



mln call

A MEDICARE LEARNING NETWORK® (MLN) EVENT

# National Partnership to Improve Dementia Care in Nursing Homes & Quality Assurance and Performance Improvement

September 10, 2019



# Acronyms in this Presentation

- **CMS** – Centers for Medicare & Medicaid Services
- **MDS** – Minimum Data Set
- **PAINAD** – Pain Assessment in Advanced Dementia



# Agenda

- **Supporting Comfort and Preferences for Residents Living with Dementia**  
Ann Wyatt, CaringKind
  
- **National Partnership Updates**  
Michele Laughman, CMS



# Supporting Comfort and Preferences for Residents Living with Dementia

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Ann Wyatt, MSW  
CaringKind



# Learning Objectives

- Comfort is a benefit to people with dementia
- People with dementia are experts on their personal comfort
- People with dementia communicate comfort and discomfort through their actions
- Everyone with dementia can be comfortable
- Comfort is **not** just for end-of-life circumstances

“Cure sometimes, treat often, comfort always.”  
- Hippocrates



# Conceptual Shift for Palliative Care

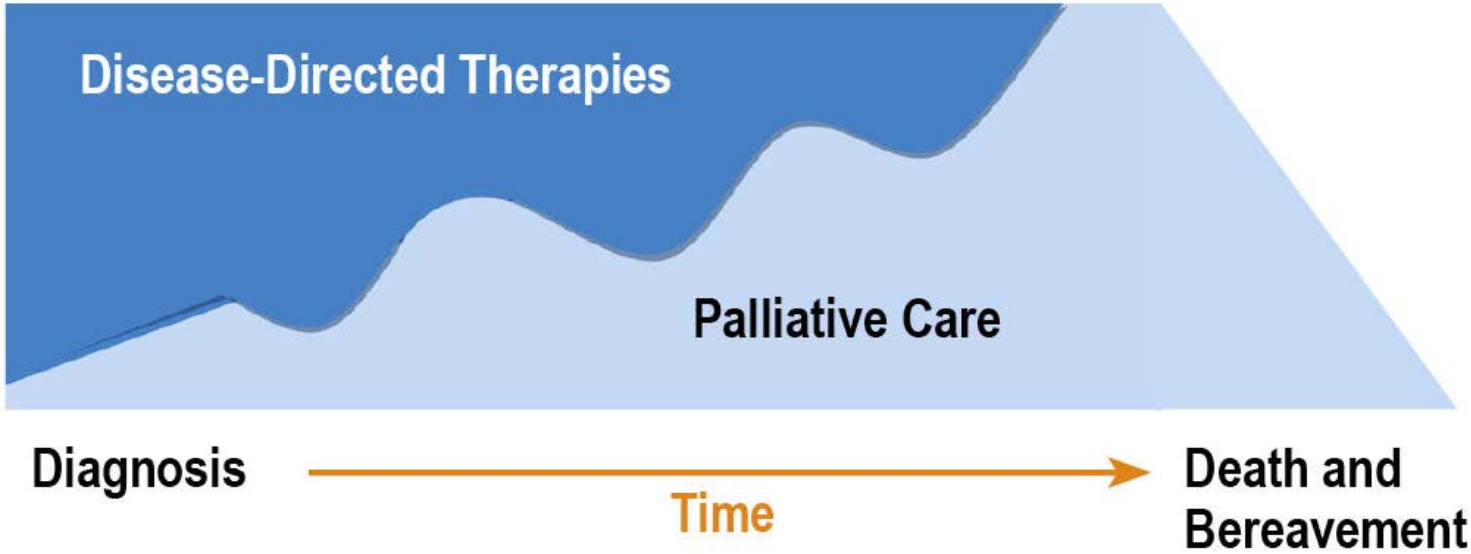


Chart Source:  
Center to Advance Palliative Care



# Why do we need to look at palliation/comfort from a dementia-specific perspective?

- Behavior is communication: It is not the dementia that causes the behavior, it is the dementia which prevents the person from expressing the cause of their distress
- Anti-psychotics may remove the person's only means of communication (and not be responsive to the underlying problem)
- Care settings/providers tend to want the person to conform to the needs of the setting, which means not only that the person's needs may not be met adequately or in a timely manner, but that the setting itself may be causing the person's distress
- Comfort will often not reach people with dementia unless dementia-specific adaptations are made in how care is delivered



