Recommended Common Data Elements for Respite Research

A white paper by the ARCH Committee for Advancement of Respite Research

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About ARCH

The mission of the ARCH National Respite Network and Resource Center is to assist and promote the development of quality respite and crisis care programs; to help families locate respite and crisis care services in their communities; and to serve as a strong voice for respite in all forums. The ARCH National Respite Network includes the National Respite Locator, a service to help caregivers and professionals locate respite services in their community, the National Respite Coalition, a service that advocates for preserving and promoting respite in policy and programs at the national, state, and local levels, and the Lifespan Respite Technical Assistance Center which is funded by the Administration for Community Living in the US Department of Health and Human Services.

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ARCH National Respite Network AND RESOURCE CENTER

ACL Administration for Community Living

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Executive Summary

The purpose of this white paper is to provide recommendations for the use of common data elements for respite research that align with the *Value of Respite Model*, developed by the ARCH Committee for Advancement of Respite Research (CARR). This paper is a companion document to the white paper *Measuring the Value of Respite* developed by the CARR.

Key Points

- There is an urgent need to identify, develop, and expand evidence-based and evidence-informed respite programs that improve caregiver outcomes.
- Current research and evaluation methods do not allow for meaningful comparison of data across and between studies, between respite models, between study populations across age, disability, culture, and caregiving circumstances, or over time.
- The use of common data elements that align with the *Value of Respite Model* is essential to advancing respite research.

Recommendations

- Researchers should utilize the recommended common data elements to enhance the ability to compare outcomes across studies. Additionally, efforts should be made to insert the recommended common data elements into ongoing studies or studies under development, when feasible.
- While the primary audience of this paper is the research community, common data elements may also be useful for respite program evaluation. Using common data elements can help programs evaluate the effectiveness of respite services over time and allow for comparison to other service models. For respite programs to be "research ready" the CARR recommends the use of common data elements as part of their evaluation plan.
- Funding opportunities should be created that encourage researchers to use common data elements and the *Value of Respite Model* as a framework for respite research.
- From a policy perspective, State and federal programs that fund respite should consider adopting common outcome measures for respite programs to assess the value it brings to individuals and families and also to understand its impact to communities and systems. Additionally, policies that incentivize data collection among respite programs should be explored and should include an emphasis on collecting data with historically marginalized populations.
- Since respite is tied to the care receiver through eligibility but benefits the caregiver, we encourage state and national leadership to adopt these measures in the HCBS Quality Measure Set and other HCBS measures developed by the Centers for Medicare and Medicaid Services (CMS) for evaluation of Medicaid Home and Community Based Services (HCBS).

Purpose

The purpose of this white paper is to provide recommendations for the use of common data elements for respite research that align with the *Value of Respite Model*, developed by the ARCH Committee for Advancement of Respite Research (CARR). It is imperative that we identify measures which can commonly be used across a variety of settings. This is a call to action asking researchers, respite program managers, funders, and state and national leadership to adopt these measures in order to quantify the value of respite. Using a consistent taxonomy will help us make comparisons across respite programs. Integrating these measures into other national data sets or into state quality metrics for Medicaid Home and Community Based Services (HCBS) will maximize the collective impact of respite across programs. Speaking a common language allows for greater understanding across all audiences. The utilization of common data elements will help researchers to measure the value of respite, help programs tailor services for maximum impacts, and help respite providers to better understand the needs of the family caregiver and care receiver*. It also provides stronger evidence for stakeholders to advocate for practices within respite programs that facilitate positive outcomes.

**Throughout this paper, we use the singular terms "caregiver" and "care receiver"; however, we recognize that some situations may involve multiple caregivers and/or multiple care receivers. The terms "family caregiver" and "caregiver" are used interchangeably; include family, friends, and neighbors; and are meant to be differentiated from professional, paid caregivers. The term "care receiver" includes persons of all ages and conditions who require supportive care.*

Background

Defining Respite

Respite is commonly referred to as a "break" from the demands of caregiving. The ARCH Expert Panel on Respite Research defined respite as "planned or emergency care that provides a family caregiver some time away from caregiver responsibilities, and results in some measurable improvement in the wellbeing of the caregiver, care receiver, and/or family system." The second half of the definition is a call to action to researchers and evaluators to ensure that outcomes of respite are measured. However, much of the current respite research focuses on identifying the need for respite among caregivers rather than describing caregiver outcomes related to respite use. Research articles that focus on outcomes may be found in the *Annotated Bibliography of Respite and Crisis Care Studies, 6th Edition*, developed by the ARCH National Respite Network and Resource Center.

ARCH Respite Research Initiative

ARCH has advanced efforts to strengthen the respite evidence base in order to assist with sustainability, promote continuous quality improvement, and help grantees and others translate research into best practices through their Respite Research Initiative. ARCH engages in strategies to collect, synthesize, disseminate, and stimulate research in the field of respite and family caregiver support.

Background continued

The ARCH Goals for Advancing Respite Research include:

- Improve access to and quality of respite services
- Identify aspects of respite services and models that make them exemplary
- Evaluate and replicate promising respite services
- Translate research findings into practice and policy
- Identify additional possibilities for advancing respite research and evaluation (e.g., funding opportunities for research)

The Expert Panel on Respite Research, convened by ARCH in collaboration with the Administration for Community Living, was instrumental in helping advance the Respite Research Initiative by engaging experts in the field in informed discussions about current respite research and possibilities for future investigation. In a final report, the Research Agenda for Respite Care (October 2015), the Expert Panel identified six key areas to establish evidence for the effectiveness of respite for improving the wellbeing of caregivers and others in their families and communities:

1. Improve research methodologies
2. Research individual, family, and societal outcomes
3. Conduct cost-benefit and cost-effectiveness research
4. Research systems change that improves respite access
5. Research improved respite provider competence
6. Translate research findings into best-practice models

On September 29 and 30, 2020, ARCH convened the first virtual Respite Research Summit, a capstone event to advance the Expert Panel's respite research agenda, with more than 130 national and international participants, including researchers, philanthropic foundation representatives, representatives from the Administration on Community Living, policy analysts, advocates, Lifespan Respite grantees and partners, and respite program providers. Researchers engaged in respite research presented their research on respite and caregiving, with specific reference to the six recommendations made by the Expert Panel of researchers, advocates and funders.

