## Clinical Care Subcommittee Agenda: Advancing Consensus on Dementia Care Elements to Guide New Outcomes Measurement

Overview of History of Dementia Care Elements and Quality Measures

Gary Epstein-Lubow, MD

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## Disclosures

- Hebrew SeniorLife
- Beth Israel Deaconess Medical Center
- Brown University
- NIMH
- NHLBI
- NSF
- Dementia Caregiving Network
  - Iohn A. Hartford Foundation
  - Gerontological Society of America
- Health and Aging Policy Fellows Program
  - Placement with CMS Division of Nursing Homes within the Center for Clinical Standards and Quality; Quality and Safety Oversight Group
- Butler Hospital

### 2017 Recommendation 10

The Advisory Council on Alzheimer's Research, Care and Services should devote one meeting to advancing the work ASPE has conducted with RTI International on defining best practices for comprehensive dementia care.

Specific topics should include:

- 1) an in-depth description of the Examining Models of Dementia Care report and appendices;
- 2) federal agency reporting of current innovative services for persons with dementia and their caregivers;
- 3) non-federal reporting from health systems and/or payers of exemplar population health solutions for dementia care; and,
- 4) Advisory Council discussion of next steps to advance consensus definitions of best practice models, including measurement targets for clinical outcomes and value-based outcomes concerning cost and the care experience.

### ASPE Response

The Examining Models of Dementia Care: Final Report is published and available on the ASPE and NAPA websites. As was discussed during the April 2017 NAPA Advisory Council meeting, there are a number of different directions in which to pursue future research, and ASPE would welcome the opportunity to discuss these opportunities in greater detail with the Advisory Council at-large, or with one or more of the relevant NAPA subcommittees.

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### Consensus-Building and a Selected History of Quality Measures

- Primer on Quality Measures
- Assessing Care of Vulnerable Elders (ACOVE; RAND Co.)
- Physician Quality Reporting System (PQRS) & Quality Payment Program (QPP)
- National Quality Forum (NQF)
  - Prioritizing Measure Gaps: Alzheimer's Dis & Rel Dementias
- UK: National Institute for Health & Care Excellence (NICE)
- ICHOM: International Consortium on Health Outcome Measures
- CMS: Meaningful Measures
  - Consumer Assessment of Healthcare Providers and Systems (CAHPS)
- ASPE & RTI: Examining Models of Dementia Care

## What are Quality Measures?

"Quality measures are tools that help us measure or quantify healthcare processes, outcomes, patient perceptions, and organizational structure and/or systems that are associated with the ability to provide high-quality health care and/or that relate to one or more quality goals for health care. These goals include: effective, safe, efficient, patient-centered, equitable, and timely care."

https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/QualityMeasures/index.html

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## Sample Measure – Dementia: Cognitive Assessment NQF 2872e

**Description:** Percentage of patients, regardless of age, with a diagnosis of dementia for whom an assessment of cognition is performed and the results reviewed at least once within a 12 month period.

**Numerator**: Patients for whom an assessment of cognition is performed and the results reviewed at least once within a 12 month period

Denominator: All patients, regardless of age, with a diagnosis of dementia

**Denominator Exclusions**: Documentation of patient reason(s) for not assessing cognition

Steward: PCPI

Process measure, e-measure, Neurology

## Types of Measures

#### Structural

 Focus on a feature of the healthcare organization or clinician related to the capacity to provide high quality care (e.g. Assessment of Patient Experience of Care)

#### **Process**

- Focus on a health care related activity performed for or on behalf of a patient (e.g., Tobacco Use Screening).
- · Most common type of quality measure

### Outcome (Patient Reported Outcome, Outcome, Intermediate Outcome)

 Focus on a health state of a patient resulting from health care (e.g., 30-Day All-Cause Unplanned Readmission Following Psychiatric Hospitalization in an Inpatient Psychiatric Facility (IPF)

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## Data Sources for Quality Measures

- Administrative Data Derived from insurance claims and enrollment files.
- Medical Records Provide details about the care being received (e.g. patient's history, condition, complications).
- <u>Patient Surveys</u> Measures patient experience with care (e.g. CAHPS).
- <u>Electronic Health Records</u> EHR Incentive Program and Meaningful Use; Hybrid data sources
- Assessment Instruments Additional to clinical services

## Reliability and Validity

- · Validity testing
  - Indicates the ability of a measure to record or quantify what it purports to measure
- · Reliability testing
  - Demonstrates that measure results are repeatable and the measurement error is acceptable, producing the same results a high proportion of the time

https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/MMS/Downloads/Blueprint-130.pdf

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## Assessing Care of Vulnerable Elders (ACOVE) RAND Corp.