# Behavior is Communication

- Use the word 'distress' rather than 'behavior'
- 'Behavior' suggests the person has control over their actions and can change if we tell them to
- 'Distress' suggests we should seek the reason for the person's discomfort and address it on their behalf (do for them what they cannot do for themselves)





# Finding Comfort: Building Blocks

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Organizational Adaptations

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Dementia-capable care practices

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Knowing the Person

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Care Planning & Active Comforts

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Getting to the Root Cause of Distress



# Organizational Adaptations

Comfort should be embedded in facility expectations and reflected in the actions, attitudes, and assumptions of administrators and managers, in how staff relate to each other, and in the mission, policies, procedures, and protocols that set guidelines for daily practice.



# Example: Anthony's Story

- Arrived with a history of combativeness, on many anti-psychotics
- Had spent time in psychiatric hospital, been asked to leave other home(s)
- Staff met with Anthony's wife and learned his custom at home had been to stay up until 4 am, have a snack, sleep until about noon, and have some breakfast



# Anthony's Story (continued)

- When was Anthony combative/resistive?
- Care Plan written to reflect Anthony's customary sleeping and eating routine
- Resistance largely disappeared, tapered off anti-psychotics, and remained so for many years until his recent death
- Wife's message to staff (before he died): "I know that if something happens to me, Anthony will be well cared for. This has been palliative care for me."



# Organizational Elements Required to Bring Comfort to Anthony (and to his wife)

- Interaction with family/friends as soon as someone admitted to learn about routines and specific comforts/discomforts
- Care plan that specifically addresses Anthony's needs for flexibility and insuring that all staff (including holiday replacements) know and understand Anthony's needs
- Food Anthony prefers available in the middle of the night
- Food Anthony prefers available when he awakens in the early afternoon
- All three shifts support each other in this schedule adjustment; No one should be questioning why the night shift didn't get him up before they left
- **Facility policies and procedures should support flexibility in waking and sleeping (including education and orientation for all staff)**
- Ongoing conversation with family about what is working and what isn't, based upon the resident's level of comfort, especially as the resident's needs change over time



# Care Practices that Promote Comfort

- Pain
- Environment
- Sleep/rest (sundowning)
- Food/nourishment
- Balance/stimulation
- Meaningful engagement
- Heat/cold
- Toileting
- Ambulation



# Pain

- Pain is what the person says it is
- People experience pain differently
- Pain does affect cognition
- Research indicates people with dementia more likely not to have pain identified/treated
- Person with dementia who is experiencing pain may (1) deny pain, and (2) express their distress through their behavior
- **Facility policies and procedures should include regular use of behavior-based pain scales (there are many), and should provide for education for all staff (including physicians) on their use**



# Pain Assessment in Advanced Dementia (PAINAD) Scale

Items*	0	1	2	Score
<b>Breathing independent of vocalization</b>	Normal	Occasional labored breathing. Short period of hyperventilation.	Noisy labored breathing. Long period of hyperventilation. Cheyne-Stokes respirations.	
<b>Negative vocalization</b>	None	Occasional moan or groan. Low-level speech with a negative or disapproving quality.	Repeated troubled calling out. Loud moaning or groaning. Crying.	
<b>Facial expression</b>	Smiling or inexpressive	Sad. Frightened. Frown.	Facial grimacing.	
<b>Body language</b>	Relaxed	Tense. Distressed pacing. Fidgeting.	Rigid. Fists clenched. Knees pulled up. Pulling or pushing away. Striking out.	
<b>Consolability</b>	No need to console	Distracted or reassured by voice or touch.	Unable to console, distract or reassure.	
<b>Total**</b>				

\*Five-item observational tool (see the description of each item below).

\*\*Total scores range from 0 to 10 (based on a scale of 0 to 2 for five items), with a higher score indicating more severe pain (0="no pain" to 10="severe pain").





