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# A scoping review of preference-based instruments for measuring carer outcomes in economic evaluations

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## A B S T R A C T

Carer-specific preference-based instruments have been developed to capture outcomes for economic evaluations but the body of evidence has yet to be collated to guide instrument selection and identify knowledge gaps for future research. This scoping review aimed to identify carer-related, preference-based instruments and summarise and assess their performance, valuation and application. Nine databases (ASSIA, CINAHL, Cochrane, DARE, Econlit, EMBASE, iHTA, PsychINFO, Pubmed) were searched until 28th May 2025 to identify peer-reviewed, English-language articles about the development, validation, valuation and application of preference-based, carer-related instruments. Study characteristics, instrument descriptions, psychometric properties and valuation information were extracted. The body of evidence and reporting quality were assessed using CREATE and the ISOQOL minimum standards for patient-reported outcome measures. In total, 140 included articles reported on five instruments: the ASCOT-Carer; the CarerQol; the CES; the ICECAP-CPM; and the SIDECAR. All carer-specific, preference-based instruments have rigorously developed scoring algorithms, albeit for differing numbers of countries. All of the instruments, except the ICECAP-CPM, have some evidence of psychometric validity in varied populations, though information on responsiveness is limited. Broadly, the CarerQol, the longest established instrument, is the most widely validated, followed by the ASCOT-Carer and CES. The SIDECAR and ICECAP-CPM require further testing. The CarerQol has the most evidence for use in carers of children, the ASCOT-Carer for adult social care settings, the CarerQoL and CES for the palliative care setting, and the ASCOT-Carer, CarerQoL, and CES for mental illness, rheumatoid arthritis, long-term care, and dementia. The CarerQol, CES and ASCOT-Carer represent the most widely used instruments for measuring carer-related outcomes in economic evaluations. The review findings assist with selecting instruments for studies alongside research objectives, population and settings. Future research should explore the responsiveness of these instruments, validate them in different countries and carer populations, and develop country-specific scoring algorithms.

## 1. Introduction

It is nearly 30 years since the influential United States Panel on Cost Effectiveness guidelines (Russell et al., 1996) recommended informal carer effects should be included in economic evaluations, yet impacts on carers are still rarely included in these analyses (Al-Janabi et al., 2013; Engel et al., 2021a,b; Henry et al., 2023; Scope et al., 2022). Under this framework, informal carers (hereon in "carers") are family members, neighbours or friends who provide regular support to older adults, an individual with a disability or someone facing a chronic, progressive, or life-limiting illness, generally without receiving compensation for the care provided (Burns et al., 2011; Engel et al., 2024; McCaffrey et al., 2020). Typically, carers assist with activities of daily living, transportation, medication management, companionship, and providing

practical and emotional support (Engel et al., 2022; McCaffrey et al., 2015a,b). In Australia alone, the estimated cost of replacing unpaid care with paid, formal care services in 2020 was estimated at AU$77.9 billion (Bucholc et al., 2023). Considering the escalating and implicit dependence of societies on carers' readiness to perform this role (Currow et al., 2011) (likely multiple times), and the economic ramifications if these carers become unavailable, it is crucial to take into account the impacts of direct and indirect effects of interventions on carers (Pennington and Al-Janabi, 2024).

A multitude of carer measures have been developed capturing outcomes such as bereavement, burden, family functioning, mood, needs, preparedness, health-related quality of life (HrQoL), satisfaction with care, and social support (Haines et al., 2015b; Hudson et al., 2010; Jones et al., 2012; Lendon et al., 2014). However, many of these measures do not incorporate values or preferences for different domains or states of health or wellbeing which are a key requirement for economic evaluation (Neumann et al., 2000). A preference-based instrument typically comprises of two main components: a descriptive system encompassing items with multiple response categories describing different dimensions of the construct under investigation such as health, wellbeing or experience, and a pre-established scoring algorithm designed to quantify preferences for states defined by the instrument (McCaffrey et al., 2016, 2024). The scoring algorithms are derived from surveys of the general population and/or carers to elicit values for specified carer-related states defined by the descriptive framework.

Commonly, economic evaluations adopt a cost-utility analysis framework which includes the quality-adjusted life-year (QALY) as the primary outcome (Engel et al., 2021a,b), whereby popular preference-based instruments, such as the EQ-5D (Brazier et al., 2017a, b) and Short-Form-6D (McCaffrey et al., 2024), are used to measure the 'Q' (HrQoL) in the QALY. However, given that these are generic instruments, they do not include important carer-valued outcomes that extend beyond health, such as relationships and fulfilment from caring (Engel et al., 2021a,b). These tools may also be insensitive to the psychological effects and positive impacts of providing care (Al-Janabi et al., 2011). Despite these limitations, the EQ-5D remains the most widely used instrument to capture patient and carer HrQoL in economic evaluations (Goodrich et al., 2012; Scope et al., 2022; Wittenberg et al., 2019).

The choice of instrument is likely influenced by government regulatory and reimbursement guidelines on evaluating the value for money of new health and care technologies (Pennington and Al-Janabi, 2024). For example, the National Institute for Health and Care Excellence (NICE, UK), the Haute Autorité de Santé (HAS, France) and Zorginstituut Nederland (ZIN, Netherlands) explicitly recommend including *health* effects for carers in health technology assessments (HTA) (Pennington et al., 2022), with the NICE endorsing the EQ-5D (National Institute for Health and Care Excellence, 2020). However, the NICE Centre for Health Technology Evaluation methods review on HrQoL highlighted that the EQ-5D might not be appropriate for measuring carer QoL, and that bespoke measures might be better suited (National Institute for Health and Care Excellence, 2020). Other HTA agencies such as the Pharmaceutical Management Agency (New Zealand) and Pharmaceutical Benefits Advisory Committee (Australia) relegate carer impacts to the supplementary, rather than primary analysis, although greater flexibility is allowed in the choice of outcome measure (Kennedy-Martin et al., 2020). Such differences possibly contribute to conflicting HTA decisions leading to global inequalities in access to support for carers (Pennington et al., 2022).

Internationally, carer-related, preference-based instruments have been developed to address concerns by measuring carer-related quality of life (CrQoL) for economic evaluations, i.e., the impact of the experience of caring on aspects of life. Desirable features of such outcome measures include sufficient coverage of key domains, ease of use, evidence of strong psychometric properties, and a preference-based scoring algorithm (Brazier et al., 2017a,b; King et al., 2020; McCaffrey et al.,

2014; Reeve et al., 2013; Xie et al., 2015). Whilst there are several empirical studies comparing the psychometric properties and content of different carer-related preference-based measures (Bucholc et al., 2023; Engel et al., 2020; Hoefman et al., 2015; McCaffrey et al., 2020; McLoughlin et al., 2020, 2023; Rand et al., 2019a,b), the body of evidence, including valuation and application of the measures, has yet to be collated to inform instrument selection and future research.

### 1.1. Aim

This scoping review aimed to provide a summary of the development, psychometric properties, valuation and application of carer-related preference-based instruments, including the extent and nature of the evidence underpinning each instrument. The findings will inform researchers, funders, service providers and policy makers on instrument selection, future research on carer-related preference-based instruments and guidelines on including carer outcomes in economic evaluations.

### 1.2. Review questions

The scoping review addressed two related research questions:

1. What preference-based instruments are available to measure carer-related outcomes in economic evaluations?
2. How have carer-related preference-based instruments been developed, validated, valued and applied?

