

Guiding an Improved Dementia Experience (GUIDE) Model Evaluation: Respite Care

ARCH Respite Research Summit

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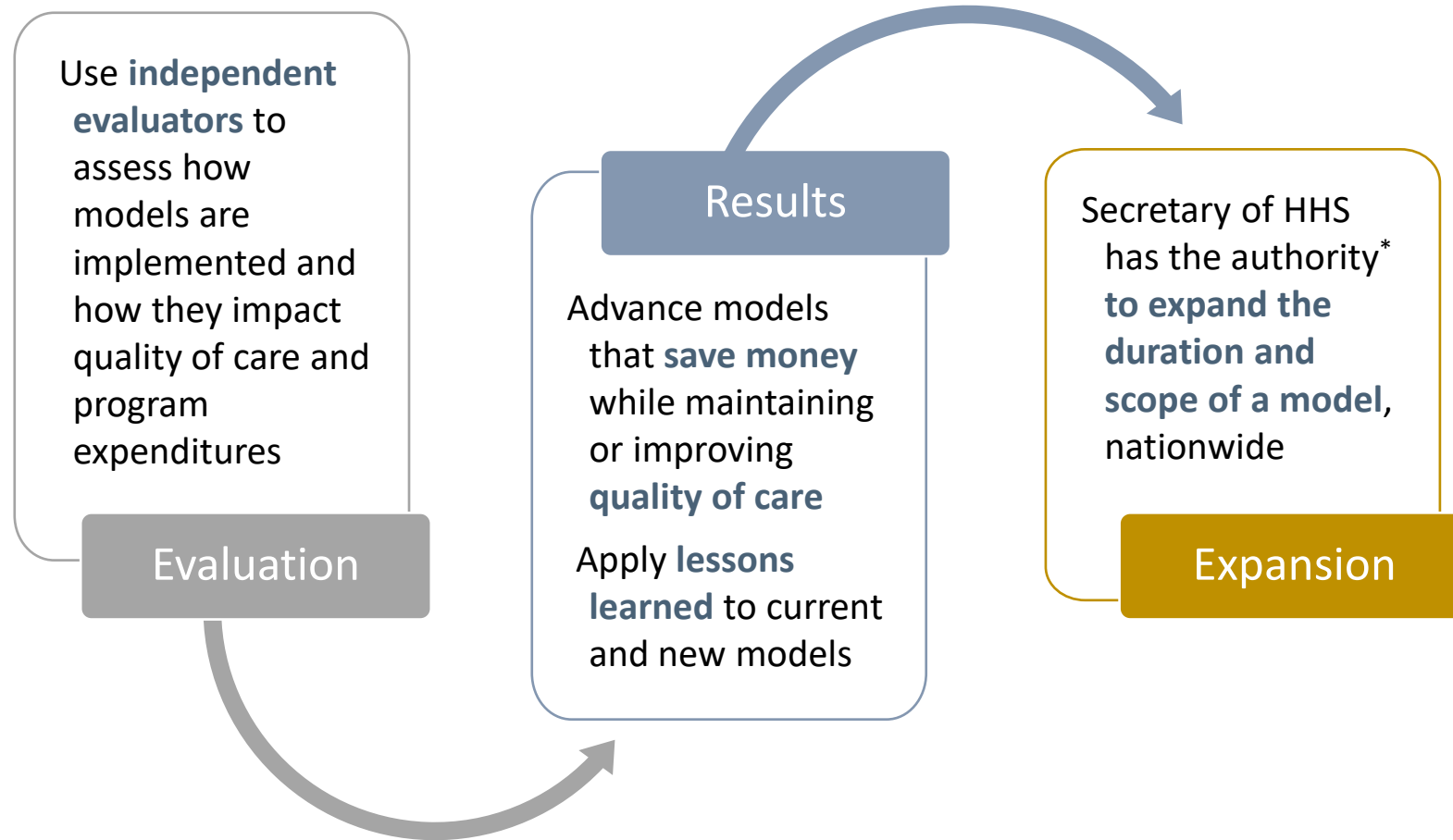
October 28, 2024

