



Atrium Health
Wake Forest Baptist

Remote Dementia Care

Lessons from D-CARE Pragmatic Clinical Trial to Achieve the
Triple Aim

2022 Autumn Move to Value Summit

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Disclosures



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Patient-centered Outcomes
research Institute



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Outline

What is comprehensive dementia care? Why now?

Landscape of dementia care clinical trials

Dementia Care (D-CARE) Study

Challenges & adaptations for rural communities

Triple aim 1: Improved patient/care partner experience

Triple aim 2: Improved quality

Triple aim 3: Lower cost

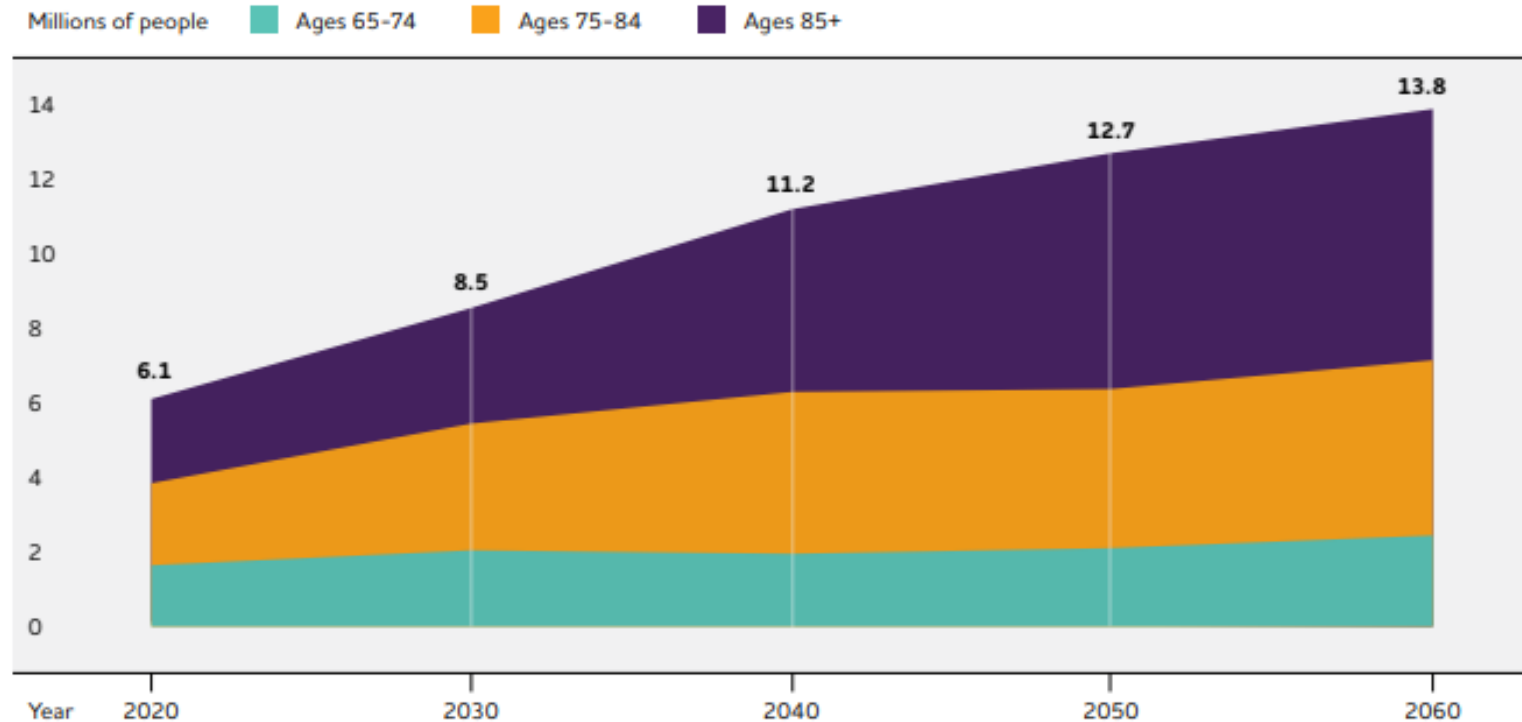
A case...Mama K

- King NC
- Lives with daughter but son is her HPOA
- Alzheimer's dementia
- Not bathing, not sleeping
- Defecating in kitchen trash can rather than using toilet
- Medicare only
- Refuses to leave home

Dementia is a growing problem

figure 5

Projected Number of People Age 65 and Older (Total and by Age) in the U.S. Population with Alzheimer's Dementia, 2020 to 2060



Created from data from Rajan et al.^{46,224}

Alzheimer's & related dementias

6.1 million Americans in 2020 → 14 million in 2060

Dementia is not just a chronic condition

Dementia affects ALL chronic conditions

3x hospitalizations
\$\$\$\$

Current dementia care quality is poor

- Primary care providers are busy and have few patients with dementia in their panels
 - Lack time & expertise

**Adaptable,
Timely,
Supportive**

- Dementia affects ALL other medical comorbidities' management + financial, legal ramifications
- Dyadic relationships
- <50% have had an evaluation for dementia
- <50% are told about the diagnosis of dementia

- Patient/family needs:
 - Accurate & timely diagnosis
 - Counseling regarding safety risks (money, med, driving)
 - Training in behavioral management
 - Coordination to community resources
 - Financial & legal planning
 - Anticipatory guidance for transitions of increasing care needs
 - Communication with other care settings (SNFs, home care, LTC)

