

# End of Life Care: Estimating the Effectiveness of 20 Years of Health System Reforms

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# Presentation Agenda

- What is End of Life Care?
- Concerns and issues with End of Life Care
- Project Overview
- Role and Findings in Project
- Lessons Learned

# End of Life (EOL) Care

- Healthcare provided to those with a terminal condition or illness that has become advanced, progressive, or incurable
- Quality EOL care goes “beyond managing physical pain, but includes a holistic perspective of care, a healthcare team dedicated to the EOL journey and a patient-centered pathway.”

Mistry B, et al. BMJ Open, 2015

# Treatment Options

- **Palliative Care**: comprehensive, specialized medical care used to improve the quality of life for individuals with life-threatening illnesses
  - Can begin at time of diagnosis
  - **Curative treatment** along with comfort care – symptom, pain, stress, & psychosocial-spiritual support
- **Hospice Care**
  - Begins when illness becomes incurable and death is expected within 6 months
  - Similar to palliative care but patients **forego** curative treatment – only symptom and pain relief is provided

Buss M, et al. Mayo Clinic Proceedings, 2017.

# Patient Preferences for End of Life Care

- Most Medicare beneficiaries in all racial/ethnic groups prefer:
  - Not to die in the hospital, but rather die at home
  - Not to receive life prolonging drugs
  - Not to receive mechanical ventilation

Barnato A, et al. JGIM, 2009,

Teno J, et al. JAMA, 2013

# Patient, Family and HCP Preferences

- Key component for good death: Patient-focused preferences for dying and a pain-free death
- “Physicians, nurses, and other HCP’s viewed optimal pain control and keeping the patient comfortable as a requirement for a good death”

Meier EA, et al. Am J Geriatr Psychiatry, 2016

# Expectations vs Reality



# Reality

## End of Life Care is:

### 1. Intensive

- Poses significant quality concerns

### 2. Expensive

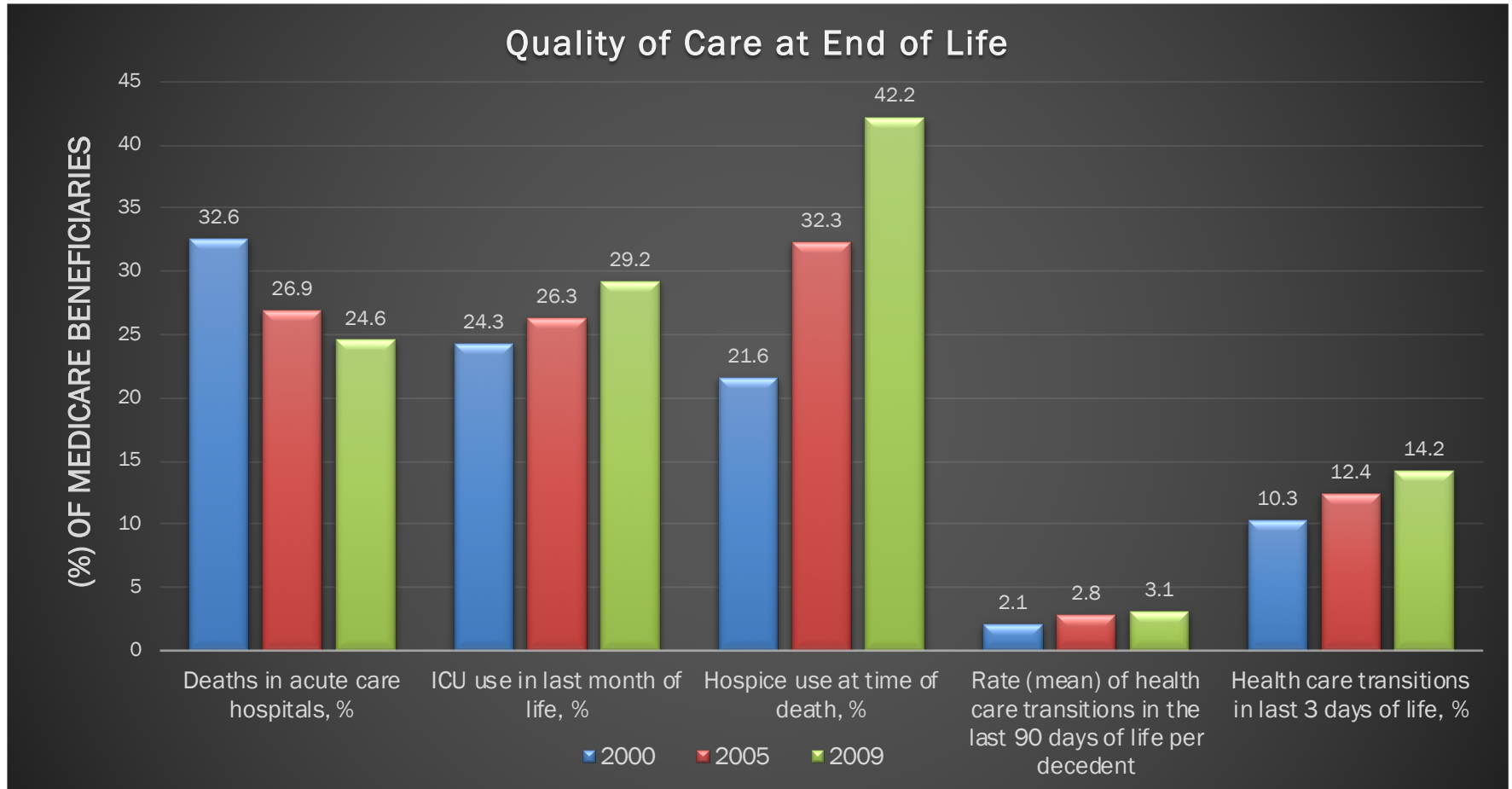
- Economic concerns – minimal marginal benefit

