preferences. This may not always be possible, however, particularly in instances where there is no obvious candidate for a proxy with a high-level of contact.

#### 4.1.4 Characteristics of the proxy and self-respondent

The literature review identified a number of reports of studies that investigate the association between individual characteristics and proxy-reported quality of life, self-reported QoL and/or the inter-rater gap. The findings of these studies are summarized below.

##### 4.1.4.1 Individual characteristics associated with proxy-reported quality of life

The findings of the identified studies indicate that proxy-rated quality of life is strongly associated with external, observable characteristics of the individual whose quality of life is being assessed: for example, with **challenging behaviour** or **lower independent living skills** (Beadle-Brown, Murphy & DiTerlizzi 2009); **neuropsychiatric symptoms** or **severity of disease** (Oczkowski, O'Donnell 2010, Schiffczyk et al. 2010, Hounsome, Orrell & Edwards 2011, Buckley et al. 2012, Sheehan et al. 2012, Graeske, Meyer & Wolf-Ostermann 2014, Zucchella et al. 2014); or **functional ability on activities of daily living** (Edelman, Fulton & Kuhn 2004, Ferri, Pruchno 2009, Moyle et al. 2012, Sheehan et al. 2012, Crespo, Hornillos & de Quiros 2013, Giebel, Sutcliffe & Challis 2014). Staff proxy ratings have been found to be particularly associated with observable characteristics, such as, behavioural symptoms, use of medication (Gomez et al. 2012) or limitation of daily activities (Moyle et al. 2012).

The proxy's own characteristics or subjective experiences have also been found to be related to the proxy-rated quality of life. For example, whilst controlling for the patients' characteristics, the proxy's work experience was found to be associated with nursing staff proxy rating of QoL. Staff with more than two years' experience were more likely to rate higher QoL than those with less than two years' experience (Makai et al. 2014). Proxy-rated quality of life has also been found to be related to self-reported quality of life by the proxy (Ferri, Pruchno 2009, Huang et al. 2009, Schiffczyk et al. 2011, Arons et al. 2013) and carer strain, burden or burnout (Rebollo et al. 2004, Gomez et al. 2012, Shearer et al. 2012, Graeske, Meyer & Wolf-Ostermann 2014). This finding was, however, not replicated in one study identified in this literature review, perhaps due to the nature of the sample, which had generally low levels of reported burden (Crespo, Hornillos & de Quiros 2013). Report of depression by the proxy is associated with lower proxy-rated quality of life (Schiffczyk et al. 2010). Proxy-rated pain is underestimated compared to self-report by proxies with depressive symptoms, yet is overestimated by proxies who experience high levels of pain (Hung et al. 2007). Interestingly, there is some evidence of a gender effect: whereas female carer proxy-rating of QoL is associated with proxy's own self-rated QoL, male carer proxy-rating is more strongly associated with patient depression (Schiffczyk et al. 2011). These findings suggest that there may be some form of 'projection' bias in substituted quality of life judgement (Ferri, Pruchno 2009), whereby the influence of proxies' own subjective experiences may contribute to an interpretative bias when forming a judgement of proxy-rated quality of life (Hung et al. 2007).

#### **4.1.4.2 Individual characteristics associated with self-reported quality of life**

Self-reported quality of life has been found to be strongly related to subjective characteristics, such as **depression, anxiety** or **mood** (Zimmermann, Endermann 2008, Hounscome, Orrell & Edwards 2011, Gomez et al. 2012, Sheehan et al. 2012, Crespo, Hornillos & de Quiros 2013, Zucchella et al. 2014). However, self-reported QoL is also associated with similar factors as proxy-report: for example, **activities of daily living** (Sheehan et al. 2012, Zucchella et al. 2014); **challenging behaviour** (Graeske, Meyer & Wolf-Ostermann 2014); **cognitive ability** (Crespo, Hornillos & de Quiros 2013); **comorbidity** (Buckley et al. 2012); and even **carer stress or burden** (Sheehan et al. 2012). These findings suggest that, although there is some indication that individuals and their proxies use different criteria to make judgements about quality of life, there is also considerable overlap in the key factors (particularly health status and functional ability) associated with QoL rating by both self and proxy.