The report *Advancing Respite Research: Findings from the Respite Research Summit* presents the findings of studies presented and summarizes recommendations and key themes from the deliberations of summit participants. Emergent themes included: defining and describing respite; research funding; measures and measurement; culturally appropriate research with diverse populations; rethinking cost-effectiveness and cost-benefit studies; workforce development and access to research; and utilizing research findings to inform and improve policy and practice. Recommendations made by both researchers and other Summit participants have been used to advise ARCH on subsequent phases of the advancing respite research agenda.

Alignment with the National Strategy to Support Family Caregivers

The work of the CARR aligns with the *2022 National Strategy to Support Family Caregivers*, which was created to support family caregivers caring for those of all ages, from youth to grandparents, regardless of where they live or what caregiving looks like for them and their loved ones. Of the five goals outlined in the National Strategy, Goal 5 is to expand data, research, and evidence-based practices to support family caregivers. The following are the three outcomes for Goal 5:

- Outcome 5.1: A national infrastructure will exist to support the collection of population-based data, using standardized wording of the definition of family caregiving, and standardized wording of questions that address the core characteristics of the family caregiving experience.
- Outcome 5.2: Family caregiver research facilitates the development and delivery of programs and services that support and enhance the health and wellbeing of the family caregiver and the person receiving support.
- Outcome 5.3: Promising and evidence-informed practices are promoted, translated, and disseminated to support family caregivers in the delivery of health care and social services.

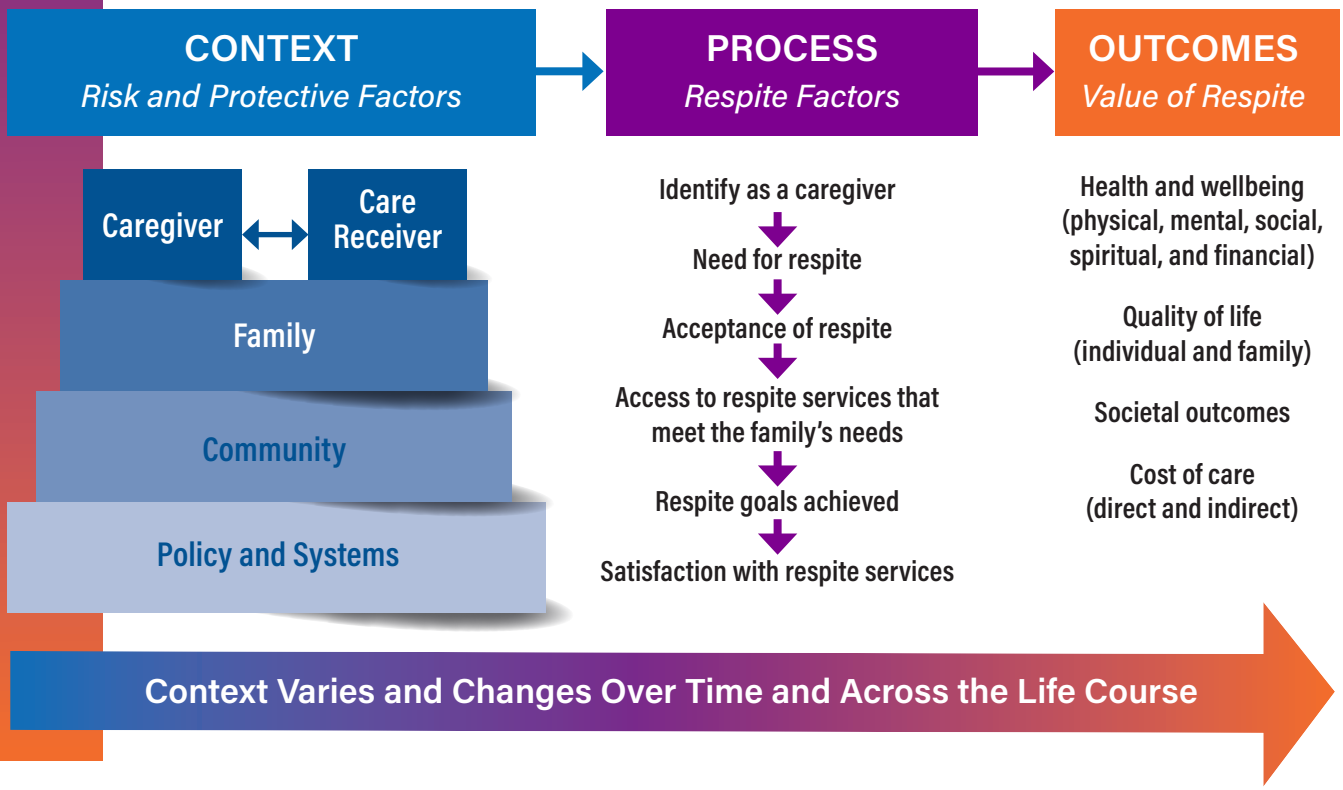
Value of Respite Model

This paper is a companion document to the white paper *Measuring the Value of Respite* developed by the CARR, which describes the Value of Respite Model (Figure A). This multi-dimensional conceptual model provides a framework for researchers and evaluators interested in measuring the value of respite across contexts and time. The model was influenced by the Individual and Family Self-Management Theory, the Life Course Framework, and the Social-Ecological Model.

In the *Value of Respite Model*, the caregiver is the main beneficiary of respite. The caregiver is interconnected with the care receiver, and both are situated in the contexts of their family, community, and policy and systems. Factors within these contexts can help protect the caregiver from or put them at risk for negative outcomes. These contexts vary and change over time and across the life course of both the caregiver and the care receiver. The caregiver goes through a process that begins with identifying themselves as a caregiver. If respite factors in this process align in ways that support the caregiver's and the family's needs, positive outcomes can occur, and the value of respite can be measured at the individual, family, community, or policy and systems levels. Likewise, if the caregiver or care receiver encounter respite factors that they do not experience as positive or supportive, these experiences may also impact their overall health and wellbeing. Specific contextual factors outside of respite, while not always controllable, also influence outcomes.

The Social-Ecological Model recognizes that relationships among persons and systems are not one-directional or linear, but that they are bi-directional, mutually influential and change over time. The Life Course Framework acknowledges that health and wellbeing are also shaped by age, social structures, setting, and time, and that there are specific times or interventions that can change an individual's "life course."