## 2. Methods

The scoping review was performed in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) guideline (Page et al., 2021) (see PRISMA-ScR checklist, Appendix 1). The study protocol was prospectively registered in PROSPERO (ID = CRD42016034188). Brief details of the review are provided below (see McCaffrey et al., 2016 for comprehensive details). The review's original scope was expanded to include all settings beyond palliative care due to the absence of a review summarizing evidence for carer-related, preference-based instruments, and one search was conducted to identify relevant studies.

### 2.1. Search strategy and selection criteria

An extensive search of the literature was conducted from database inception until 28th May 2025 (ASSIA, CINAHL, Cochrane library, Econlit, EMBASE, iHTA, PsychINFO and PubMed) to find relevant articles meeting the *a priori* eligibility criteria (Table 1). Published, peer-reviewed, English-language articles reporting on the development, validation, valuation and application of a preference-based, carer-related outcome measure were included.

The search strategy was informed by published, peer-reviewed systematic reviews of carer outcome measurement tools and preference-based instruments (Haines et al., 2015a, 2015b; Hudson et al., 2010; Michels et al., 2016; Shilling et al., 2016; Sonntag et al., 2013; Whitty et al., 2014). MeSH terms and key words included: carer, caregiver, care-related, family, instrument, outcome assessment, preference-based, questionnaire, utility and volunteer, and the search was adapted for each database (Appendix 2). Additionally, a pearl growing method, involving forward citation tracing of key articles ('pearls') was conducted (Helter et al., 2020; Mitchell et al., 2017; Peasgood et al., 2024; Schlosser et al., 2006) to supplement the search and comprehensively capture relevant articles (Engel et al., 2021a,b). Two reviewers (CH, NM) with experience in carer-related and health economics research identified a list of key, peer-reviewed articles for each carer-related preference-based instrument from the included articles and advice from the research team (Appendix 3), and checked the literature for relevant publications citing these articles using SCOPUS.

**Table 1**

Eligibility criteria.

| Inclusion | Exclusion |
|---|---|
| Primary or secondary research directly related to the topic, i.e. there are no restrictions regarding research methods | Study protocols |
| | Reviews |
| Population includes informal carers of adults or children, e.g. spouse, sibling, relative, friend or neighbour | Does not include, or is not investigating, informal carers. |
| | Paid carers, e.g. health care professional or care worker |
| Any articles reporting the development, valuation, validation or application of a preference-based measure (PBM) for capturing carer-related outcomes | A generic (non-specific) PBM, i.e. not carer-related, e.g. EQ-5D, SF-6D, and AQOL |
| | Non-preference-based measure, e.g., instruments using raw scores or a weighted *average* score rather than preference weights |
| | Proxy measure |
| | Uni-dimensional measure |
| English language | Non-English language |
| Peer-reviewed journal article | Editorial, comment, book or discussion papers, conference articles or grey literature |
| Full article available | Abstract only |

AQoL = Assessment of Quality of Life.

*2.2. Selection process*

Initially, n = 50 titles and abstracts from the final list of potential studies were reviewed independently by four researchers (CH, BK, LE, NM). This process was implemented to pilot the screening process, and refine inclusion and exclusion criteria, thereby clarifying the initial screening phase. Following a meeting to discuss the initial screening results, the remaining titles and abstracts were reviewed by three reviewers (CH, BK, LE) with decisions based on consensus. Full text articles were retrieved when the abstract contained insufficient information. Two researchers (CH, LE) independently reviewed the full text articles to determine eligibility. Any disagreement was resolved by a third reviewer (NM). Multiple publications from a single study that reported different measurement properties were included in the review. However, when multiple publications reported on the same study using one of the care-related, preference-based instruments ('applied studies'), only the first publication was included to illustrate the tool's application.

*2.3. Data extraction and synthesis*

Study characteristics, a description of the instrument, psychometric properties and information on valuation were extracted from the included articles by one reviewer and checked by a second McCaffrey et al., 2016. The included articles were divided into three categories, development and validation, valuation, and applied studies. A narrative description, and tables summarizing results are provided for each category.

The checklist for reporting valuation studies of multi-attribute utility-based instruments (CREATE) was used to evaluate the reporting of the valuation studies (LE, NM) (Xie et al., 2015). For this review, each checklist item was scored either yes or no for individual articles and the percentage score of reported items was calculated (Bahrampour et al., 2020). Two reviewers conducted the assessment independently. Any discrepancies were identified and resolved by consensus amongst the research team.

The International Society for Quality of Life Research (ISOQOL) minimum standards for patient-reported outcome measures (Reeve et al., 2013) were used to guide data extraction for psychometric properties, assess the body of evidence published in peer-reviewed publications for each preference-based instrument and to identify gaps in knowledge (CH, NM). Ideally, the carer-related, preference-based instrument should accurately measure the intended concept (content validity), demonstrate meaningful theoretical relationships with other measures (construct validity), and consistently produce the same results under similar conditions (test-retest reliability) (McCaffrey et al., 2014). Furthermore, the tool should detect actual differences in observed outcomes when they occur (responsiveness) and be suitably designed for the specific target population (feasibility) (McCaffrey et al., 2014). The following criteria were used to aid interpretation of the measurement properties of the instruments: content validity (carer feedback on the relevance, comprehensiveness, importance or framing of the content); feasibility, <5 % missing data; floor or ceiling effects, ≥15 % of the sample had extreme scores; burden, >90 % completion rates; internal consistency, Cronbach's alpha ≥0.70; test-retest reliability, intraclass correlation coefficient ≥0.70; construct validity, *a priori* hypotheses confirmed, strong (≥0.51), moderate (0.31–0.50), weak (0.11–0.30) and no correlation (0–0.10); known group validity (discriminative validity), *a priori* hypotheses confirmed; responsiveness, *a priori* hypotheses confirmed, small (0.2), moderate (0.5) or large (0.8) responsiveness statistic (Chen et al., 2018; Cohen, 1992; King et al., 2020; McCaffrey et al., 2020; McLoughlin et al., 2020; Reeve et al., 2013; Streiner and Norman, 2008).

**3. Results**

The results of the literature search and selection process are summarised in Fig. 1.

Overall, 10,225 citations were identified by the search after removing duplicates, and 9,890 citations were excluded following title and abstract screening. Consideration of the full text reports resulted in 108 included articles, with 31 additional articles identified from pearl growing and 1 article identified by the research team (based on their extensive expertise in carer-related research). Articles that initially appeared to meet the inclusion criteria based on the title and abstract but were ultimately excluded are listed in Appendix 4, along with the reasons for exclusion. In total, 140 articles describing five carer-related, preference-based instruments were included in this review: the Adult Social Care Outcomes Toolkit for Carers (ASCOT-Carer) (Rand et al., 2015); the Care-related Quality of Life instrument (CarerQol) (Brouwer et al., 2006); Carer Experience Scale (CES) (Al-Janabi et al., 2011); the ICEpop CAPability measure for Adults – Close Person Measure (ICECAP-CPM) (Canaway et al., 2017); and the Scales measuring the Impact of DEmentia on CARers (SIDECAR) (Webb et al., 2020).

An overview of the instruments is presented in Table 2, including a description of the number of development and validation, valuation, and application studies for each instrument.

Details of the publications investigating psychometric properties, and the valuation studies are provided in Appendices 5 and 6 respectively, categorised according to the ISOQOL minimum standards and CREATE checklist. A summary of the studies applying the instruments is presented in Appendix 7. The included studies organised by category are listed in Appendix 8.