#### **4.1.4.3 Individual characteristics associated with the inter-rater gap**

In order to identify potential sources of divergence in rating (or 'bias'), some studies have sought to investigate the factors associated with the difference between self- and proxy-rated QoL. These studies have identified that the key factor associated with divergence is severity of disease or health status. There is some tentative evidence that supports the hypothesis of a U-shaped relationship between patient health status and the degree of self- and proxy-rating agreement. with best agreement for patients with very good or very poor health: for example, this U-shaped relationship has been found in studies of cancer patients (von Essen 2004) and people with dementia (Crespo et al. 2012).

In a study of terminally ill people with cancer and their proxies, disease progression and cognitive difficulties were found to be associated with better concordance of QoL ratings (Jones, Edwards & Hounscome 2012). The inter-rater gap is smaller when the patient has fewer difficulties with activities of daily living or reported neuropsychiatric symptoms (Martinez-Martin et al. 2004, Rebollo et al. 2004, Zhao et al. 2012, Zucchella et al. 2014). There is also evidence that people with mild/moderate dementia who experience fewer impairments or difficulties with activities of daily living have a smaller inter-rater gap (Kunz 2010). By contrast, adults with more severe dementia-related symptoms tend to have a smaller inter-rater gap (Buckley et al. 2012, Zhao et al. 2012), although this finding was not replicated in a study of people with dementia where increased severity of disease (MMSE score) was associated with a larger inter-rater gap (Schiffczyk et al. 2010). Overall, these results indicate that proxies may find it easier to concur with the people whose quality of life they are rating when it is 'clear cut' (i.e. the individual's quality of life is very good or very bad). The mid-part of the curve may be due to psychological adaptation by the patient to their disability or poor health, which results in an adjusted expectation of quality of life that is not shared by the proxy (Martinez-Martin et al. 2004, Rebollo et al. 2004, Zhao et al. 2012, Zucchella et al. 2014).

Some studies indicate that factors other than health status, symptoms or disease progression are also associated with the inter-rater gap. Better agreement has been observed when patients have a higher educational level (Arons et al. 2013) and higher quality of the proxy-patient relationship (Huang et al. 2009). A smaller inter-rater gap is also associated with lower levels of carer burden, psychological distress or depression; carers with depressed mood or high levels of subjective burden may be particularly susceptible to a cognitive bias to underestimate proxy-rated QoL (Rebollo et al. 2004, Martinez-Martin et al. 2004, Williams et al. 2006, Huang et al. 2009, Kunz 2010, Zhao et al. 2012, Zucchella et al. 2014). This finding has not, however, been replicated in all studies in this review (Schmidt et al. 2010). Younger proxies have been found to rate QoL closer to self-report than older carers (Zimmermann, Endermann 2008). The authors hypothesised that this finding may be related to the study sample of self-respondents, which comprised young adults (aged 18-40 years). Younger caregiver proxies may be closer than older proxies to the generationally-dependent worldview, perceptions and experiences of the self-respondents. Finally, a small discrepancy between self- and proxy-report is associated with patient depression; this may be due to the tendency for depressed people to rate quality of life lower and hence rate QoL closer to proxy-report (Williams et al. 2006, Zucchella et al. 2014, Lewis et al. 2014). (Interestingly, however, one study found that this finding held only with the EQ-5D, whereas the opposite trend was observed for a disease-specific measure of QoL, the PDQ-8; this indicates that the relationship may be associated with the intrinsic properties of the instrument (Martinez-Martin et al. 2004)). Overall, the evidence indicates that there are a number of complex, overlapping relationships between individual or health-related characteristics or properties of the measurement instrument that either independently influence or co-vary with self-rated QoL and proxy-rated QoL - and thus affect the size of the inter-rater gap.

