

Appendix A

Recommended Common Data Elements Aligned with the Value of Respite Model

Introduction and Purpose

Common data elements, according to the [National Institutes of Health](#), have been defined the following way:

“A common data element is a standardized, precisely defined question that is paired with a set of specific allowable responses, that is then used systematically across different sites, studies, or clinical trials to ensure consistent data collection.”

As stated previously in this paper, common data elements allow data to be collected in the same way across multiple research studies, and they allow for more meaningful comparison of data across and between studies, between study populations across age, disability, and culture, and over time. Common data elements also increase statistical power when data are aggregated from multiple sources.

Organization of the Tables

We have organized individual common data elements according to four domains that align with the *Value of Respite Model: Caregiving Context; Care Receiver Context; Respite Process; and Value of Respite/Outcomes*. Listed within the four domains are key concepts that the CARR Common Data Elements Work Group believes are important to measure. The measures included in the tables were recommended according to the five criteria cited in this paper (see page 11). The framework allows researchers to easily locate and choose the recommended data elements that best fit the purposes of their study.

Selection of Common Data Elements Concepts and Measures

Ideally, the respite research community would have sufficient resources to create a unified repository or data base similar to [PROMIS®](#) (Patient-Reported Outcomes Measurement Information System) but tailored to respite research. Absent those resources, the present effort to identify essential respite-related concepts and create a practical framework for selecting and using common data elements for respite research is an important step toward the longer-term goal of a creating a unified data base.

Three Types of Data Elements

The tables contain three types of recommended common data elements.

1. **Existing Multi-Item Measurement Tools.** For the most part, the CARR Common Data Elements Work Group recommends using psychometrically sound and widely available measurement tools, and advises against extracting and using individual items from those measurement tools. We make this recommendation for two reasons. First, extracting individual items from existing measures compromises the validity and reliability of those measures, and therefore makes them unsuitable for

research purposes. Second, intellectual property rights and terms of use specify that individual items may not be extracted, modified, or altered without written permission from developers and publishers. Some recommended measures may be proprietary, require permission from the author of the measure, and/or entail an associated cost.

Several tools are included that measure more than one concept. When a single measurement tool measures multiple concepts, researchers may examine single responses or response clusters of interest to their study after the entire measure has been administered.

2. **Single Non-Proprietary Items.** The CARR Common Data Elements Work Group has included several individual items extracted from surveys, but that assess relatively straightforward, non-proprietary content (as contrasted with concepts or constructs). Age, race/ethnicity, and languages spoken are examples of single non-proprietary items.
3. **Original Items.** When available measurement tools could not be found to measure concepts that the CARR Common Data Elements Work Group saw as important, the Work Group created original items. These single items have not yet been evaluated or field tested, and do not currently have established reliability, validity, or sensitivity.

Recommended Common Data Elements Aligned with the Value of Respite Model

CONTEXT: CAREGIVER <i>Core concepts that help to describe risk and protective factors of the caregiver</i>	
Core Concept: Caregiver Demographics	Recommended Common Data Elements (Items or Measures)
Age	What is your age in years? (U.S. Census)
Race/ethnicity	What is your race or ethnicity? <i>Please select all that apply.</i> <input type="checkbox"/> White <input type="checkbox"/> Hispanic or Latino <input type="checkbox"/> Black or African American <input type="checkbox"/> Asian <input type="checkbox"/> American Indian or Alaska Native <input type="checkbox"/> Middle Eastern or North African <input type="checkbox"/> Native Hawaiian or Pacific Islander (Federal Register, proposed changes to U.S. Census, 2023)
Language	What language(s) do you usually speak at home? <input type="checkbox"/> English <input type="checkbox"/> Spanish <input type="checkbox"/> American Sign Language [Add additional closed-ended options based on the population.] (Revised item from <i>National Survey of Family Growth</i>)