Figure A: The Value of Respite Model



Common Data Elements

To adequately measure the value of respite, it is important to identify and consistently use common data elements that align with concepts in the *Value of Respite Model*. According to the National Institutes of Health:

> *"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."*

In other words, common data elements are developed so that data can be collected in the same way across multiple research studies. Using common data elements allows for more meaningful comparison of data across and between studies, between study populations across age, disability, and culture, and over time. Using common data elements also increases statistical power when data are aggregated from multiple sources.

While there are many benefits to using common data elements, there are also potential barriers to using common data elements that must be understood and considered, including:

- Adequate human and technical resources
- Associated costs
- Availability of psychometrically sound measures
- Ease or difficulty of administering measures
- Participant burden
- Utility of collecting data to participating programs
- Relevance of data elements to research aims

Research Considerations for Using Common Data Elements

Recommendations for the use of common data elements presuppose that, in addition to being familiar with the Value of Respite Model cited in this paper, researchers are versed in methodological design and analysis. Methodological design considerations expressly for respite research are explored in depth in the final report by the Expert Panel on Respite Research, *A Research Agenda for Respite Care*. In particular, the report emphasizes the importance of carefully defining independent variables (the particular respite service components) and including multiple dependent variables (expected positive outcomes) accruing to individual caregivers, care recipients, families, and society. The Expert Panel's report also stresses the importance of measuring both proximal outcomes (those occurring immediately after respite use) and distal outcomes (those that take a longer time to emerge). These considerations should inform what variables researchers elect to measure (from the common data elements), as well as when and how they measure change. A taxonomy of proximal and distal outcomes is presented on pages 16 and 17 of the Expert Panel's final report.

Process and Methods

The CARR Common Data Elements Work Group was formed by ARCH and tasked with identifying specific data elements that can be used across respite research studies or evaluation activities that will allow cross-study comparisons, serve as benchmarks of progress, and demonstrate the value of respite. The Work Group included six members of the CARR. The Work Group met six times over a period of 18 months from January 2022 through July 2024. Lead authors met at least monthly to work on revisions that were shared with the full Work Group for review and feedback.

Their work began with a broad comprehensive review of measures and constructs commonly used in respite and caregiving research. The Work Group used this information to populate an initial draft of data elements aligned with the *Value of Respite Model*, shared this draft with members of the CARR and other experts in the respite field for review and feedback, and reconvened to discuss item-by-item the extent to which measures and data elements included in the draft aligned with the *Value of Respite Model*. Next, they identified additional data categories and elements needed to more fully represent the *Value of Respite Model*. Through this iterative process, the Work Group identified five basic criteria for inclusion of both individual data elements and broader measures that include a data element or elements. Those criteria are as follows:

1. Include instruments that measure concepts that align with and are essential to the *Value of Respite Model*. (For example, published tools that measure caregiver burden, stress, or anxiety.)
2. Include measures that have established reliability and validity.
3. Include individual data elements that are widely used within caregiving-related fields and are essential to the model. (For example, demographic data collected by the Census Bureau; discrete survey questions about respite dose; or complexity of care receivers' health or disability condition.)
4. Identify concepts or individual data elements that are essential to the model or have been identified through inductive measurement processes as important but are not widely measured or included in available psychometrically sound measures or in existing experimental research designs. (For example, caregiver trust in individuals or institutions.)
5. Include measures, such as instruments with short forms, that impose the least burden on caregivers participating in research studies.

Results: Recommended Common Data Elements for Respite Research

The CARR recognizes that it is not feasible to measure every concept in the *Value of Respite Model* in a single study. However, we strongly recommend that every study measures **at least one core concept** within each of the four *Value of Respite Model* domains: Caregiving Factors, Care Receiver Factors, Respite Factors, and Outcomes (with a focus on caregiver outcomes). Figure B provides the list of *Recommended Core Concepts Aligned with the Value of Respite Model* developed by the CARR. Appendix A provides a list of *Recommended Common Data Elements Aligned with Core Concepts of the Value of Respite Model* identified by the CARR. Whenever possible, we recommend validated measures; however, due to the limitations of the current measures available, we also propose new original items and measures for consideration, including

Figure B:
Recommended Core Concepts Aligned with the Value of Respite Model

CONTEXT *Risk and Protective Factors* CAREGIVER	CONTEXT *Risk and Protective Factors* CARE RECEIVER	PROCESS *Respite Factors*	OUTCOMES *Value of Respite*
Core concepts that help to describe risk and protective factors of the caregiver, include:	*Core concepts that help to describe risk and protective factors of the care receiver, include:*	*Core concepts that help to describe respite factors, include:*	*Core concepts that help to describe the value of respite, include:*
Caregiver Demographics ▪ age ▪ race/ethnicity ▪ language	**Care Receiver Demographics** ▪ age ▪ race/ethnicity ▪ language	**Description of Respite Model** ▪ 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	**Caregiver Physical Wellbeing** ▪ global health ▪ sleep ▪ fatigue
Caregiver Wellbeing* ▪ physical ▪ mental ▪ social ▪ spiritual ▪ financial ▪ quality of life	**Care Receiver Wellbeing** ▪ condition(s)/disability(ies) ▪ functional status ▪ condition stability	**Caregiver Experience with Respite** ▪ 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	**Caregiver Mental Wellbeing** ▪ stress ▪ anxiety ▪ depression ▪ self-efficacy ▪ resilience **Caregiver Social Wellbeing** ▪ loneliness ▪ social engagement **Caregiver Spiritual Wellbeing** **Caregiver Financial Wellbeing** ▪ financial burden ▪ job loss/reduced hours **Quality of Life** ▪ individual ▪ family
Caregiving Circumstances ▪ relationship to care receiver ▪ time as a caregiver ▪ care receiver needs (companion vs skilled) ▪ care complexity of care receiver ▪ living situation ▪ perception of caregiving burden ▪ caregiving intensity			

** We recommend obtaining baseline measures of caregiver wellbeing that align with outcome measures of interest, when feasible.*

the *Respite Model Description Tool* (Appendix B) and the *Caregiver Experience with Respite Tool* (Appendix C). We recommend researchers conduct studies that help to validate these new items and measures with caregivers and care receivers and encourage the creation of new, validated measures related to all concepts in the *Value of Respite Model*. Please note that recommended measures may change as new measures become available. New measures will be available on the ARCH website.