## 4.2 Proxy perspective

The conceptual framework of proxy response presented by Pickard and Knight (2005) identifies two distinct proxy perspectives. The proxy-patient perspective requires proxies to project themselves into the patient's internal state, whereas the proxy-proxy perspective is based on the proxy's judgement. It is argued that the latter perspective may differ from self-report without compromising construct validity, and that this information may be used to complement self-report. The inter-rater gap between self-report and proxy-report based on the proxy-patient perspective is hypothesised to be smaller than for the proxy-proxy perspective (Pickard, Knight 2005), and may therefore be preferred in instances where proxy-report is used to substitute for self-report. Alternatively, since the intra-proxy gap may approximate the inter-rater gap in some circumstances (Pickard, Knight 2005), it has been suggested that both perspectives could be collected as separate sources of information. This would especially be useful in situations, such as evaluation of health or social care interventions, where the data collection aims to reconstruct a wider view of quality of life from multiple perspectives.



Based on Pickard and Knight's (2005) conceptual framework, studies have been conducted to empirically test the hypothesis that different proxy perspectives affect rating of quality of life (Gundy, Aaronson 2008, McPhail, Beller & Haines 2008, Pickard et al. 2009). Although the proxy-patient perspective has been found to be closer to self-report than the proxy-proxy perspective for the EQ-5D Visual Analogue Scale (VAS), EORTC QLQ-C30 (Pickard et al. 2009) and EQ-5D (McPhail, Beller & Haines 2008), this finding was not replicated in a study of cancer patients and their proxies using the EORTC QLQ-C30 (Gundy, Aaronson 2008). In the latter study, there was a small yet significant difference between both proxy perspectives and self-report without a corresponding significant difference in the assessment of overall quality of life between the proxy-proxy and patient-proxy perspectives. The authors suggest that this finding may be attributable to ambiguity in the instructions for proxies, which did not explain the two different perspectives to respondents and, therefore, may have led to a lack of clarity (Gundy, Aaronson 2008). The existing literature, therefore, provides some tentative evidence that the perspective adopted by proxy-report questions based on instructions may affect the difference between proxy-report and self-report.

Interestingly, the literature suggests that the inter-rater gap between self-report and proxy-report based on the patient-proxy perspective (Pickard, Knight 2005) may vary by aspect of quality of life: for example, the inter-rater gap was found to be smallest for rating of symptoms (diarrhoea) (Gundy, Aaronson 2008). The intra-proxy gap between the patient-proxy and proxy-proxy perspectives (Pickard, Knight 2005) has also been found to vary by QoL domain, with a larger difference for emotional functioning than other domains (Pickard et al. 2009). These findings may relate to other studies discussed earlier in this report, which indicate that there is generally greater concordance between self- and proxy-rating in domains that capture an external, observable element. Observable aspects may make it easier for proxies to adopt the 'proxy-patient' perspective using these external indicators to 'step into' the patient's experience. Likewise, the patient-proxy perspective may encourage proxies to be more aware of potential differences in perspective on the more subjective domains. Although this evidence is limited, these findings suggest that both the inter-rater gap, the intra-proxy gap and, therefore, the difference between self-report and the proxy-proxy perspective, may vary with the extent to which the QoL domain captures observable elements.

Both the inter-rater gap and the intra-proxy gap have been found to be associated with the characteristics of the proxy or situation. The inter-rater gap is smaller when proxies have better knowledge of the respondent (Schmidt et al. 2010) or closer proximity through co-residence with the patient (Muus, Petzold & Ringsberg 2009). There is also evidence that the inter-rater gap may reduce over time. The inter-rater gap was smaller for physician rating of QoL based on the patient-proxy perspective at discharge compared to admission to a Geriatric Rehabilitation Unit (22 to 67 days earlier) (Gundy, Aaronson 2008). Family carer proxies had better agreement with self-reported QoL at six-month follow-up compared to 2

