



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 <i>Risk and Protective Factors</i> CAREGIVER	CONTEXT <i>Risk and Protective Factors</i> CARE RECEIVER	PROCESS <i>Respite Factors</i>	OUTCOMES <i>Value of Respite</i>
<p><i>Core concepts that help to describe risk and protective factors of the caregiver, include:</i></p> <p>Caregiver Demographics</p> <ul style="list-style-type: none"> <input type="checkbox"/> age <input type="checkbox"/> race/ethnicity <input type="checkbox"/> language <p>Caregiver Wellbeing*</p> <ul style="list-style-type: none"> <input type="checkbox"/> physical <input type="checkbox"/> mental <input type="checkbox"/> social <input type="checkbox"/> spiritual <input type="checkbox"/> financial <input type="checkbox"/> quality of life <div style="background-color: #0072bc; color: white; padding: 10px; margin-top: 10px;"> <p>Caregiving Circumstances</p> <ul style="list-style-type: none"> <input type="checkbox"/> relationship to care receiver <input type="checkbox"/> time as a caregiver <input type="checkbox"/> care receiver needs (companion vs skilled) <input type="checkbox"/> care complexity of care receiver <input type="checkbox"/> living situation <input type="checkbox"/> perception of caregiving burden <input type="checkbox"/> caregiving intensity </div>	<p><i>Core concepts that help to describe risk and protective factors of the care receiver, include:</i></p> <p>Care Receiver Demographics</p> <ul style="list-style-type: none"> <input type="checkbox"/> age <input type="checkbox"/> race/ethnicity <input type="checkbox"/> language <p>Care Receiver Wellbeing</p> <ul style="list-style-type: none"> <input type="checkbox"/> condition(s)/disability(ies) <input type="checkbox"/> functional status <input type="checkbox"/> condition stability 	<p><i>Core concepts that help to describe respite factors, include:</i></p> <p>Description of Respite Model</p> <ul style="list-style-type: none"> <input type="checkbox"/> type of respite <input type="checkbox"/> timing of respite <input type="checkbox"/> location of respite <input type="checkbox"/> dose of respite <input type="checkbox"/> cost of respite <input type="checkbox"/> respite service model <input type="checkbox"/> person- and family-centeredness <input type="checkbox"/> respite provider <input type="checkbox"/> cultural and linguistic competence <p>Caregiver Experience with Respite</p> <ul style="list-style-type: none"> <input type="checkbox"/> identify as a caregiver <input type="checkbox"/> need for respite <input type="checkbox"/> acceptance of respite <input type="checkbox"/> access to respite services that meet the family's needs <input type="checkbox"/> respite goals achieved <input type="checkbox"/> satisfaction with respite services 	<p><i>Core concepts that help to describe the value of respite, include:</i></p> <p>Caregiver Physical Wellbeing</p> <ul style="list-style-type: none"> <input type="checkbox"/> global health <input type="checkbox"/> sleep <input type="checkbox"/> fatigue <p>Caregiver Mental Wellbeing</p> <ul style="list-style-type: none"> <input type="checkbox"/> stress <input type="checkbox"/> anxiety <input type="checkbox"/> depression <input type="checkbox"/> self-efficacy <input type="checkbox"/> resilience <p>Caregiver Social Wellbeing</p> <ul style="list-style-type: none"> <input type="checkbox"/> loneliness <input type="checkbox"/> social engagement <p>Caregiver Spiritual Wellbeing</p> <p>Caregiver Financial Wellbeing</p> <ul style="list-style-type: none"> <input type="checkbox"/> financial burden <input type="checkbox"/> job loss/reduced hours <p>Quality of Life</p> <ul style="list-style-type: none"> <input type="checkbox"/> individual <input type="checkbox"/> family

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