The articles were published between 2006 and 2025, and the instruments were applied in 29 countries, most often in the Netherlands (29 %), United Kingdom (UK) (20 %), and the United States of America (USA) (12 %) (see Fig. 2). The CarerQol was the most widely applied carer-related preference-based instrument (n = 88), likely due to early development and widespread translation of the questionnaire into multiple languages (see Appendix 8). The ASCOT-Carer was applied in 10 studies, the CES in 7, and no studies were identified that administered the ICECAP-CPM or the SIDECAR. Overall, 90 % of studies used self-administered questionnaires. Forty-nine percent (n = 50) of the applied studies did not use or explicitly state which scoring algorithm (if any) was used to generate the utility weights, hindering between study comparisons.

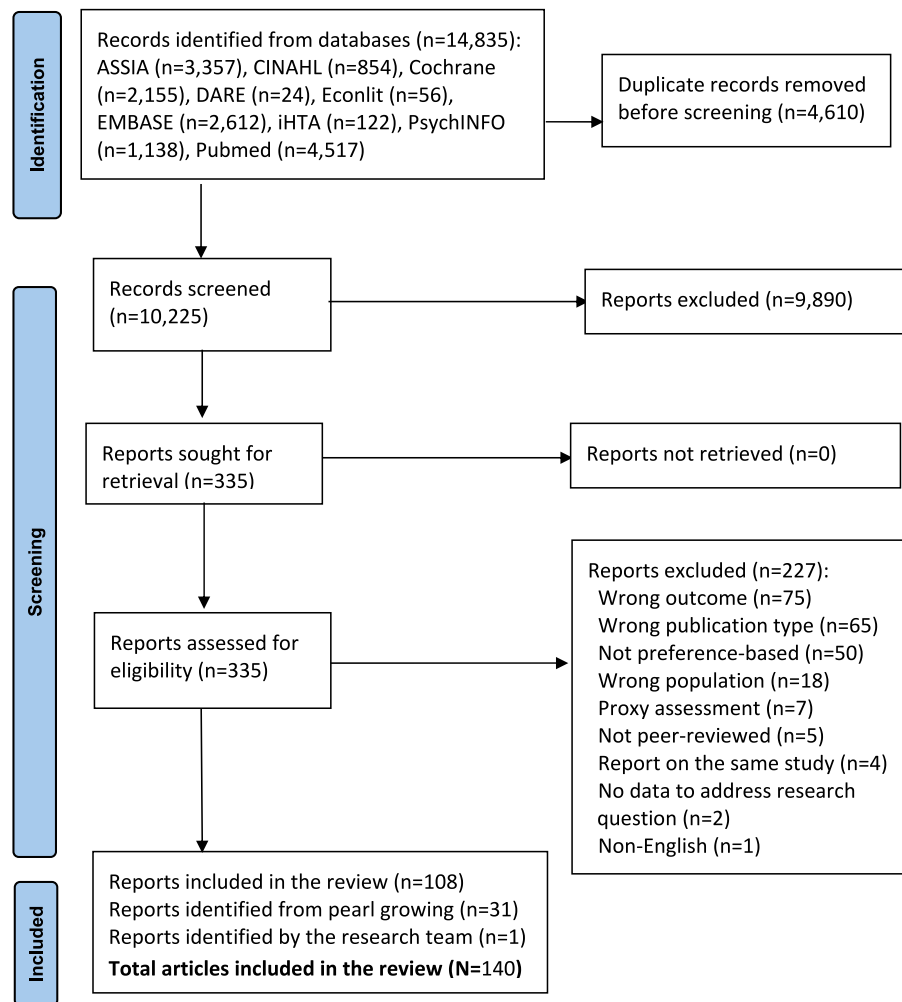The studies most commonly included carers supporting children (n

**Fig. 1.** Study selection process (adapted from Page and colleagues(Page et al., 2021)).

= 26) (Almojuela et al., 2022; Biswas et al., 2023; Brown et al., 2019; Chambers et al., 2020; Chu et al., 2020; Chu et al., 2023; De Cuyper et al., 2019; Estes et al., 2025; Fitzgerald et al., 2018; Gil-Nagel et al., 2023; Grazziotin et al., 2022; Hoefman et al., 2014a,b; Jain et al., 2018; Lee et al., 2023; Materula et al., 2024; Mirenda et al., 2022; Payakachat et al., 2011; Randell et al., 2022; Robertson et al., 2024; Rodríguez et al., 2022; Rodríguez et al., 2024; Shdaifat, 2025; ten Hoopen et al., 2020; Tilford et al., 2015; Verstraete et al., 2024; Widjaja et al., 2024), including those with Autism Spectrum Disease (n = 8) (Brown et al., 2019; Chu et al., 2020; Hoefman et al., 2014a,b; Lee et al., 2023; Mirenda et al., 2022; Randell et al., 2022; ten Hoopen et al., 2020; Tilford et al., 2015), carers of individuals diagnosed with dementia (n = 24) (Bailey et al., 2025; Birkenhäger-Gillesse et al., 2020; Christie et al., 2022; Eikelboom et al., 2023; Gonçalves-Pereira et al., 2024; Gridley et al., 2019; Handels et al., 2018; Hoel et al., 2022; Janssen et al., 2017; Jones et al., 2014; Karg et al., 2018; Kerpershoek et al., 2018; Kraijo et al., 2014; Longo et al., 2019; MacNeil Vroomen et al., 2015; Mbakile-Mahlanza et al., 2020; Perry-Duxbury et al., 2020; Potter et al., 2023; Rand et al., 2022a,b; Richters et al., 2017; Tahami Monfared et al., 2024; van Haeften-van Dijk et al., 2020; Van Hezik-Wester et al., 2023; Wiegelmann et al., 2023) and carers of older adults (n = 10) (Janse et al., 2014; Linnosmaa et al., 2024; Metzelthin et al., 2017; Oldenkamp et al., 2016, 2017; Pendergrass et al., 2019; Steiner-Brett and Basu, 2024; van Dam et al., 2017; van de Ree et al., 2017; Vluggen et al., 2021).

The following sections summarise the body of evidence for each instrument.

### 3.1. Adult Social Care Outcomes Toolkit-carer (ASCOT-carer)

The ASCOT-Carer, originating in the United Kingdom (UK), is one of a suite of measures that capture Social Care-Related Quality of Life (SCRQoL) (Rand et al., 2015), defined as "those aspects of QoL that may be affected by adult social care services and are relevant to service users or carers"(Rand et al., 2022a,b). In the UK, adult social care refers to homecare, day centres and other types of non-medical community-based support, such as meals services, specialist carer support services (including peer support or short breaks), advocacy, information or advice, and residential or nursing care. The ASCOT-Carer, first published in 2015 (Rand et al., 2015), measures SCRQoL of adult carers aged 18 years or over caring for an adult, where the carer and/or adult with support needs are accessing adult social care services. The measure has seven domains: control over daily life; feeling supported and encouraged; occupation ("doing things I value and enjoy"); personal safety; self-care; social participation and involvement; and time and space to be yourself (Rand et al., 2015). The content was informed by insights from focus groups and interviews involving care managers and carers (McCaffrey et al., 2020; Rand et al., 2015). Registration and licensing is required to use the ASCOT-Carer, which is free of charge for non-commercial use (see https://research.kent.ac.uk/ascot/).