### 3. Highly dependent on where one lives

- Equity concerns – geographical variation



# Quality Concerns

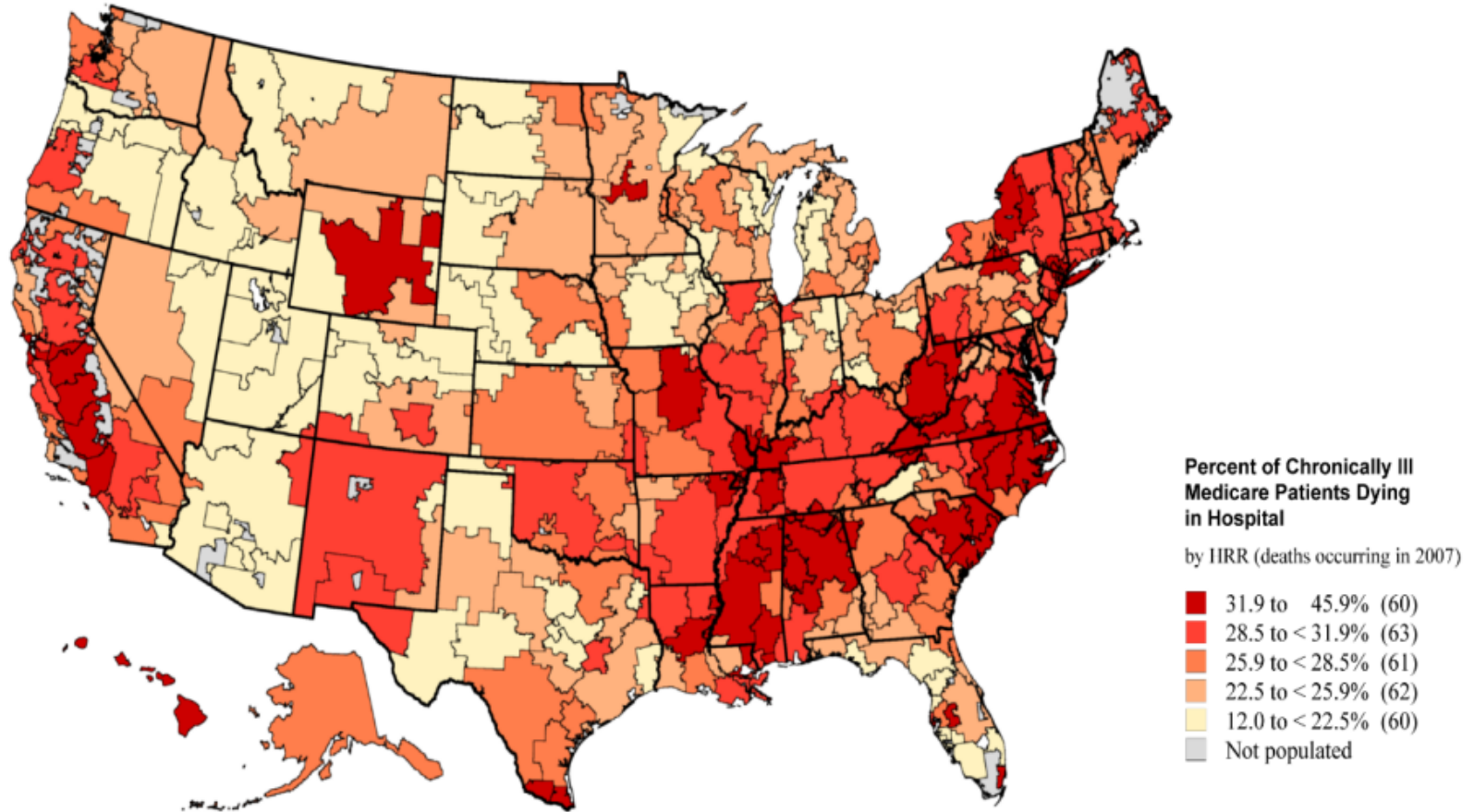


Teno J, et al. JAMA, 2013

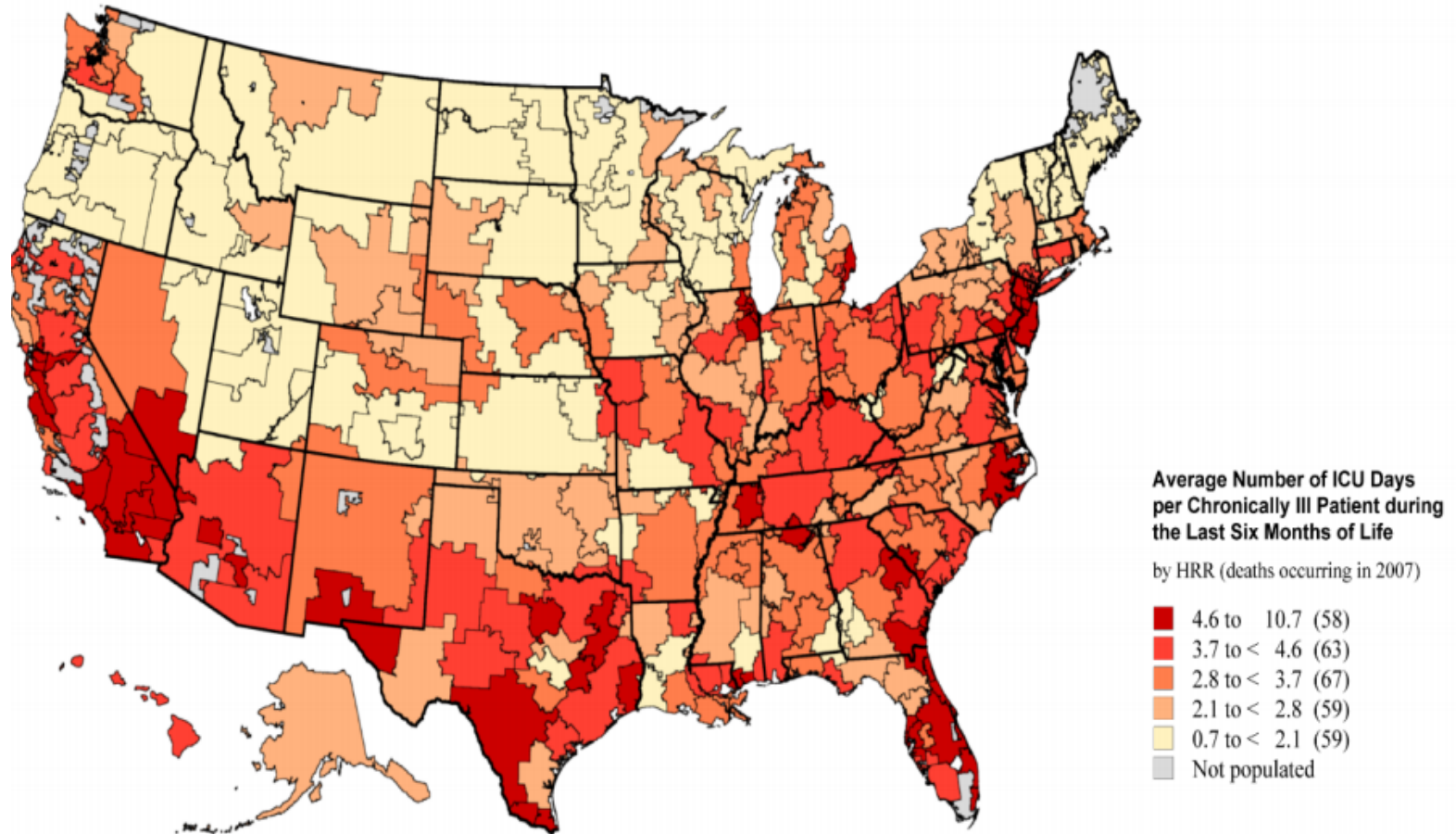
# Economic Concerns

- In 2015, Medicare spent around \$35,000 per decedent
  - Nearly 3.8 times the amount spent on other beneficiaries
- 25% of national healthcare expenditures → 6% of patients who die each year
- Medicare spending for beneficiaries in the last year of life accounts for nearly one-quarter of all Medicare expenditures
- Intensive care at EOL is not associated with better outcomes or greater satisfaction with care
  - Fragmented Fee for service payment structure = greater incentive for more services