- Cognitive and Functional Screening
- Medication Review
- Laboratory Testing
- Neuroimaging
- Cholinesterase Inhibitors
- Caregiver Support and Patient Safety

- Screening for Depression
- Depression Treatment
- Driving Privileges
- Restraints (in hospital)
- Memory Loss (without previous diagnosis of dementia)

### 2001 RAND

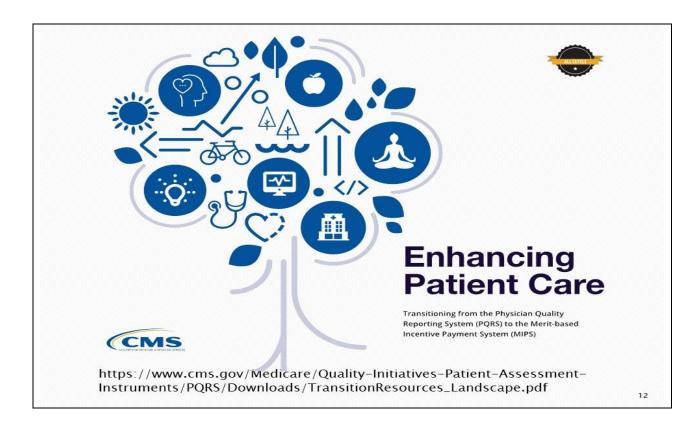
https://www.rand.org/pubs/reprints/RP1130.html

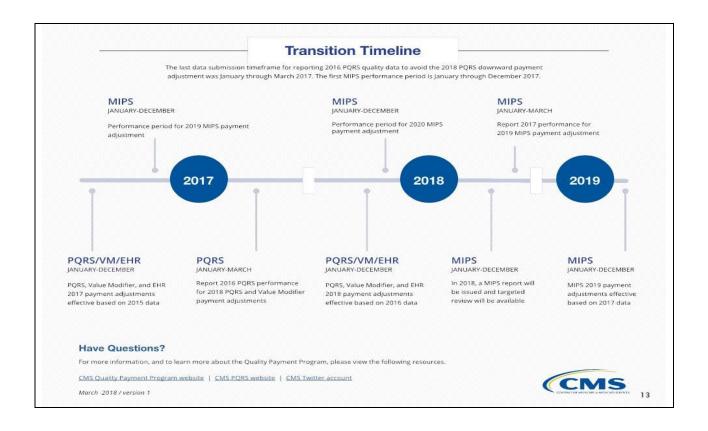
## Physician Quality Reporting System (PQRS)

### 2015 PQRS MEASURES IN DEMENTIA MEASURES GROUP:

- ▶ #47 Care Plan
- #280 Dementia: Staging of Dementia
- #281 Dementia: Cognitive Assessment
- #282 Dementia: Functional Status Assessment
- #283 Dementia: Neuropsychiatric Symptom Assessment
- #284 Dementia: Management of Neuropsychiatric Symptoms
- #285 Dementia: Screening for Depressive Symptoms
- #286 Dementia: Counseling Regarding Safety Concerns
- #287 Dementia: Counseling Regarding Risks of Driving
- #288 Dementia: Caregiver Education and Support