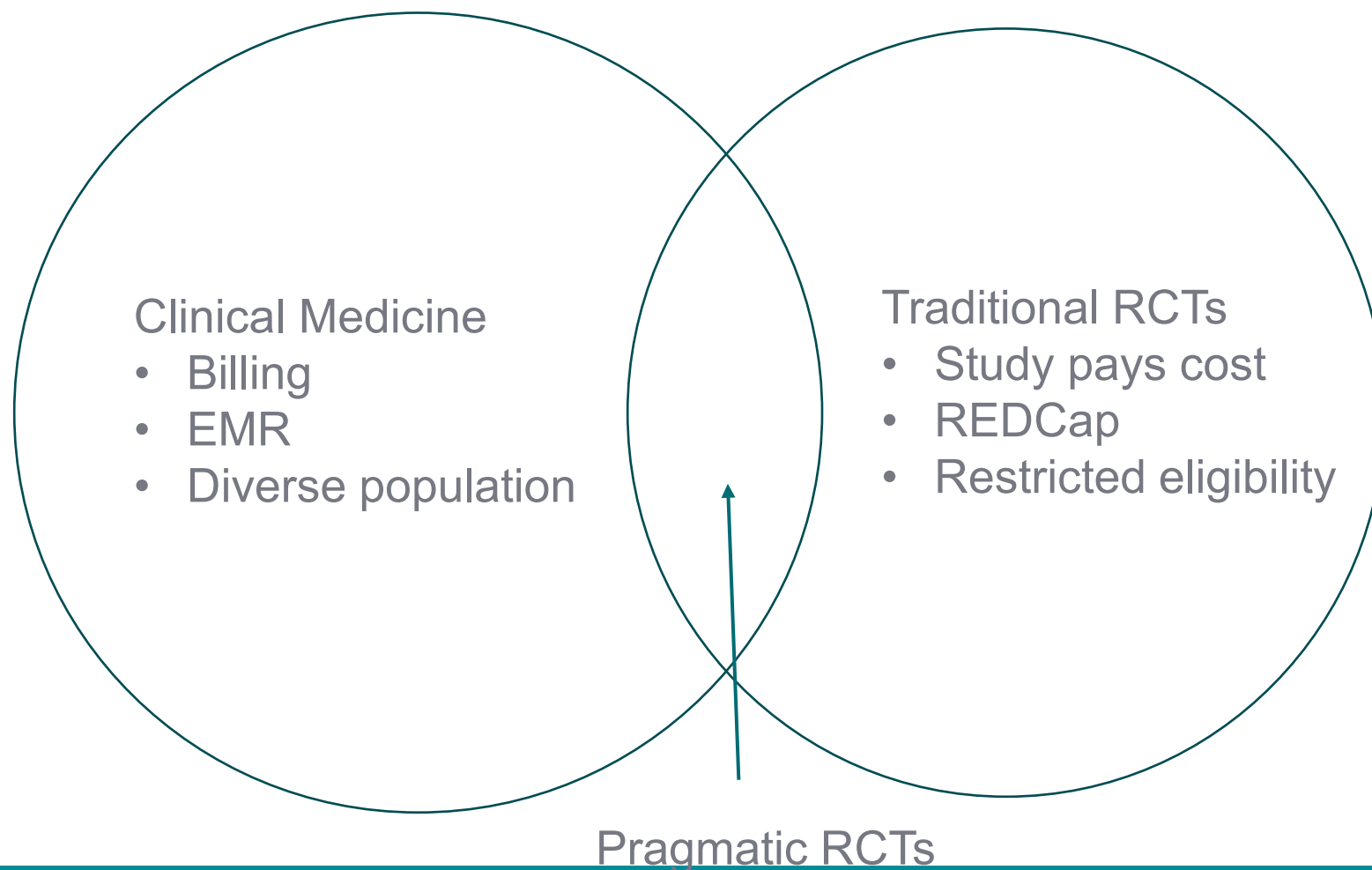
Mama K meets Dementia Care Specialist

- Dr. C is Mama K's primary care physician
- Her ICD 10 code for dementia - patients with dementia on Dr. C's panel
- D-CARE team reached out to Dr. C to collaborate
- D-CARE team reached out to son to consent
- Baseline visit over the phone
- Randomized to health system arm

Goal of D-CARE Study

- To compare the effectiveness and cost-effectiveness of community-based (CBDC) versus health system-based dementia care (HSDC) and to compare both interventions to Usual Care in:
 - a pragmatic randomized clinical trial
 - at 4 clinical trial sites representing a range of
 - geographic regions
 - types of healthcare organizations
 - predominant payment systems

Pragmatic clinical trial



N: 2,150 dyads

Diverse: 22% Black + Latinos

Pragmatic: both research assessments & clinical/routine assessments

- Use EMR to recruit

Intervention: both evidence-based

Randomized to 7:7:1 over 18 months

Community-based dementia care

- Local non-profits
- Social worker
- Study covers cost
- *BRI model

Health-system dementia care

- 4 health systems
- NPs, PAs
- Bill for encounters
- Rx
- *UCLA ADC model

Usual Care

- Alzheimer's Association hotline
- List of local resources

D-CARE Study sites



Central Program
Management: UCLA

Data Coordinating Center:
Yale

1. Baylor Scott & White
2. University of Texas
Medical Branch-
Galveston
3. Geisinger
4. Wake Forest

Landscape of Dementia care trials

Clinical Trial	Sample size
Callahan Collaborative Care	153
San Diego ACCESS	408
MIND at Home	634
Care Ecosystem	780
D-CARE	2,176



