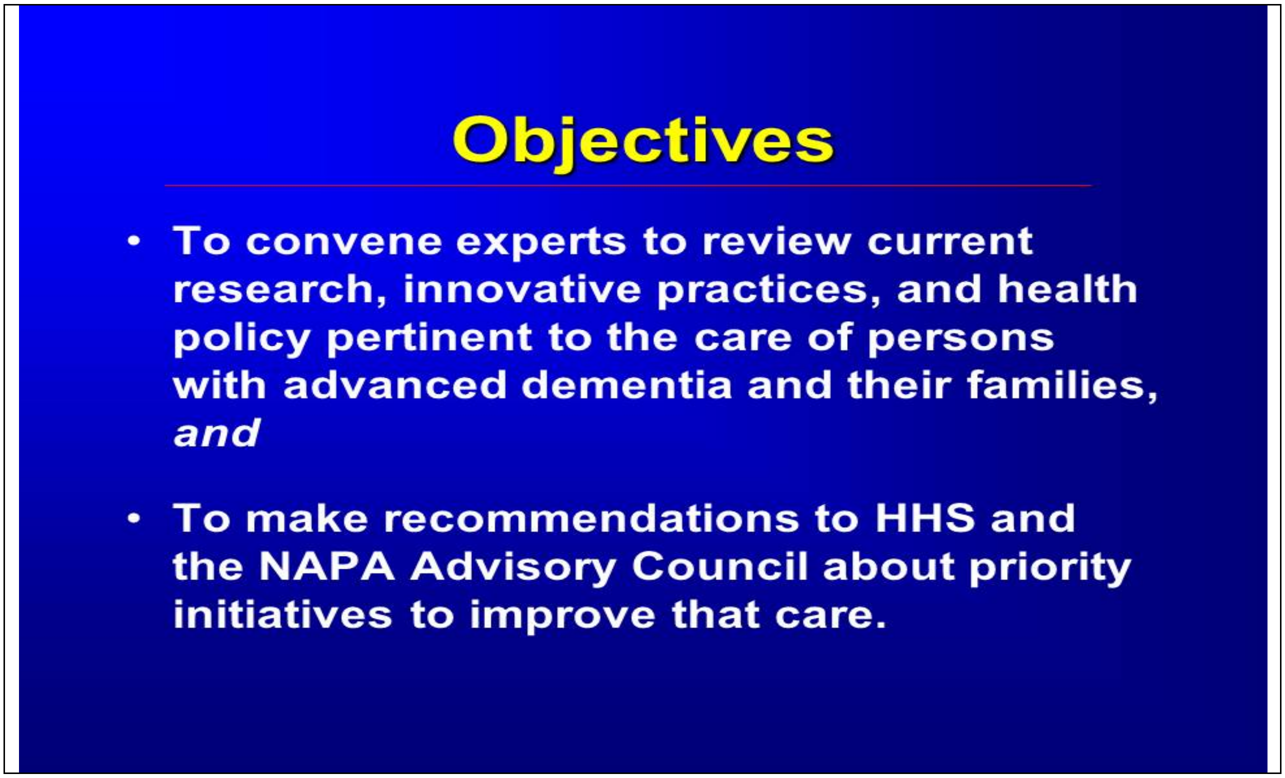
Advanced Dementia Expert Panel Summary and Key Recommendations