https://mdinteractive.com/files/uploaded/file/CMS2015group/Dementia-2015.pdf



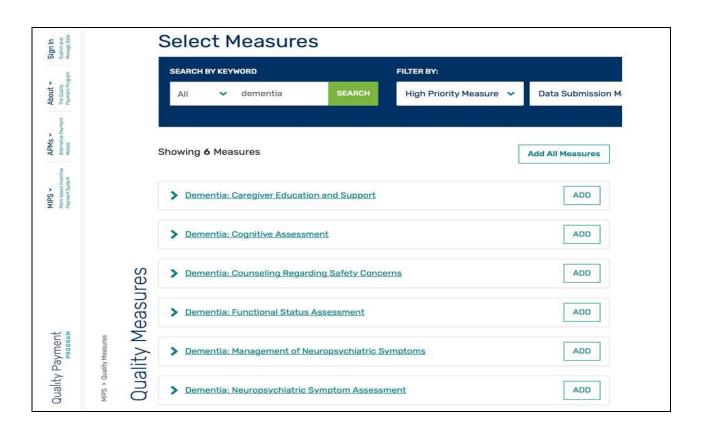


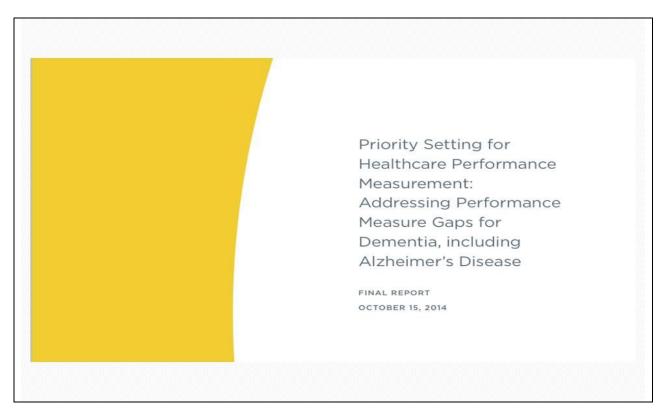
Physician Quality Reporting System (PQRS) Updated to Merit-based Incentive Payment System (MIPS) and located in the Quality Payment Program (QPP)

## 2015 PQRS MEASURES IN DEMENTIA MEASURES GROUP (now in MIPS / QPP):

- #47 Care Plan
- #280 Dementia: Staging of Dementia
- #281 Dementia: Cognitive Assessment
- #282 Dementia: Functional Status Assessment
- #283 Dementia: Neuropsychiatric Symptom Assessment
- \* #284 Dementia: Management of Neuropsychiatric Symptoms
- #285 Dementia: Screening for Depressive Symptoms
- #286 Dementia: Counseling Regarding Safety Concerns
- #287 Dementia: Counseling Regarding Risks of Driving
- #288 Dementia: Caregiver Education and Support

 $https://mdinteractive.com/files/uploaded/file/CMS2015group/Dementia-2015.pdf \\ https://qpp.cms.gov/mips/quality-measures$ 





### National Quality Forum (NQF) - Prioritizing Measure Gaps: Alzheimer's Disease & Related Dementias

- > Comprehensive Patient Measure
  - diagnosis, function, resources, driving, AD, proxy, caregiving needs
- > Comprehensive Caregiver Measure
  - caregiver's needs, expectations, communication, training, education, advocacy
- Dementia Capability
  - Levels: Healthcare System; Community

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### **Dementia Capability Assessment Tool**

(Note: If your organization is an ADI-SSS or ADSSP grantee or project partner, please contact Sari Shuman at sshuman@rti.org prior to completing this tool.)

### Instructions

This assessment tool is designed to measure the dementia capability of the long-term services and supports in various organizations. The information resulting from this assessment will assist in measuring changes in dementia capability over time.

Any organization can complete an individual assessment of its dementia capability. Questions 1 through 5 are used to identify the responding organization and its focus areas. Questions 6 through 9 are used to measure various aspects of dementia capability. The goal of the assessment is to demonstrate dementia capability throughout the organization. Due to organizational changes over time, periodic re-evaluation of dementia capability is strongly recommended.

https://nadrc.acl.gov/node/117





8. Providing specialized services to people with a cognitive impairment or dementia and their caregivers

Does your organization: (Circle the letters of ALL that apply.)

- a. Conduct a formal assessment to determine the specific needs of people with cognitive impairment or dementia?
  - i. If so, what assessment tool is used?
- b. Conduct an assessment of caregivers of people with cognitive impairment or dementia to determine their service needs?
- c. Have a standard procedure for providing referrals to people with dementia?
- d. Have a standard procedure for providing referrals to caregivers?
- e. Have a list of dementia-capable providers and organizations to which people with dementia and their caregivers are referred?
- f. Track referrals to determine if the person with dementia or their caregivers contact the organization they are referred to?