Objectives

- 1 | Briefly describe the purpose of CMS Innovation Center model evaluations
- 2 | Share GUIDE evaluation approach (to date), with a focus on respite care
- 3 | Discuss alignment with ARCH's Committee for Advancement of Respite Research (CARR) framework and common data elements

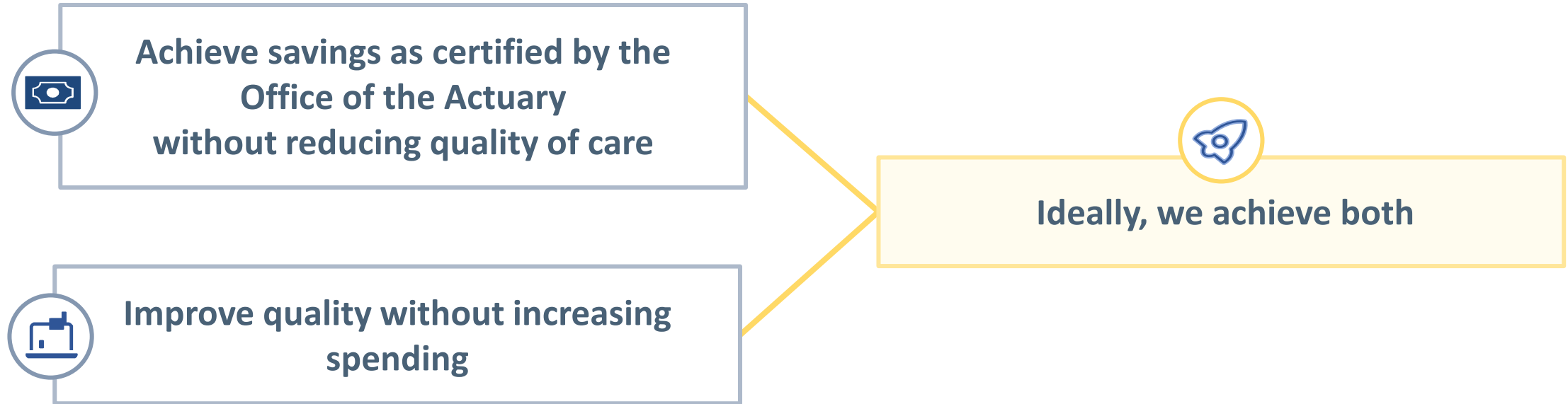
CMS Innovation Center

Evaluating results and advancing best practices



* Under Section 1115A(c) of the Social Security Act pending model expansion determinations performed by CMS under section 1115A(b)(4).

Pathways to model expansion



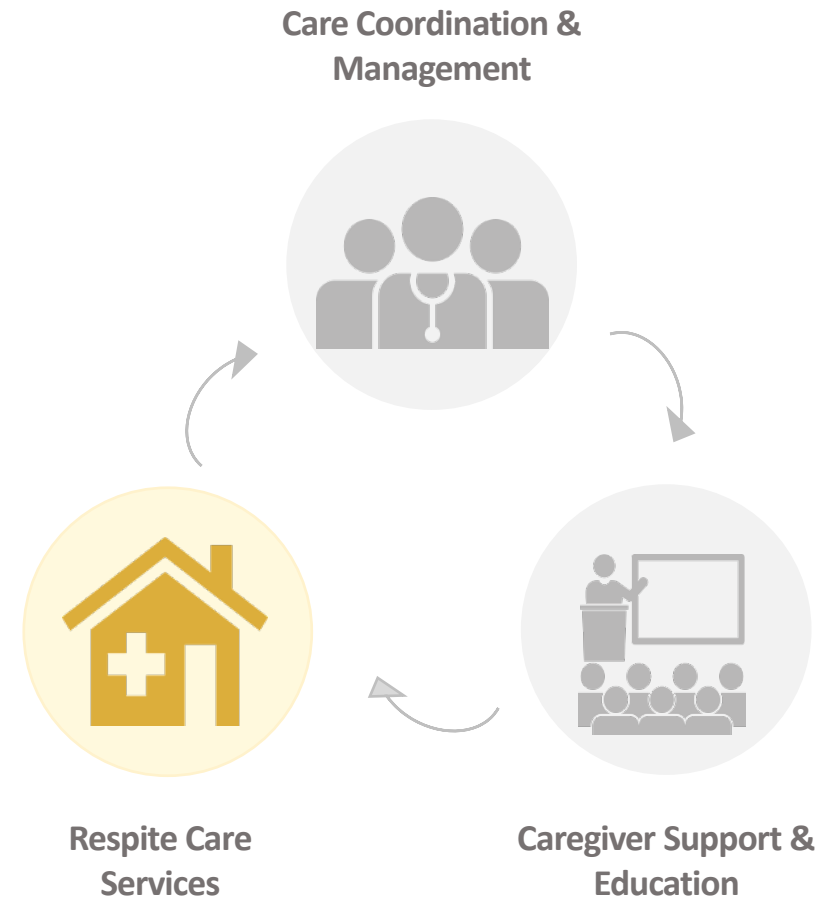
Evaluations are required by statute to inform whether we achieved these goals and to release timely public results.