The ASCOT-Carer has been translated into Japanese, Finnish and German (Trukeschitz et al., 2021; Personal Social Services Research Unit, 2021). Thus far, there are Austrian (German) (Trukeschitz et al., 2021), English (Batchelder et al., 2019), Finnish (Nguyen et al., 2022a, b) and Japanese (Shiroiwa et al., 2015) scoring algorithms based on

**Table 2**
Overview of the carer-related preference-based instruments.

| Instrument | ASCOT-Carer | CarerQol | CES | ICECAP-CPM | SIDECAR |
|---|---|---|---|---|---|
| Country of origin | UK | Netherlands | UK | UK | UK |
| Year of 1st publication | 2015 | 2006 | 2008 | 2017 | 2019 |
| Mode of administration | Self-report | Self-report | Self-report | Self-report | Self-report |
| Languages | English, Japanese, Finnish, German | Chinese, Dutch, English, German, Hungarian, Italian, Japanese, Norwegian, Persian, Polish, Portuguese Slovenian, Spanish, Swedish | English[a] | Chinese (Singapore), Dutch, English, Icelandic, Norwegian, Swedish | English |
| Recall period | Current[b] | At the moment | Current | Current[b] | Today |
| Target construct | Social-care related QoL[e] | Subjective burden and well-being | Caring experience | End-of-life care benefits[e] | QoL of those caring for people with dementia |
| Description of dimensions | Control over daily life, feeling supported & encouraged, occupation ('doing things I value and enjoy'), personal safety, self-care, social participation, space & time to be yourself | Financial problems, fulfilment from caring, mental health problems, physical health problems, problems with daily activities, relational problems, support with care tasks | Activities outside caring, assistance from organizations & the government, control over caring, fulfilment from caring, getting on with the person you care for, support from family & friends | Communication, emotional distress, emotional support, practical support, privacy & space, preparing & coping | Direct impact of caring, indirect impact of caring, support & information |
| Items, n (levels) | 7 (4) | 7 (3) | 6 (3) | 6 (5) | D 18 (2), I 10 (2), S 11 (2) |
| Availability | There is a licensing system for sharing and use | Freely available | Registration required | Registration required | There is a licensing system for sharing and use |
| Development publications[c, d], n | 12 | 18 | 10 | 1 | 2 |
| Development of descriptive system | Literature review on the factors affecting carers' QoL and focus groups and interviews with carers and care managers | Literature review of burden scales and survey of carers | Meta-synthesis of qualitative studies on caring and qualitative interviews | Qualitative interviews | Qualitative interviews |
| Valuation studies[d], n | 4 | 3 | 1 | 1 | 1 (Scale D) |
| Valuation method | BWS, TTO | DCE | BWS | Deliberative | BWS, VAS |
| Value set[d] | Austria, Finland, Japan, UK | Australia, Germany, Hungary, Netherlands, Poland, Slovenia, Sweden, UK, USA | UK | UK | UK |
| Applied studies[d], n | 10 | 88 | 7 | 0 | 0 |

[a] the CES may have been translated into other languages but translated versions have not been published.
[b] timeframe not explicitly stated.
[c] includes qualitative and psychometric validation studies.
[d] published as peer-reviewed journal articles.
[e] underpinned by the capability framework; BWS = best-worst scaling; QoL = quality of life; TTO = time trade-off; VAS = visual analogue scale.

preferences observed within the general population and scores range from 0, indicating the worst carer SCRQoL, to 1, signifying the best carer SCRQoL (Batchelder et al., 2019) (Table 2). Generally, the valuation studies for the ASCOT-Carer were well reported, although justification for the sample sizes was not provided in the UK (Batchelder et al., 2019) or Austrian valuation studies (Trukeschitz et al., 2021a,b) and the response rates were not explicitly stated for any of the studies (Batchelder et al., 2019; Lien Nguyen et al., 2022a,b; T. Shiroiwa et al., 2022; Trukeschitz et al., 2021a,b) (see Appendix 6).

Twelve articles included in the review contained information on the measurement properties of the ASCOT-Carer (Bucholc et al., 2023; Engel et al., 2020; McCaffrey et al., 2020; McLoughlin et al., 2020, 2023; Nakamura-Thomas et al., 2022; Rand et al., 2015, 2019, 2022; Silarova et al., 2023; Trukeschitz et al., 2021a,b) in carers supporting people in mixed populations and settings (mixed, n = 4 (Bucholc et al., 2023; Engel et al., 2020; McCaffrey et al., 2020; Rand et al., 2015); dementia, n = 4 (McLoughlin et al., 2020, 2023; Rand et al., 2015; Silarova et al., 2023); stroke, n = 2 (McLoughlin et al., 2020, 2023); mental illness, n = 2 (McLoughlin et al., 2020, 2023); rheumatoid arthritis, n = 2 (McLoughlin et al., 2020, 2023); adults requiring long-term care, n = 2 (Nakamura-Thomas et al., 2022; Rand et al., 2019a,b); older adults, n = 1 (Trukeschitz et al., 2021a,b)). Overall, the unidimensional structure of

the ASCOT-Carer was confirmed (n = 4) (Engel et al., 2020; Nakamura-Thomas et al., 2022; Rand et al., 2015, 2022), albeit with some indication "personal safety" may need further investigation based on Rasch analysis (n = 1) (Silarova et al., 2023). Three studies support the content validity of the ASCOT-Carer (Bucholc et al., 2023; McLoughlin et al., 2020; Trukeschitz et al., 2021). No ceiling or floor effects were detected (n = 2) (Bucholc et al., 2023; Silarova et al., 2023). Non-completion and error rates were low (n = 5) (McCaffrey et al., 2020; Rand et al., 2015; Silarova et al., 2023; Trukeschitz et al., 2021a,b; McLoughlin et al., 2020). There is a comprehensive body of peer-reviewed literature to support convergent and known group validity, particularly for duration and hours of care (n = 6) (McCaffrey et al., 2020; Rand et al., 2015, 2019; Silarova et al., 2023; Trukeschitz et al., 2021a,b; McLoughlin et al., 2020) and the instrument appears to have good internal reliability (n = 3) (McCaffrey et al., 2020; Rand et al., 2015; Silarova et al., 2023). More research is needed to investigate sensitivity to change, and to confirm the ASCOT-Carer has high test-retest reliability (n = 1) (McCaffrey et al., 2020). The ASCOT-Carer displayed minimal responsiveness to changes in HrQoL (measured with the EQ-5D) and reduction in caring hours over 12 months (n = 1) (McLoughlin et al., 2020), although these factors are not directly related to the measure's construct of SCRQoL, whereby sensitivity to quality and effectiveness of social
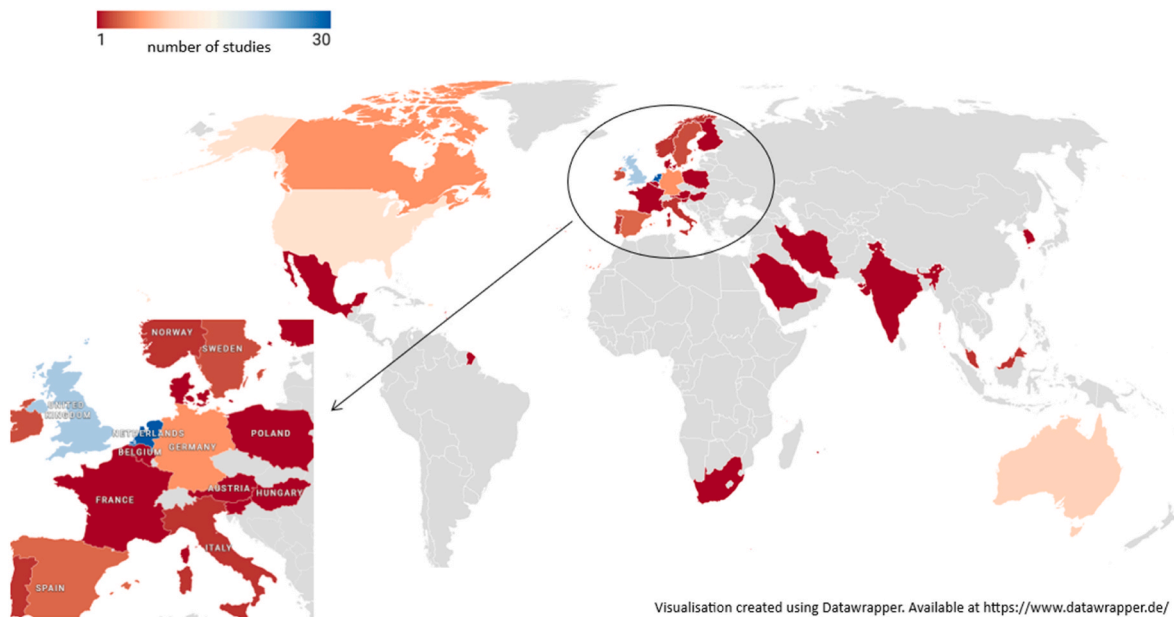
**Fig. 2.** Global distribution of studies applying the carer-related, preference based instruments where the country was explicitly identified.

care is perhaps more relevant (Rand et al., 2020). Appendix 5 provides further details on the psychometric properties.