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### Consumer Assessment of Healthcare Providers and Systems (CAHPS)

CAHPS Home and Community Based Services Survey:

### Overview

The CAHPS Home and Community-Based Services Survey (HCBS CAHPS) is the first cross-disability survey of home and community-based service beneficiary's experience receiving long-term services and supports. It is designed to facilitate comparisons across the hundreds of state Medicaid HCBS programs throughout the country that target different adults with disabilities, e.g., including frail elderly, individuals with physical disabilities, persons with developmental or intellectual disabilities, those with acquired brain injury and persons with severe mental illness. The HCBS CAHPS Survey is available for voluntary use in HCBS programs as part of quality assurance and improvement activities and public reporting.

https://www.medicaid.gov/medicaid/quality-of-care/performance-measurement/cahps-hcbs-survey/index.html

## UK: National Institute for Health & Care Excellence (NICE) - Dementia

- Anti-psychotic medication
- Laboratory Assessment
  - complete blood count, calcium, glucose, renal and liver function, thyroid function, B12 and folate
- Care plan reviewed in face-to-face meeting
- Contact details of named carer on record
- Attendance at a memory assessment service

https://www.nice.org.uk/standards-and-indicators/index/All/Dementia

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### Dementia overview

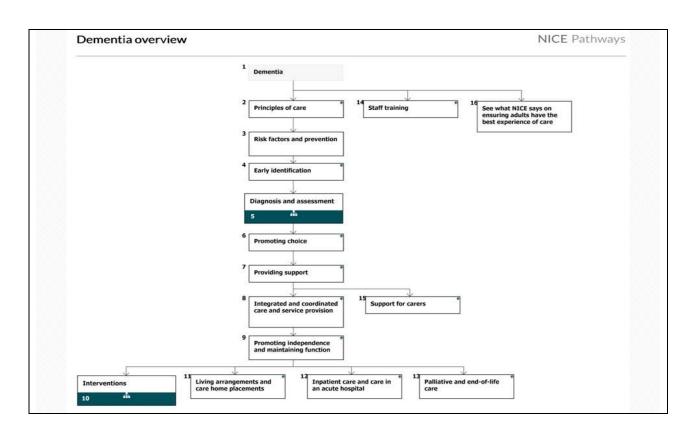
NICE Pathways bring together everything NICE says on a topic in an interactive flowchart. NICE Pathways are interactive and designed to be used online.

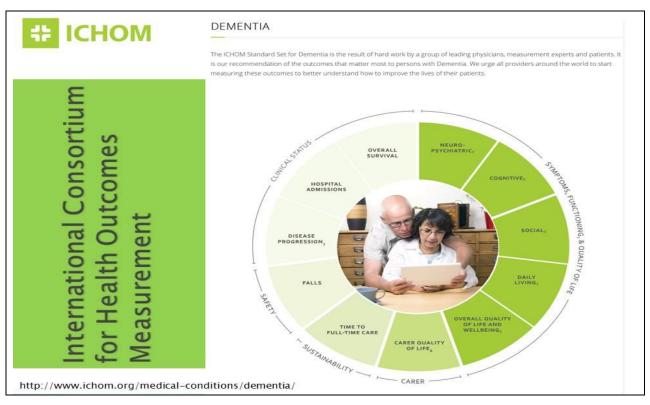
They are updated regularly as new NICE guidance is published. To view the latest version of this NICE Pathway see:

http://pathways.nice.org.uk/pathways/dementia

NICE Pathway last updated: 27 March 2018

This document contains a single flowchart and uses numbering to link the boxes to the associated recommendations.





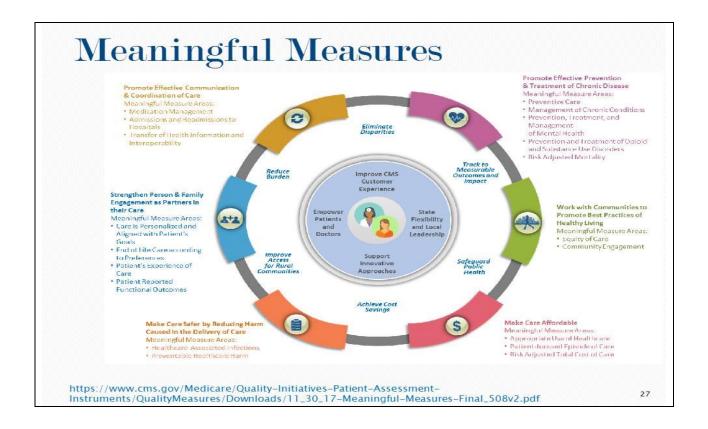
### ICHOM: International Consortium on Health Outcome Measures - Dementia Care Categories