GUIDE Model Overview

GUIDE Model purpose

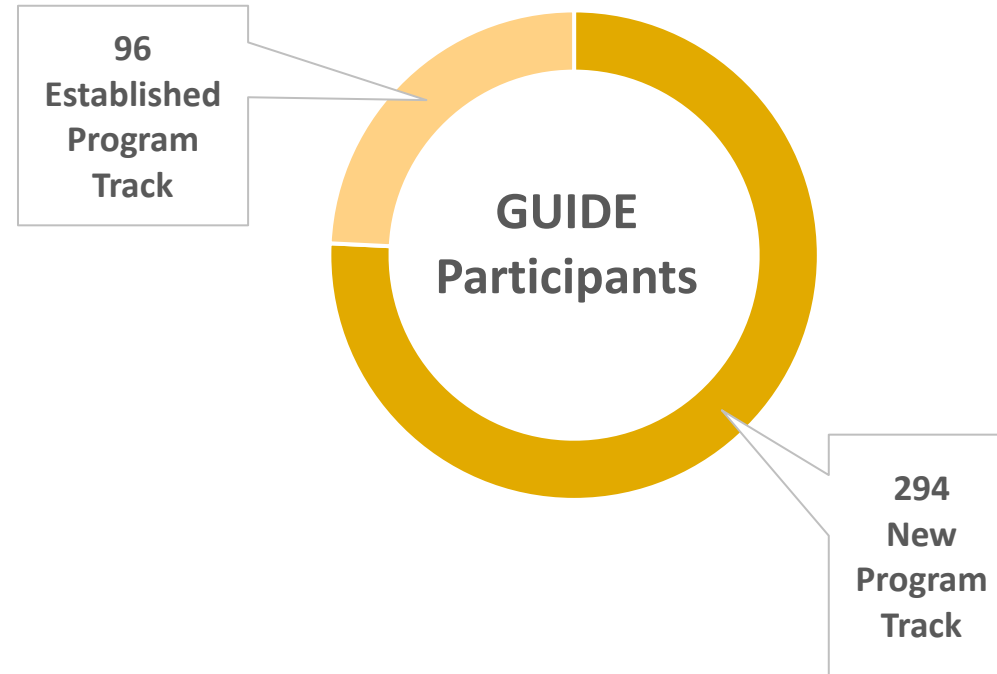
To test whether a comprehensive package of services **including respite care** can:

1. Improve the quality of care and **quality of life** for people living with dementia
2. Reduce **caregiver burden** and strain
3. Enable more people to remain at home by reducing or delaying **long-term nursing home stays**



GUIDE Model status

- **390 participants in 46 states**
- Established Program Track started aligning patients in July 2024
- New Program Track starts in July 2025 after a pre-implementation period*
- **200,000 Medicare beneficiaries** with dementia and their families are anticipated to be served over **8-year model test**.



* New program development is intended to help increase beneficiary access to specialty dementia care, particularly in underserved communities.