# Nutritional Needs



# The Care Environment

- Noise
- Activities
- Staff activities, shift-change, etc.
- Comfortable places to be
- Uncomfortable places to be
- Visitor experience
- Sundowning



# Rest and Sleep/Wake Routines: The Importance of Resting When Tired

- Dementia is tiring
- Balance of stimulation
- Customary routines
- Changes in routine
- Frequency
- Finding what works for someone



# Rethinking Activities: Meaningful Engagement for People with Advanced Dementia

- People with advanced dementia can still feel lonely, bored, or frustrated
- Every interaction holds the potential for meaningfulness (or its absence)
- Importance of one-on-one and small groups
- All staff involved
- Personalized music programs



# Meaningful Engagement



# Processes

- Weekly interdisciplinary meetings on-unit
- Huddles
- At time of admission, comprehensive assessment of care needs, habits, and comforts
- Education for families (advance directives)
- Care plans (what comforts me)
- Roadmaps for distress
- Care plan meetings (the Minimum Data Set (MDS))
- PAINAD



# Road Map to Comfort

## Beatitudes Campus Comfort Road Map



<b>Dementia-related Behavior</b> <i>Describe what the person is actually doing, avoid using words such as agitated or combative</i>	<b>What is the Person Communicating</b> <i>Consider all possible meanings of the person's actions</i>	<b>Possible Remedies</b> <i>Consider all possible options that could help</i>



# Every Day Causes: Examples

- Pain
- Too hot, too cold
- Overstimulation
- Boredom
- Lack of sleep
- Need for more exercise
- Need to go outside
- Weighing risk





# The Relevance of Past Trauma

- Military service
- Domestic violence
- Child abuse
- Holocaust
- Political asylum due to serious threat of physical harm
- Prolonged past medical trauma
- Sexual abuse



# Care Plan Meetings and the MDS

- Resistance to care
- Verbal behavioral symptoms directed to others
- Physical behavioral symptoms directed to others
- 'Other' behavioral symptoms not directed to others

Avoid using 'agitation' and 'combative'---instead, find out specifics about potential contributing factors to the distress



# Put it in the Care Plan

- Not just problems
- Comforts: Italian operas; the color red; walking up and down the hall holding hands; naps after lunch; hot tea first thing in the morning; lollipops; walk outdoors; hugs; favorite photos



# Comprehensive Care Plan – What Brings Me Comfort Care Plan

RESIDENT'S NAME: Ms. A

UNIT: B5

ROOM #

RESIDENT'S STRENGTH: Involved Daughter and Son

DATE	PROBLEMS/NEEDS /STRENGTHS	GOALS/EXPECTED OUTCOME	DATE	INTERVENTIONS	DISC.	DATE	EVALUATION / OUTCOME
03/14/14	<input type="checkbox"/> I have difficulty hearing so I like it when people look directly at me when speaking to me. <input type="checkbox"/> I like to have a cup of coffee with a donut every day and I like to drink a lot of water. <input type="checkbox"/> I like to be well groomed each day. <input type="checkbox"/> I am very social and like to be with people and like to listen to music. <input type="checkbox"/> I like to walk around the unit and like when people let me hold their arm and talk to me as we walk. <input type="checkbox"/> I need help being redirected back to my room as I tend to want to lie down in bed throughout the day. <input type="checkbox"/> I like take naps throughout the day.	<input type="checkbox"/> I will be spoken to face to face by others over the next 90 days. <input type="checkbox"/> I will have my cup of coffee and donut every day as indicated over the next 90 days. <input type="checkbox"/> I will be assisted with dressing in the clothes I prefer everyday over the next 90 days. <input type="checkbox"/> I will hear music as indicated and be encouraged to engage with my peers as appropriate over the next 90 days. <input type="checkbox"/> I will be engaged with by staff as I walk on the unit over the next 90 days. <input type="checkbox"/> I will be redirected as needed to my room to lay down over the next 90 days. <input type="checkbox"/> I will get as much sleep as I need over the next 90 days.	03/14/14	<input type="checkbox"/> Staff will look directly at Ms. A. when speaking to her. <input type="checkbox"/> Staff will offer Ms. A. coffee and donuts as indicated as well as water on a daily basis. <input type="checkbox"/> Staff will groom and dress Ms. A as she likes on a daily basis. <input type="checkbox"/> Staff will engage Ms. A in TR programs with her peers and play music she likes on a daily basis. <input type="checkbox"/> Staff will socialize with Ms. A. as she walks on the unit on a daily basis. . <input type="checkbox"/> Staff will redirect Ms. A. back to her room as indicated on a daily basis. <input type="checkbox"/> Staff will encourage resident to sleep in her own bed as appropriate on a daily basis.	T N,TR, D N TR, N,SW T T T		