- Demographic Factors
- Baseline Clinical Status
- Associated Clinical History
- Medication Variables
- Symptoms, Functioning and Quality of Life
- Carer
- Sustainability
- Safety
- Clinical Status

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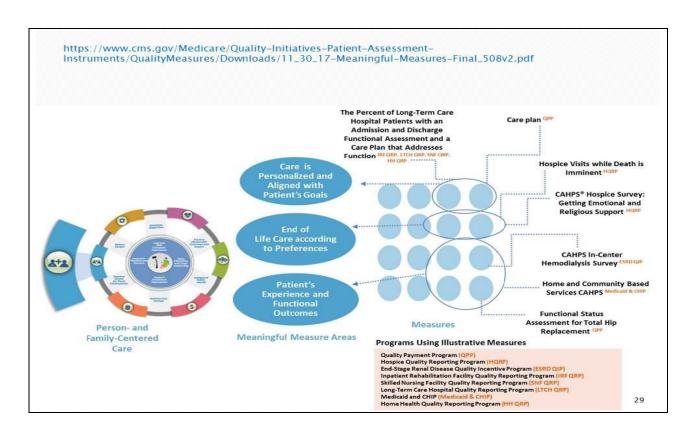
### ICHOM: International Consortium on Health Outcome Measures - Dementia Outcomes Assessment Measures

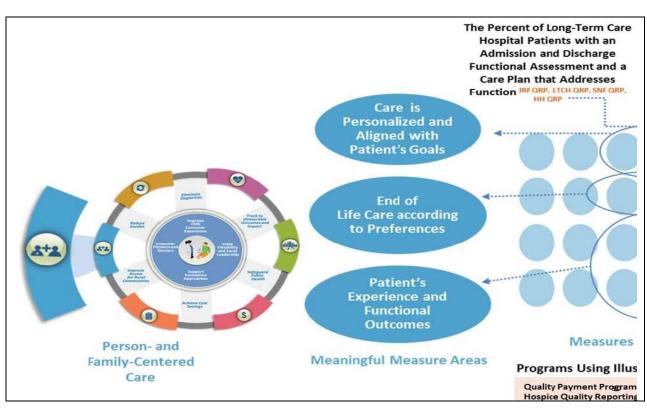
- Neuropsychiatric Inventory (NPI)
- Bristol Activities Daily Living Scale (BADLS)
- Quality of Life-AD (QOL-AD)
- Quality of Wellbeing Scale Self Adm (QWB-SA)
- EuroQol-5D (EQ-5D)
- Clinical Dementia Rating (CDR)
- Montreal Cognitive Assessment (MoCA)

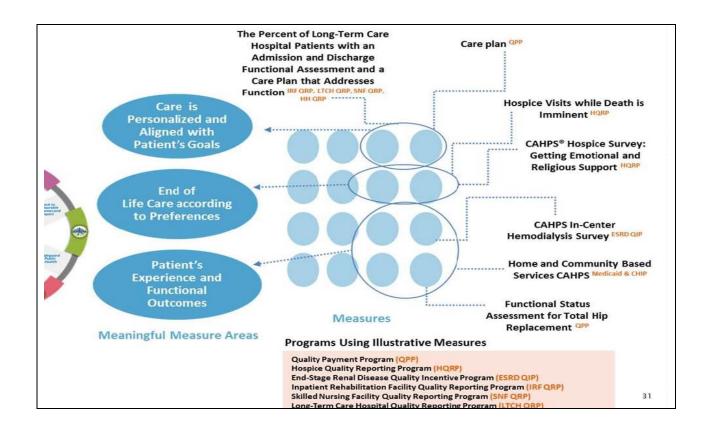


## CMS - Meaningful Measures

- Promote Effective Prevention & Treatment of Chronic Disease
- Work with Communities to Promote Best Practices of Healthy Living
- Make Care Affordable
- Make Care Safer by Reducing Harm Caused in the Delivery of Care
- Strengthen Person & Family Engagement as Partners in their Care
- Promote Effective Communication & Coordination of Care