GUIDE beneficiary eligibility requirements



Dementia diagnosis

Beneficiary has dementia confirmed by attestation from clinician practicing in a participating GUIDE dementia care program



Enrolled in Medicare Parts A & B

Must have Medicare as primary payer and not enrolled in Medicare Advantage or Special Needs Plans (SNPs)



Not residing in long-term nursing home

Resides in the community in a service area of the model participant



Has not elected the Medicare hospice benefit

Services overlap with services under the GUIDE Model



Not enrolled in PACE

Services overlap with services under the GUIDE Model

Voluntary Alignment Process

Participants must document that a beneficiary (or their legal representative if applicable) consents to align to the participant.

Participants may have beneficiaries self-referred to them based on letters sent by CMS, or by other provider referrals.

Care delivery requirements

COMPREHENSIVE ASSESSMENT

Beneficiaries and caregivers receive separate assessments to identify their needs and a home visit to assess safety.

CARE PLAN

Beneficiaries receive care plans that address their goals, preferences, and needs, which helps them feel certain about next steps.

24/7 ACCESS

Beneficiaries and caregivers have 24/7 access to a member of their care team or help line (may be a 3rd party vendor off-duty hours).

ONGOING MONITORING & SUPPORT

Care navigators provide long-term help to beneficiaries and caregivers and revisit goals and needs at any time.

REFERRAL & SUPPORT COORDINATION

Beneficiaries' care navigator connects them and their caregivers to community-based services and supports.

CARE COORDINATION & TRANSITION

Beneficiaries receive timely referrals to specialists to address other health issues, such as diabetes, and the care navigators coordinate with specialist.

MEDICATION MANAGEMENT

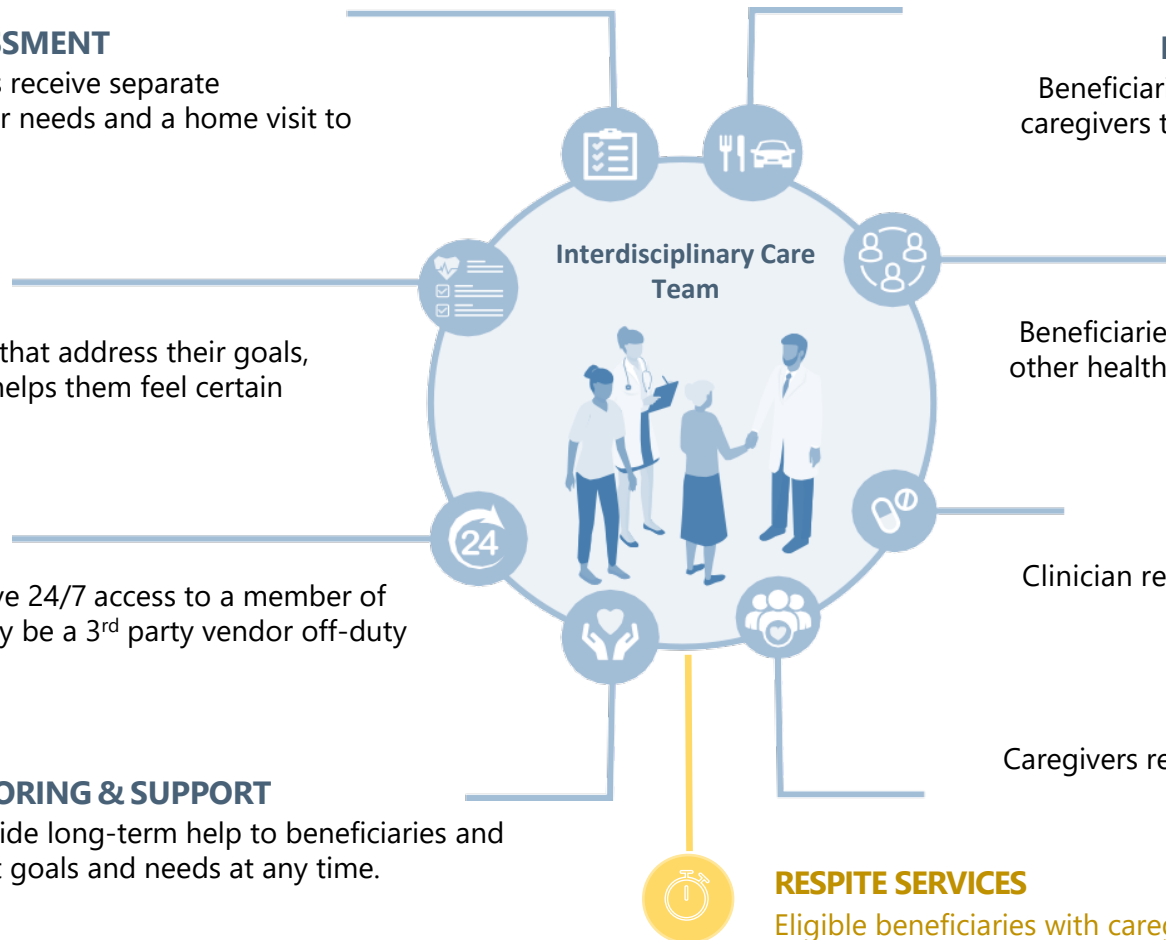
Clinician reviews and reconciles medication as needed.