# Equity Concerns- Geographic Variation

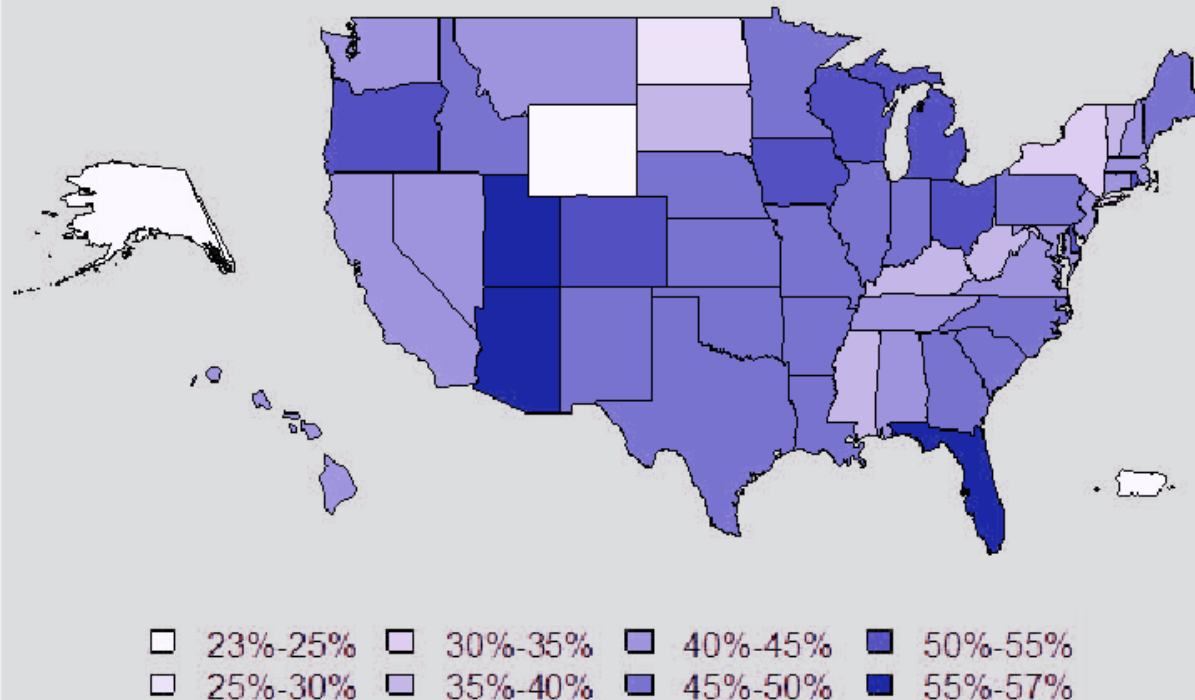


# Equity Concerns- Geographic Variation



# Equity Concerns- Geographic Variation

FIGURE 2. GEOGRAPHIC VARIATION IN THE PROPORTION OF MEDICARE DECEDENTS WHO DIED WHILE RECEIVING HOSPICE CARE IN 2015



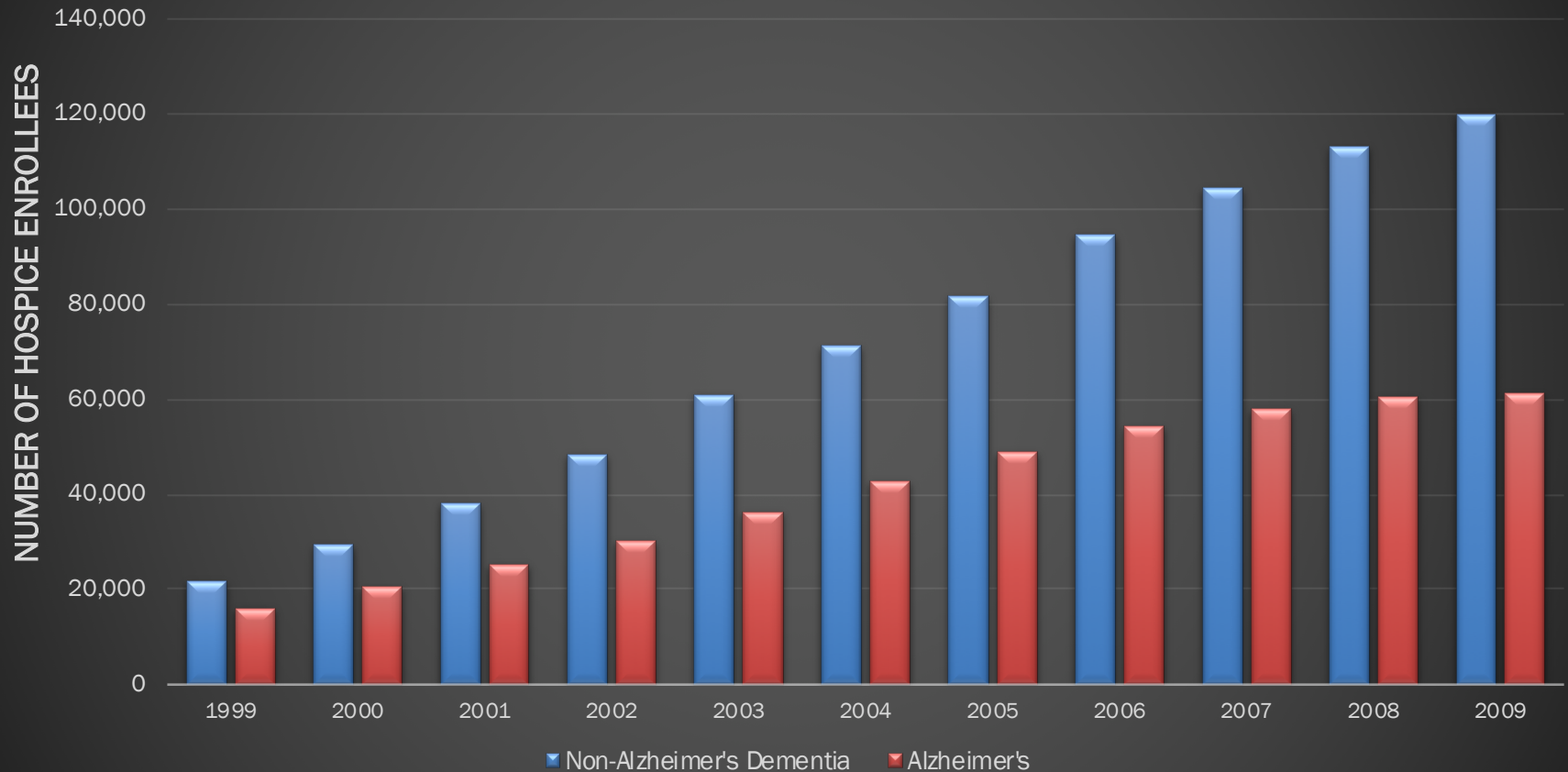
# Alzheimer's and Related Dementia (ADRD) Concern