The CARR has also developed the *Common Data Elements for Respite Research Worksheet* (Appendix D) to help researchers identify the most appropriate common data elements for their studies that align with the core concepts of the *Value of Respite Model*. The CARR strongly encourages researchers, program administrators, and evaluators to adopt additional measures meaningful to their respite model. Using multiple measures can lead to a better understanding of the relationships among factors and support a greater understanding of the value of respite.

Implications for Research, Evaluation, and Policy

Research Implications

Researchers should utilize the recommended common data elements to enhance the ability to compare outcomes across studies. Additionally, efforts should be made to insert the recommended common data elements into ongoing studies or studies under development, when feasible. Methods suited to conducting research in family contexts should also be better understood and applied to caregiving research, especially in situations where there is more than one primary caregiver.

Researchers must also carefully consider the context of the research setting and characteristics of the participants. Measurement tools should be validated among caregivers, in non-English languages, and in historically marginalized or under-resourced populations in order to assure that the measures are relevant to and congruent with the lived experiences of those populations. Furthermore, not only is the **measure** used important, so also is **who** collects the data, **how** it is collected, and **when** it is collected. Quantitative and qualitative data gathered through interviews and focus groups can also be extremely meaningful and may be the preferred method when sensitive information is collected; when programs or services are at early phases of development; and when it is desirable to discover or better understand respite concepts or experiences according to participants including caregivers, care receivers, family members, community members, and respite program staff. Additional guidelines and resources for using common data elements in respite research should be developed.

Evaluation Implications

While the primary audience of this paper is the research community, common data elements may also be useful for respite programs. Using common data elements can help programs monitor progress toward goals, establish fidelity to the service model, evaluate program effectiveness over time, and allow for comparison to other programs or services. For respite programs to be "research ready", the CARR recommends the use of common data elements as part of their evaluation plan. However, additional guidelines and resources for using common data elements in respite program evaluation are needed.

Policy Implications

Funding opportunities should be created that encourage researchers to use common data elements and the *Value of Respite Model* as a framework for respite research. Funding is needed to create a unified repository or database of common data elements (similar to PROMIS® Measures). State and federal programs that fund respite should consider adopting common outcome measures for respite programs to assess the value it brings to individuals and families and also to understand its impact on communities and systems. Additionally, policies that incentivize data collection among respite programs should be explored and should include an emphasis on collecting data with historically marginalized and under-resourced populations. Since respite is tied to the care receiver through eligibility but benefits the caregiver, we encourage state and national leadership to adopt these measures in the HCBS Quality Measure Set and other HCBS measures developed by the Centers for Medicare and Medicaid Services (CMS) for evaluation of Medicaid Home and Community Based Services (HCBS).

Conclusion

This paper is a call to action for researchers, state and federal programs, and other organizations that fund or provide respite to adopt the common data elements identified in this paper. The recommendations provided should be used as a guide to enhance research and evaluation methods which, ultimately, may lead to increased access to evidence-based respite that improves caregiver outcomes.

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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 *Core concepts that help to describe risk and protective factors of the caregiver*	
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? *Please select all that apply.* ☐ White ☐ Hispanic or Latino ☐ Black or African American ☐ Asian ☐ American Indian or Alaska Native ☐ Middle Eastern or North African ☐ Native Hawaiian or Pacific Islander (Federal Register, proposed changes to U.S. Census, 2023)
Language	What language(s) do you usually speak at home? ☐ English ☐ Spanish ☐ American Sign Language [Add additional closed-ended options based on the population.] (Revised item from National Survey of Family Growth)

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)? ☐ Husband/wife/spouse ☐ Unmarried partner ☐ Biological son or daughter ☐ Adopted son or daughter ☐ Stepson or stepdaughter ☐ Brother or sister ☐ Father or mother ☐ Grandparent ☐ Grandchild ☐ Parent-in-law ☐ Son-in-law or daughter-in-law ☐ Other relative ☐ Roommate or housemate ☐ Foster child ☐ 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)? ☐ 0 to 5 months ☐ 6 to 11 months ☐ 1 year ☐ More than one year ☐ 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? ☐ Yes ☐ No (Original item)
Care complexity of care receiver	Does the person you provide care for (care receiver) require: ☐ 24-hour care ☐ 8 or more hours of care per day ☐ Occasional care (Original item)

	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? ☐ Everyday ☐ Most days ☐ Some days ☐ Rarely ☐ Never (Revised item from the National Survey of Caregiving)
Living situation	Do you currently live with the person you provide care for (care recipient)? ☐ Yes ☐ No (Original item)
Perception of caregiving burden	Zarit Burden Interview – (22-, 12-, or 4-item) Modified Caregiver Strain Index
Caregiving intensity	Think about all the care that the person you care for receives. Approximately how much of that care (what percentage) do YOU provide? ☐ I provide about _____% of the care (Original item) Archangel Caregiving Intensity Index II

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	▪ 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) (Revised item from U.S. Census)
Race/ethnicity	What is the race or ethnicity of the person you care for? *Select all that apply.* ☐ White ☐ Hispanic or Latino ☐ Black or African American ☐ Asian ☐ American Indian or Alaska Native ☐ Middle Eastern or North African ☐ Native Hawaiian or Pacific Islander (Federal Register, proposed changes to U.S. Census, 2023)
Language	What language(s) does the person you care for usually speak at home? ☐ English ☐ Spanish ☐ American Sign Language [Add additional closed-ended options based on the population.] (Revised item from National Survey of Family Growth) Does the person you care for use augmentative or alternative communication devices? If so, please describe. (Original item)