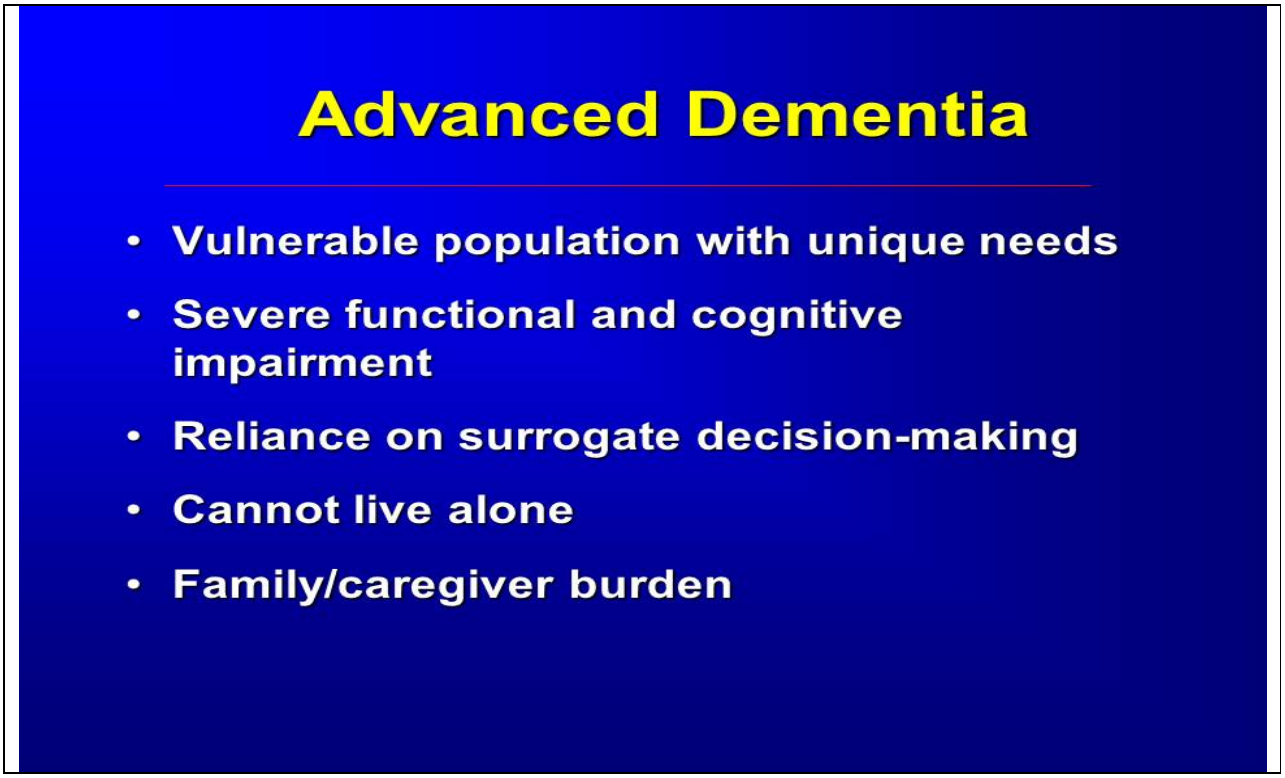


Objectives

- To convene experts to review current research, innovative practices, and health policy pertinent to the care of persons with advanced dementia and their families, *and*
- To make recommendations to HHS and the NAPA Advisory Council about priority initiatives to improve that care.

Rationale

- ~ 1,000,000 Americans with advanced dementia
- Pressing need to provide high quality care for these persons and families
- Special considerations



Advanced Dementia

- Vulnerable population with unique needs
- Severe functional and cognitive impairment
- Reliance on surrogate decision-making
- Cannot live alone
- Family/caregiver burden

Organization

- **Co-Chairs**: Susan Mitchell MD MPH, and Laurel Coleman MD
- **Facilitator**: Katie Maslow, IOM
- **Core Group**: Attend all meetings, formulate final recommendations
- **Experts**: Specific meetings
- **Observers**: public, professional and provider organizations, advocates, and staff from many federal agencies (AoA/ACL, AHRQ, ASPE. CDC,CMS, HRSA, NIA, NINR, SAMHSA, and VA)

Core Group +

- Co-Chairs: Coleman, Mitchell
- A. Bonner PhD: Northeastern, *policy*
- S. Brangman MD: SUNY, *care delivery, education*
- M. Ersek RN: UPenn, *nursing, research, care delivery*
- L. Hanson MD, MPH: UNC, *clinical research*
- R. Sean Morrison MD: Mount Sinai, *research, policy*

Also participated in drafting final recommendations

- D. Meier MD: Center to Advance Palliative Care, *policy*
- M. Gallagher DNP: Hospice of the Valley, *care delivery*
- G. Sachs MD: Indiana University, *clinical research*
- J. Teno MD: Brown University, *clinical and policy research*
- D. Hoffman: NY State Health Department, *public policy*

Meetings

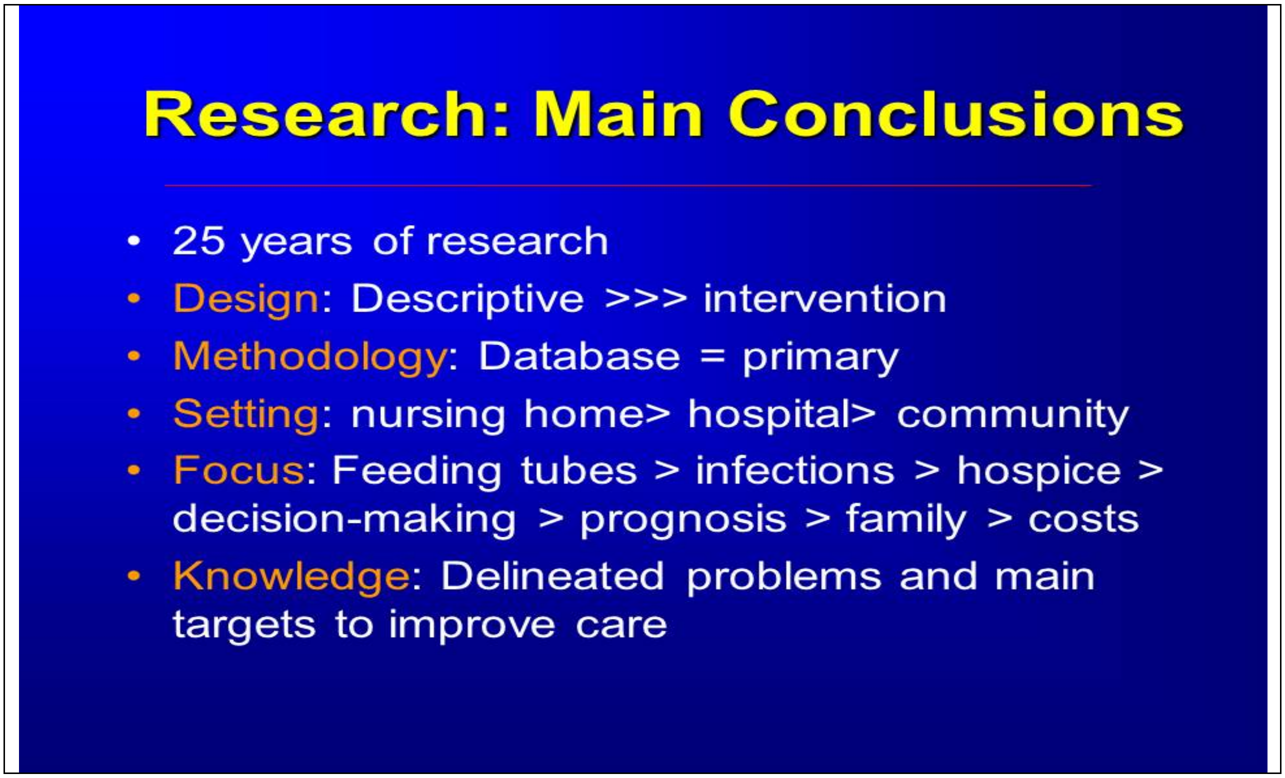
1. **Research**
   - January 28, 2014
2. **Clinical Practice**
   - September 28, 2014
3. **Policy**
   - January 21, 2015