## C.M.Callahan; Health Affairs 2014

Redesigning Systems of Care for Older Adults with AD

#### COMPONENTS OF BEST PRACTICE MODELS

- 1. Make a formal diagnosis using a standardized instrument and with input from a family member;
- 2. Evaluate the patient for treatable causes of cognitive impairment or excess disability;
- 3. Consider referral to a specialty memory care practice;
- 4. Educate the patient and family about the diagnosis and care options;
- 5. Accept the caregiver-care recipient dyad as the target of care
- 6. Refer the patient to relevant community support services;
- Regularly assess patient for problem behaviors and train the caregiver in identifying and managing these behaviors
- 8. Discuss goals of care
- 9. Discuss driving and home safety
- 10. Consider cognitive enhancing drugs
- 11. Regularly reassess the psychoactive side effects of prescription and non-prescription medications and alcohol and other substance abuse
- 12. Facilitate regular cognitive, physical, and social activity
- 13. Detect and treat vascular risk factors
- 14. Manage the patients comorbid conditions in the context of dementia
- 15. Track patient outcomes and adjust goals of care as appropriate

### ASPE & RTI: Examining Models of Dementia Care

- Detection of Possible Dementia
- Diagnosis
- 3. Assessment and Ongoing Reassessment
- 4. Care Planning
- 5. Medical Management
- 6. Information, Education, and Informed and Supported Decision-Making
- Acknowledgement and Emotional Support for the Person with Dementia
- Assistance for the Person with Dementia with Daily Functioning and Activities

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### ASPE & RTI: Examining Models of Dementia Care

- Involvement, Emotional Support, and Assistance for Family Caregiver(s)
- Prevention and Mitigation of Behavioral and Psychological Symptoms of Dementia
- 11. Safety for the Person with Dementia
- 12. Therapeutic Environment, Including Modifications to the Physical and Social Environment of the Person with Dementia
- 13. Care Transitions
- 14. Referral and Coordination of Care and Services that Match the Needs of the Person with Dementia and Family Caregiver(s) and Collaboration Among Agencies and Providers

# J.W. Wiener; RTI and HHS ASPE Examining Models of Dementia Care

	TABLE 2-1. Dementia Care Framework Components			
1.	Detection of Possible Dementia	Examine for cognitive impairment when there is a decline from previous function in daily activities, occupational ability, or social engagement.		
2.	Diagnosis	Obtain a comprehensive evaluation and diagnosis from a qualified provider when cognitive impairment is suspected.		
3.	Assessment and Ongoing Reassessment	Assess cognitive status, functional abilities, behavioral and psychological symptoms of dementia, medical status, living environment, and safety. Reassess regularly and when there is a significant change in condition.		
4.	Care Planning	Design a care plan that will meet care goals, satisfy the person's needs, and maximize independence.		
5.	Medical Management	Deliver timely, individualized medical care to the person with dementia, including prescribing medication and managing comorbid medical conditions in the context of the person's dementia.		
6.	Information, Education, and Informed and Supported Decision Making	Provide information and education about dementia to support informed decision making including end-of-life decisions.		
7.	Acknowledgement and Emotional Support for the Person with Dementia	Acknowledge and support the person with dementia. Allow the person's values and preferences to guide all aspects of the care. Balance family involvement with individual autonomy and choice.		
8.	Assistance for the Person with Dementia with Daily Functioning and Activities	Ensure that persons with dementia have sufficient assistance to perform essential health-related and personal care activities and to participate in activities that reflect their preferences and remaining strengths; help to maintain cognitive, physical, and social functioning for as long as possible; and support quality of life. Provide help as needed with medication management and pain control.		