N=Nursing MD =Physician D=Dietary SW=Social Work TR=Therapeutic Recreation PT/OT/ST=Physical/Occupational/Speech Therapy T= Team

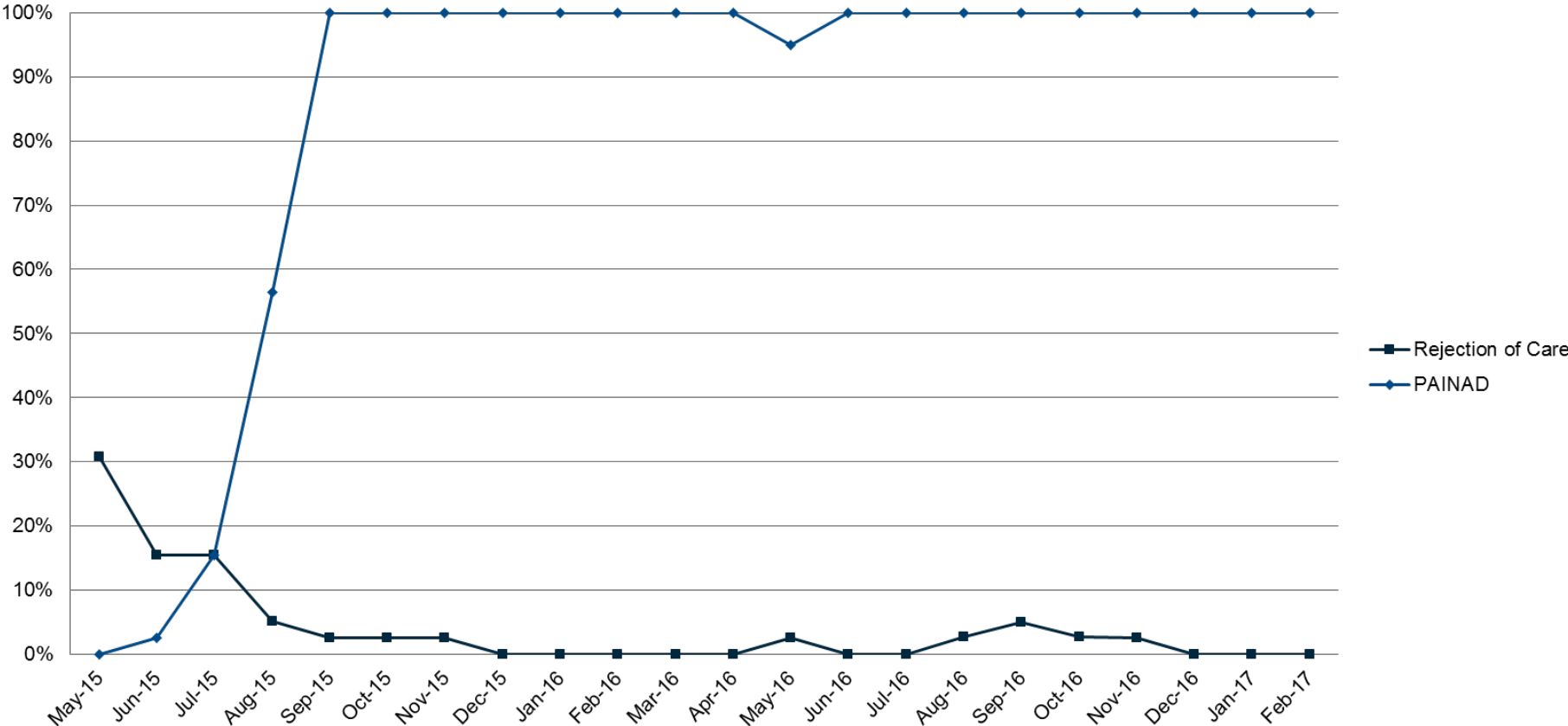


# Performance Improvement and the Usefulness of Data

- Use it to test effectiveness of implementation strategies
- Use it to help staff see the results of their efforts (the why of change)
- Use it to understand if a policy, practice or protocol also works for people with dementia (or are there additional adjustments that need to be addressed, i.e., behavior-based pain scale)