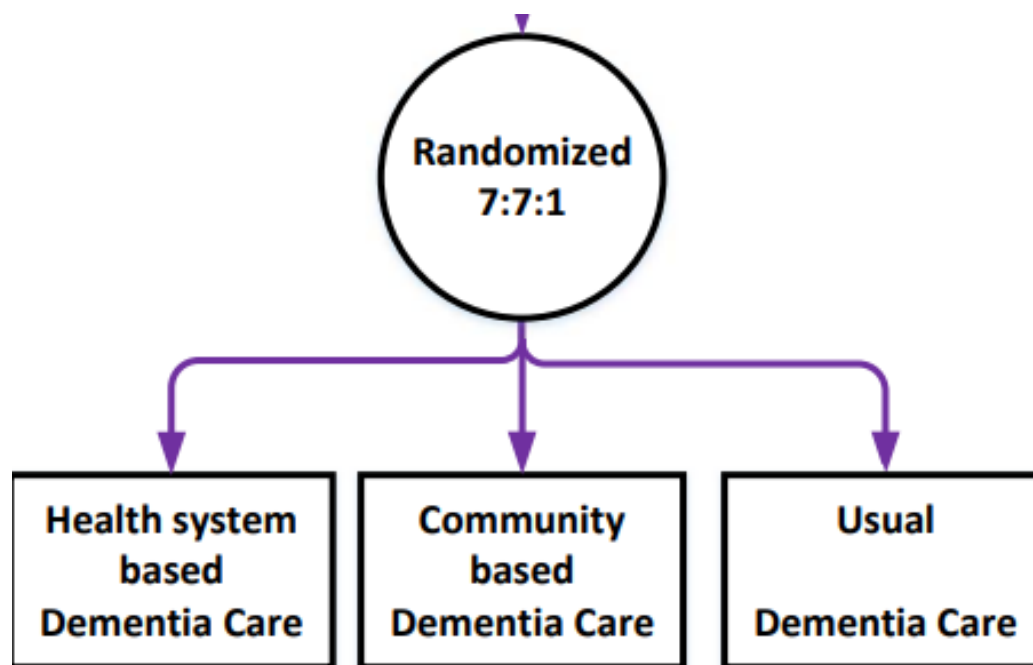
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Pragmatic & Randomized

- Both interventions already have evidence that they work!
- Broad inclusion criteria: ICD9/10 billing codes for Alzheimer's disease & related dementias
- Few exclusions: hospice, long-term care nursing home resident, moving out of area, paid caregiver only

Study Design and Sample

- Pragmatic 18-month randomized (patient/caregiver dyad) 3-arm superiority trial
- Sample size: 2150 total: 1000 in each intervention arm and 150 in the Usual Care group



D-CARE Outcomes

Primary	NPI-Q Severity Scale		
	Modified Caregiver Strain Index		
Secondary	NPI-Q Distress (caregiver)		
	Caregiver depression (PHQ-8)		
	Caregiver self-efficacy		
Tertiary	Cognition (MOCA)	Acute inpatient rehabilitation use	Dementia Burden Scale-Caregiver
	Functional status (FAQ)	Post-acute SNF use	Clinical Benefit
	Goal attainment scaling	Hospice use	Quality of Life in Alzheimer's Disease
	Mortality	Long-term nursing home use	Positive Aspects of Caregiving
	Days spent at home	Caregiver Rating of Dementia Care Quality	Cost-effectiveness analysis
	Inpatient hospital use	Caregiver satisfaction with dementia care	

Preliminary Outcomes

Baseline PLWD (N=1,069)	Mean (SD)
Age	80.5 (8.7)
Female	60%
Hispanic/Latino	8%
Black/African American	14.4%
White	81.9
Black or Hispanic	22.3%
High school or less	34%
Lives alone	15%

Baseline PLWD	Mean (SD)
NPI-Q (0-36, higher/worse)	9.6 (6.4)
MoCA (Dong version 0-12)	3.6 (2.8)
FAQ (0-30, higher/worse)	21.5 (7.5)

Baseline Care Partners (N = 1,069)	Mean (SD)
Age	65.4 (12.7)
Female	75%
High school or less	20%
Spouse	46%
Son/Daughter	44.2%
MCSI (0-26, higher/strained)	11 (6.2)
PHQ-8 (0-27, higher/depressed)	4.9 (4.8)

Mama K's initial D-CARE assessment

- 90 min via video telehealth visit
- Dementia Care Specialist: dementia-trained APP
- Given stage of disease: moderate AD
- Detailed medication review: dgt at home is sporadic regarding giving patient meds
- Given information on counseling for non-pharm behavioral modifications, dementia education, referred to Wake Forest House Call Program

D-CARE timeline

Original Timeline:



Revised Timeline:



Lessons from Covid-19

- As of March 14, 2020, a total of 412 had been enrolled.
- By March 16, all Clinical Trial Sites had suspended in-person recruitment visits.
- On March 19, switch the baseline assessment and informed consent to telephone with verbal consent.
 - Health system-based dementia care to telehealth
- On May 4, 2020, after central and CTS IRBs approval, enrollment restarted.
- **Expanded rural area outreach: partnered with Catawba AAA**