Research: Participants

- **Core Group**
- **Invited Experts**
  - **Marilyn Albert, PhD**
  - **Ken Covinsky, MD**
  - **Joan Teno MD, MSc**
  - **Richard Schultz, PhD**
  - **Constantine Lyketsos, PhD**
  - **Greg Sachs, MD**
- **Observers**

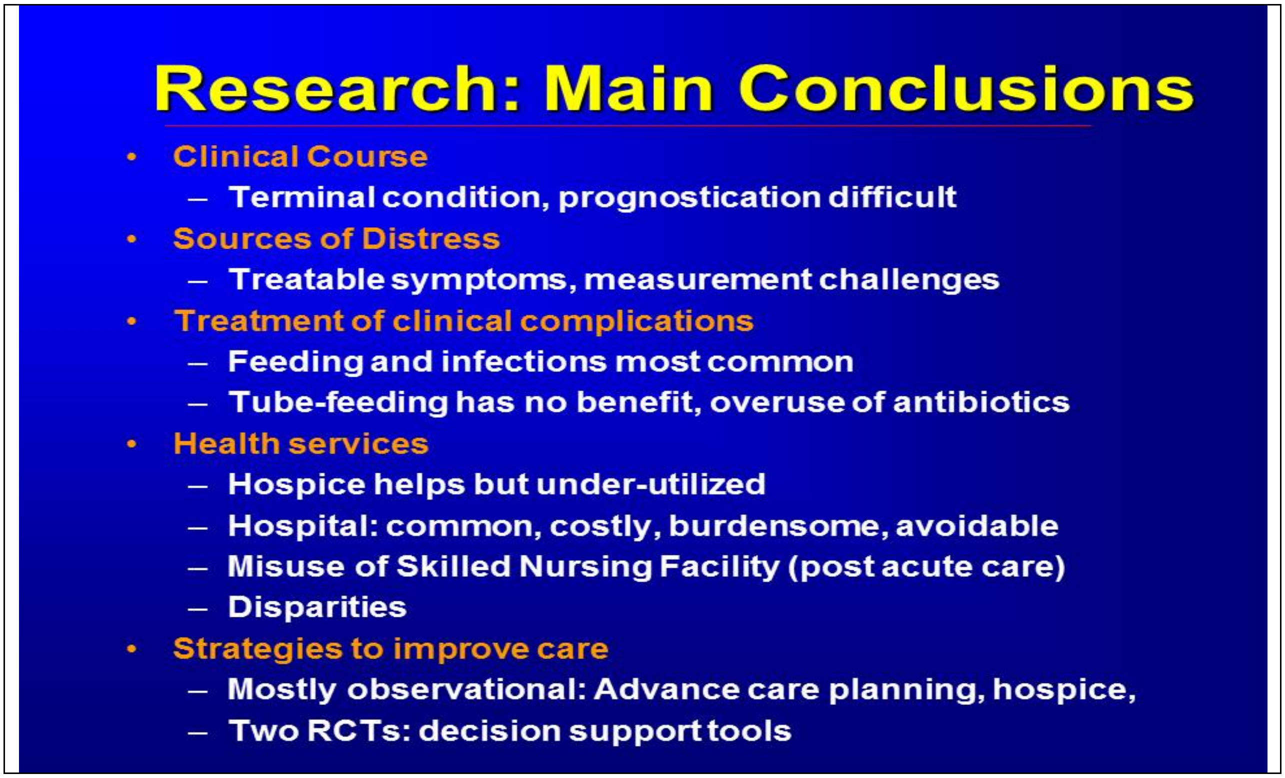
Research: Agenda

- **Advanced Dementia Research Overview- *Mitchell***
- **Patient Experience- *Hanson***
- **Family Experience- *Ersek***
- **Health Services Utilization- *Teno***
- **Infrastructure and Funding-*Morrison***