# Rejection of Care & PAINAD



**“You matter because you are you and you matter to the end of your life.”**

-Dame Cicely Saunders, Nurse, Physician,  
and founder of the hospice movement



# National Partnership Updates

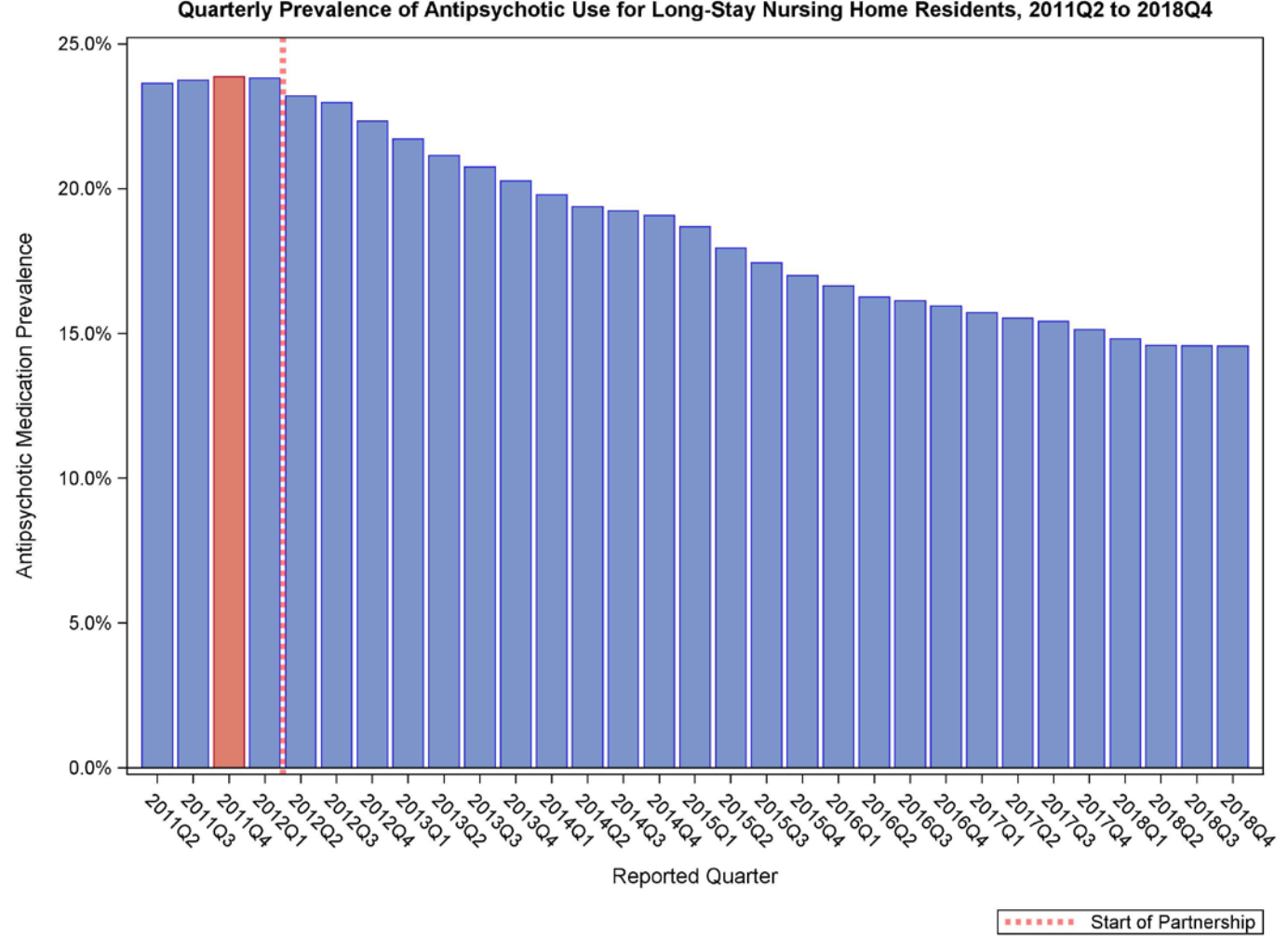
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Michele Laughman, CMS