- High disease prevalence of ADRD
- ADRD patients spend 40% of survival time in most severe stages
  - EOL Care significantly hindered – inability for communication
- Increased intensiveness at End of Life Care
  - ICU in the last 30 days of Life has increased over time
- Over 25% of ADRD patients are dual-eligible
  - No coordination between Medicaid and Medicare → more likely to have fragmented care across multiple healthcare providers (SNFs and hospitals) and payers (Medicare and Medicaid)
    - Fee for Service = excessive care → more intensive treatment

Teno, et al. New England Journal of Medicine, 2011

# Alzheimer's and Dementia

Volume of Hospice Care: Medicare Enrollees



# Project Overview

Estimate  
Effectiveness of  
Reforms on ADRD  
Cohort

Understand  
Geographic  
Variation

Estimate the Effectiveness of the  
last 20 years of health system  
reforms on EOL Care

Identify future efforts  
needed for  
improvement

Identify how  
EOL is changing



# Project Aims

## Aims:

1. Create and disseminate a database of health system reforms – at the insurer, hospital, local, and federal level – that provide financial incentives or encourage care coordination, and thus have the potential to influence EOL care delivery
2. Measure the effect of the health system reforms in changing the delivery of EOL care
3. Separately estimate the effect of the health system reforms on planning vs. communication vs. facilitation of providing less-intensive EOL care to those who want it

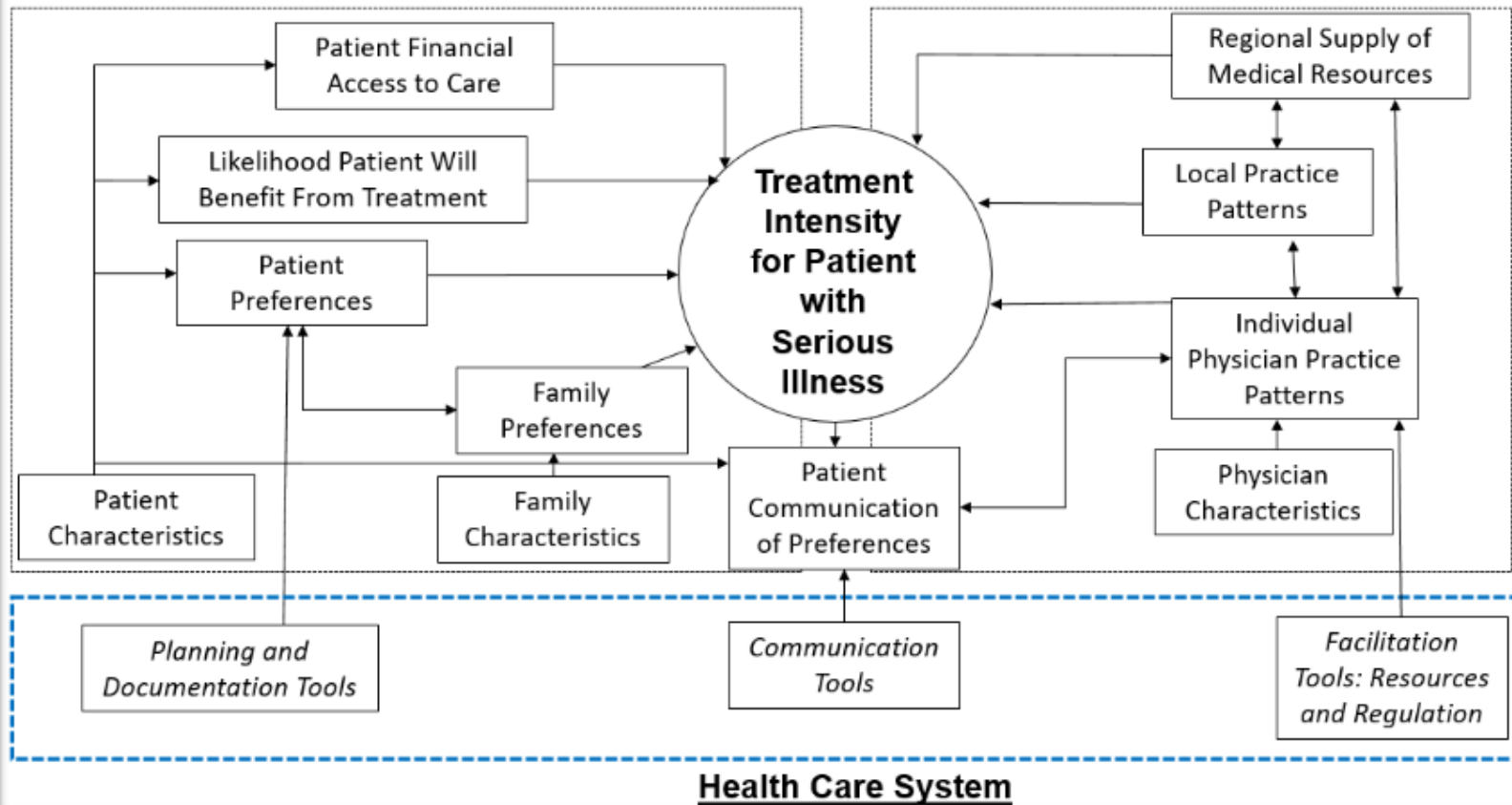
# Improvement in EOL Care is Multi-faceted