Research: Main Conclusions

- 25 years of research
- Design: Descriptive >>> intervention
- Methodology: Database = primary
- Setting: nursing home> hospital> community
- Focus: Feeding tubes > infections > hospice > decision-making > prognosis > family > costs
- Knowledge: Delineated problems and main targets to improve care



Research: Main Conclusions

- Clinical Course
  - Terminal condition, prognostication difficult
- Sources of Distress
  - Treatable symptoms, measurement challenges
- Treatment of clinical complications
  - Feeding and infections most common
  - Tube-feeding has no benefit, overuse of antibiotics
- Health services
  - Hospice helps but under-utilized
  - Hospital: common, costly, burdensome, avoidable
  - Misuse of Skilled Nursing Facility (post acute care)
  - Disparities
- Strategies to improve care
  - Mostly observational: Advance care planning, hospice,
  - Two RCTs: decision support tools

Research: Main Conclusions

- Clearly delineated opportunities to improve care
- Current research priority: determine how to address opportunities
  - Design and test clinical interventions and models of care to improve advanced dementia care
  - Design and evaluate health policy initiatives that incentivize high quality goal-directed care

Clinical Practice: Participants

- Core Group
- Invited Experts
  - Margaret Noel MD – MemoryCare
  - Jody Comart PhD - Hebrew Senior Life
  - Jed Levine - NY Chapter of Alzheimer's Association
  - Ashley Shreves MD – Mt. Sinai Hospital, NY
  - Maribeth Gallagher DNP – Hospice of the Valley
  - Dayna Cooper MSN – VA Geriatrics and Extended Care
  - Greg Sachs MD – Indiana University
  - Ann Wyatt MSW – Alzheimer's Association consultant
  - Tena Alonzo MA – Beatitudes CCRC

Clinical Practice: Agenda

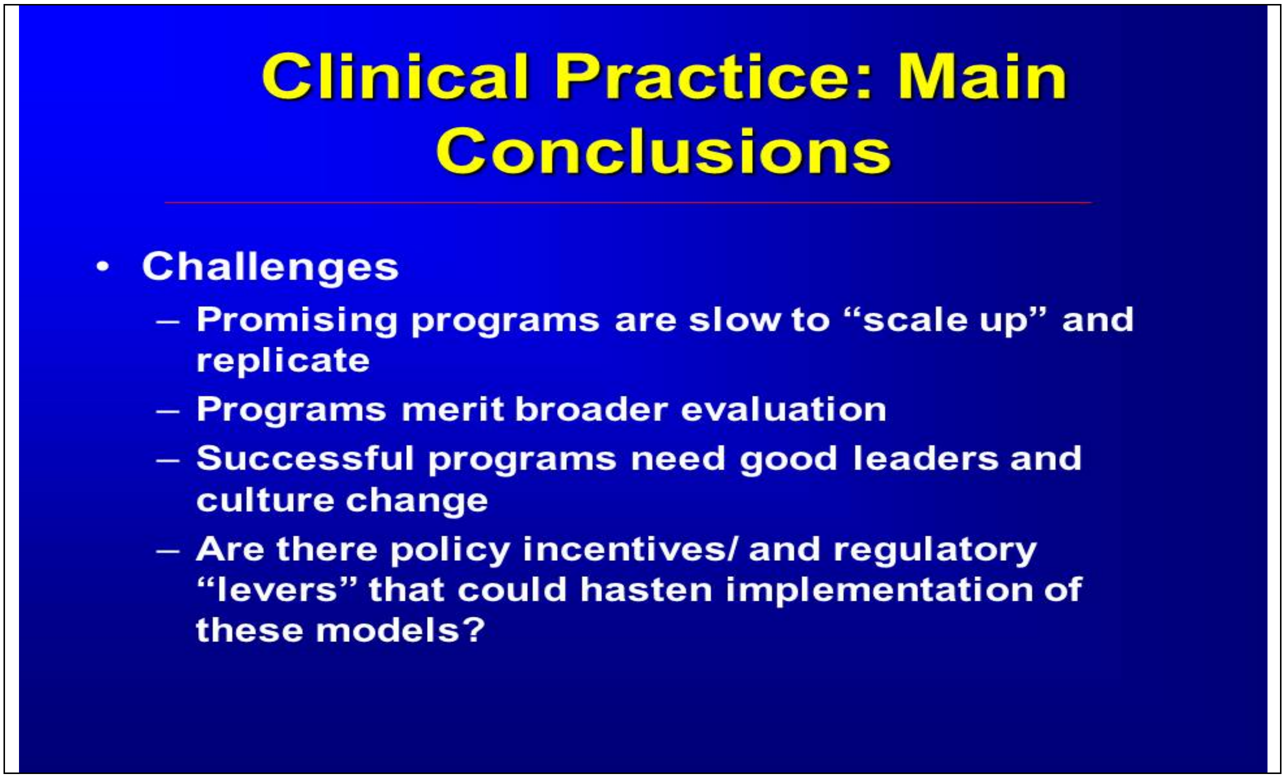
- Innovative practices in care for persons with advanced dementia in:
  - Nursing homes
  - At home and in the community
  - In hospice
  - In the hospital and emergency department
  - Support and training for families and other caregivers

Clinical Practice: Main Conclusions

- **Nursing Home Program – Beatitudes**
  - High family and staff satisfaction
  - Low medication use and reduced hospital and ER use.
- **Community programs –**
  - Focus on palliative care - support for family/caregivers
  - Advance care planning is common theme.
  - Persons with dementia are less likely to die in the hospital and have lower levels of pain and distress.