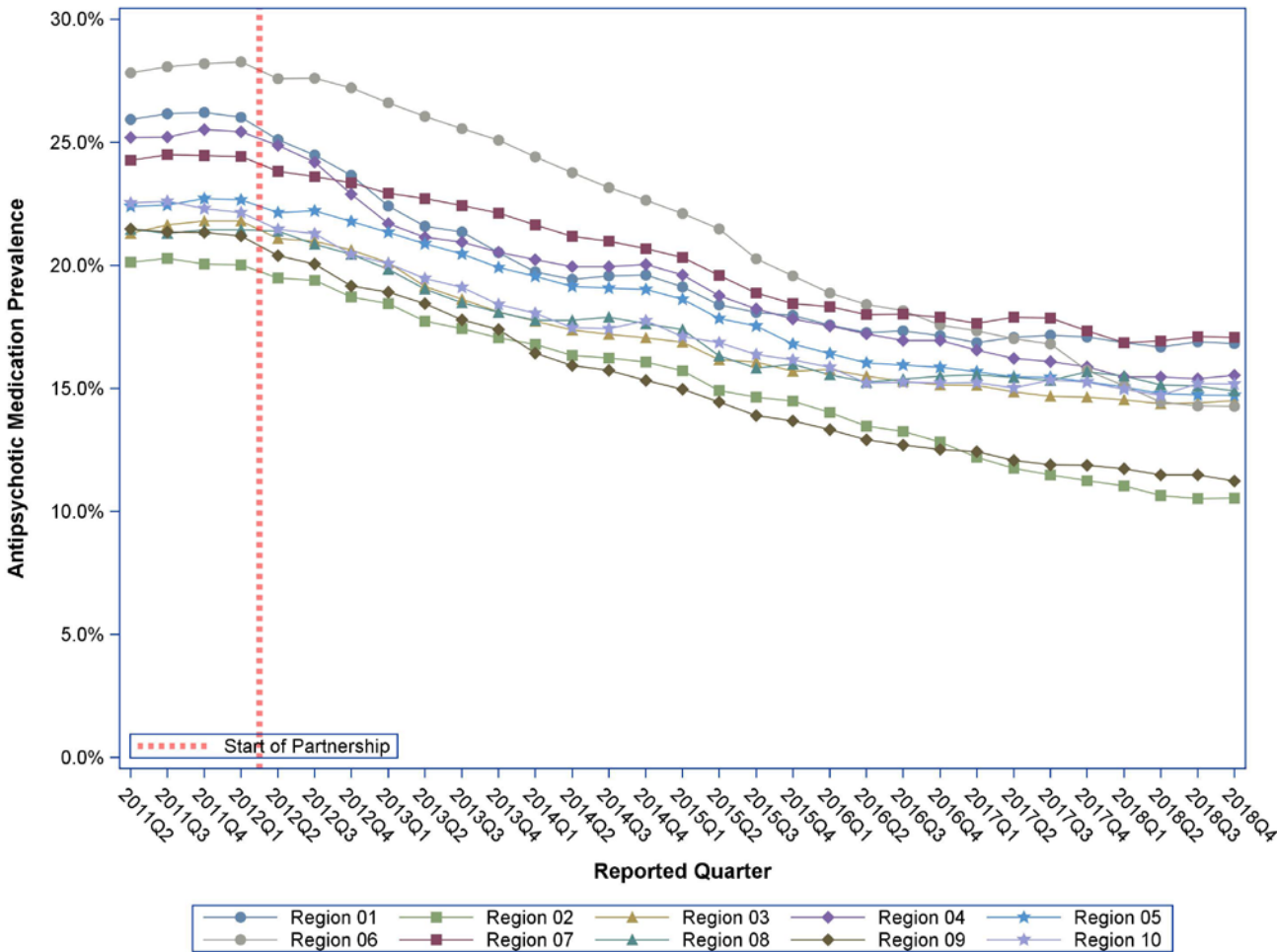




# Quarterly Data Update - National

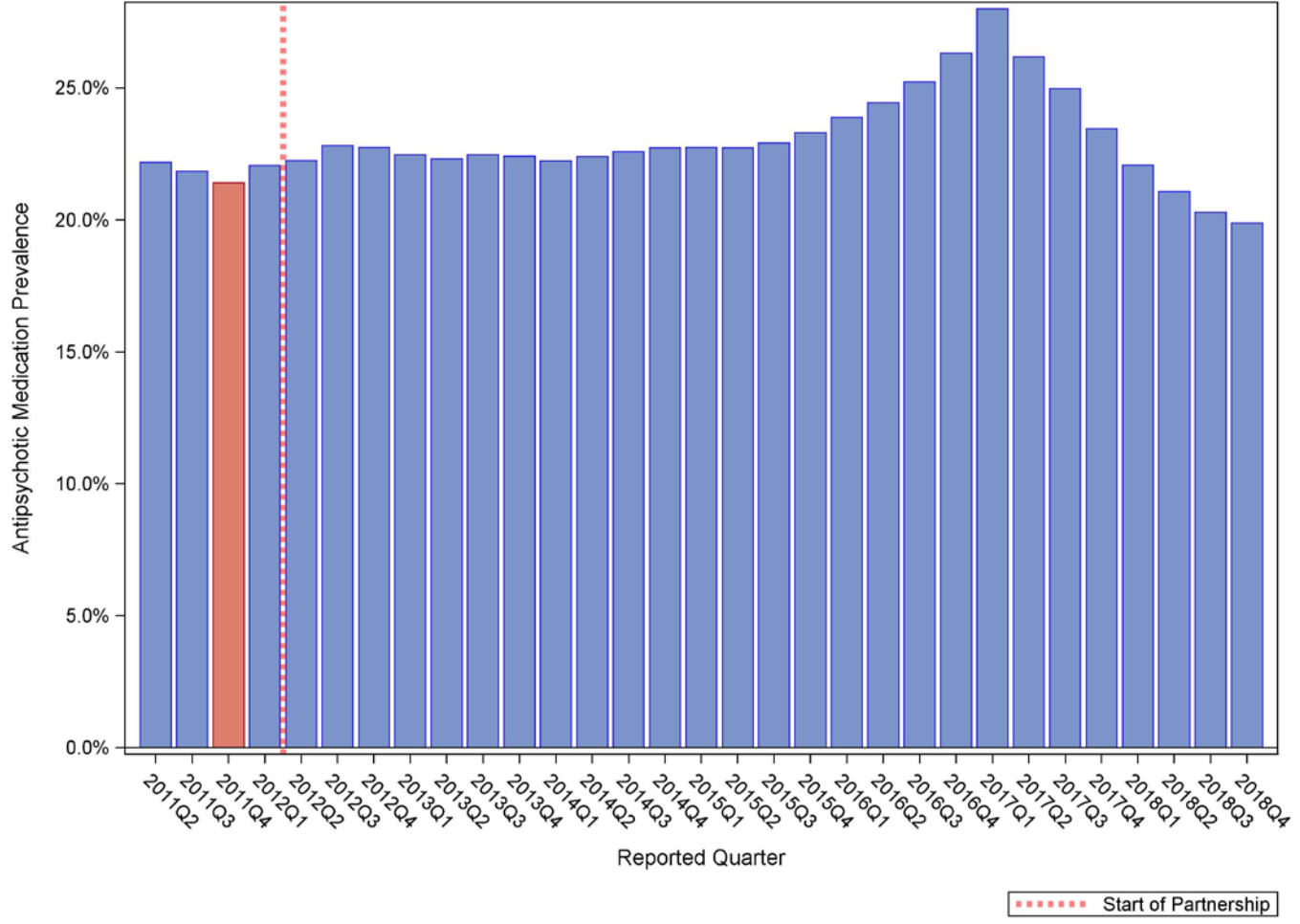


# Quarterly Data Update - Regional

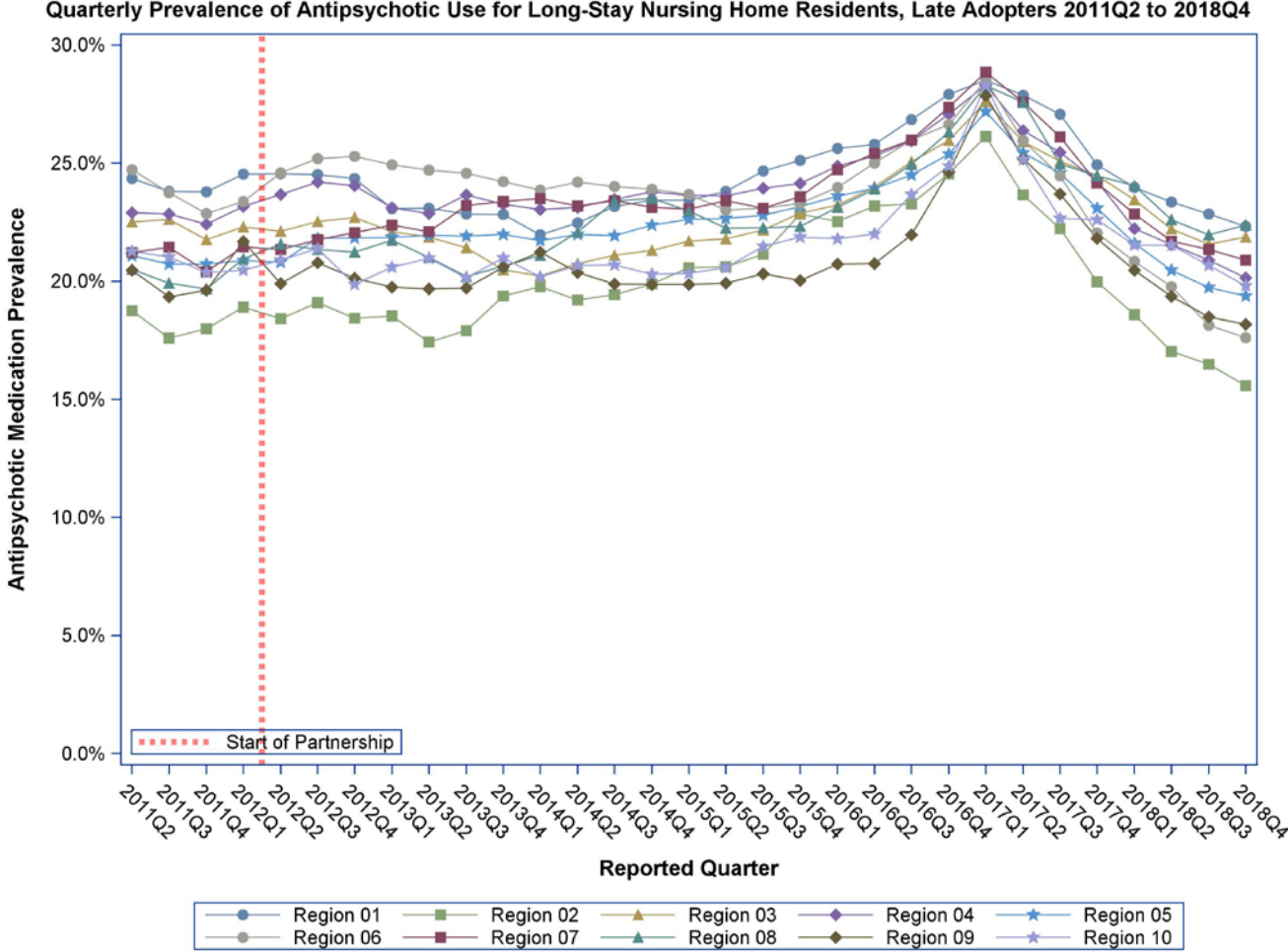


# Quarterly Data Update - Late Adopters National

Quarterly Prevalence of Antipsychotic Use for Long-Stay Nursing Home Residents, Late Adopters 2011Q2 to 2018Q4



# Quarterly Data Update - Late Adopters Regional



# Question & Answer Session

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## Contact the National Partnership:

- [dnh\\_behavioralhealth@cms.hhs.gov](mailto:dnh_behavioralhealth@cms.hhs.gov)

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