Core Concept: Care Receiver Wellbeing	Recommended Common Data Elements (Items or Measures)
Condition(s)/disability(ies)	Which of the following conditions does the person you care for have? *Select all that apply. If you check "Other", please describe the condition.* **PHYSICAL DISABILITIES** ☐ Brain or spinal cord injury ☐ Amputations ☐ Spina Bifida ☐ Cerebral Palsy ☐ Multiple Sclerosis ☐ Muscular Dystrophy ☐ Epilepsy ☐ Other neuromuscular disorder **SENSORY DISABILITIES** ☐ Deafness or hearing impairment ☐ Visual impairment including blindness ☐ Sensory processing disorder ☐ Other sensory disorder **INTELLECTUAL AND DEVELOPMENTAL DISABILITIES** ☐ Autism/Autism Spectrum Disorder ☐ Down Syndrome ☐ ADD/ADHD ☐ Other intellectual or developmental disability **BEHAVIORAL DISORDERS** ☐ Generalized Anxiety Disorder ☐ Obsessive Compulsive Disorder ☐ Post Traumatic Stress Disorder ☐ Other behavioral disorder **NEUROLOGICAL DISORDERS** ☐ Alzheimer's/Dementia ☐ Traumatic Brain Injury ☐ Other neurological disorder **PHYSICAL HEALTH CONDITIONS** ☐ Complex medical conditions ☐ Palliative or Hospice Care ☐ Other physical health conditions (Original item)
Functional status	Katz Index of Independence in Activities of Daily Living Lawton Instrumental Activities of Daily Living (IADL) Scale Waisman Activities of Daily Living Scale (W-ADL)

Condition stability	Which of the following describes the condition of the person you care for (care receiver)? ☐ Their condition is getting BETTER ☐ Their condition is getting WORSE ☐ Their condition is remaining about the SAME ☐ Their condition is fluctuating or CHANGING (Original item)

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**	***Description of Respite Model Tool*** (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**	***Caregiver Experience with Respite Tool*** (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? ☐ All the time ☐ Some of the time ☐ 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? *Select all that apply.* ☐ I had to cut back the number of hours I work. ☐ I had to quit my job. ☐ I had to change to a different job. ☐ I was fired or let go from a job. ☐ No impact. ☐ 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

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Appendix B

Respite Model Description Tool

The purpose of the **Respite Model Description Tool** is to help researchers describe key aspects of respite interventions using common data elements that align with the *Value of Respite Model*. The following is a comprehensive list of questions that can be used to help describe key aspects of respite interventions. While it may not be feasible to assess all aspects, researchers are encouraged to include as many questions as possible in order to provide a comprehensive description of the respite intervention.

Population Served

What **age(s)** does the respite model serve? *Select all that apply.*

- ☐ Infants (birth to 3 years old)
- ☐ Preschool-age children (3-5 years old)
- ☐ School-age children (6-12 years old)
- ☐ Adolescents (13-17 years old)
- ☐ Young adults (18-29 years old)
- ☐ Adults (30-64 years old)
- ☐ Older adults (65 years and older)
- ☐ Other (please describe)

What types of **disabilities** and **conditions** does the respite model serve? *Select all that apply.*

- ☐ Physical disabilities (e.g., brain and spinal cord injury, amputations, spina bifida, multiple sclerosis, cerebral palsy, muscular dystrophy, epilepsy, and other neuromuscular disorders)
- ☐ Sensory disabilities (e.g., deafness/hard of hearing, visual impairment including blindness, sensory processing disorder)
- ☐ Intellectual and developmental disabilities (e.g.. Autism/ASD, Down syndrome)
- ☐ Behavioral disabilities (e.g., generalized anxiety disorder, obsessive compulsive disorder, PTSD)
- ☐ Alzheimer's and Dementia
- ☐ Complex medical conditions
- ☐ Palliative or hospice care
- ☐ Functional limitations
- ☐ None
- ☐ Other (please describe)

Does the respite model serve any of the following historically **underrepresented populations**? *Select all that apply.*

- ☐ Hispanic or Latino
- ☐ Black or African Americans
- ☐ Asian
- ☐ American Indian or Alaska Native
- ☐ Middle Eastern or North African
- ☐ Native Hawaiian or Pacific Islander
- ☐ Immigrants
- ☐ Refugees
- ☐ LGBTQ+
- ☐ Individuals experiencing homelessness
- ☐ Children served in crisis nurseries
- ☐ Children living in environments that increase the risk of adverse experiences
- ☐ Children cared for by grandparents or other relatives
- ☐ Veterans or military families
- ☐ Other (please describe)

Location of Respite

Where does respite occur? *Select all that apply.*

- ☐ Caregiver's home
- ☐ Care receiver's home
- ☐ Respite provider's home
- ☐ Respite facility
- ☐ Community-based
- ☐ Faith-based
- ☐ Hospital
- ☐ Skilled nursing facility
- ☐ Assisted living
- ☐ Adult Day Services
- ☐ Group home
- ☐ Foster home
- ☐ Virtual (by phone or internet)
- ☐ Other (please describe)

Type of Respite

Which of the following describes the **type** of respite provided? *Select all that apply.*

- ☐ Formal respite program (administered by an organization)
- ☐ Informal respite (provided by family and friends)
- ☐ Volunteer respite program (provided by volunteers)
- ☐ Faith-based respite program (provided by faith-based organization)
- ☐ Student respite program (provided by students)
- ☐ Shared respite model (caregiver participates with care receiver during respite)

What type of **care** is provided during respite? *Select all that apply.*

- ☐ Companion care
- ☐ Instrumental care (activities of daily living)
- ☐ Administering medication
- ☐ Medical (non-nursing) care
- ☐ Skilled nursing care
- ☐ Therapies (physical, occupational, speech)
- ☐ Other (please describe)

What **activities** do respite providers do with the care receiver during respite? *Select all that apply.*

- ☐ Rest and relaxation
- ☐ Self-care activities (i.e. take a bath, get a massage, enjoy time in nature)
- ☐ Housework (i.e. cleaning, doing dishes, doing laundry)
- ☐ Watch TV
- ☐ Run errands (i.e. get groceries, get gas, go to post office)
- ☐ Go shopping
- ☐ Help others
- ☐ Eat
- ☐ Cook
- ☐ Exercise
- ☐ Read or write
- ☐ Time with friends
- ☐ Listen to music
- ☐ Travel
- ☐ Personal or medical care
- ☐ Recreation
- ☐ Participate in sports
- ☐ Play cards or board games
- ☐ Arts and crafts
- ☐ Watch movies
- ☐ Attend concerts
- ☐ Attend plays and musicals
- ☐ Go out to eat
- ☐ Go to the movies
- ☐ Attend community events
- ☐ Other (please describe)

Timing of Respite

When is respite provided? *Select all that apply.*

- ☐ Regular scheduled/preventive
- ☐ As needed/on demand
- ☐ During transitions
- ☐ Crisis/emergency respite
- ☐ Other (please describe)

Is there currently a **waitlist** for respite?

- ☐ Yes (please describe)
  - ○ How many people are currently on the waitlist?
  - ○ What is the average wait time for services?
- ☐ No

Is **free transportation** provided to/from respite?