- To improve EOL care, 3 things must happen:
  1. **Planning** – Individuals must state preferences for care
  2. **Communication** – providers and family members must be informed of those preferences
  3. **Facilitation** – regulations and resources supported by the state and local healthcare systems

Figure 5: Conceptual Model: Factors Effecting Treatment Intensity for Patients with Serious Illness

**Patient & Family Determinants**

**Region & Physician Determinants**



# Role – Data Collection

Aim 1 – Create a database of health system reforms – insurer, hospital, local, and national level

- National Level:
  - Total Volume of Hospice Care Provided
  - Hospice Reimbursement Rates
  - Skilled Nursing Facility Reimbursement Rates
- State & County Level
  - Medicare Advantage Enrollment & # of Plan Types
  - Medicaid Managed Care Enrollment
- Hospital Level
  - American Hospital Association – Palliative Care Program (STATA!)

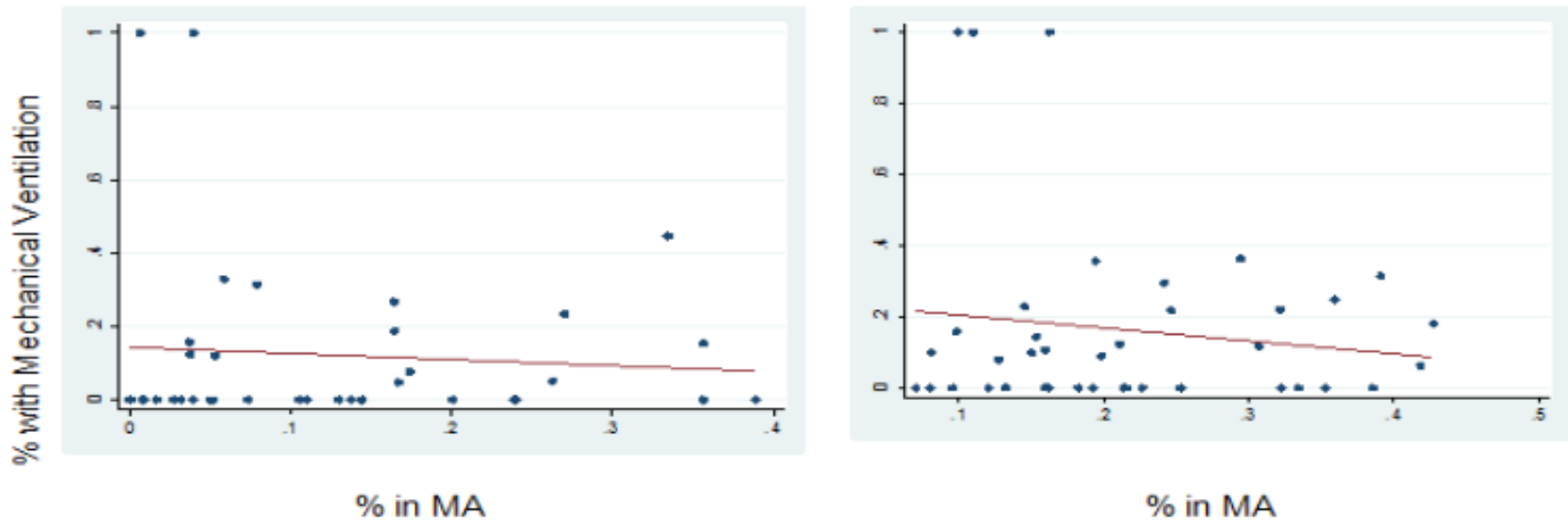
# Medicare Advantage

- Plans are paid on a per-person, rather than per-service basis
  - Capped payment structure rewards efforts to manage chronic disease and minimize treatment intensity
- Study results found that Medicare Advantage decedents had less intense EOL care
  - Fewer in-patient services and increased hospice enrollment (financial incentive)