Pre vs post covid pivots

Recruitment, baseline visits, HSDC intervention

Pre-Covid

In-person presentations to primary care clinic team meetings

Baseline visit in-person: clinic or in-home

Intervention visit: if randomized to health system arm: in clinic

Mostly participants in Forsyth & Guilford Counties

Post-Covid

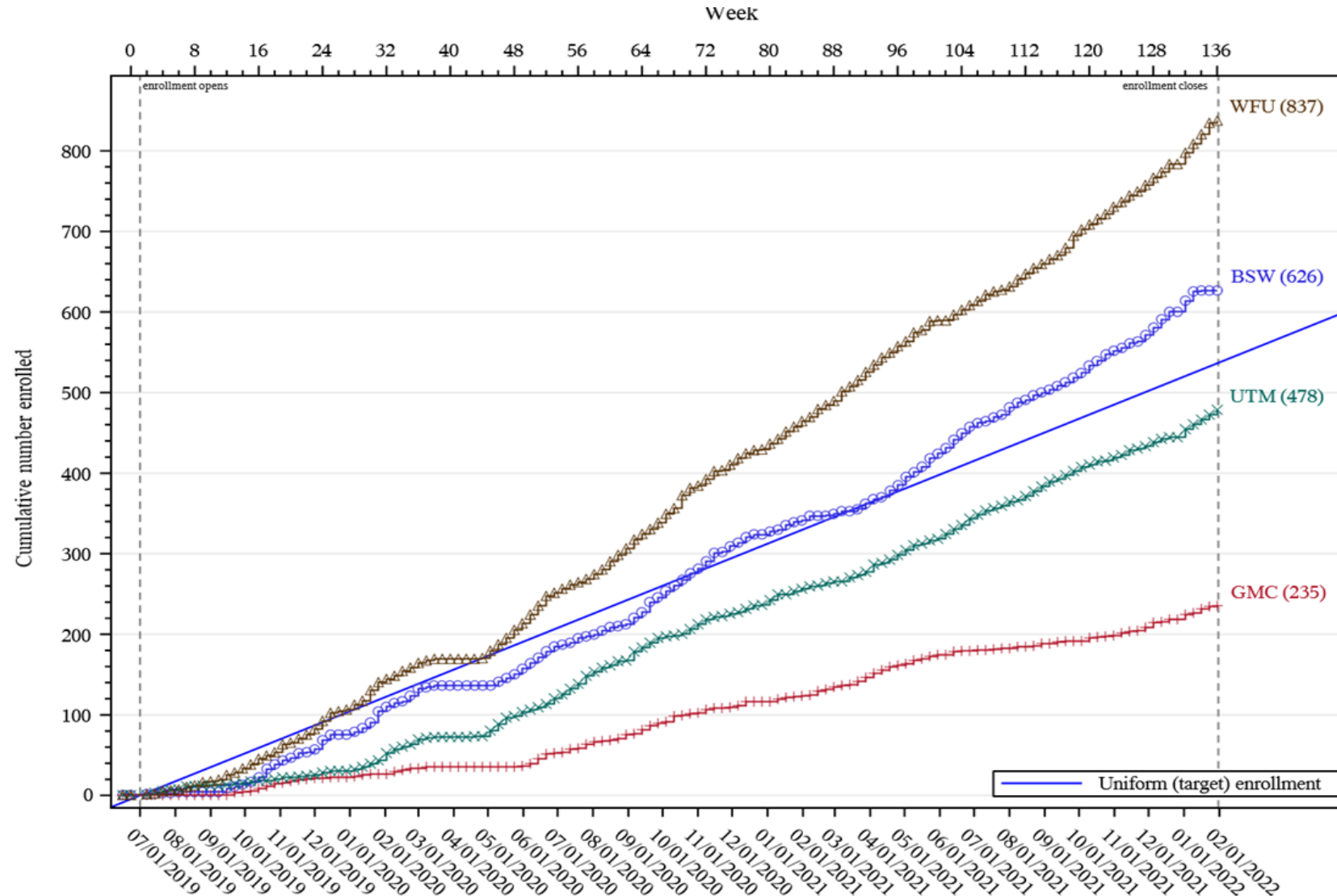
Remote, telephone-only recruitment/screening

