

Invitation to Participate

DEVELOPING A QUALITY MEASURE FOR CAREGIVERS OF PEOPLE WITH DEMENTIA

The CMS Innovation Center (CMMI) is interested in reducing the strain on unpaid caregivers of people with dementia

The National Quality Forum and Yale Center for Outcomes Research and Evaluation invite you to participate in the development of a caregiver-reported outcome measure on behalf of CMMI.

This measure will help assess the impact of the [Guiding an Improved Dementia Experience \(GUIDE\) Model](#), which is testing an alternative payment method for providing comprehensive dementia care and support for Medicare beneficiaries and their caregivers.

The measure will use the Zarit Burden Interview (ZBI) to assess caregiver burden. The online questionnaires will be automatically sent to enrolled caregivers via email or text message.

Your Role in Measure Testing

Recruit

Identify patients with dementia and their unpaid caregivers.

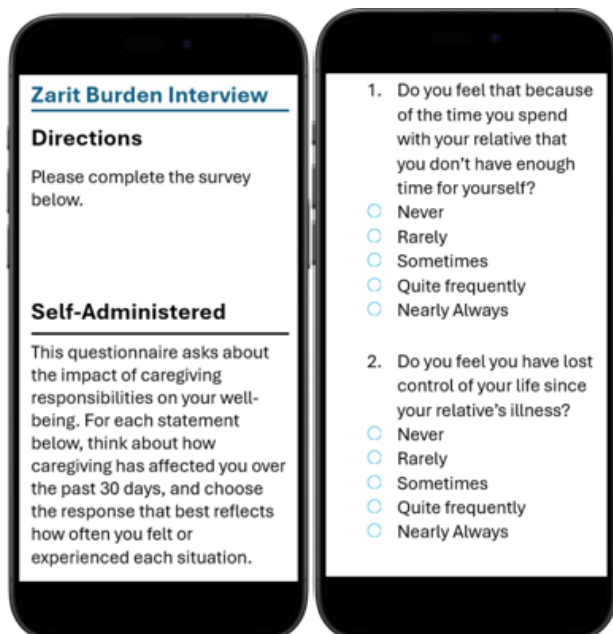
Provide handouts to caregivers and confirm whether they are interested in participating.

Enroll

Answer a few short questions about each caregiver and the person they care for in a secure online portal **before July 1, 2025**.

Share Insight

Provide feedback on implementation and clinical considerations to optimize measure development and use.



Clinical sites with large panels of dementia patients that are not currently participating in the GUIDE model may be eligible for this measure development and implementation testing opportunity.

Your input could help to shape a measure that will support caregivers and clinicians, and which may be incorporated into future accountability and value-based payment programs.

To learn more, contact us at caregiverburden@qualityforum.org



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Frequently Asked Questions

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Participation Eligibility

Q: For the purposes of this project, what is the definition of an “unpaid caregiver”?

An unpaid caregiver is defined as a relative or unpaid nonrelative who assists the beneficiary with activities of daily living and/or instrumental activities of daily living. The assistance may be episodic, daily, or occasional.

Q: Who is eligible for participation?

Any unpaid caregiver (defined as a relative or unpaid nonrelative who assists the beneficiary with activities of daily living and/or instrumental activities of daily living, whether the assistance is episodic, daily, or occasional) of a patient treated in the community with a diagnosis of dementia is eligible, regardless of the patient’s age or payer status.

Q: We are participating in the CMMI GUIDE Model. Can we be a test site for measure development?

GUIDE sites are not eligible to participate in this project at this time given the overlap with GUIDE Model activities.

Data Collection and Handling

Q: What patient information will need to be shared?

Only minimal patient information is required since the primary focus is on the unpaid caregiver burden. We will need the patient’s first name and age to match with Medicare data. Patient ZIP code will also be used for an [Area Deprivation Index](#) calculation.

Q: Do you require signed patient or caregiver consent?

This project does not require participating sites to obtain patient consent or IRB review. As background, activities designed to support measuring and reporting provider performance are not considered “research.” Please see the HHS Office for Human Research Protections FAQ document on quality improvement-related studies [here](#), and we will provide additional guidance upon enrollment.

Q: Can we see caregivers’ responses to the ZBI?

As part of this collaboration with NQF and Yale/CORE, you will be able to export caregiver-level data from PatientIQ, including question-by-question responses to the ZBI-22 instrument. However, New Program Track GUIDE sites are not able to use the data collected for this project (NQF collaboration) as part of the GUIDE Model initial assessment. The GUIDE Model requires that you re-assess the caregiver at the time of beneficiary alignment to the GUIDE model.

Q: For New Program Track GUIDE sites, can we use the data collected for measure testing to complete the GUIDE Model initial assessment starting July 1?

No, data collected for measure testing is independent and cannot be used to complete the GUIDE Model initial assessment. New Program Track GUIDE sites should plan to administer the ZBI again for submission to the GUIDE model at the time of beneficiary alignment, following GUIDE model data submission instructions.

Time Commitment

Q: What role will the practice play in identifying and connecting us with eligible caregivers?

The practice or clinician will be responsible for identifying the unpaid caregiver and entering basic information into a secure web portal, a process that takes approximately 2-5 minutes per patient/caregiver. We will provide a short training video prior to participation and offer ongoing technical assistance throughout the process.



If you are considering participation, email
caregiverburden@qualityforum.org