to 3 weeks after stroke (Pickard et al. 2004). Non-spousal carers have been found to have a significantly larger mean difference between their ratings of role functioning based on the two proxy perspectives than spousal carers, with a similar finding for male compared to female proxies (Pickard et al. 2009). Likewise, proxies with lower levels of literacy had significantly smaller intra-proxy gap for rating of physical functioning than proxies with higher literacy, and proxies with depressive symptoms had a larger intra-proxy gap for rating of overall health and cognitive functioning than non-depressed proxies (Pickard et al. 2009). These findings indicate that the intra-proxy gap and the inter-rater gap may be influenced by both the duration, intimacy or proximity of the proxy's relationship to the individual whose quality of life is being rated, which may affect the depth of insight that the proxy has into the individual's daily life and perspective, and the ability of the proxy to comprehend and respond to the written instructions that distinguish the two proxy perspectives. It also raises the question of whether proxy-proxy rating of non-observable domains by proxies with depressive symptoms may be particularly sensitive to proxy bias.

### **4.3 Limitations**

Although the literature review used systematic elements (for example, a specified search strategy, identification of research questions to guide the review, and systematic review criteria for inclusion in the review), the review presented in this report is limited since only one researcher chose the search terms, reviewed the articles and analysed the data. Furthermore, there was no evaluation of the identified articles for quality, which is standard practice in systematic review methods. Instead, the literature search included only articles from peer-reviewed journals, since these have been through a quality review process. This approach excludes grey literature, which limits the comprehensiveness of the review. These methodological decisions were informed by the resources available for the literature review and the view that a narrative review based on systematic methods was adequate to meet the aims of this study. Specifically, a narrative review based on systematic methods provides an overview of the literature based on rigorous and transparent methodology, which provides a framework for discursive engagement with the evidence (Bryman 2012).

## **5 Implications for survey data collection**

This literature review aimed to identify the methodological challenges associated with measuring proxy-reported quality of life. The review has identified that a significant challenge is that proxy-report and self-report are not interchangeable. There is evidence for systematic differences between proxy-report and self-report (in studies where the individual is able to answer on his/her own behalf). This proxy bias or 'inter-rater gap' between self- and proxy-report may be associated with:

1. The nature (professional/familial, formal/informal) of the relationship, or the frequency of contact, intimacy and proximity between the proxy and the individual

whose quality of life is to be assessed. This may affect the criteria used by the proxy to rate quality of life (see point 2 below), or the degree to which the proxy is aware of the individual's worldview, values and preferences.

2. The use of different criteria by proxies and patients to rate quality of life. Proxy report tends to rely more on external, observable behaviours and correlates of quality of life (e.g. difficulties with activities of daily living) than self-report (Huang et al. 2009).
3. Differences in evaluation or judgement of criteria in instances where both proxies and patients use the same criteria (e.g. physical functioning) to assess quality of life. An individual with a long-term condition that entails functional impairment or other changes is likely to emotionally and psychologically adapt to these changes to maintain wellbeing, whereas the proxy may observe and interpret these changes to be a source of distress to the care recipient (Huang et al. 2009) or otherwise influence the proxy's view of the individual's quality of life (Lewis et al. 2014).
4. Systematic differences between proxy-respondents' and self-respondents' comprehension and interpretation of quality of life questions. For example, there is some evidence that the *usual activities* question in the EQ-5D is ambiguous, and it has been hypothesised that the discrepancy in self- and proxy-report may be partly attributable to different understandings of what constitutes a 'usual' activity (Hounscome, Orrell & Edwards 2011).
5. The proxy's own quality of life or subjective experience. This may influence his/her judgement and rating of proxy-reported quality of life (Ferri, Pruchno 2009, Huang et al. 2009).

The studies identified in this literature review provide some evidence that all of these hypothesised factors may be associated with the proxy bias or 'inter-rater gap'. Indeed, since quality of life is a function of individual expectations and actual circumstances (Calman, 1982 cited in Pickard & Knight, 2005), it may also be said that potential differences in rating may be attributed to individual differences in expectations, values, attitudes, characteristics or circumstances. In addition, the frame of reference when answering the question (i.e. proxy perspective) or the influence of individual characteristics and circumstances on comprehension, evaluation, judgement and response to the questions may also contribute to the observed inter-rater gap.