Clinical Practice: Main Conclusions

- **Hospice Program**
  - Published results with lower use of restraints, feeding tubes, lower rates of hospitalizations.
  - Works cooperatively with long term care facilities
  - Excellent symptom management and family satisfaction.
- **New strategies and programs –**
  - All show promising results: training family caregivers, ER consultations, printed guides for advance care planning/education.
- **Very POSITIVE and encouraging day for all.**



Clinical Practice: Main Conclusions

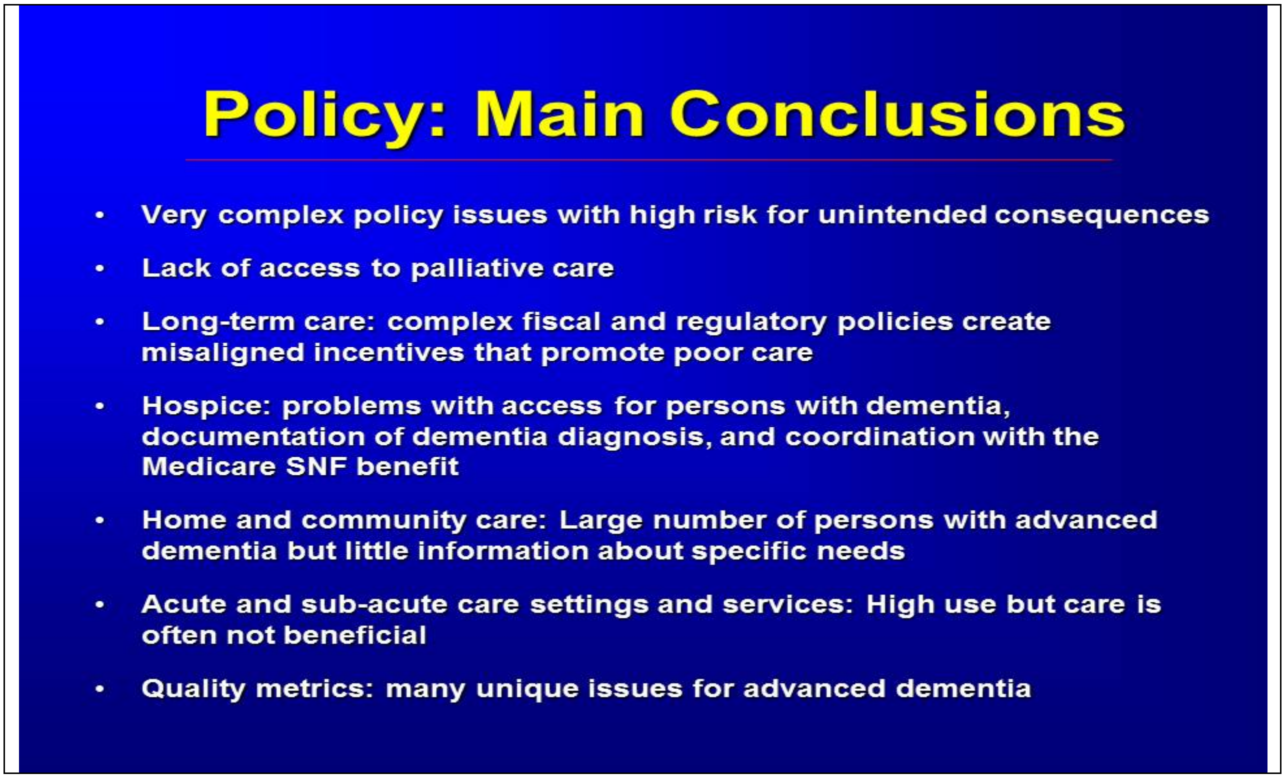
- Challenges
  - Promising programs are slow to “scale up” and replicate
  - Programs merit broader evaluation
  - Successful programs need good leaders and culture change
  - Are there policy incentives/ and regulatory “levers” that could hasten implementation of these models?

Policy: Participants

- Core Group - and David Hoffman
- Invited Experts:
  - Diane Meier MD: Mt. Sinai Hospital, CAPC
  - Joan Teno MD: Brown University
  - Susan Miller PhD: Brown University
  - David Grabowski PhD: Harvard University
  - Greg Sachs MD: Indiana University