Baseline visit via phone only

Health-care arm intervention via telehealth or in-person in clinic

Expanded participation to rural participants

Recruitment over time: 7/2019-2/2022



WFU: 837

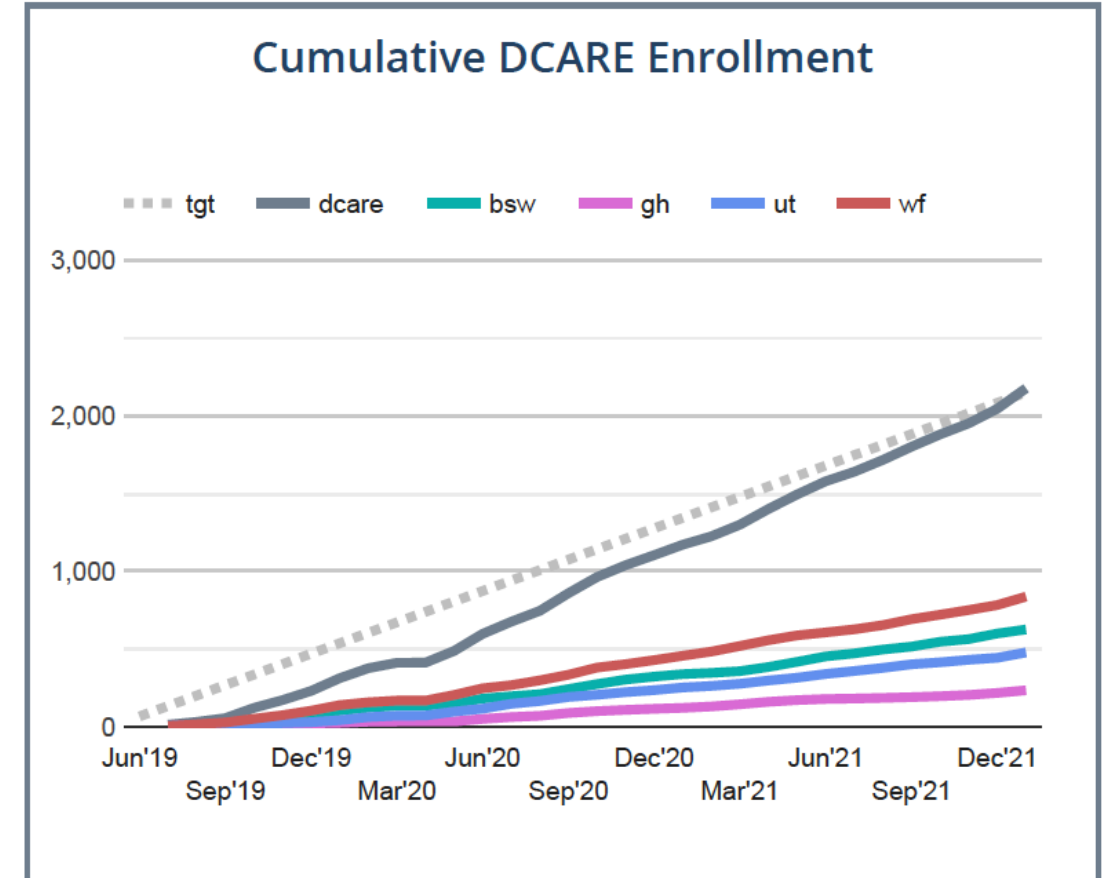
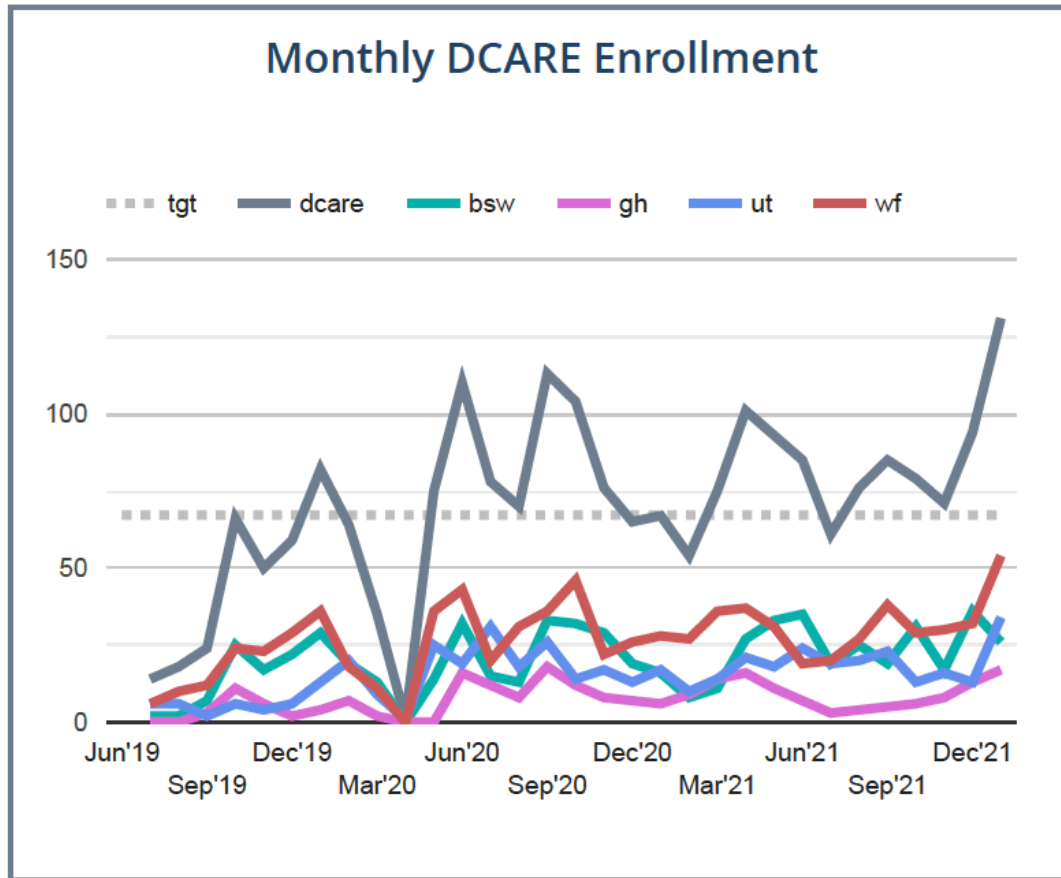
BSW: 626