- ☐ Yes
- ☐ No
- ☐ Not applicable

What type of **community** does the respite model serve? *Select all that apply.*

- ☐ Rural (open country and towns or cities with fewer than 2,500 people)
- ☐ Small town or city (towns or cities between 2,500 and 49,000 people)
- ☐ Medium city (between 50,000 and 99,000 people)
- ☐ Medium-large city (between 100,000 and 250,000 people)
- ☐ Large city (over 250,000 people)

Dose of Respite

Describe the **dose** of respite. Consider both frequency (how often) and duration (how long) respite occurs.

Examples:

- 2 hours of respite 5 days a week during the school year (9 months/year)
- 8 hours of overnight respite every month
- 3 weekends of respite per year
- 1 week of respite every summer

Cost of Respite

How are respite costs **paid**? *Select all that apply.*

- ☐ Caregiver pays out of pocket
- ☐ Public insurance (e.g., Medicaid, Medicare, Veterans Affairs)
- ☐ Private insurance
- ☐ Government funding
- ☐ Grant funding
- ☐ Charitable organization
- ☐ Individual sponsors/donors
- ☐ Other (please describe)

What is the out-of-pocket **cost** of respite to caregivers?

- ☐ No cost (Free to caregiver)
- ☐ Sliding scale based on income (please describe)
- ☐ Set amount per unit of respite (please describe)
- ☐ Other (please describe)

Respite Service Model

Which of the following best describes the **respite service model**?

- ☐ Stand-alone service
- ☐ Integrated within another program
- ☐ Other (please describe)

How long (in years) has the program provided respite?

_____ years

Person- and Family-Centeredness

Which of the following **core concepts** of Person- and Family-Centered Care* for planning, delivery, and evaluation of respite services are achieved by the respite model? *Select all that apply.*

- ☐ **Respect and Dignity**

  Respite providers listen to and honor the perspectives and choices of family caregivers and care receivers. Caregivers' and care receivers' knowledge, values, beliefs, and cultural backgrounds are integrated into the planning and delivery of respite services to ensure that care respects their unique needs and preferences.

- ☐ **Information Sharing**

  Respite care providers communicate and share complete, unbiased information with family caregivers and care receivers in ways that are clear and supportive. Caregivers receive timely, accurate, and relevant information to actively participate in the planning and decision-making related to respite.

- ☐ **Participation**

  Family caregivers, and care receivers (if possible), are encouraged and supported to engage in the planning and decision-making of respite at their preferred level. They have the opportunity to be involved in decisions that affect the care of their loved ones, according to their comfort and preference.

- ☐ **Collaboration**

  Family caregivers, care receivers, and respite providers collaborate in developing, implementing, and evaluating respite services. This collaboration ensures that caregiver input and feedback are integral to the delivery and improvement of respite.

** Adapted from the Institute for Patient- and Family-Centered Care and informed by the National Center on Advancing Person-centered Practices and Systems (NCAPPS)*

Respite Provider

Which of the following describes the **respite providers**? *Select all that apply.*

- ☐ Respite providers are **trained**
- ☐ Respite providers are **experienced**
- ☐ Respite providers are **paid**
- ☐ Respite providers receive **benefits**
- ☐ Respite providers are **volunteers**
- ☐ Respite providers receive **volunteer hours**
- ☐ Respite providers are **students**
- ☐ Respite providers receive **course credit**
- ☐ Respite providers understand the **culture** of the caregiver
- ☐ Respite providers speak the preferred **language** of the caregiver
- ☐ Respite is consistently provided by the **same** provider or group of providers
- ☐ Respite is provided by **different** providers as available
- ☐ Other (please describe)

Cultural and Linguistic Competence

Which of the following **culturally and linguistically competent services standards*** are achieved by the respite model? *Select all that apply.*

- ☐ Provide effective, equitable, understandable, and respectful quality respite services that are responsive to diverse cultural health beliefs and practices, preferred languages, health literacy, and other communication needs.
- ☐ Recruit, promote, and support a culturally and linguistically diverse governance, leadership, and respite workforce that are responsive to the population in the service area.
- ☐ Educate and train governance, leadership, and respite workforce in culturally and linguistically appropriate policies and practices on an ongoing basis.
- ☐ Offer language assistance to individuals who have limited English proficiency and/or other communication needs, at no cost to them, to facilitate timely access to respite services.
- ☐ Provide easy-to-understand print and multimedia materials and signage in the languages commonly used by the populations in the service area.

** Adapted from the CLAS Standards and informed by the ARCH Cultural and Linguistic Competence Assessment for Respite Organizations*

Open Ended

Please provide any **additional information** that helps to describe the respite intervention.

The *Respite Model Description Tool* was developed by Dr. Kim Whitmore in conjunction with the work of the ARCH Committee for Advancement of Respite Research. This tool has not yet undergone formal validation procedures. For more information about the tool, email kimberly.whitmore@marquette.edu.

Suggested Citation: Whitmore, K. (2024). *Respite Model Description Tool*. ARCH National Respite Network and Resource Center. Available online at https://archrespite.org/library/cde-white-paper/.

Appendix C

Caregiver Experience with Respite Tool

The purpose of the **Caregiver Experience with Respite Tool** is to help researchers better understand the respite process and caregiver experience with respite using common data elements that align with the *Value of Respite Model*. The following is a comprehensive list of questions that researchers can use to help describe key aspects of the respite process and caregiver experience with respite. While it may not be feasible to assess all aspects, we encourage researchers to include as many questions as possible in order to provide a comprehensive description of the respite process and caregiver experience with respite.

Identify as a Caregiver

A family caregiver is someone who provides care and support to a family member, neighbor, or friend of any age who is ill or has a disability, or is at risk for adverse experiences. A family caregiver is not a paid professional. Care and support can include help with daily activities, managing medications, coordinating medical appointments, providing transportation, managing finances, running errands and providing emotional support.

Do you **identify** as a family caregiver?

☐ Yes ☐ No ☐ Unsure

Need for Respite

Respite is commonly referred to as a "break" from the demands of caregiving.

The ARCH Expert Panel on Respite Research defined respite as "planned or emergency care that provides a family caregiver some time away from caregiver responsibilities, and results in some measurable improvement in the wellbeing of the caregiver, care receiver, and/or family system."