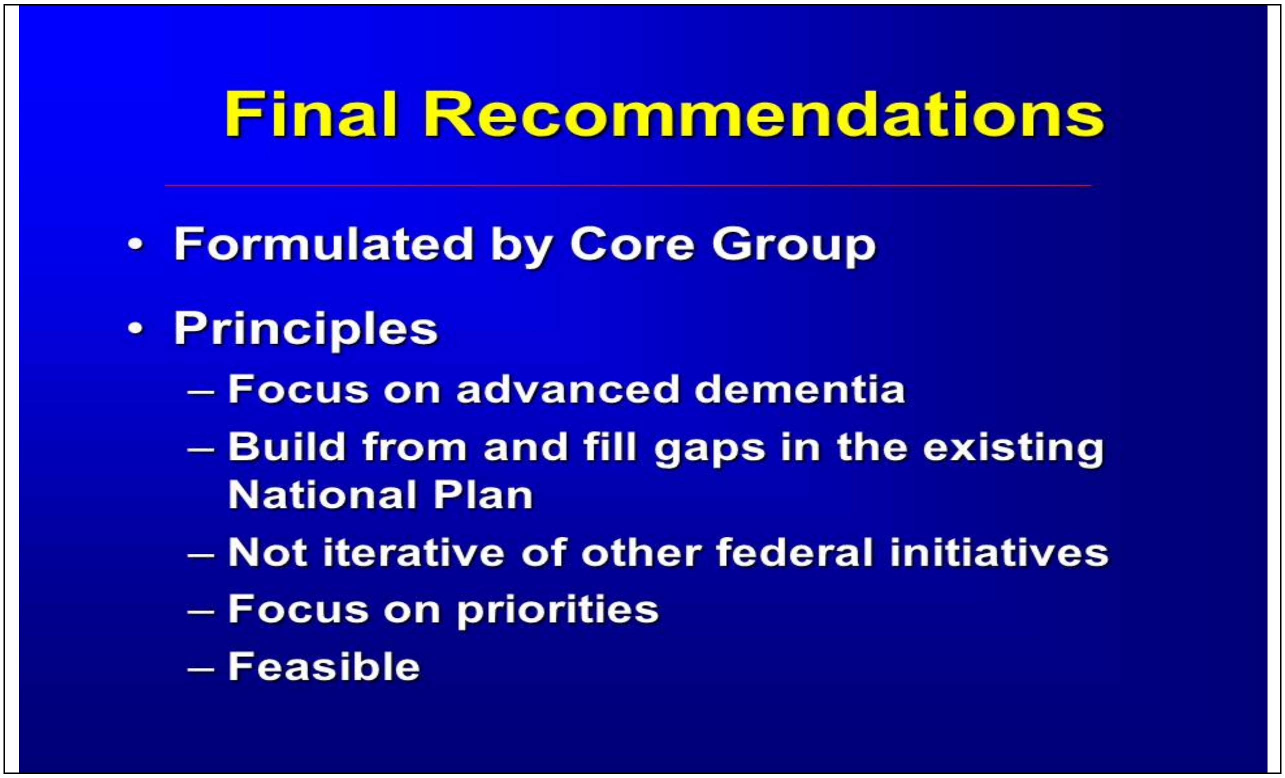
Policy: Agenda

- Transforming care for persons with advanced dementia – what will it take?
- How do we measure quality for this population?
- Policy barriers and opportunities for providing good care in various settings:
  - Home and community
  - Nursing home
  - Hospice
  - Hospital and care transitions



