

End of Life Care: Estimating the Effectiveness of 20 Years of Health System Reform" README

Common Terminology:

1. **ACO:** [Accountable Care Organization](#)
2. **ACP:** [Advance Care Planning](#)
3. **AD:** [Advance Directive](#)
4. **ALF:** [Assisted Living Facility](#)
5. **CAPC:** [Center to Advance Palliative Care](#)
6. **CON Laws:** [Certificate of Need Laws](#)
7. **DOA:** [Durable Power of Attorney](#)
8. **EHR:** Electronic Health Record
9. **EMR:** Electronic Medical Record
10. **HA:** [Home Health Agency](#)
11. **HMO:** [Health Maintenance Organization](#)
12. **MA:** [Medicare Advantage](#)
13. **Magnet:** [Magnet Recognition Program](#)
14. **PAC:** [Post-Acute Care Providers](#)
15. **POLST:** [Physician Orders for Life-Sustaining Treatment](#)
16. **POS:** [Provider of Service File](#)
17. **PPO:** [Preferred Provider Organization](#)
18. **SNF:** [Skilled Nursing Facility](#)

Data Dictionary

1. Medicare Advantage penetration

- a. *File Name:* Medicare_advantage_penetration.dta
- b. *Description of Data:* This data presents a state-by-state breakdown of various Medicare plans from 1997-2016, including total MA penetration and the number of various Medicare plans.
- c. *Data Source:* The Kaiser Family Foundation and Mathematica Policy Research's analysis of CMS "Monthly MA Enrollment by State/County" and "Monthly MA Enrollment by State/County/Contract" files.
- d. *Variables:*
 - i. state = state
 - ii. year = year
 - iii. ma_penetration_rates = % of Medicare beneficiaries enrolled in Medicare Advantage
 - iv. hmo_plans = number of local HMO plans
 - v. ppo_plans = number of local PPO plans
 - vi. ppo_regionalplans = number of regional PPO plans
 - vii. pffs_plans = number of private fee-for-service plans
 - viii. msa_plans = number of local Medicare Medical Savings Account plans

2. Medicare Reimbursement – ACP (2016)

- a. *File Name:* ACP_reimbursement_policy.dta
- b. *Description of Data:* Dataset of state-by-state policies surrounding the ACP reimbursement or inclusion of ACP into the “Welcome to Medicare Visit” from 1999-2016.
- c. *Data Source:* Cannot be found
- d. *Variables:*
 - i. state = state
 - ii. year = year
 - iii. acp_reimbursement = reimbursement for ACP in Medicare (2016) (1=Yes; 0=No)
 - iv. acp_welcomevisit = inclusion of ACP in Welcome to Medicare visit (2008) (1=Yes; 0=No)

3. Medicare Reimbursement – Hospice

- a. *File Name:* Medicare_hospice_reimbursement.dta
- b. *Description of Data:* Dataset providing Medicare reimbursement rates for various healthcare services from 1995-2016. Reimbursement rates are paid to Medicare-participating hospices for each day of service based on level of care. This data also includes the aggregate cap amount, which limits the amount of Medicare payments a provider may receive in an accounting year.
- c. *Data Source:* Hospice rate records from CMS, the National Hospice and Palliative Care Organization, and CGS, a Celerian Group Company.
- d. *Variables:*
 - i. year = year
 - ii. chc_rate = rate for home care provided during periods of patient crisis (continuous home care)
 - iii. gic_rate = rate for inpatient care to treat symptoms that cannot be managed in another setting (general inpatient care)
 - iv. hospice_cap = hospice aggregate cap amount per beneficiary
 - v. rhc_rate = rate for home care provided on a typical day (routine home care)
 - vi. irc_rate = rate for inpatient care for a short period to provide respite for primary caregiver (inpatient respite care)

4. Medicare Reimbursement – SNF

- a. *File Name:* Medicare_reimbursement_rates.csv
- b. *Description of Data:* The dataset presents a record of different types of healthcare services with associated Medicare Reimbursement daily rates, wage-indexed components, and quality data submission status from 2004-2018.

- c. *Data Source:* CMS consolidated billing for SNF reports.
- d. *Variables:*
 - i. Year = year
 - ii. Type of care = type of care provided by SNF (General Inpatient Care, Inpatient Respite Care, Routine Home Care, or Continuous Home Care)
 - iii. Daily Rate = Wage Comp. Subj. to Index + Non-Weighted Amount
 - iv. Wage Comp. Subj. to Index = labor component for each level of care/worker wages
 - v. Non-Weighted Amount = non-labor component for each level of care
 - vi. Quality Data = mandated through 2010 Affordable Care Act; Hospice Item Set (HIS) and experience of care survey (CAHPS)
 - vii. Area Specific Payment rate = (Geographic Wage Index * Wage Component Subj. to Index) + Non-Labor Component
 - viii. 2016- SIA rate (Service Intensity Add-On) = made for a visit by a social worker/RN when provided during routine home care in last seven days of life.
- e. *Notes:* 1998-2003 missing; 2008 missing General Inpatient Care & Inpatient Respite Care.