Stevenson et al. Med Care, 2013

# Medicare Advantage & EOL

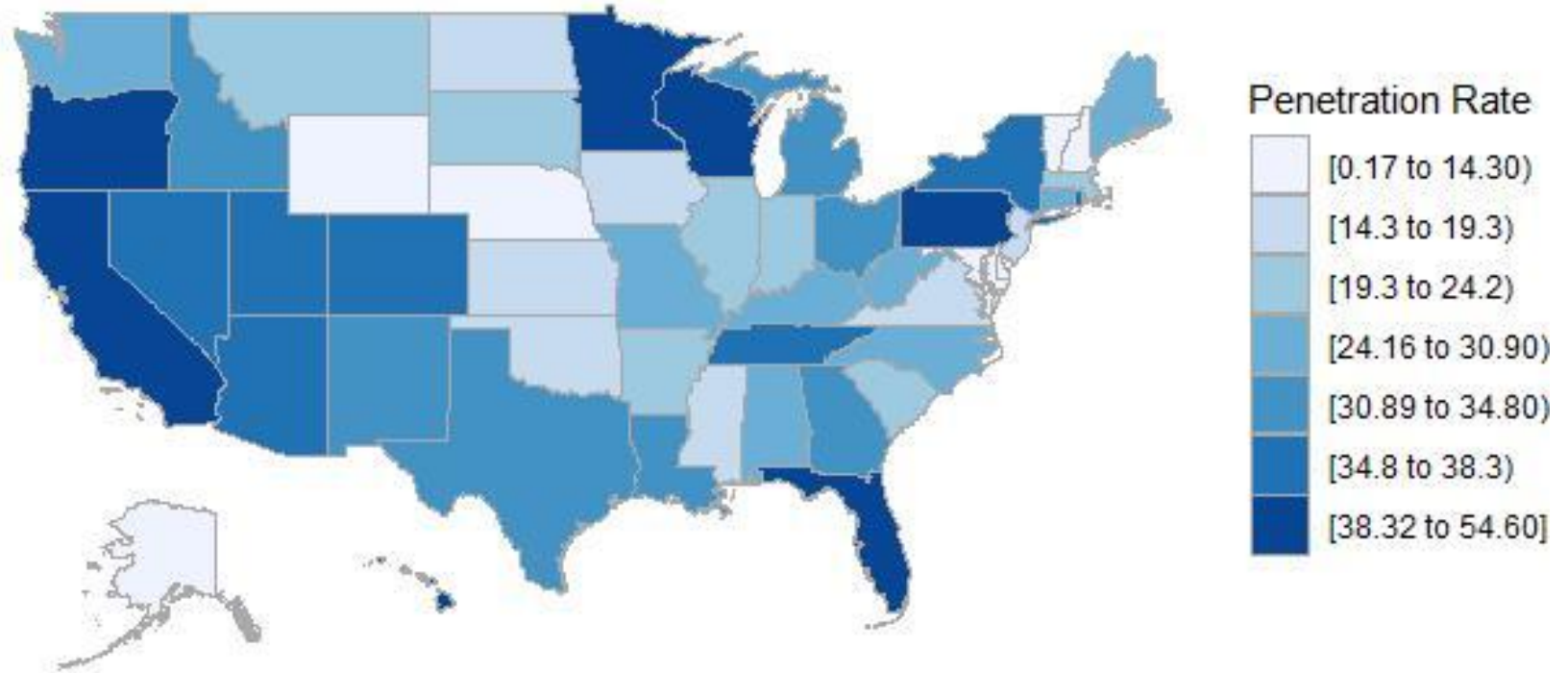
**Figure 3: Mechanical Ventilation rates, by MA penetration at the state-level**  
2000 2010