UTMB: 478

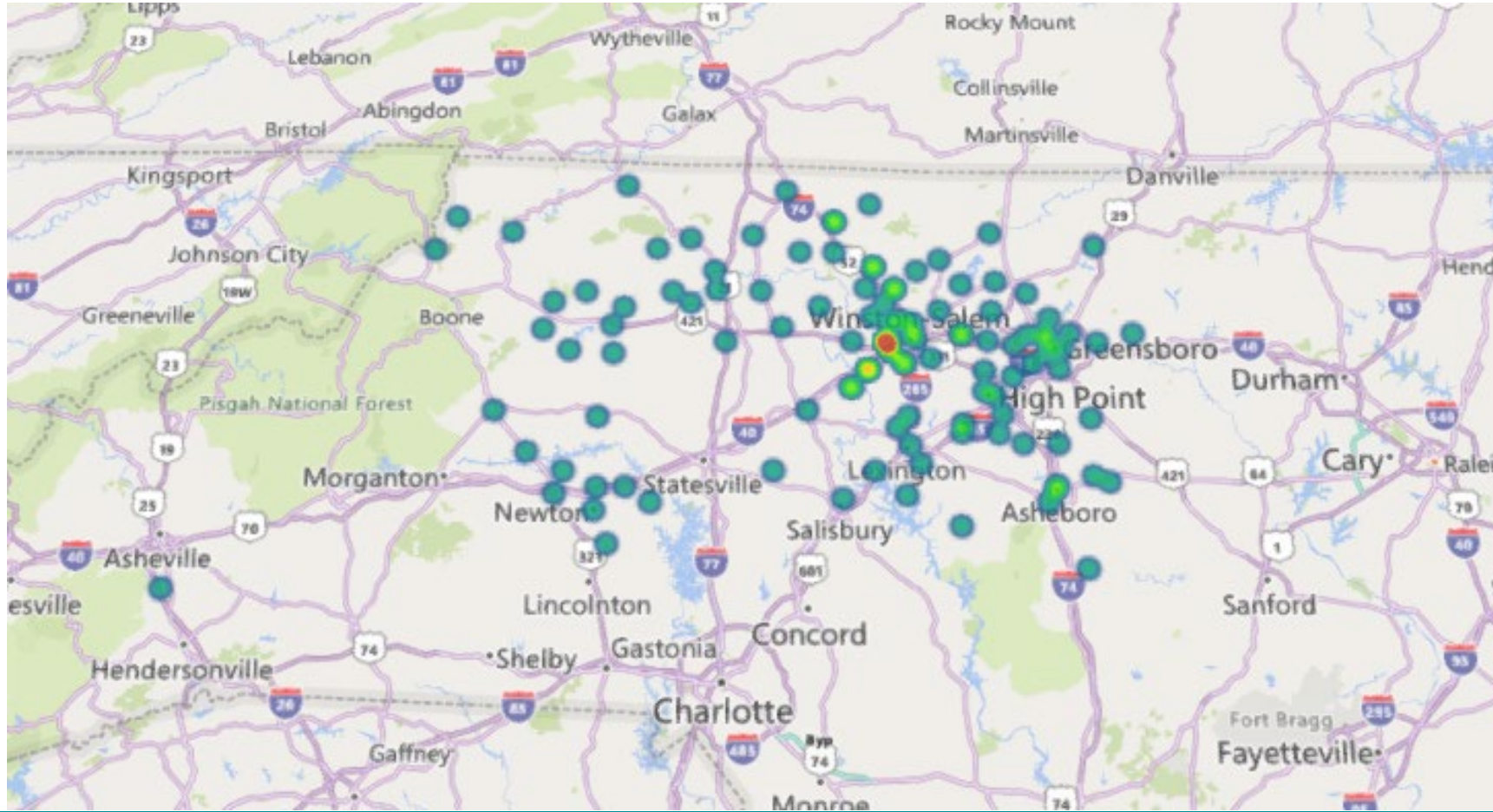
GMC: 235

Total: 2,176

Cumulative Enrollment: June 2019 - Jan 2022



Zip codes from which we recruited



Mama K received community resources

- Home-based primary care: mostly telehealth + in-person
- Local nursing home had no beds
- Mama K did not have Medicaid, dgt depended on living in her house
- DCS APP proactively called q2mo to monitor behavior and counseling dgt and son

Triple Aim 1: Patient/Caregiver Experience

“The D-Care study has been a life saver for me and I’m so grateful to you and the research team and the wisdom I have received during this process. I have learned so much about dementia and Alzheimer’s and have made some significant changes in my own behavior. I have learned to express my own frustrations in more appropriate ways. Murder was not an option. LOL I can’t believe these 18 months have come to an end so quickly. “

“Our meeting with you was the best we've had with anyone about her illness. Thanks for being there for us.”

Our dementia care specialist “had been more active with us over the last 18 months than any healthcare provider” and that her perspective had “value”

“Thank you for your expert assessment. It was difficult to come to terms with her quick diminishment and it gave me peace of mind to hear your assessment”

"my wife and I have been married for over 60 years. She's always been there to help me. I don't know how to deal with this (dementia). Thank you for helping me to help her!"

Patient's experience (*data from UCLA pgm)

- Patients' behavioral symptoms (e.g., agitation, irritability, apathy) improved by 22%
- Patients' depressive symptoms were reduced by 34%
- reduces acute care utilization and overall healthcare costs. Compared to matched persons with dementia receiving usual care,
 - 20% fewer Emergency Department visits
 - shorter hospital lengths of stay (26% fewer bed days)
 - 64% more likely to receive hospice services in the last 6 months of life.⁸
 - 40 percent less likely to be admitted to long-term care.