The ASCOT-Carer was applied in 10 studies included in the review across five countries Austria (Linnosmaa et al., 2024), Australia (Robertson et al., 2024), Finland (Linnosmaa et al., 2024), UK (Linnosmaa et al., 2024; Longo et al., 2019; Potter et al., 2023; Rand et al., 2017, 2019, 2022), USA (Kuharic et al., 2024) and a broad range of carers, including carers of persons with dementia (Longo et al., 2019; Potter et al., 2023; Rand et al., 2022a,b) (see Appendix 7).

### 3.2. Care-related quality of life instrument (CarerQol)

The CarerQol, measuring care-related QoL, includes a descriptive system capturing seven dimensions of carer burden (financial problems, fulfilment, mental health problems, physical health problems, problems combining daily activities with care, relational problems, and support) and a visual analogue scale (VAS) capturing happiness (Brouwer et al., 2006; Hoefman et al., 2015). Developed in the Netherlands and first published in 2006, the descriptive system was informed by the findings from a review of burden measures (Brouwer et al., 2006). Findings from a small pilot study indicated the CarerQol is clear, understandable, easy to use and includes all important carer burden dimensions, although detailed information was not provided in the article to validate the results (Brouwer et al., 2006). The CarerQol is available for use without registration (https://www.imta.nl/questionnaires/carerqol/).

The CarerQol is available in 14 languages (Table 2). There are scoring algorithms for nine countries based on general population preferences, with scores ranging from 0 to 100, indicating the worst and best informal care situations respectively (Baji et al., 2020; Hoefman et al., 2014, 2017) (Table 2). The VAS ranges from 0 to 10, representing completely unhappy to completely happy (Hoefman et al., 2015). None of the valuation studies reported the response rates (Baji et al., 2020; Hoefman et al., 2014, 2017) (see Appendix 6). Baji and colleagues (Baji et al., 2020) did not provide justification for the sample size and reasons for excluding respondents and goodness-of-fit statistics were missing in Hoefman et al. (2014) (Hoefman et al., 2014a,b) and Hoefman et al. (2017) (Hoefman et al., 2017). The model specifications and independent variable explanation were also not presented in the latter article.

Eighteen articles included in the review provided evidence on the measurement properties of the CarerQol (Table 2) in carers of mixed populations and settings (mixed, n = 8 (Baji et al., 2021; Brouwer et al., 2006; Bucholc et al., 2023; Engel et al., 2020; Hoefman et al., 2011a,b; Hoefman et al., 2013; Lutomski et al., 2015; McCaffrey et al., 2020; Xu et al., 2025); dementia, n = 3 (McLoughlin et al., 2020, 2023; Voormolen et al., 2021); stroke, n = 2 (McLoughlin et al., 2020, 2023); mental illness, n = 2 (McLoughlin et al., 2020, 2023); rheumatoid arthritis, n = 2 (McLoughlin et al., 2020, 2023); adults requiring long-term care, n = 1 (Hoefman et al., 2011a,b); children, n = 2 (Hoefman et al., 2014a,b; Payakachat et al., 2011); palliative care, n = 1 (Hoefman et al., 2015); multiple sclerosis, n = 1 (Faraji et al., 2024); general population, n = 1 (Hoefman et al., 2017)). There appears sufficient evidence on the content validity (n = 2) (Bucholc et al., 2023; McLoughlin et al., 2023) of the CarerQol, no dimension ceiling or floor effects were detected (n = 3) (Lutomski et al., 2015; McCaffrey et al., 2020; Xu et al., 2025), and non-completion and error rates were low (n = 4) (Brouwer et al., 2006; Hoefman et al., 2011a,b; McCaffrey et al., 2020; McLoughlin et al., 2023). Three studies explored the underlying concepts of the CarerQol and measurement model (Brouwer et al., 2006; Engel et al., 2020; Faraji et al., 2024). There is a comprehensive body of peer-reviewed evidence supporting convergent, clinical and known group validity (n = 14) (Baji et al., 2021; Brouwer et al., 2006; Faraji et al., 2024; Hoefman et al., 2011, 2011, 2013, 2014, 2015; Hoefman et al., 2011a,b; Lutomski et al., 2015; McCaffrey et al., 2020; McLoughlin et al., 2020; Payakachat et al., 2011; Voormolen et al., 2021), two studies suggesting moderate internal consistency (Faraji et al., 2024; McCaffrey et al., 2020), some evidence that the CarerQol is moderately reliable (n = 3) (Hoefman et al., 2011a,b; McCaffrey et al., 2020) and limited evidence suggesting minimal responsiveness to changes in HrQoL, stable results when CrQoL doesn't change, and reduction in caring hours over 12 months (n = 2) (McLoughlin et al., 2020; Xu et al., 2025). More details are provided in Appendix 5. Additional research is needed to assess the responsiveness of the CarerQol.

The CarerQol was applied in 88 studies included in the review, across a wide range of countries in the Americas, Asia, Europe, and Oceania, and diverse populations (see Appendix 7 for a full list of studies).

### 3.3. Carer Experience Scale (CES)

The CES, originating from the UK, comprises six dimensions (activities outside caring, control over the caring, fulfilment from caring, getting on with the care recipient, institutional support, and social support) aimed at comprehensively assessing the caregiving experience

(Al-Janabi et al., 2011). The instrument was first published in 2008 and the content was informed by a meta-ethnographic synthesis of qualitative studies on caregiving dynamics and insights from interviews with carers (Al-Janabi et al., 2011). Registration is required to use the CES, which is free of charge (https://www.bristol.ac.uk/population-health-sciences/projects/icecap/ces/).

The instrument was originally published in English (Table 2). Unlike the other carer-related preference-based instruments, the scoring algorithm was developed based on the preferences of carers of older people in the UK themselves rather than the general population, with scores ranging between 0 and 100, i.e., worst to best caring experience, respectively (Al-Janabi et al., 2018). The CES valuation study (Al-Janabi et al., 2011) reported all items listed in the CREATE (Xie et al., 2015) (see Appendices 6 and 9).