Although the inter-rater gap is generally small, the use of proxy respondents in survey data collections may introduce systematic bias. This is further complicated by the overlapping factors associated with self-rated QoL, proxy-rated QoL and the inter-rater gap, all of which present a challenge to the use of proxy-report in survey data collections. In the case of cross-sectional survey data collections, it is not possible to use experimental design to control for differences that may be due to the mix of proxy-/self-respondents or other proxy-related characteristics. It may be possible to use statistical methods, such as risk adjustment (Iezzoni 2013), to 'adjust out' the proxy-response bias and provide an estimate

of quality of life to the exclusion of proxy-related factors (Stineman et al. 2004, Kane et al. 2005, Malley, Fernandez 2014). Such adjustment would require specific research designed to explore the systematic proxy bias associated with a particular instrument and, ideally, also the cognitive processes behind such bias before applying any adjustment factor (Stineman et al. 2004). A significant limitation is, however, that such statistical adjustment is an estimate based on an essentially unknown difference. It would have the same limitation as reliability studies that compare self- and proxy-report before extrapolating to situations where a respondent would not be able to answer on their own behalf (see Box 1).

There are other approaches to proxies: for example, the exclusion of proxy responses from analyses; separate analysis of proxy and self-report data; collection of data by self-report and proxy-report for all respondents with separate analyses to recognise their status as different sources of information (Verdugo et al. 2005). These, however, are limited since they may exclude people from 'having a voice' or are infeasible due to sample size limitations or the additional resources required for data collection (i.e. printing of two sets of questionnaires, coordination, data entry etc.). Therefore, statistical adjustment may be preferable to other approaches. Indeed, there is ongoing work on the ASCS to explore the use of statistical adjustment of the data, and proxy response or the type or source of help to answer questions have been considered as potential risk adjustors (Forder et al. 2014, Malley, Fernandez 2014).

In conclusion, this review has highlighted the many complexities and challenges inherent in the development of proxy versions of quality of life measures. It has also identified some of the ethical concerns around who should complete a proxy questionnaire, when is it appropriate to use them, and the potential risk associated with over-use. In addition, it provides a good basis on which to make some recommendations for the development of proxy tools.

## **6 Recommendations**

The following recommendations may be drawn from this literature review:

1. Instructions about how the proxies are to complete the questionnaire, especially with regard to the use of the proxy-proxy and/or proxy-patient perspectives (Pickard, Knight 2005), should be clear. Cognitive testing should explore comprehension of proxy perspective, and how this is used in weighing up options and responding to questions.
2. If there is no clear justification for the use of one proxy perspective over the other, the development of the instrument should consider both proxy-proxy and patient-proxy perspectives (Pickard, Knight 2005). Cognitive testing should consider the implications of inclusion of two proxy perspectives on: clarity and comprehension; and face validity of the questionnaire to family/friend and health or social care professional proxies.

3. The questionnaire, especially if it is to be included in a postal survey, should include guidelines as to who should complete the survey on behalf of someone else. This should indicate that, ideally, the person who completes the questionnaire should know the individual well and have frequent contact.
  
4. In the development of a proxy tool, even if the questionnaire is designed for proxy respondents, it should be noted that the evidence strongly suggests that proxy-report is not directly interchangeable with self-reported quality of life. Proxy versions of questionnaires may seek to improve the face validity of the questionnaire for proxies, and to guide the choice of proxy or other survey-completion factors that may influence the degree of proxy response bias; however, they are not able to eliminate this completely. It is, therefore, recommended that alongside the development of proxy versions of questionnaires, other approaches to proxy response should be considered: for example, how proxy responses are analysed and whether statistical/risk adjustment may be an appropriate methodology to employ in the analysis of cross-sectional data (Verdugo et al. 2005).

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