Core Concept: Caregiver Wellbeing	Recommended Common Data Elements (Items or Measures)
Physical Mental Social Spiritual Financial Quality of Life	Please see: Outcomes: Value of Respite (page 22) Use the same selected common data elements to establish baseline and to measure short and longer-term outcomes.
Core Concept: Caregiving Circumstances	Recommended Common Data Elements (Items or Measures)
Relationship to care receiver	How are you (caregiver) related to the person you care for (care receiver)? <input type="checkbox"/> Husband/wife/spouse <input type="checkbox"/> Unmarried partner <input type="checkbox"/> Biological son or daughter <input type="checkbox"/> Adopted son or daughter <input type="checkbox"/> Stepson or stepdaughter <input type="checkbox"/> Brother or sister <input type="checkbox"/> Father or mother <input type="checkbox"/> Grandparent <input type="checkbox"/> Grandchild <input type="checkbox"/> Parent-in-law <input type="checkbox"/> Son-in-law or daughter-in-law <input type="checkbox"/> Other relative <input type="checkbox"/> Roommate or housemate <input type="checkbox"/> Foster child <input type="checkbox"/> Other nonrelative (Revised item from the household roster of the American Community Survey [ACS])
Time as a caregiver	How long have you provided care to (care receiver)? <input type="checkbox"/> 0 to 5 months <input type="checkbox"/> 6 to 11 months <input type="checkbox"/> 1 year <input type="checkbox"/> More than one year <input type="checkbox"/> If more than one year, how many years? _____ years (Revised item from American Time Use Survey [ATUS])
Care receiver needs (companion vs skilled)	Does the person you care for require skilled nursing care during respite? <input type="checkbox"/> Yes <input type="checkbox"/> No (Original item)
Care complexity of care receiver	Does the person you provide care for (care receiver) require: <input type="checkbox"/> 24-hour care <input type="checkbox"/> 8 or more hours of care per day <input type="checkbox"/> Occasional care (Original item)

	<p>During the past month, how often did you help the care receiver with personal care such as eating, showering or bathing, dressing, grooming, or using the toilet?</p> <p><input type="checkbox"/> Everyday <input type="checkbox"/> Most days <input type="checkbox"/> Some days <input type="checkbox"/> Rarely <input type="checkbox"/> Never</p> <p>(Revised item from the National Survey of Caregiving)</p>
Living situation	<p>Do you currently live with the person you provide care for (care recipient)?</p> <p><input type="checkbox"/> Yes <input type="checkbox"/> No</p> <p>(Original item)</p>
Perception of caregiving burden	<p>Zarit Burden Interview - (22-, 12-, or 4-item)</p> <p>Modified Caregiver Strain Index</p>
Caregiving intensity	<p>Think about all the care that the person you care for receives. Approximately how much of that care (what percentage) do YOU provide?</p> <p><input type="checkbox"/> I provide about _____% of the care</p> <p>(Original item)</p> <p>Archangel Caregiving Intensity Index II</p>

CONTEXT: CARE RECEIVER
Core concepts that help to describe risk and protective factors of the care receiver

Core Concept: Care Receiver Demographics	Recommended Common Data Elements (Items or Measures)
Age	<ul style="list-style-type: none"> • How old in years is the person you care for? (For persons 6 years and older) • How old in months is the child you care for? (For children birth to 6 years) <p>(Revised item from U.S. Census)</p>
Race/ethnicity	<p>What is the race or ethnicity of the person you care for? <i>Select all that apply.</i></p> <p><input type="checkbox"/> White</p> <p><input type="checkbox"/> Hispanic or Latino</p> <p><input type="checkbox"/> Black or African American</p> <p><input type="checkbox"/> Asian</p> <p><input type="checkbox"/> American Indian or Alaska Native</p> <p><input type="checkbox"/> Middle Eastern or North African</p> <p><input type="checkbox"/> Native Hawaiian or Pacific Islander</p> <p>(Federal Register, proposed changes to U.S. Census, 2023)</p>
Language	<p>What language(s) does the person you care for usually speak at home?</p> <p><input type="checkbox"/> English</p> <p><input type="checkbox"/> Spanish</p> <p><input type="checkbox"/> American Sign Language</p> <p>[Add additional closed-ended options based on the population.]</p> <p>(Revised item from National Survey of Family Growth)</p> <p>Does the person you care for use augmentative or alternative communication devices? If so, please describe.</p> <p>(Original item)</p>