Ten articles included in the review contained information on the measurement properties of the CES (Al-Janabi et al., 2008, 2011; Bucholc et al., 2023; Engel et al., 2020; Goranitis et al., 2014; Hoefman et al., 2015; Jones et al., 2014; McCaffrey et al., 2020; McLoughlin et al., 2020, 2023; Rand et al., 2019a,b) (Table 2) in carers of mixed populations and settings (mixed, n = 4 (Bucholc et al., 2023; Engel et al., 2020; Goranitis et al., 2014; McCaffrey et al., 2020); dementia, n = 3 (Jones et al., 2014; McLoughlin et al., 2020, 2023); stroke, n = 2 (McLoughlin et al., 2020, 2023); mental illness, n = 2 (McLoughlin et al., 2020, 2023); rheumatoid arthritis, n = 2 (McLoughlin et al., 2020, 2023); older adults, n = 1 (Al-Janabi et al., 2011); adults requiring long-term care, n = 1 (Rand et al., 2019a,b); palliative care, n = 1 (Hoefman et al., 2015)). In summary, the multi-factor measurement model of caring experience in the CES has been confirmed in three studies (Al-Janabi et al., 2011; Engel et al., 2020; Rand et al., 2019a,b), as has content validity (Bucholc et al., 2023; Jones et al., 2014; McLoughlin et al., 2023). No floor or ceiling effects were detected (n = 1) (McCaffrey et al., 2020), and error rates were low (n = 1) (McLoughlin et al., 2023), with mixed results for completion rates, possibly driven by differences in survey length in the studies (n = 2) (Goranitis et al., 2014; McCaffrey et al., 2020). There is comprehensive evidence supporting convergent and known group validity (n = 5) (Goranitis et al., 2014; Hoefman et al., 2015; McCaffrey et al., 2020; McLoughlin et al., 2020; Rand et al., 2019a,b) and one study reporting moderate internal consistency (McCaffrey et al., 2020). More research is needed to confirm the CES has high test-retest reliable (n = 1) (McCaffrey et al., 2020) and responsiveness (n = 1, minimal responsiveness to changes in HrQoL and reduction in caring hours over 12 months (McLoughlin et al., 2020)). Further details are provided in Appendix 5.

The CES was applied in seven studies in the review across two countries Australia (Chang et al., 2023; Lovell et al., 2022; Shah et al., 2020), UK (Hughes et al., 2022; Jones et al., 2014; Mioshi et al., 2024; Shah et al., 2020; Squire et al., 2017), and a broad range of populations (see Appendix 7).

### 3.4. ICEpop CAPability measure for adults – Close Person Measure (ICECAP-CPM)

The ICECAP-CPM, developed in the UK, captures the impacts of end-of-life care on people in a close relationship (friends, family members, partners) with individuals at the end of life within the capability framework (Canaway et al., 2017). This carer-related instrument, published in 2017, adopts Amartya Sen's perspective on well-being, which emphasizes individuals' abilities to engage in, and achieve, meaningful aspects of life, yielding an index that assesses capability (Grewal et al., 2006). The instrument has six domains (being able to prepare and cope, emotional support, free from emotional distress, good communication, practical support, privacy and space) developed from interviews with individuals close to somebody receiving end-of-life care and bereaved individuals (Canaway et al., 2017). Registration is required to use the ICECAP-CPM, which is free of charge (https://www.bristol.ac.

uk/population-health-sciences/projects/icecap/icecap-cpm/).

According to the University of Bristol website (Bristol), the ICECAP-CPM has been translated into five other languages (Chinese, Dutch, Icelandic, Norwegian, Swedish; Table 2). An additive, preference-based algorithm was developed to derive scores ranging between 0 and 1 using a deliberative approach with the general population in focus groups (Kinghorn et al., 2022). The weights for the attribute levels were calculated using visual analogue scales, and a budget pie was used to calculate the relative weighting of each attribute. All items listed in CREATE (Xie et al., 2015) were reported in the valuation study (Kinghorn et al., 2022) except those related to modelling which are not applicable for this type of valuation study.

Research is needed to establish the psychometric properties of the ICECAP-CPM.

### 3.5. Scales measuring the impact of DEmentia on CARers (SIDECAR)

The SIDECAR instrument, first published in 2019 (Oyebode et al., 2019), is the most recently developed carer-related preference-based instrument. This instrument measures the QoL of family members and friends caring for individuals living with dementia. The content was developed from interviews with carers of relatives with dementia in the UK (Horton et al., 2021). This is the longest instrument with 39 items across three scales ("SIDECAR Scales measuring the Impact of Dementia on CARers,"), covering the direct (SIDECAR-D, n = 18) and indirect (SIDECAR-I, n = 10) impacts of caring, and support and information (SIDECAR-S, n = 11). Free registration is required to use this instrument.

Thus far, SIDECAR is available in English only. The UK scoring algorithm was developed for the SIDECAR-D scale only using general population preferences, with scores ranging from 0 (indicating death) and 1 (full health) (Webb et al., 2020). Details about the response rate are missing from the valuation study (Webb et al., 2020), although all other items from CREATE (Xie et al., 2015) are reported (see Appendices 6 and 9).

Initial results on the measurement properties of SIDECAR are promising, with evidence from one study of acceptable content validity (Oyebode et al., 2019), and another study reporting no floor or ceiling effects, low non-completion rates, good internal consistency, some evidence of construct validity, and excellent reliability (Horton et al., 2021). Minimally important differences were calculated for each scale. The SIDECAR scales showed small (I, S) to moderate levels (D) of responsiveness (D) for detecting worsening of QoL over six months (Horton et al., 2021). Overall, the SIDECAR-D demonstrated the most robust measurement properties of the three scales (Horton et al., 2021). Further details are provided in Appendix 5. Additional research is needed to confirm these initial findings.

Application of the SIDECAR has yet to be reported in the peer-reviewed literature at the time of this review.

### 3.6. Care setting

When validating instruments in specific carer populations, all have been tested in carers of people with dementia except the ICECAP-CPM. The CarerQol and CES have been validated in palliative care settings, while the ASCOT-Carer, CarerQol and CES have been tested in carers of adults requiring long-term care (the population for which the ASCOT-Carer was specifically developed), and the ASCOT-Carer and CES in carers of older adults. Three studies have directly compared the CarerQoL, CES and/or ASCOT-Carer in specific populations.

Hoefman and colleagues (Hoefman et al., 2015) found that the CarerQol and CES effectively measured the impact of caregiving in the palliative care setting, with no clear indication that either instrument performs better. The ASCOT-Carer and CES demonstrated construct validity in capturing partially overlapping aspects of QoL beyond health in carers of adults using long-term care (Rand et al., 2019a,b). McLoughlin and colleagues observed there were more statistically

significant associations between contextual factors and QoL scores and the ASCOT-Carer compared to the CarerQol and CES in carers of people with varied conditions (dementia, stroke, mental illness, rheumatoid arthritis) (McLoughlin et al., 2020). Specifically, the ASCOT-Carer and CES performed similarly in the dementia setting; the ASCOT-Carer performed the best in the stroke setting; the ASCOT-Carer and CarerQol were comparable for mental illness; and all three instruments performed similarly for rheumatoid arthritis.

### 3.7. Head-to-head comparisons of the instruments

Four studies included in the review directly compared the psychometric properties of multiple carer-related preference-based instruments (Bucholc et al., 2023; Engel et al., 2020; Hoefman et al., 2015; McCaffrey et al., 2020; McLoughlin et al., 2020, 2023; Rand et al., 2019a,b). Hoefman and colleagues (Hoefman et al., 2015) concluded both the CarerQol and CES appear to capture the impact of caregiving in the end-of-life care setting with neither instrument clearly outperforming the other. The ASCOT-Carer and CES both provided valuable insights into the social and emotional well-being of carers beyond traditional health measures when considering long-term care (also known as social care) (Rand et al., 2019a,b). McLoughlin and colleagues (McLoughlin et al., 2020) found evidence for the psychometric validity of the ASCOT-Carer, CarerQol and CES, with the ASCOT-Carer displaying the strongest evidence for construct validity. However, none of the instruments demonstrated strong evidence of sensitivity to change (responsiveness), although this is possibly related to the choice of anchor and external measures. All of the instruments displayed sufficient content validity, feasibility and acceptability in carers of adults in the UK (N = 24) (McLoughlin et al., 2020). The ASCOT-Carer, CarerQol and CES exhibited some degree of feasibility, reliability and validity when the psychometric properties of the instruments were compared by McCaffrey and colleagues in an Australian carer population (McCaffrey et al., 2020). The ASCOT-Carer demonstrated the highest level of consistency, closely followed by the CES then CarerQol. Although the ASCOT-Carer had the highest level of internal consistency, between-item consistency is perhaps less relevant for a multi-attribute, preference-based instrument than the relevance of the items to carers' preferences (Brazier and Deverill, 1999; Kwon et al., 2023). The study findings also suggested that despite some overlap, the three measures tap into different constructs of CrQoL and caring experiences (Engel et al., 2020).