Do you feel you have a **need** for respite?

☐ Yes ☐ No ☐ Unsure

Overall, are your respite needs being **met**?

☐ Yes ☐ No ☐ Unsure

Acceptance of Respite

Are you willing to **accept** (receive) respite?

☐ Yes ☐ No ☐ Unsure

[If "no" or "unsure"] What makes you **unwilling** or hesitant to accept (receive) respite? *Select all that apply.*

- ○ I am worried about the **cost** of respite
- ○ I am worried that respite providers do not have adequate **training** to care for my loved ones
- ○ I am worried about the **safety** of my loved one
- ○ I do not **trust** anyone else to care for my loved one
- ○ I feel **guilty** about taking a break from caring for my loved one
- ○ I am worried about **what others will think** of me if I take a break from caring for my loved one
- ○ I do not feel respite providers will provide services that align with my family's **culture**
- ○ Other (please describe)

Access to Respite Services that Meet the Family's Need

Have you **ever** received respite?

☐ Yes ☐ No

[If "no"] **Why** haven't you received respite?
Select all that apply.

- ○ I feel **I do not need** respite at this time
- ○ I do not know **where to find** respite
- ○ I am **unable** to find respite that meets the needs of my family
- ○ There are **no respite providers** in my area
- ○ There is a **waitlist** for respite
- ○ I cannot afford the **cost** of respite
- ○ Respite is not provided at the right **time**
- ○ The **location** of respite is not convenient
- ○ I do not have **transportation** for respite
- ○ I feel I cannot **trust** the respite provider
- ○ I do not feel my loved one is **safe** during respite
- ○ The respite provider does not understand or respect my **culture**
- ○ The respite provider does not speak my preferred **language**
- ○ Other (please describe)

Type of Respite

Do you **currently** receive respite?

☐ Yes ☐ No

There are many **types** of respite. For each type listed below, mark whether you have used this type of respite in the past, are currently using this type of respite, or desire to have this type of respite.

Type of Respite	Used in Past	Currently Using	Desire This Type
Respite provided at your (caregiver's) home	○	○	○
Respite provided at the home of the person you care for (care receiver)	○	○	○
Respite provided at the respite provider's home	○	○	○
Respite provided at a respite facility	○	○	○
Respite provided in the community	○	○	○
Respite provided at a faith-based location	○	○	○
Respite provided in a hospital	○	○	○
Respite camp	○	○	○
Adult Day Services	○	○	○
Overnight respite	○	○	○
Family members helping out, so you can have a break (informal respite)	○	○	○
Friends or neighbors helping out, so you can have a break (informal respite)	○	○	○
Respite provided by a paid respite provider	○	○	○
Respite provided by volunteers	○	○	○

Type of Respite	Used in Past	Currently Using	Desire This Type
Respite provided by students	○	○	○
Respite provided by a faith-based organization	○	○	○
Virtual respite (by phone or internet)	○	○	○
Short time-outs or "me-time" in or around your home (without anyone helping out)	○	○	○
Help from someone while I spend time with the person I care for without having the full responsibility of providing care (shared respite)	○	○	○
Other (please describe)			

On average, how many **hours** of respite do you get in a typical week? These would be hours that you can completely turn-off your caregiving responsibilities, while the needs and safety of your family member are not your primary responsibility.

_____ hours/week

How many hours of respite would you **like to get** in a typical week?

_____ hours/week

In general, is your respite **scheduled in advance**?

- ☐ Yes, I have a regular respite schedule that I can count on
- ☐ Sometimes
- ☐ No, I rarely know when or if I will get respite

Which of the following statements best describe the respite you are **currently receiving**? *Select all that apply*.

- ☐ I receive the right **type** of respite
- ☐ I receive respite at the right **time**
- ☐ Respite is provided in the right **location**
- ☐ I have adequate **transportation** for respite
- ☐ I receive the right **amount** of respite
- ☐ Respite is provided often enough (**frequency**)
- ☐ Respite is provided for the right length of time (**duration**)
- ☐ I can afford the **cost** of respite
- ☐ I have the right respite **provider**
- ☐ I feel I can **trust** the respite provider
- ☐ I feel my loved one is **safe** during respite
- ☐ The respite provider understands and respects my **culture**
- ☐ The respite provider speaks my preferred **language**

Overall, does the respite you are currently receiving **meet the needs** of your family?

☐ Yes ☐ Somewhat ☐ No

Respite Goals Achieved

From the list below, please select the activities you **desire** to participate in and the **actual** activities you participate in during respite. *Select all that apply.*

Activities	Desired *Activities you plan or hope to participate in during respite*	Actual *Activities you actually participate in during respite*
Sleep or nap	○	○
Time with family	○	○
Rest and relaxation	○	○
Self-care activities (i.e. take a bath, get a massage, enjoy time in nature)	○	○
Housework (i.e. cleaning, doing dishes, doing laundry)	○	○
Watch TV	○	○
Run errands (i.e. get groceries, get gas, go to post office)	○	○
Go shopping	○	○
Help others	○	○
Eat	○	○
Cook	○	○
Exercise	○	○
Read or write	○	○
Time with friends	○	○
Listen to music	○	○
Travel	○	○
Personal or medical care	○	○
Recreation	○	○
Hobby	○	○
Religious activity	○	○
Attend support group	○	○
Receive education to help in my role as a caregiver	○	○
Attend school (i.e. high school, technical school, college)	○	○
Work a job for pay	○	○
Volunteer	○	○
Attend medical appointments	○	○
Spend time with the person I care for	○	○
Other (please describe)		

Answer each statement about the respite you are **currently** receiving:

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
I am happy with what I choose to do during my respite time.	○	○	○	○	○
I look forward to my respite time.	○	○	○	○	○
I am able to do things I want to do during respite.	○	○	○	○	○
I didn't use my respite time the way I wanted.	○	○	○	○	○
I could improve how I use my respite time.	○	○	○	○	○

Overall, how **satisfied** are you with the activities you participate in during respite?

- ☐ Extremely satisfied
- ☐ Satisfied
- ☐ Somewhat satisfied
- ☐ Dissatisfied
- ☐ Extremely dissatisfied

Please describe your **goals** for respite:

Overall, are your goals for respite **met**?

☐ Yes ☐ Somewhat ☐ No

Satisfaction with Respite Services

Overall, how **satisfied** are you with the respite services you receive?