# J.W. Wiener; RTI and HHS ASPE Examining Models of Dementia Care

9.	Involvement, Emotional Support, and Assistance for Family Caregiver(s)	Involve caregiver in evaluation, decision making, and care planning and encourage regular contact with providers. Provide culturally sensitive emotional support and assistance for the family caregiver(s).
10.	Prevention and Mitigation of Behavioral and Psychological Symptoms of Dementia	Identify the causes of behavioral and psychological symptoms, and use nonpharmacological approaches first to address those causes. Avoid use of antipsychotics and other medications unless the symptoms are severe, create safety risks for the person or others, and have not responded to other approaches. Avoid physical restraints except in emergencies.
11.	Safety for the Person with Dementia	Ensure safety for the person with dementia. Counsel the person and family as appropriate about risks associated with wandering, driving, and emergency preparedness. Monitor for evidence of abuse and neglect.
12.	Therapeutic Environment, Including Modifications to the Physical and Social Environment of the Person with Dementia	Create a comfortable environment, including physical and social aspects that feel familiar and predictable to the person with dementia and support functioning, a sustained sense of self, mobility, independence, and quality of life.
13.	Care Transitions	Ensure appropriate and effective transitions across providers and care settings.
14.	Referral and Coordination of Care and Services that Match the Needs of the Person with Dementia and Family Caregiver(s) and Collaboration Among Agencies and Providers	Facilitate connections of persons with dementia and their family caregivers to individualized, culturally and linguistically appropriate care and services, including medical, other health-related, residential, and home and community-based services. When more than 1 agency or provider is caring for a person with dementia, collaborate among the various agencies and providers to plan and deliver coordinated care.

ASPE & RTI: Examining Models of Dementia Care	ACOVE	PQRS & QPP	ACL: Dementia Capability	Alzheimer's Association: Dementia Care Practice Recommendations	
Detection of possible dementia	Cognitive & Functional Screening; Memory Loss	Cognitive Assessment		Detection & Diagnosis	
2. Diagnosis	Medication Review; Laboratory Testing; Neuroimaging	Staging of Dementia; Functional Status Assessment	Identification and Awareness of Dementia		
Assessment and ongoing reassessment			Measuring Functional Ability for Care Planning	Assessment & Care Planning	
4. Care planning		Care Plan	and Resource Allocation		
5. Medical management	Cholinesterase Inhibitor			Medical Management	
6. Information, education, and informed and supported decision making			Understanding Decision- making Capacity for Care Planning & Resource Allocation	Information, Education and Support	
7. Acknowledgement and emotional support for the person with dementia			Support Resources for Persons with ADRD	Cupport	
Assistance for the person with dementia with daily functioning and activities			Support Resources for Persons with ADRD	Ongoing Care for BPSD and Support for ADLs	
Involvement, emotional support, and assistance for family caregivers	Caregiver Support (and Patient Safety)	Caregiver Education and Support	Caregiver Support Resources		

				Recommendations
9. Involvement, emotional support, and assistance for family caregivers	Caregiver Support (and Patient Safety)	Caregiver Education and Support	Caregiver Support Resources	
10. Prevention and mitigation of behavioral and psychological symptoms of dementia	Screening for Depression; Depression Treatment	Neuropsychiatric Symptom Assessment; Management of Neuropsychiatric Symptoms; Screening for Depressive Symptoms	Understanding Decision- making Capacity for Care Planning & Resource Allocation	Ongoing Care for BPSD and Support for ADLs
11. Safety for the person with dementia	(Caregiver Support) and Patient Safety; Driving Privileges; Restraints	Counselling Regarding Safety Concerns; Counselling Regarding Risks of Driving	Safety Resources	
12. Therapeutic environment, including modifications to the physical and social environment of the person with dementia				Supportive and Therapeutic Environment
13. Care transitions				
14. Referral and coordination of care and services that match the needs of the person with dementia and family caregiver(s) and collaboration among agencies and providers			Information, Referral, and Assistance Services Capable of Meeting the Unique Needs of Persons with Dementia and Caregivers	Transition and Coordination of Services
			Options Counselling and Assistance	
			Resources for Diverse and Underserved Persons with Dementia and Caregivers	
			Self-directed Services	
			Workforce Training and Tools	Workforce
			Quality Assurance Systems	

## Session 1: Advancing Consensus on Dementia Care Elements

- Alzheimer's Association Dementia Care Practice Recommendations
  - Sam Fazio and Doug Pace, Alzheimer's Association
- Quality Care from the Perspectives of People Living with Dementia
  - Cynthia Huling Hummel, NAPA Council Member
- Care Planning and Health Information Technology: How to Aid Dementia Quality Care
  - Liz Palena Hall, ONC

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## Session 2: Exemplar Models Informing the Need for New Outcomes Measurement