CAREGIVER EDUCATION & SUPPORT

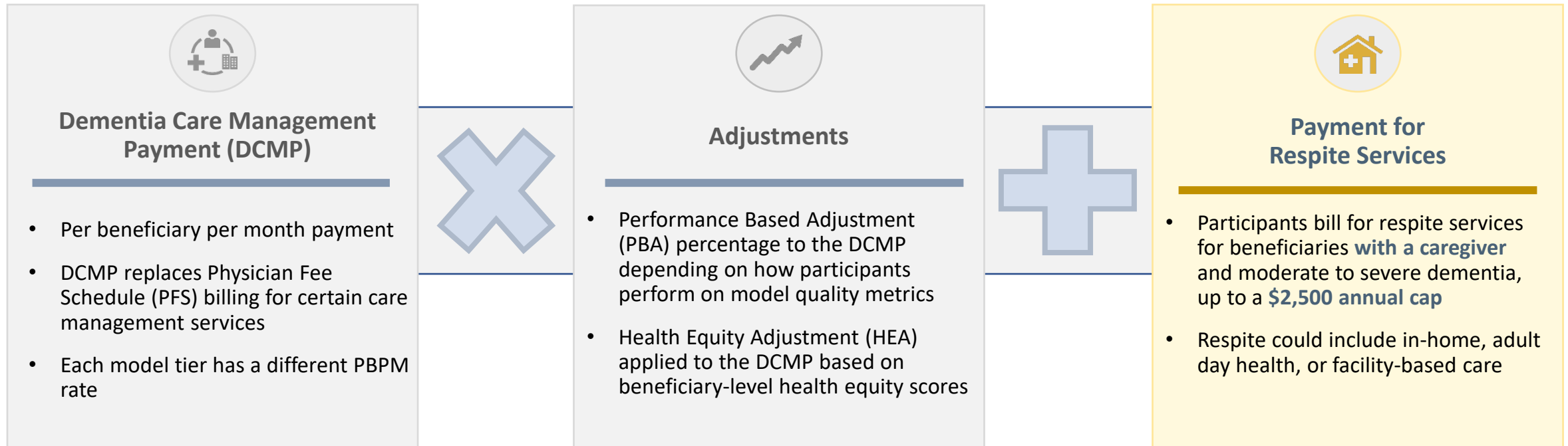
Caregivers receive education and support via ad hoc calls and caregiver training.

RESPITE SERVICES

Eligible beneficiaries with caregivers may receive GUIDE respite services.



Payment methodology



Participants classified as safety-net providers may also be eligible for a one-time infrastructure payment.