Core Concept: Care Receiver Wellbeing	Recommended Common Data Elements (Items or Measures)
Condition(s)/disability(ies)	<p>Which of the following conditions does the person you care for have? <i>Select all that apply. If you check "Other", please describe the condition.</i></p> <p>PHYSICAL DISABILITIES</p> <ul style="list-style-type: none"> <input type="checkbox"/> Brain or spinal cord injury <input type="checkbox"/> Amputations <input type="checkbox"/> Spina Bifida <input type="checkbox"/> Cerebral Palsy <input type="checkbox"/> Multiple Sclerosis <input type="checkbox"/> Muscular Dystrophy <input type="checkbox"/> Epilepsy <input type="checkbox"/> Other neuromuscular disorder <p>SENSORY DISABILITIES</p> <ul style="list-style-type: none"> <input type="checkbox"/> Deafness or hearing impairment <input type="checkbox"/> Visual impairment including blindness <input type="checkbox"/> Sensory processing disorder <input type="checkbox"/> Other sensory disorder <p>INTELLECTUAL AND DEVELOPMENTAL DISABILITIES</p> <ul style="list-style-type: none"> <input type="checkbox"/> Autism/Autism Spectrum Disorder <input type="checkbox"/> Down Syndrome <input type="checkbox"/> ADD/ADHD <input type="checkbox"/> Other intellectual or developmental disability <p>BEHAVIORAL DISORDERS</p> <ul style="list-style-type: none"> <input type="checkbox"/> Generalized Anxiety Disorder <input type="checkbox"/> Obsessive Compulsive Disorder <input type="checkbox"/> Post Traumatic Stress Disorder <input type="checkbox"/> Other behavioral disorder <p>NEUROLOGICAL DISORDERS</p> <ul style="list-style-type: none"> <input type="checkbox"/> Alzheimer's/Dementia <input type="checkbox"/> Traumatic Brain Injury <input type="checkbox"/> Other neurological disorder <p>PHYSICAL HEALTH CONDITIONS</p> <ul style="list-style-type: none"> <input type="checkbox"/> Complex medical conditions <input type="checkbox"/> Palliative or Hospice Care <input type="checkbox"/> Other physical health conditions <p>(Original item)</p>
Functional status	<p>Katz Index of Independence in Activities of Daily Living</p> <p>Lawton Instrumental Activities of Daily Living (IADL) Scale</p> <p>Waisman Activities of Daily Living Scale (W-ADL)</p>



Condition stability	<p>Which of the following describes the condition of the person you care for (care receiver)?</p> <p><input type="checkbox"/> Their condition is getting BETTER</p> <p><input type="checkbox"/> Their condition is getting WORSE</p> <p><input type="checkbox"/> Their condition is remaining about the SAME</p> <p><input type="checkbox"/> Their condition is fluctuating or CHANGING</p> <p>(Original item)</p>
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PROCESS: RESPITE FACTORS
Core concepts that help to describe respite factors

Core Concept: Description of Respite Model	Recommended Common Data Elements (Items or Measures)
Type of respite Timing of respite Location of respite Dose of respite Cost of respite Respite service model Person- and family-centeredness Respite provider Cultural and linguistic competence	<i>Description of Respite Model Tool</i> (See Appendix B, page 26.)
Core Concept: Caregiver Experience with Respite	Recommended Common Data Elements (Items or Measures)
Identify as a caregiver Need for respite Acceptance of respite Access to respite services that meet the family's needs Respite goals achieved Satisfaction with respite Services	<i>Caregiver Experience with Respite Tool</i> (See Appendix C, page 31.)

