

Roundtable Discussion Guide

Group 1: Individual, family, and societal outcomes research

Overview of the Key Recommendation

The Panel identified the family caregiver as the “portal of entry” for future respite research and set the expectation that at least one outcome relating to caregiver well-being and quality of life be measured during any research study. However, the Panel specified that a focus on family caregiver outcomes does not negate the need to study additional outcomes. Recommendations reflect the Panel’s recognition of benefits that may also accrue from respite to the care receiver, the family system, and society, and are therefore appropriate for inclusion in research studies.

Overarching question

What is needed to advance respite-related outcomes research?

Equity lens reminder

In our discussion, consider how we can ensure respite-related outcomes research represents the broad diversity of family caregivers and care-receivers across the lifespan.

Question 1

If resources were not an issue, what are the respite-related outcomes research/evaluation questions that you would want answered? Consider:

- If you work with a respite program, what outcomes matters most to you?
- If you are a researcher, what research design and methods you would use to measure outcomes?
- Are there questions you would want answered related to a specific racial or ethnic group or other under-represented group?
- What aspects of caregiver well-being and quality of life should we be measuring?
- What outcomes related to the care receiver, the family system, and society should we be measuring?
- How should we measure these outcomes? Do you have any recommended survey tools or instruments we should consider?

Question 2

What are the major barriers to conducting high quality respite-related outcomes research and how can we work together to overcome them?

- What are the barriers to conducting outcomes research that represents the broad diversity of family caregivers and care-receivers? Consider specific racial and ethnic groups or other underrepresented groups you work with.
- How can we overcome recruitment and retention barriers for family caregivers?
- How can we overcome funding barriers for respite-related outcomes research?

Question 3

How can we make respite-related outcomes research more relatable and transferrable to respite practice?

- What methods of dissemination should we consider? What is the best way to share research findings with practice partners, funders, and policymakers?
- What are effective strategies for engaging respite providers, family caregivers, and care-receivers in the research process?

Summary

We now want to take a few minutes to reflect on the overall conversation. Consider the following questions:

- What key themes did you notice?
- What stood out to you as key ideas from our conversation?
- What questions do you still have?
- What do you feel is the most important thing we can do to advance respite-related outcomes research?