Caregiver experience

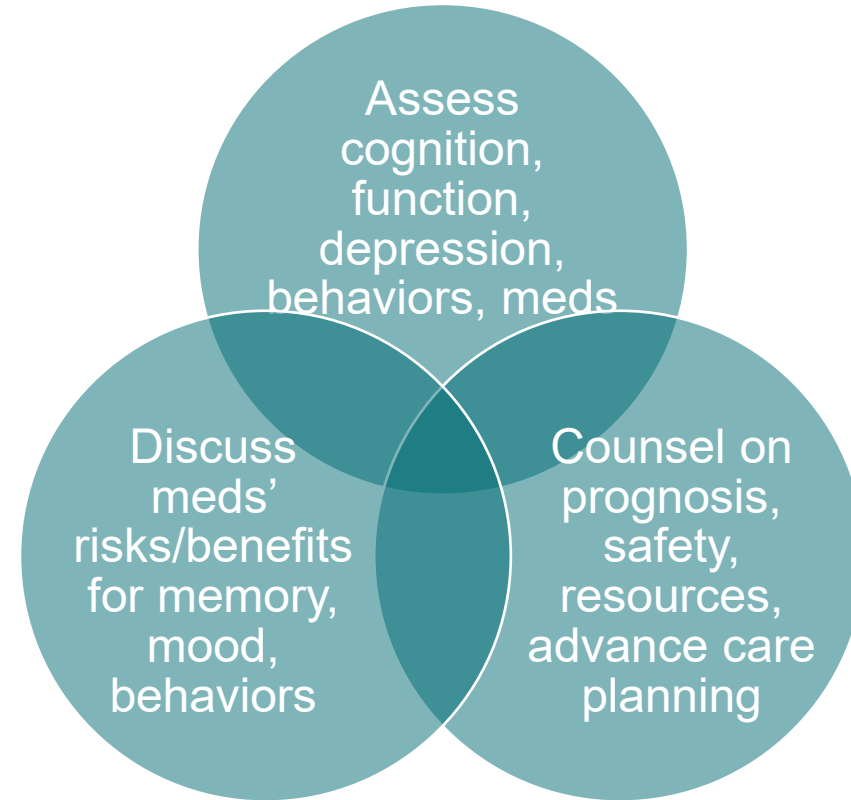
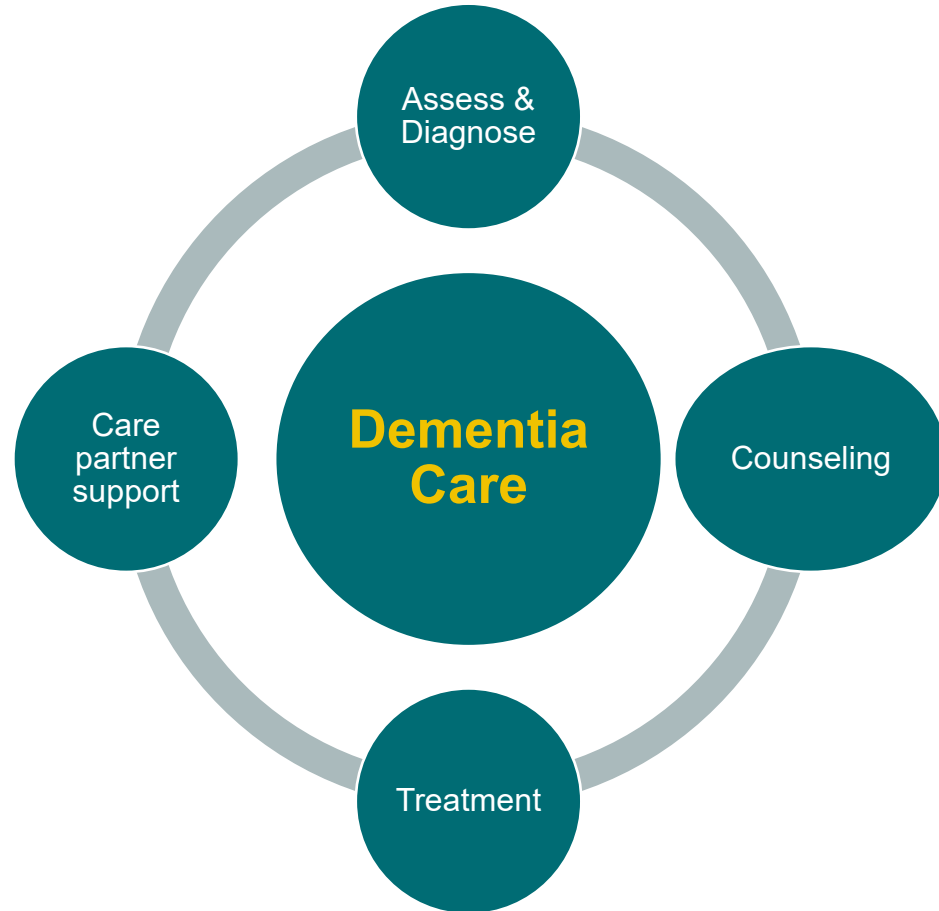
- 94% of caregivers felt that their role was supported
- 92% would recommend the program to others.
- At 1 year, their confidence in handling problems and complications of Alzheimer's disease and dementia improved by 79%
- Caregiver distress related to behavioral symptoms was reduced by 31%
- Caregiver depression scores improved by 24%

Mama K's experience

- Significantly reduced polypharmacy
 - Limited as needed medications for behaviors
 - Behaviors improved and willing to leave home
 - Paying for weekly caregiver for bathing at home
 - Son & dgt decided to keep her at home rather than move to nursing home
-
- Offers me cake every time I visit

Triple Aim 2: Improved dementia care quality

Domains of quality dementia care



ACOVE QI	ACOVE Obs Studies	ACOVE intervention studies	Alzheimer's & Dementia Care
Assess cognition annually	42%	39%	94%
Assess function	6%	65%	97%
Screen depression	73%	86%	99%
Screen behaviors	47%	44%	99%
Assess meds	0	65%	99%
Counselled on driving	23%	20%	93%
Discussed AChEI	83%	66%	86%
Treat behavior non-pharm first	34%	16%	69%
Discontinued meds	0	25%	27%