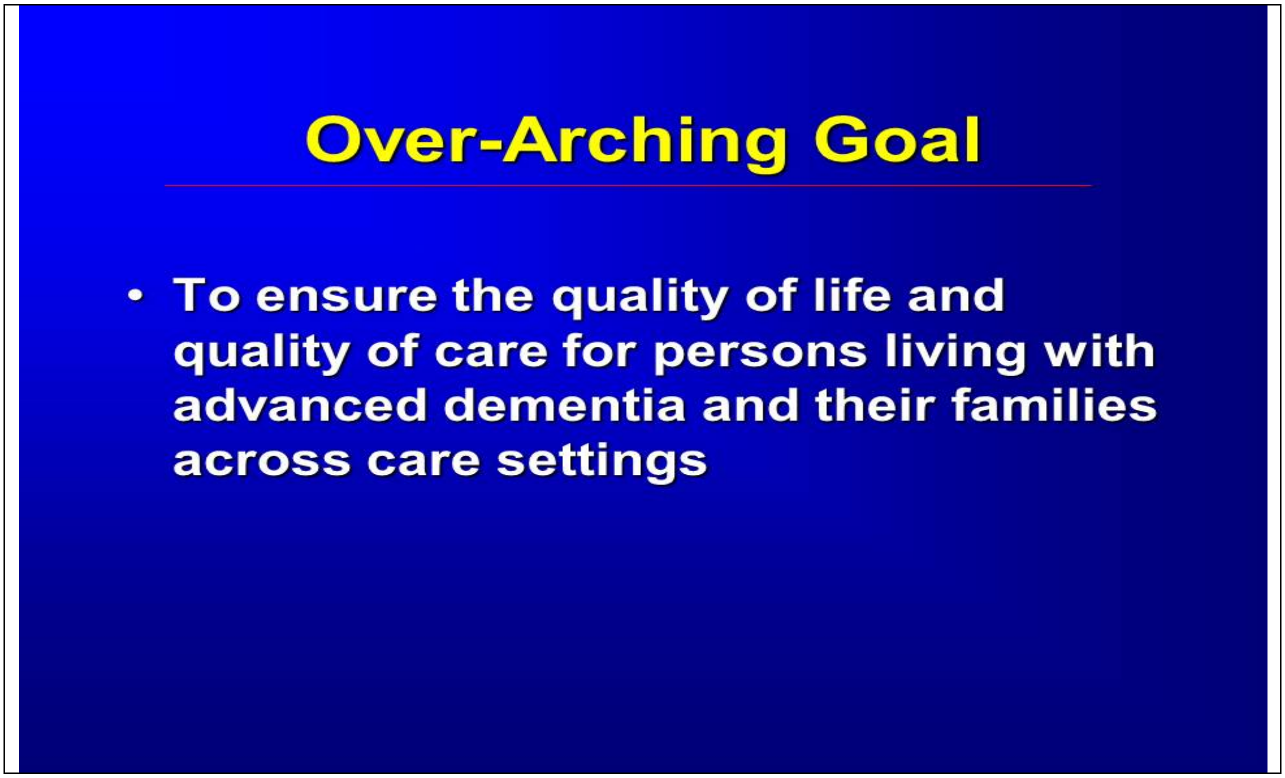
Policy: Main Conclusions

- Very complex policy issues with high risk for unintended consequences
- Lack of access to palliative care
- Long-term care: complex fiscal and regulatory policies create misaligned incentives that promote poor care
- Hospice: problems with access for persons with dementia, documentation of dementia diagnosis, and coordination with the Medicare SNF benefit
- Home and community care: Large number of persons with advanced dementia but little information about specific needs
- Acute and sub-acute care settings and services: High use but care is often not beneficial
- Quality metrics: many unique issues for advanced dementia



Final Recommendations

- Formulated by Core Group
- Principles
  - Focus on advanced dementia
  - Build from and fill gaps in the existing National Plan
  - Not iterative of other federal initiatives
  - Focus on priorities
  - Feasible



Over-Arching Goal

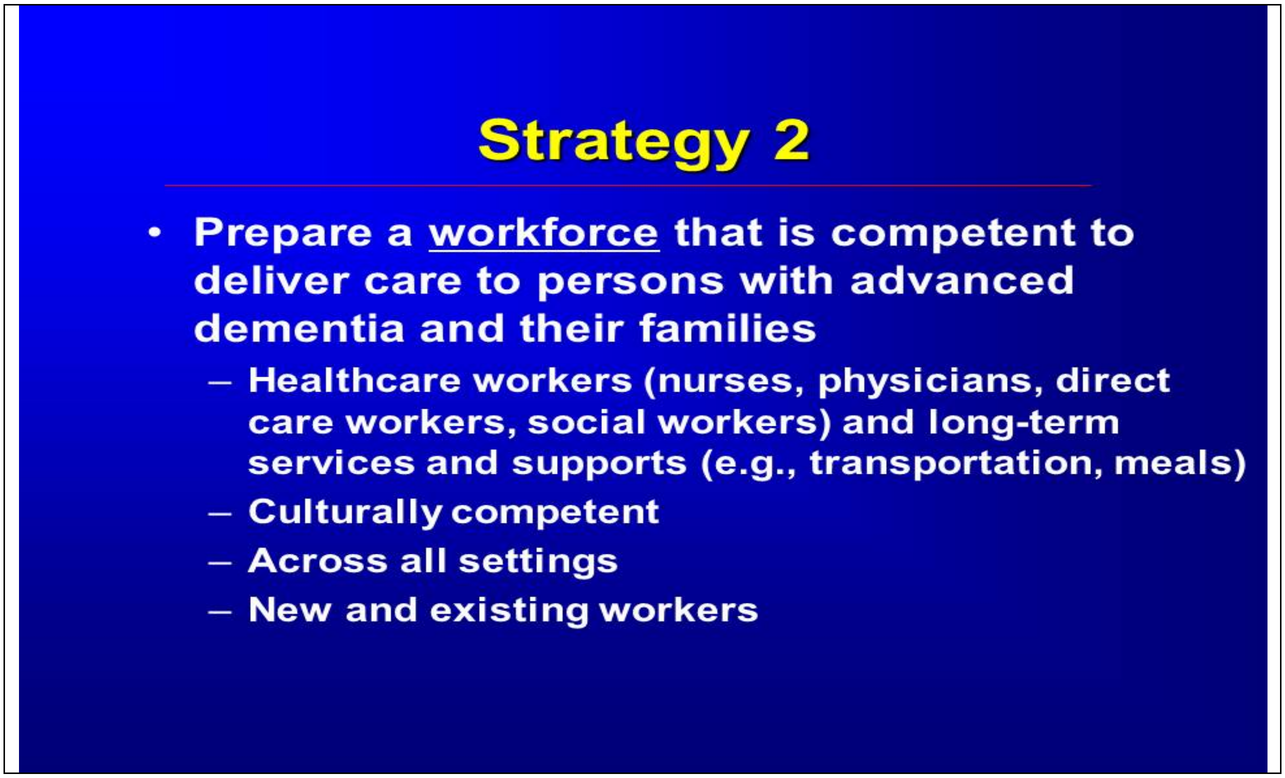
- To ensure the quality of life and quality of care for persons living with advanced dementia and their families across care settings