### 3.8. Reporting quality and minimum standards

The table in Appendix 9 summarises the evaluation of the reporting quality of the valuation studies using the CREATE checklist. Generally, the valuation studies were well-reported with eight of the ten studies recounting over 80 % of the CREATE items.

Overall, the majority of the articles scored highly with an average score of 90 per cent (range 76–100 per cent). However, just two of the 10 valuation studies reported the response rates (Al-Janabi et al., 2011; Kinghorn et al., 2022). Other missing items included justification for the sample size (n = 3) (Batchelder et al., 2019; Hoefman et al., 2014a,b; Trukeschitz et al., 2021a,b), provision of goodness of fit statistics (n = 3) (Baji et al., 2020; Hoefman et al., 2017; Trukeschitz et al., 2021a,b), reasons for excluding respondents (n = 2) (Baji et al., 2020; Hoefman et al., 2017) and criteria for preferred model selection (n = 2) (Batchelder et al., 2019; Trukeschitz et al., 2021a,b). The findings suggest future valuation studies should ensure that the response rate is clearly reported.

An assessment of the ISOQOL minimum standards for the instruments is provided in Appendix 10. The psychometric properties of the ICECAP-CPM have not yet been tested. All of the other instruments met the minimum standards for response burden, although the CES showed mixed results based on completion rates (Goranitis et al., 2014;

McCaffrey et al., 2020). Only one study, using the SIDECAR, explicitly discussed the interpretability of changes in scores (Horton et al., 2021). The SIDECAR-D satisfied all of the minimum standards, while the ASCOT-Carer, CarerQol, and CES met most of the criteria.

## 4. Discussion

### 4.1. Instrument characteristics and psychometric evidence

Five carer-specific, preference-based instruments for measuring outcomes in economic evaluations were identified by this scoping review. Each instrument measures different, albeit overlapping constructs related to unpaid care (Engel et al., 2020; Rand et al., 2019a,b). The ASCOT-Carer measures the social-care related QoL of carers (i.e., those aspects of QoL most relevant to carers and that may be affected by social care services) (Rand et al., 2015), the CarerQol captures burden and happiness (wellbeing) (Brouwer et al., 2006), the CES evaluates the experience of caring (Al-Janabi et al., 2011), the ICECAP-CPM investigates the impacts of end-of-life care on carers (Canaway et al., 2017), and the SIDECAR measures the impact on QoL of caring for someone with dementia (Oyebode et al., 2019). Whilst the first two instruments provide measures for adult carers across populations and caring relationships, the ASCOT-Carer, ICECAP-CPM and SIDECAR were developed for specific settings and populations.

In line with best practice (Patrick et al., 2011; Terwee et al., 2018), the descriptive systems of the instruments were developed from interviews and focus groups with the target population, except for the CarerQol which was informed by a review of burden measures. Using qualitative methods to generate the content of preference-based instruments promotes comprehensiveness and relevance, and ensures the dimensions are acceptable and reflect carers' perspectives (Ricci et al., 2019). Each instrument demonstrated at least some evidence of face or content validity, as established through pilot testing or qualitative interviews.

All of the instruments had some evidence of psychometric validity, except the ICECAP-CPM. Generally, the instruments had minimal response burden, aided by the concise nature of the preference-based instruments. No domain floor or ceiling effects were detected for any of the instruments. The CarerQol, the first carer-related preference-based instrument to be developed, had the largest body of evidence for psychometric properties, closely followed by the ASCOT-Carer and CES. The most frequently documented aspects were construct validity and content validity. All of the instruments demonstrated satisfactory internal consistency. The psychometric properties of the ICECAP-CPM are yet to be reported (other than the development of the measurement model). Despite the availability of the ICECAP-CPM, studies often use the ICECAP-O or ICECAP-A to evaluate carer outcomes (Afentou and Kinghorn, 2020; Proud et al., 2019), possibly because these generic measures can also be used with patients, whereas the ICECAP-CPM is specific to care for those close to people at the end of life, limiting broader application. Interpretation of changes in scores (minimally important differences) was mentioned for the SIDECAR (Henry et al., 2020) only.

There is also limited evidence for the responsiveness of the carer-related, preference-based instruments. Only two studies (Horton et al., 2021; McLoughlin et al., 2020) have used changes in recipient HrQoL and hours of care over 12 months, and worsening self-reported HrQoL over six months, respectively, as anchors. If carer-related, preference-based measures are to be routinely included in economic evaluations comparing the costs and benefits of alternative courses of action, it is vital these instruments are sensitive to changes in CrQoL to usefully inform such evaluations. More research is urgently needed to investigate the responsiveness of the carer-related, preference-based instruments over different time periods and populations, and a broader range of carer characteristics and settings, to support wider implementation of carer-related, preference-based measures in economic evaluations.

## 4.2. Implications for economic evaluation and policy

Whilst carer-related utilities cannot be combined with utilities generated from generic preference-based instruments to calculate QALYs in economic evaluations, the former can be considered alongside patient utilities using innovative techniques such as multiple outcomes cost-effectiveness analysis (MOCEA) (Alarid-Escudero et al., 2019; McCaffrey & Eckermann, 2017; McCaffrey et al., 2015), or more traditional approaches such as multi-criteria decision analysis or cost-benefit analysis. In MOCEA, two or more outcomes are simultaneously compared with costs under uncertainty on the cost-disutility plane. Alternatively, an exchange rate could be applied to value CrQoL in HrQoL terms to quantitatively compare and aggregate CES or CarerQol-7D outcomes with EQ-5D-5L outcomes in economic evaluations that include both effects (Dhanji et al., 2021). Dhanji and colleagues estimated that a one-point gain in the CarerQol and CES scores is equal to a 0.014 and 0.033 gain in EQ-5D-5L scores respectively (Dhanji et al., 2021).

Although more than a quarter of the applied studies measured carer-related outcomes in people providing support for children, this review found only two studies specifically investigating the measurement properties in this carer population, both involving the CarerQol (Hoefman et al., 2014a,b; Payakachat et al., 2011). These studies provided evidence of convergent validity, similar to studies investigating experiences of providing informal care for older populations, but there was no evidence on reliability, interpretability, and responsiveness in this group, unlike the more comprehensive psychometric evidence available for the latter. Ideally, a carer-related, preference-based instrument validated in the population of interest should be used to ensure that the data collected are accurate, reliable, and relevant to that specific group (Reeve et al., 2013). This is important because evidence suggests that carers of people with different conditions and age groups have varied experiences, likely influenced by the specific demands and challenges associated with the condition of the care recipient (de Oliveira et al., 2015; Li et al., 2022). The ASCOT-Carer was designed to measure the impact of adult social care, so it is unsurprising this instrument has not been validated in a population caring for children.