OUTCOMES: VALUE OF RESPITE

Core concepts that help to describe the value of respite

Core Concept: Caregiver Physical Wellbeing	Recommended Common Data Elements (Items or Measures)
Global health	PROMIS® Scale v1.2 – Global Health-2 (GH2) PROMIS® Scale v1.0 – Global Health Short Form Zarit Burden Interview – (22-, 12-, or 4-item)
Sleep	How often do caregiving responsibilities negatively impact your quality of sleep? <input type="checkbox"/> All the time <input type="checkbox"/> Some of the time <input type="checkbox"/> None of the time How many nights a week on average do you get up during the night to provide care? _____ How many times on average do you get up in a single night to provide care? _____ (Original items)
Fatigue	PROMIS® v1.0 – Fatigue – Short Form A PROMIS® Global Health Short Form v1.0
Core Concept: Caregiver Mental Wellbeing	Recommended Common Data Elements (Items or Measures)
Stress	Perceived Stress Scale (PSS-4 OR PSS-10) PROMIS® Adult Measures: PROMIS®-57 Profile Zarit Burden Interview – (22-, 12-, or 4-item)
Anxiety	Generalized Anxiety Disorder (GAD-7) PROMIS® Global Health Short Form v1.0
Depression	Patient Health Questionnaire (PHQ-4 or PHQ-9) PROMIS® Global Health Short Form v1.0
Self-efficacy	Generalized Perceived Self-Efficacy Scale PROMIS® Bank v1.0 – General Self Efficacy
Resilience	Brief Resilient Coping Scale (BRCS) Conner-Davidson Resilience Scale (CDRISC)
Core Concept: Caregiver Social Wellbeing	Recommended Common Data Elements (Items or Measures)
Loneliness	UCLA 3-Item Loneliness Scale
Social engagement	Lubben Social Network Scale (6 – Item) (12 – Item) PROMIS® Global Health Short Form v1.0 Zarit Burden Interview – (22-, 12- or 4-item)

Core Concept: Caregiver Spiritual Wellbeing	Recommended Common Data Elements (Items or Measures)
Spiritual	Functional Assessment of Chronic Illness – Spiritual Well-Being 12 Item Scale (FACIT-SP-12)
Core Concept: Caregiver Financial Wellbeing	Recommended Common Data Elements (Items or Measures)
Financial burden	How much of a financial strain would you say caring for your (relation) is/was for you? (1 – No strain at all, to 5 – Very much a strain) (Caregiving in the U.S. 2020 Report) Zarit Burden Interview – (22-, 12-, or 4-item)
Job security/reduced hours	Which of the following describes the impact your role as a caregiver has had on your employment? <i>Select all that apply.</i> <input type="checkbox"/> I had to cut back the number of hours I work. <input type="checkbox"/> I had to quit my job. <input type="checkbox"/> I had to change to a different job. <input type="checkbox"/> I was fired or let go from a job. <input type="checkbox"/> No impact. <input type="checkbox"/> Other (please describe) (Original item)
Core Concept: Quality of Life	Recommended Common Data Elements (Items or Measures)
Individual	PROMIS® Global Health Short Form v1.0
Family	Global Family Quality of Life Scale (G-FQOLS) (3-Items) Family Quality of Life Survey