- ☐ Extremely satisfied
- ☐ Satisfied
- ☐ Somewhat satisfied
- ☐ Dissatisfied
- ☐ Extremely dissatisfied

Respite Outcomes

Which of the following statements describe the **benefits** you feel you receive from respite? *Select all that apply.*

HEALTH AND WELLBEING

- ☐ Respite improves my **physical health** and wellbeing
- ☐ Respite improves my **mental health** and wellbeing
- ☐ Respite improves my **social health** and wellbeing
- ☐ Respite improves my **spiritual health** and wellbeing
- ☐ Respite improves my **financial health** and wellbeing

QUALITY OF LIFE

- ☐ Respite improves **my individual** quality of life
- ☐ Respite improves the quality of life of t**he person I care for**
- ☐ Respite improves the quality of life of **my family**

RELATIONSHIPS

- ☐ Respite improves my relationship with **the person I care for**
- ☐ Respite improves my relationship with **my spouse/partner**
- ☐ Respite improves my relationship with **my children**
- ☐ Respite improves my relationship with **other family members**
- ☐ Respite improves my relationship with **my friends**

SOCIALIZATION

- ☐ Respite allows **me** to engage in more socialization
- ☐ Respite allows **the person I care for** to engage in more socialization

INCLUSION

- ☐ Respite allows **me** to feel more included in society
- ☐ Respite allows **the person I care for** to feel more included in society

COMMUNITY CONNECTEDNESS

- ☐ Respite allows **me** to feel more connected to the community
- ☐ Respite allows **the person I care for** to feel more connected to the community

EMPLOYMENT

- ☐ Respite allows me to **maintain** employment
- ☐ Respite allows me to **increase** hours I can work
- ☐ Respite allows me to be **more productive** at work
- ☐ No impact

HEALTHCARE UTILIZATION

- ☐ Respite improves my ability to access healthcare services **I need to stay healthy**
- ☐ Respite reduces the frequency of using **urgent care or emergency room services** for the person I care for
- ☐ Respite reduces the need for **institutional care** settings, such as assisted living, nursing homes, or hospitals, for the person I care for

SOCIAL SERVICES UTILIZATION

- ☐ Respite reduces my dependance on **social services** (i.e. food stamps, unemployment, childcare subsidies, and other welfare programs)

OTHER BENEFITS

- ☐ I receive **other benefits** from respite not previously listed (please describe)

Open-Ended Questions

How do you feel **before** receiving respite?

How do you feel **after** receiving respite?

How would you feel if you were **no longer able to receive any respite**?

Please describe **anything else** you would like to share about your experience with respite.

The *Caregiver Experience with Respite Tool* was developed by Dr. Kim Whitmore in conjunction with the work of the ARCH Committee for Advancement of Respite Research. We want to especially acknowledge the contribution of items from Dr. Rebecca Utz at the University of Utah. This tool has not yet undergone formal validation procedures. For more information about the tool, email kimberly.whitmore@marquette.edu.

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Appendix D

Common Data Elements for Respite Research Worksheet

The purpose of the **Common Data Elements for Respite Research Worksheet** is to help researchers identify the most appropriate common data elements for their projects by selecting from the list of recommended core concepts aligned with the *Value of Respite Model*.

Step 1

First, answer the following questions.

1. What **question(s)** do you hope to answer from your research or evaluation?

2. What **caregiver factors** do you need to know about to best understand the question you are trying to answer?
   Select at least one from the list of recommended core concepts aligned with the Value of Respite Model.

3. What **care receiver factors** do you need to know about to best understand the question you are trying to answer?
   Select at least one from the list of recommended core concepts aligned with the Value of Respite Model.

4. What **caregiver circumstances** do you need to know about to best understand the question you are trying to answer?
   Select at least one from the list of recommended core concepts aligned with the Value of Respite Model.

5. What **respite factors** do you need to know about to best understand the question you are trying to answer?
   Select at least one from the list of recommended core concepts aligned with the Value of Respite Model.

6. What **outcomes** are you interested in measuring?
   Select at least one from the list of recommended core concepts aligned the Value of Respite Model.

Recommended Core Concepts Aligned with the Value of Respite Model

CONTEXT *Risk and Protective Factors* CAREGIVER	CONTEXT *Risk and Protective Factors* CARE RECEIVER	PROCESS *Respite Factors*	OUTCOMES *Value of Respite*
Core concepts that help to describe risk and protective factors of the caregiver, include:	*Core concepts that help to describe risk and protective factors of the care receiver, include:*	*Core concepts that help to describe respite factors, include:*	*Core concepts that help to describe the value of respite, include:*
Caregiver Demographics ☐ age ☐ race/ethnicity ☐ language	**Care Receiver Demographics** ☐ age ☐ race/ethnicity ☐ language	**Description of Respite Model** ☐ 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	**Caregiver Physical Wellbeing** ☐ global health ☐ sleep ☐ fatigue
Caregiver Wellbeing* ☐ physical ☐ mental ☐ social ☐ spiritual ☐ financial ☐ quality of life	**Care Receiver Wellbeing** ☐ condition(s)/disability(ies) ☐ functional status ☐ condition stability	**Caregiver Experience with Respite** ☐ 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	**Caregiver Mental Wellbeing** ☐ stress ☐ anxiety ☐ depression ☐ self-efficacy ☐ resilience **Caregiver Social Wellbeing** ☐ loneliness ☐ social engagement **Caregiver Spiritual Wellbeing** **Caregiver Financial Wellbeing** ☐ financial burden ☐ job loss/reduced hours **Quality of Life** ☐ individual ☐ family
Caregiving Circumstances ☐ relationship to care receiver ☐ time as a caregiver ☐ care receiver needs (companion vs skilled) ☐ care complexity of care receiver ☐ living situation ☐ perception of caregiving burden ☐ caregiving intensity			

** We recommend obtaining baseline measures of caregiver wellbeing that align with outcome measures of interest, when feasible.*

Step 2

Review the list of *Recommended Common Data Elements* to identify the best way to measure the concepts you have identified. Use the table below to document this process.

Concept	Measure(s)

The *Common Data Elements for Respite Research Worksheet* was developed by Dr. Kim Whitmore in conjunction with the work of the ARCH Committee for Advancement of Respite Research. For more information about the tool, email kimberly.whitmore@marquette.edu.

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