Strategy 1

- To ensure access to high quality palliative care for persons with advanced dementia and their families across all settings
  - Primary palliative care
  - Palliative care consultation
  - Hospice
    - Beneficial but ...
    - Major access concerns

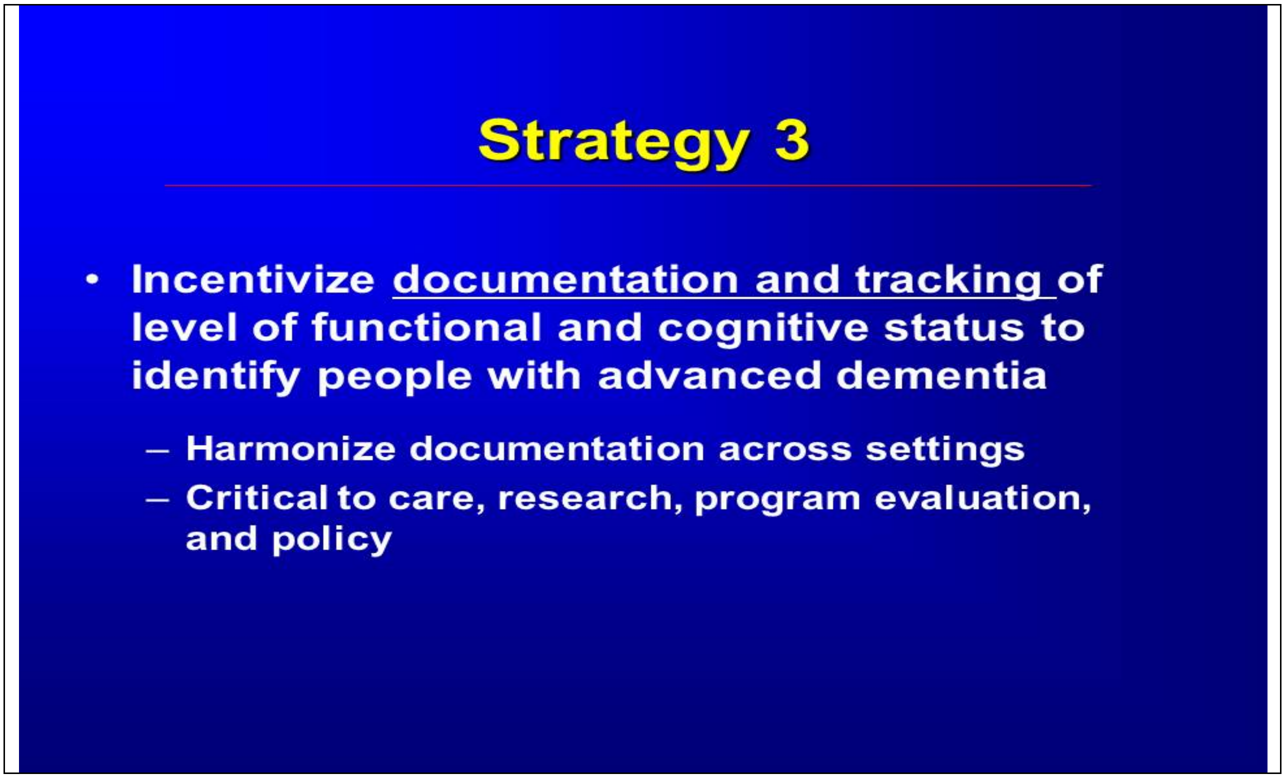
What is Palliative Care?

- Specialized medical care for persons with serious illnesses.
- Relief from the symptoms, pain, and stress of a serious illness - whatever the diagnosis.
- Improves quality of life for the person and family.
- Team of doctors, nurses, and other specialists who work with a person's other doctors to provide an extra layer of support.
- Appropriate at any age and at any stage in a serious illness, and can be provided together with curative treatments.



Strategy 2

- Prepare a workforce that is competent to deliver care to persons with advanced dementia and their families
  - Healthcare workers (nurses, physicians, direct care workers, social workers) and long-term services and supports (e.g., transportation, meals)
  - Culturally competent
  - Across all settings
  - New and existing workers



Strategy 3

- Incentivize documentation and tracking of level of functional and cognitive status to identify people with advanced dementia
  - Harmonize documentation across settings
  - Critical to care, research, program evaluation, and policy

Strategy 4

- Support research, evaluation and dissemination of models of care to meet the needs of persons with advanced dementia and their families
  - Across care settings
  - Align payment and delivery
  - Unique considerations that merit focus on advanced dementia

Strategy 5

- Leverage existing mechanisms to ensure access to high quality care for persons with advanced dementia and their families
- Examples: payment, regulatory, and public reporting
  - Consider existing infrastructure, e.g. state coalitions to improve dementia care, QIOs (Quality Improvement Organizations), HHS Partnership for Patients

Strategy 6

- Support <u>quality metrics</u> that ensure transparency and accountability for the care of persons with advanced dementia and their families
  - Must include proxy reporting (e.g. family, nurse)
  - Examples of unique metrics
    - Effective symptom assessment and management
    - Burdensome, non-beneficial treatments (e.g., tube feeding, transitions)
    - Care concordant with values and preferences
  - Critical for clinical care accountability and research and policy evaluation