References

- Archangels. 2020. *The Caregiver Intensity Index: A Novel Tool to Assess and Describe the Unpaid Family Caregiver Experience – Updated: July 2020*. https://tpi.org/wp-content/uploads/2020/10/072020_aa_caregiver_intensity_foundational_research_updated.pdf
- Burckhardt, C. S., & Anderson, K. L. (2003). The Quality-of-Life Scale (QOLS): reliability, validity, and utilization. *Health and quality of life outcomes*, 1, 60. <https://doi.org/10.1186/1477-7525-1-60>
- CD RISC Connor Davidson Resiliency (2024). <https://www.cd-risc.com/>
- Chmitorz, A., Wenzel, M., & Stieglitz, R.D., et al. (2018). Population-based validation of a German version of the Brief Resilience Scale. *PLoS One*. 2018;13(2):e0192761. [doi:10.1371/journal.pone.0192761](https://doi.org/10.1371/journal.pone.0192761)
- Connor, K. M., & Davidson, J. R. (2003). Development of a new resilience scale: the Connor-Davidson Resilience Scale (CD-RISC). *Depression and anxiety*, 18(2), 76–82. <https://doi.org/10.1002/da.10113>
- The Council on Quality and Leadership. (2024). Personal Outcome Measures® Manual for Adults. <https://www.c-q-l.org/resources/manuals/personal-outcome-measures-manual-for-adults>
- Diener, E., Emmons, R.A., Larson, R.J., & Griffin, S. (2010). The satisfaction with life scale. *Journal of Personality Assessment*, 49, 71-75. https://www.tandfonline.com/doi/abs/10.1207/s15327752jpa4901_13
- Epstein-Lubow, G., Gaudiano, B.A., Hinckley, M., Salloway, S., & Miller, I.W. (2010). Evidence for the validity of the American Medical Association's Caregiver Self-Assessment Questionnaire as a screening measure for depression. *Journal of the American Geriatrics Society*, 58(2), 387-388. <https://agsjournals.onlinelibrary.wiley.com/doi/10.1111/j.1532-5415.2009.02701.x>
- Hays, R. D., Schalet, B. D., Spritzer, K. L., & Cella, D. (2017). Two-item PROMIS® global physical and mental health scales. *Journal of patient-reported outcomes*, 1(1), 2. <https://doi.org/10.1186/s41687-017-0003-8>
- Health Measures (September, 2024). PROMIS Adult Measures. Northwestern University. National Institute of Health. <https://www.healthmeasures.net/explore-measurement-systems/promis/intro-to-promis/list-of-adult-measures>
- Kuzmik, A., Boltz, M., BeLue, R., Resnick, B., Scott, J., Mogle, J., Leslie, D., & Galvin, J. E. (2023). The Modified Caregiver Strain Index in Black and White Dementia Caregivers at Hospital Discharge. *Clinical gerontologist*, 46(4), 574–584. <https://doi.org/10.1080/07317115.2022.2106927>
- Lawton, M.P. & Brody, E.M. (1969). Assessment of Older People: Self-Maintaining and Instrumental Activities of Daily Living. *The Gerontologist* (3)1, 179-186. https://academic.oup.com/gerontologist/article-abstract/9/3/Part_1/179/552574
- Maenner, M.J., Smith, L.E., Hong, J., Makuch, R., Greenberg, J.S., & Malick, M.R. (2013). Evaluation of an activities of daily living scale for adolescents and adults with developmental disabilities. *Disability Health Journal*. 6(1):8-17. <https://www.sciencedirect.com/science/article/abs/pii/S1936657412001185?via%3Dihub>
- Marks, R., Jones, N., & Battle, K. (April, 2024). *What Updates to the OMB's Race and Ethnicity Standards Mean for the Census Bureau*. US Census Bureau. <https://www.census.gov/newsroom/blogs/random-samplings/2024/04/updates-race-ethnicity-standards.html>
- McMillan, S.C., & Mahon, M. (1994). The impact of hospice services on the quality of life of primary caregivers. *Oncology Nursing Forum*, 21(7):1189-95. PMID: 7971429. <https://m3ewb.research.uconn.edu/measure/caregiver-quality-of-life-index/>
- National Center for Health Statistics (2024). *National Survey of Family Growth*. Centers for Disease Control. <https://www.cdc.gov/nchs/nsfg/index.htm>
- National Health and Aging Trends Study (2024). *National Survey of Caregiving*. https://www.nhats.org/researcher/nhats/methods-documentation?id=data_collection
- National Institute on Aging (2024). *Midlife in the United States*. National Institute of Health. <https://www.nia.nih.gov/research/resource/midlife-united-states>

National Library of Medicine (Undated). *Common Data Elements*. U.S. Department of Health and Human Services, National Institutes of Health. [https://www.nlm.nih.gov/oet/ed/cde/tutorial/03-100.html#:~:text=A%20common%20data%20element%20\(CDE,to%20ensure%20consistent%20data%20collection](https://www.nlm.nih.gov/oet/ed/cde/tutorial/03-100.html#:~:text=A%20common%20data%20element%20(CDE,to%20ensure%20consistent%20data%20collection)