GUIDE Model Evaluation

Main goals of the GUIDE evaluation

- To assess GUIDE's effects on Medicare beneficiaries'
 - **Quality of life** and quality of care
 - Experiences of care, including **caregiver burden**
 - Medicare expenditures and **long-term nursing home stays**
 - Health care service use and disparities in health outcomes
- To understand **factors associated with effects, including GUIDE Model components such as respite care**, and how effects differ across participants and beneficiaries
- To understand participants' and beneficiaries' **care decisions and GUIDE implementation**



Overview of approach to implementation assessment



Dyad experience survey & interviews



Participant site visits



State & Medicaid leader interviews



Care navigator survey & interviews



GUIDE program/application data



Claims **including respite services (G-code)**



- Understanding model participation
- Characterizing patient pathways into the model
- Describing model implementation and health care transformation

Primary data

Secondary data

Overview of impact estimation

Data & outcomes

- Beneficiary-caregiver dyad experience **survey** to measure **experience of care, quality of life, and caregiver burden**
- Medicare and Medicaid **claims** and enrollment/encounter data to measure **service use, health expenditures, and quality of care**
- Measures of **disparities**, based on both survey and claims data



Estimating impacts

- Compare **outcomes** between **GUIDE-aligned beneficiaries** and a **matched comparison group** receiving usual care in the same states and time periods
- Conduct **subgroup analyses** to assess variation in impacts
- Use a **difference-in-differences analysis** to estimate impacts on area-level measures of dementia diagnosis disparities and access to providers

Overview of approach to patient experience assessment

Survey a **subset of GUIDE-aligned and matched comparison** beneficiary-caregiver dyads over time to collect:

- **Quality of life** and care (PROMIS-10)*
 - **Caregiver burden** and strain (ZBI-12)*
 - Experience and **satisfaction** with care **including respite services** (PCPCM-PRO, other)*
 - Demographics and **health-related social needs** (AHC HRSN)*
- Conduct **longitudinal dyad interviews** to understand care experience and satisfaction over time (intervention group only)
 - Use program/application **data submitted by model participants** to understand care delivery, assessments, quality, and health equity (intervention group only, aggregate)

** Measures for these outcomes are not available in claims data. Data will need to be collected directly from beneficiaries and caregivers.*

An integrated mixed methods approach

Tying lessons together

Reports will synthesize implementation and impact results and **assess the potential for model expansion** and broader health **transformation**



Equitable evaluation principles

Patient, caregiver, and participant experiences **including respite care**, will be used to estimate effects and examine how structural and social conditions moderate effects

Discussion with ARCH

Consistent and inclusive definitions and terminology

- **Identify consistent definitions**

- *“Respite care provides short-term relief for primary caregivers, giving them time to rest, travel, or spend time with other family and friends. The care may last anywhere from a few hours to several weeks at a time. Respite care can take place at home, in a health care facility, or at an adult day care center.”*
- **“What is respite care?”** <https://www.nia.nih.gov/health/caregiving/what-respice-care>
- Align with terminology from federal and state partners and recommendations from ARCH CARR and other advocates

- **Include descriptive phrases in data collection**

- Ensure that all respondents can understand survey items and questions and provide accurate responses, even if not familiar with the term **respite care**
- Consider the diverse needs and responsibilities of caregivers
- Minimize burden

Possible respite measures/items for GUIDE evaluation

Claims and programmatic data

- **Percentage of participants providing GUIDE respite services** by mode
 - home, facility, adult day health
 - types of partner organizations, if used
- **Frequency of respite service use**
 - number per year per beneficiary with caregivers
 - number per year among users
- **Distributions** by percentile of participants' total and per-beneficiary monthly respite payments
- **Dollars per beneficiary per month** for GUIDE respite care and other GUIDE payments
- **Use of HCBS respite care** through Medicaid

Survey and interview items

- **Sociodemographic** data
- **Use of respite services** and other support
- **Satisfaction** with respite care received
- **Process for deciding to use respite care**
 - goals of care
 - access to outside support
- **Identity** as a caregiver, experience with/without respite care
- **Out-of-pocket expenses** for care
- **Self-reported health** (caregiver and patient)
- **Wellness**, physical and emotional
- **Unmet needs**

Effect of respite care on GUIDE outcomes

- **GUIDE is testing a *package* of comprehensive services**
 - What factors or GUIDE Model components **including respite services** appeared to be associated with the pattern of results?
 - Data availability, response rates
 - Qualitative data on experience using respite services
- **Hypothesis-testing**
 - **Reduced caregiver burden and strain** (through caregiver training and education) **combined with use of GUIDE respite services** could delay or prevent beneficiaries' needs for health service use, long-term nursing home care, and possibly hospice care.
 - Conversely, better coordination with other providers or shared decision making could facilitate hospice enrollment more often or earlier.