- Comprehensive Primary Care Plus (CPC+): Exemplar of governmental initiative
  - Laura Sessums, CMS/CMMI
- Age-Friendly Health Systems: Exemplar of Non-governmental initiative
  - · Amy Berman, John A. Hartford Foundation
  - Kedar Mate, Institute for Healthcare Improvement

## **Discussion Questions**

- Are there next steps regarding the 14 Dementia Care Elements from RTI / ASPE?
- (How) does the Advisory Council address best practice recommendations?
- Should there be increased focus on assessing dementia capability and/or on outcome measures, including PROMs?
- How can the use of a care plan for persons living with cognitive symptoms contribute to improving care quality?
- What are the health information needs for IT interoperability to help advance clinical care & LTSS?

Domain	Suggested measures
Cognition	Mini-Cog
	GPCOG
	Short MoCA
Function	FAQ (IADL), Katz (ADL), Lawton- Brody (IADL)
Stage of cognitive impairment	Mini-Cog + FAQ
	Dementia Severity Rating Scale
Decision-making	3-level rating: able to make own decisions, not able, uncertain/needs more evaluation
Neuropsychiatric symptoms	NPI-Q
Depression	BEHAVE 5+
	PHQ-2
Neuropsychiatric symptoms  Depression  Medication review and reconciliation  Safety	Med list + name of person overseeing home meds
Safety	Safety Assessment Guide

### April 27, 2018 -- Advisory Council Meeting #28

The meeting was held on Friday, April 27, 2018, in Washington, DC. During the meeting, the Clinical Care Subcommittee took charge of the theme, focusing on advancing consensus on dementia care elements to guide new outcomes measurement. The Council heard speakers in two sessions, one focused on developing consensus about dementia care elements, and the second on models that are informing outcomes measurement. The meeting also included updates on work from the previous meetings, a presentation on the final report from the October 2017 Care Summit, and federal workgroup updates. Material available from this meeting is listed below and at <a href="https://aspe.hhs.gov/advisory-council-alzheimers-research-care-and-services-meetings#Apr2018">https://aspe.hhs.gov/advisory-council-alzheimers-research-care-and-services-meetings#Apr2018</a>.

Comments and questions, or alerts to broken links, should be sent to <a href="mailto:napa@hhs.gov">napa@hhs.gov</a>.

### **General Information**

Agenda	[HTML Version] [PDF Version]
Meeting Announcement	[HTML Version] [PDF Version]
Meeting Summary	[HTML Version] [PDF Version]
Public Comments	[HTML Version]

### **Handouts**

Main Summit Recommendations	[HTML Version] [PDF Version]
National Research Summit on Care, Services, and Supports for Persons with Dementia and Their Caregivers: Report to the National Advisory Council on Alzheimer's Research, Care, and Services	[HTML Version] [PDF Version]

### **Presentation Slides**

Age-Friendly Health Systems	[HTML Version] [PDF Version]
Alzheimer's Disease and Related Dementias Research Update	[HTML Version] [PDF Version]
Care Planning and Health Information Technology: How to Aid Dementia Quality Care	[HTML Version] [PDF Version]

Clinical Care Subcommittee Agenda: Advancing Consensus on Dementia Care Elements to Guide New Outcomes Measurement	[HTML Version] [PDF Version]
Clinical Subcommittee Update	[HTML Version] [PDF Version]
Defining Quality Dementia Care	[HTML Version] [PDF Version]
Final Report to the NAPA Advisory Council	[HTML Version] [PDF Version]
<b>Long-Term Services and Supports Committee Update</b>	[HTML Version] [PDF Version]
Quality Care from the Perspectives of People Living with Dementia	[HTML Version] [PDF Version]
Research Summit on Dementia Care: Building Evidence for Services and Supports Process Report	[HTML Version] [PDF Version]
Testing the Promise of Primary Care: Comprehensive Primary Care Plus (CPC+)	[HTML Version] [PDF Version]
Updates and Follow-Up from January Meeting	[HTML Version] [PDF Version]

## **Videos**

Introductions and Updates	[Video]
Clinical Care Agenda Session 1	[Video]
Public Comments	[Video]
Clinical Care Agenda Session 2	[Video]
Care Summit Final Report	[Video]
MEETING WRAP-UP: Final Report to the NAPA Advisory Council	[Video]

Last Updated: 06/09/2018