Collectively, the findings from this review can guide the selection of instruments for measuring CrQoL in specific populations and settings. The CarerQol has the most evidence for use in carers of children, and the CarerQoL and CES for the palliative care setting (pending more evidence for the ICECAP-CPM). The ASCOT-Carer, CarerQoL, and CES have evidence supporting their use in mental illness, rheumatoid arthritis, long-term care, and dementia, (awaiting further evidence for SIDECAR). The ASCOT-Carer is particularly well evidenced for adult social care settings, as it was specifically designed for this context. More generally, these findings help inform instrument choice in future studies when considered alongside research objectives, population and target construct.

Very few economic evaluations were identified in the review (Gridley et al., 2019). However, the search strategy was designed to identify relevant articles on the development, validation, valuation and application of carer-related, preference-based instruments, not economic evaluations. Consequently, the absence of such evaluations could be due to the search strategy or a lack of application of carer-related, preference-based instruments. The inclusion of CrQoL appears relatively uncommon in HTA (Pennington, 2020), and inconsistent globally, possibly driven by different recommendations by international HTA organizations (Pennington et al., 2022). Whilst the development of carer-related, preference-based instruments has progressed over recent years, challenges remain when using these instruments in economic evaluations, including: judging how many and which carer impacts to include in the evaluation; the additional recruitment costs and challenges associated with collecting carer-related outcomes in clinical trials and longitudinal studies (Al-Janabi et al., 2021); accounting for the relative value of patient and carer QoL; and deciding the time horizon of the analysis (until patient or carer death) (Al-Janabi et al., 2022; Bourke

et al., 2024; Pennington and Al-Janabi, 2024; Becky Pennington et al., 2022). Further, there is limited guidance on how to incorporate carer impacts in economic evaluations, including the selection of suitable outcome measures (Henry et al., 2023; McCaffrey and Currow, 2015). Recent consensus recommendations published by the Spillovers in Health Economic Evaluation and Research (SHEER) task force suggested new, generic preference-based measures capturing spillover effects should be developed to include patient and carer impacts (Henry et al., 2023). The EQ Health and Wellbeing (EQ-HWB), and shortened version (EQ-HWB-S) (Kuharic M et al., 2024), designed for use in health and social care and public health, have been developed with input from carers and may fit the bill (Brazier et al., 2022). Emerging evidence suggests these are valid instruments for evaluating the health and wellbeing of adult carers when compared with the ASCOT-Carer and CarerQol (Kuharic et al., 2024). If the EQ-HWB-S can be used to measure patient and carer impacts then scores could be used to generate total QALYs in economic evaluations. However, the EQ-HWB and EQ-HWB-S are still in the experimental stages and more evidence is needed before recommending wide implementation (EuroQoL). Whilst such a measure would usefully inform the evaluation of strategies aimed at the patient, carer-specific measures are still vital for informing interventions targeting informal carers. Tools used to detect impacts on carers should reflect what carers highly value, like getting along with the care recipient (Al-Janabi et al., 2011), to more accurately assess effectiveness and cost-effectiveness (McCaffrey et al., 2009). Carer-specific measures will also continue to add value alongside generic measures given their greater sensitivity to contextual factors such as caregiving intensity (Kuharic M et al., 2024).

Overall, based on the findings of this scoping review, priority should be given to assessing the responsiveness of the existing carer-related, preference-based instruments, validating the instruments in more countries and different carer populations, developing a broader range of country-specific scoring algorithms given potential differences in preference weights (Hoefman et al., 2017; T. Shiroiwa et al., 2022), and exploring methods to simultaneously consider patient and carer QoL, such as MOCEA (Alarid-Escudero et al., 2019; McCaffrey et al., 2015a,b) and exchange rates (Dhanji et al., 2021).

## 4.3. Limitations

The following caveats should be considered when interpreting the findings from the review. As the synthesis was predominantly descriptive, identified the availability of evidence, and highlighted gaps in knowledge, the typology was changed from a systematic review to a scoping review. Some relevant articles may have been missed by the searches, particularly applied studies as abstracts may not mention carer-related, preference-based instruments. However, the comprehensive search strategy, including database searches and pearl growing, is expected to have identified all key articles. Seminal articles are unlikely to have been missed given that the review team includes the creators of some of the most widely used and well-developed carer-related instruments. Due to resource constraints, the review focused on peer-reviewed literature. This may have led to the exclusion of some relevant grey literature, especially articles related to instrument development and translation. Further, instruments like the CES have likely been translated into other languages based on study registrations (Professor Hareth Al-Janabi, personal communication, 24 January 2025) but have not been published in the translated version. However, foundational research in this area is typically published in peer-reviewed journals, ensuring a high level of methodological rigor and accessibility. Evaluation of the reporting quality and minimum standards is inherently subjective. Therefore, the CREATE checklist results and ISOQOL minimum standards are provided in Appendices 9 and 10 respectively to indicate how the authors evaluated the studies and to allow for alternative interpretations and assessments. Finally, the content validity in this review was appraised based on the authors' interpretations of

included articles, which employed a variety of methods that may not align with established qualitative research standards such as those adopted by COSMIN (Terwee et al., 2018). Notably, comprehensibility (whether the measure's content was understood as intended) was not explicitly addressed. Accordingly, information on the content validity of the included measures is preliminary and interpreted in the context of the original studies cited.

## 5. Conclusion

This review provides an inventory of the psychometric evidence, valuation and application of five carer-related, preference-based instruments, the ASCOT-Carer, CarerQol, CES, ICECAP-CPM and SIDECAR to guide instrument selection and future research. Although the CarerQol has the largest body of evidence, the ASCOT-Carer and CES performed well psychometrically and have been robustly valued. The ICECAP-CPM and SIDECAR, developed for the end-of-life care and dementia settings respectively, are newer and require further psychometric validation. Overall, based on the findings of this scoping review, priority should be given to researching the responsiveness of the existing carer-related, preference-based instruments, validating the instruments in different carer populations and countries, and developing country-specific scoring algorithms.

## CRediT authorship contribution statement

**Nikki McCaffrey:** Writing – original draft, Visualization, Supervision, Resources, Project administration, Methodology, Investigation, Funding acquisition, Formal analysis, Data curation, Conceptualization. **Lidia Engel:** Writing – review & editing, Visualization, Supervision, Resources, Methodology, Investigation, Funding acquisition, Formal analysis. **Benjamin Karnon:** Writing – review & editing, Validation, Investigation, Formal analysis. **Julie Ratcliffe:** Writing – review & editing, Validation, Methodology, Investigation, Funding acquisition, Conceptualization. **Renske Hoefman:** Writing – review & editing, Validation, Methodology, Investigation, Funding acquisition, Conceptualization. **Stacey Rand:** Writing – review & editing, Visualization, Validation, Investigation. **Hareth Al-Janabi:** Writing – review & editing, Methodology, Conceptualization. **David Currow:** Writing – review & editing, Methodology, Funding acquisition, Conceptualization. **Madison Frith:** Writing – review & editing, Investigation, Formal analysis. **Claire Hutchinson:** Writing – review & editing, Visualization, Validation, Methodology, Investigation, Formal analysis, Data curation.

## Ethics approval and consent to participate

Ethics approval was not required to conduct the systematic review of peer-reviewed, published articles because the research does not involve human participants.

## Funding

## Declaration of competing interest

Professor Hareth Al-Janabi is the lead developer of the CES and a co-developer of the ICECAP-CPM and SIDECAR. Dr Stacey Rand is the ASCOT Programme Lead and a co-developer of the ASCOT-Carer. Dr Renske Hoefman is a co-developer of the CarerQol. All other authors have no conflicts of interest to declare.

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## Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.socscimed.2025.118762.

## Data availability

This review did not involve the collection of primary data. All relevant details for this study have been provided in the paper and Appendices.

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