Office of Strategic Coordination-The Common Fund (2024). *Patient-Reported Outcomes Measurement Information System (PROMIS)*. U.S. Department of Health and Human Services, National Institutes of Health. [https://commonfund.nih.gov/promis/index#:~:text=The%20PROMIS%20\(Patient%2DReported%20Outcomes,a%20variety%20of%20chronic%20diseases](https://commonfund.nih.gov/promis/index#:~:text=The%20PROMIS%20(Patient%2DReported%20Outcomes,a%20variety%20of%20chronic%20diseases)

Onega, L.L. (2013). The Modified Caregiver Strain Index. Shirley Ryan Ability Lab. *The Hartford Institute Geriatric Nursing*. <https://www.sralab.org/sites/default/files/2017-07/issue-14.pdf>

Ridosh, M. M., Sawin, K. J., Brei, T. J., & Schiffman, R. F. (2018). A Global Family Quality of Life Scale: Preliminary psychometric evidence. *Journal of Pediatric Rehabilitation Medicine*, 11(2), 103–114. <https://doi.org/10.3233/PRM-170477>

Robinson B. C. (1983). Validation of a Caregiver Strain Index. *Journal of Gerontology*, 38(3), 344–348. <https://doi.org/10.1093/geronj/38.3.344>

Sapra, A., Bhandari, P., Sharma, S., Chanpura, T., & Lopp, L. (2020). Using Generalized Anxiety Disorder-2 (GAD-2) and GAD-7 in a Primary Care Setting. *Cureus*, 12(5), e8224. <https://doi.org/10.7759/cureus.8224>

Smith, B. W., Dalen, J., Wiggins, K., Tooley, E., Christopher, P., & Bernard, J. (2008). The brief resilience scale: assessing the ability to bounce back. *International Journal of Behavioral Medicine*, 15(3), 194–200. <https://doi.org/10.1080/10705500802222972>

Schwarzer, R., & Jerusalem, M. (1995). *General Self-Efficacy Scale (GSE)* [Database record]. APA PsycTests. <https://doi.org/10.1037/t00393-000>

US Bureau of Labor Statistics (Undated). *American Time Use Survey (ATUS)*. <https://www.bls.gov/tus/>

US Census Bureau (September, 2024). *American Community Survey (ACS)*. <https://www.census.gov/programs-surveys/acs>

US Census Bureau (August, 2024). *Respond to the 2024 National Census Survey*. <https://www.census.gov/programs-surveys/decennial-census/decade/2030/planning-management/plan/research-and-testing/2024-national-census-survey.html>

Wang, H. L. (March, 2024). National Public Radio. *Next U.S. Census will Have Boxes for 'Middle Eastern or North African,' 'Latino,' All Things Considered*. <https://www.npr.org/2024/03/28/1237218459/census-race-categories-ethnicity-middle-east-north-africa>

Wuttke-Linnemann, A., Palm, S., Scholz, L., Geschke, K., & Fellgiebel, A. (2021). Introduction and Psychometric Validation of the Resilience and Strain Questionnaire (ResQ-Care)- A Scale on the Ratio of Informal Caregivers' Resilience and Stress Factors. *Frontiers in Psychiatry*, 12, 778633. <https://doi.org/10.3389/fpsy.2021.778633>

Ye, Y. C., Wu, C. H., Huang, T. Y., & Yang, C. T. (2022). The difference between the Connor-Davidson Resilience Scale and the Brief Resilience Scale when assessing resilience: confirmatory factor analysis and predictive effects. *Global Mental Health (Cambridge, England)*, 9, 339–346. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9806974/>

Yomim, L. (2011). *Zarit Caregiver Burden Assessment Instruments*. Wisconsin Alzheimer's Institute. Center for Healthy Living, Inc. <https://wai.wisc.edu/wp-content/uploads/sites/1129/2021/11/Zarit-Caregiver-Burden-Assessment-Instruments.pdf>

Zarit, S.H., Reever, K.E., & Bach-Peterson, J. (1980). Relatives of the impaired elderly: correlates of feelings of burden. *The Gerontologist*, 20:649. <https://pubmed.ncbi.nlm.nih.gov/7203086/>