Model resources

The GUIDE Model team has a host of resources to support interested organizations. To see the latest resources, visit <https://innovation.cms.gov/innovation-models/guide>

Model Factsheets

[Model Overview](#), [Dementia Pathways Infographic](#), and [Participant Incentives](#)

Data Link

To access reports and data, go to [HealthData.gov](https://www.healthdata.gov)

Helpdesk

If you have questions for the GUIDE Model team, please email us at GUIDEModelTeam@cms.hhs.gov

[Follow us @CMSinnovates](#)

Guiding an Improved Dementia Experience (GUIDE) Model Overview Factsheet

MODEL PURPOSE

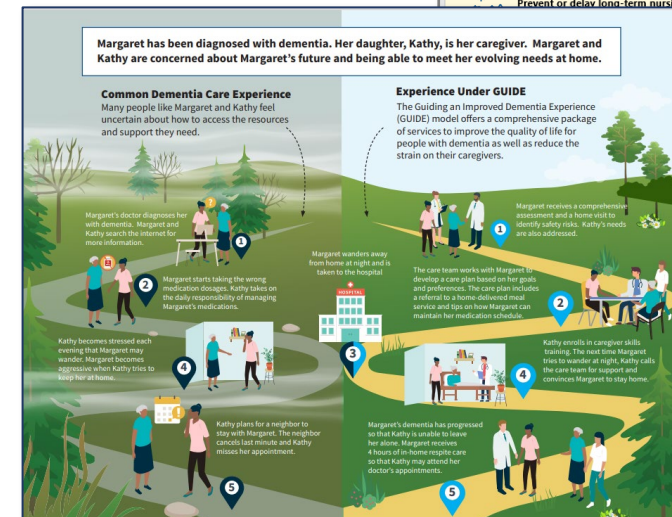
Alzheimer's Disease and Related Dementia (ADRD) is a major public health issue and is increasingly affecting the American population. About 6.7 million Americans currently live with Alzheimer's disease or another form of dementia, a number that is projected to grow by nearly 14 million by 2060. To help address this, the GUIDE Model aims to:

- Improve quality of life for people with dementia** by addressing their behavioral health needs and functional status, coordinating care for dementia and co-occurring conditions, and improving transitions between community, hospital, and post-acute settings.
- Reduce burden and strain on unpaid caregivers of people with dementia** by providing caregiver skills training, support services, referring to community-based social services and supports, 24/7 care team access, and respite services.
- Prevent or delay long-term nursing home care** for as long as appropriate by helping people with dementia to remain in safety.

...defining and requiring a comprehensive, ...
...the following:
...ary care ...
... A training requirement for care navigators who are part of the care team.
... by creating and maintaining a person-...
...the beneficiary's goals, strengths, and needs; ...
...ditions for service providers and ...

CAREGIVER SERVICES

Participants will assess and address caregiver needs and include the caregiver as part of the care team. Caregiver services will include ongoing monitoring and support and 24/7 hotline access to a support line.



Thank you for attending this session!

Please email your comments to lynn.miescier@cms.hhs.gov

Appendix

GUIDE participation requirements



Meet the interdisciplinary care team, care delivery, and training requirements (see the Care Delivery section and Appendix B of the RFA).



Use an electronic health record platform that meets CMS and Office of the National Coordinator for Health Information Technology (ONC) standards for Certified Electronic Health Record Technology (CEHRT).



May provide care delivery services virtually or in-person but must have the ability to conduct an initial home visit in-person for aligned beneficiaries who have moderate to severe dementia.



Must make available for eligible beneficiaries **GUIDE Respite Services** in the beneficiary's home. Participants have the option to offer eligible beneficiaries GUIDE Respite Services at an adult day center or a facility that can provide 24-hour care.



Maintain an up-to-date GUIDE Practitioner Roster and Partner Organization Roster (if applicable).



Comply with all model reporting requirements, including care delivery, sociodemographic data, and quality reporting.