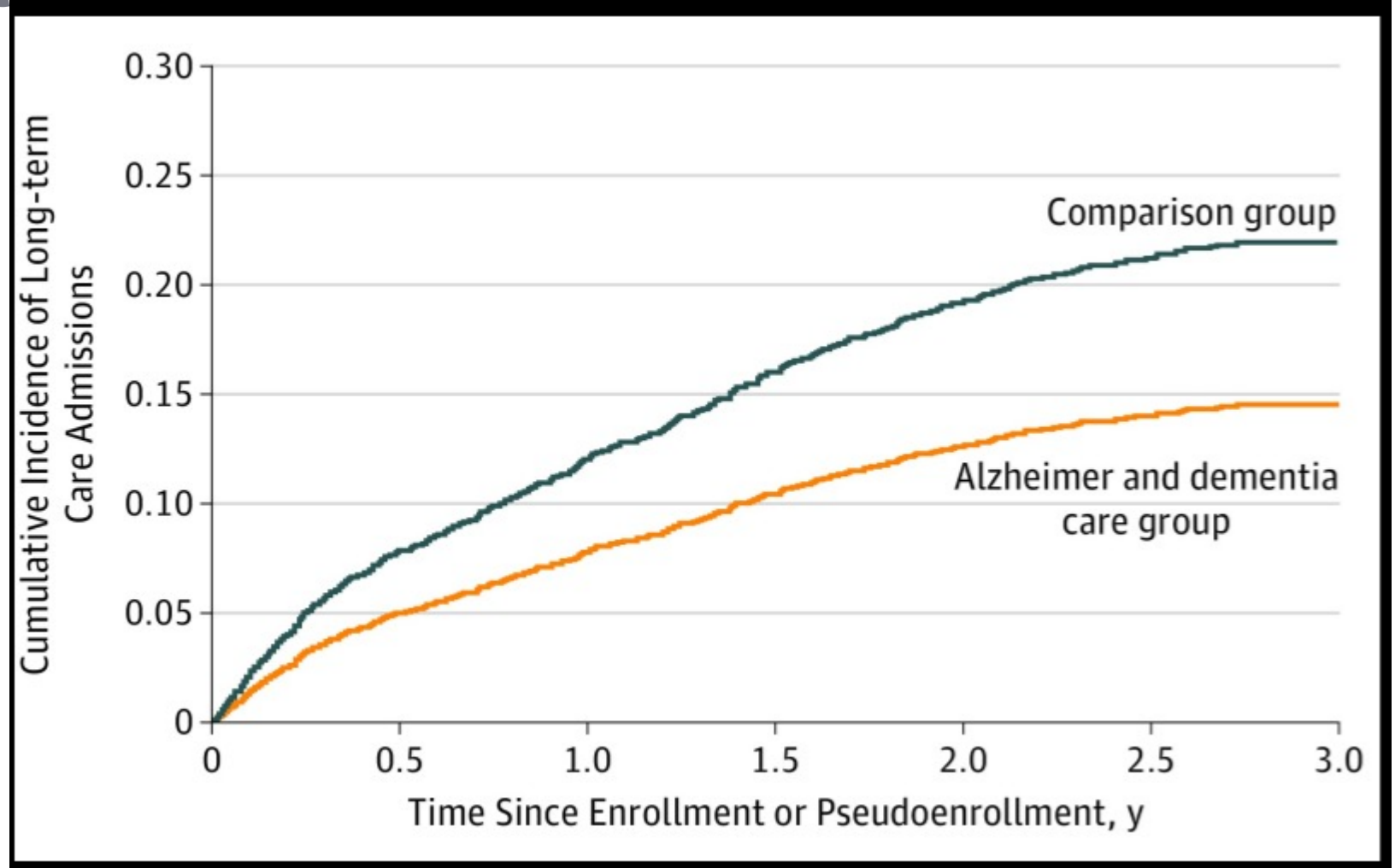
Lessons learned from rural D-CARE participants

- Less access to video-technology for telehealth visits
 - More distrust of research/healthcare system
 - Less self-efficacy from caregivers to seek out help
 - Less community resources for respite
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- Telehealth could provide quality dementia care
 - Opportunities for partnering with community organizations

Triple Aim 3: Lower cost

Cost estimate

- Lower total Medicare costs of care (\$2404 per year)
- Lower admission to long-term care/Medicaid



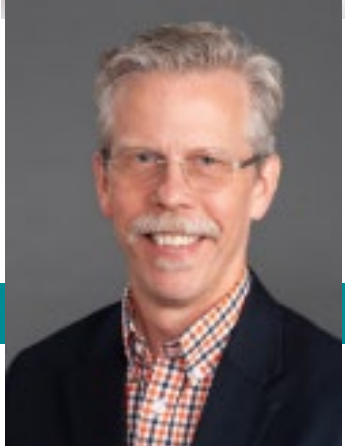
Full trial results pending but...

- CMMI possible payment for Comprehensive Dementia Care
- Congress introduced Comprehensive Dementia Care payment reform
- Multiple health systems already adopted health system model & more in the contemplative phase
- Unique opportunity within Value-Based systems

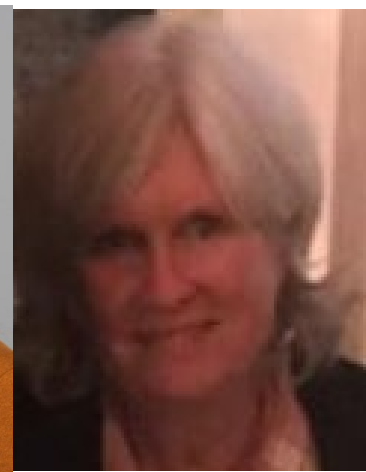
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Thanks to D-CARE
team!



Patient-centered Outcomes
research Institute



Questions?

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