Source: author's calculations of the 2000 and 2010 decedent cohorts of the HRS

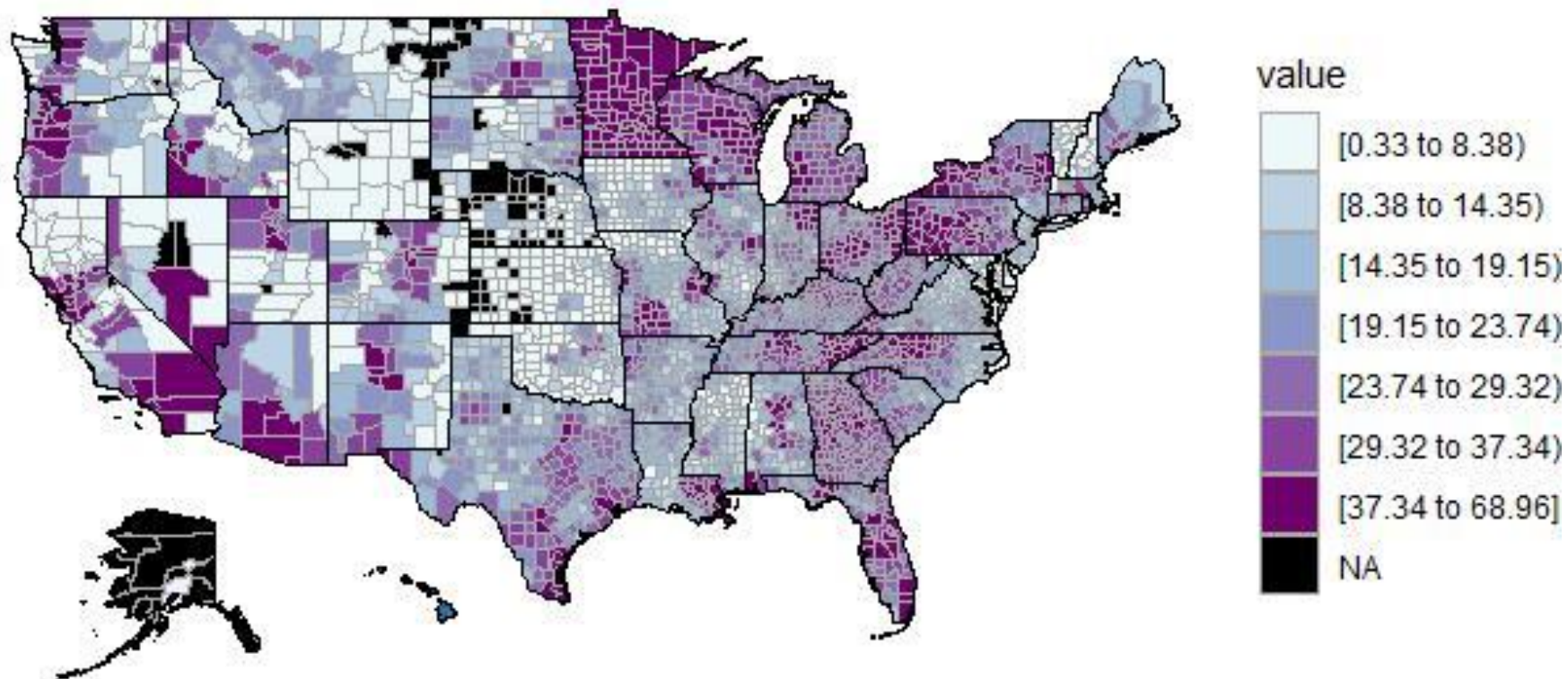
# Medicare Advantage, by State

2016 Medicare Advantage Penetration Rates



# Medicare Advantage, by County

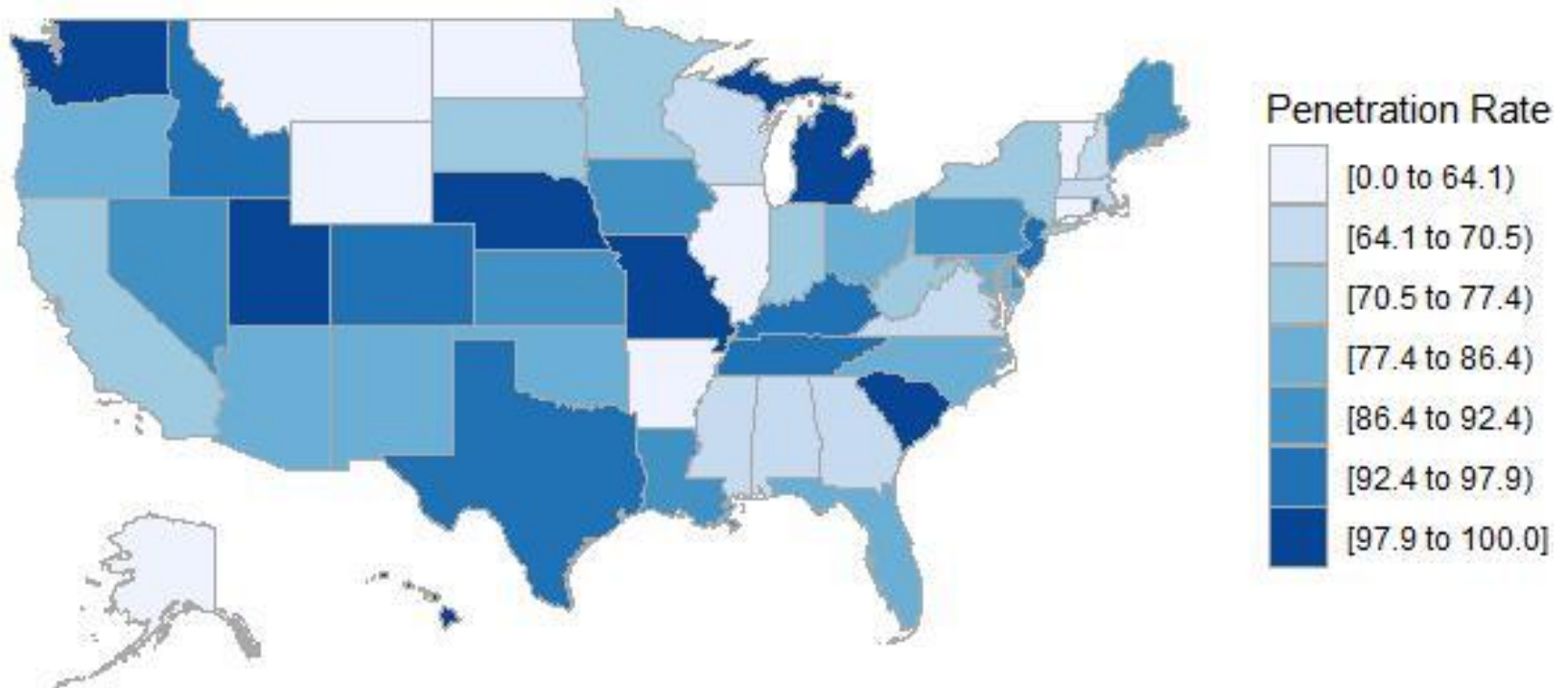
2016 Medicare Advantage Penetration Rates





# Medicaid Managed Care, by State

2016 Medicaid Managed Care Penetration Rates



# Lessons Learned

- Data collection (Google sensei) and reorganization
- STATA Skills
  - **Attention to detail**
    - Problems with merging two datasets – differences in year
  - **Patience**: 3,4, and 9 Digit Zip codes
- The Importance of Interdisciplinary Work
  - Health Econ, Law, Medicine

# Acknowledgements

## End of Life Care Team

- Dr. Norma B. Coe, PI
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- Melissa Berkowitz, Senior Research Coordinator

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