5. SNF/hospital partnerships

- a. *File Name:* 2010-2016_hospital_partnership.sas7bdat
- b. *Description of Data:* Dataset of hospitals noting whether they have attached SNF, HHA, or PAC services from 2010-2016.
- c. *Data Source:* CMS Healthcare Provider Cost Reporting System files.
- d. *Variables:*
 - i. hosp_prvdrnum = Hospital Provider Number
 - ii. rpt_date = Receipt Date
 - iii. snf_prvdrnum = Hospital-based SNF Provider Number
 - iv. hha_prvdrnum = Hospital-based HHA Provider Number
 - v. hosp_snf = Hospital-based SNF (Yes = 1 or No = 0)
 - vi. hosp_hha = Hospital-based HHA (Yes = 1 or No = 0)
 - vii. hosp_pac = Hospital-based PAC (Yes = 1 or No = 0)
 - viii. year = year
 - ix. rpt_rec_num = Record Number
 - x. prvdr_bsd_fac_sw Provider Based Facility

6. Medicaid HMO penetration

- a. *File Name:* Medicaid_HMO_penetration.dta
- b. *Description of Data:* This dataset tracks the Medicaid Managed Care Penetration Rate across various states from 1997 to 2017.
- c. *Data Source:* Total Medicaid MCO enrollment from the Kaiser Family Foundation.
- d. *Variables*
 - i. state = state

- ii. year = year
- iii. mcaid_mco = Medicaid Managed Care Penetration Rate

7. Medicaid Informal Care Supports

- a. *File Name:* State_informal_care_policies.csv
- b. *Description of Data:* This data presents a state-by-state breakdown of informal care policies and expenditures across the United States from 2000 to recent years.
- c. *Data Source:* Cannot be found
- d. *Variables:*
 - i. state = state name
 - ii. year = year
 - iii. st = state number by alpha. order
 - iv. cfc = active Affordable Care Act's Community First Choice policy (0 = No; 1 = Yes)
 - v. bip = Balancing Incentives Program (0 = No; 1 = Yes)
 - vi. hcbs = Home- and Community-Based Services (0 = No; 1 = Yes)
 - vii. mcaid_exp = Medicaid Expansion (0 = No; 1 = Yes)
 - viii. care = Cannot be found
 - ix. ltc = long-term care insurance (0 = No; 1 = Yes)
 - x. spouse_pay_mcaid = spouse paying for Medicaid (0 = No; 1 = Yes)
 - xi. first = first year with informal care policies
 - xii. start = starting year of informal care policies
 - xiii. rel_yr = year relative to first year with informal care policies

8. Medicaid Reimbursement - Hospice

- a. *File Name:* Medicaid_reimbursement_hospice.csv
- b. *Description of Data:* The dataset contains variables on Medicaid reimbursement for hospice care, detailing annual rates by care type, geographical adjustments, and quality data compliance across different regions and facilities from 2007-2018.
- c. *Data Source:* CMS reports on wage indices in the Federal Register, and hospice reimbursement rate notices to Medicaid Associate Regional Administrators.
- d. *Variables:*
 - i. Year = year
 - ii. Type.of.Care = The category of hospice care provided. For 2016-18, Routine Home Care splits into Routine Home Care 1-60 & Routine Home Care 61+.
 - iii. Daily.Rate = The Medicaid reimbursement rate per day for the specified hospice care.
 - iv. Sub.to.Index = Indicates if the daily rate is subject to adjustments based on an index for wages or cost of living.

- v. Non.Weighted.Amount = The portion of the daily rate that remains constant, not adjusted by the wage index or other factors.
- vi. Submitted.Required.Quality.Data = A status indicating whether the hospice has met the obligation to submit quality data, which may affect rates or compliance.
- vii. CBSA = Core Based Statistical Area; The designated geographic area for statistical purposes where the hospice service is located.
- viii. Area = The geographic location or region of the hospice service.
- ix. Wage.Index = A numerical value adjusting the reimbursement rate for regional wage variations.
- x. Area.Type = The classification of the geographic area, influencing the wage index and reimbursement rates, categorized by urban or rural standards.
- xi. CBSA.Rate = The adjusted reimbursement rate for hospice services within the Core Based Statistical Area.

9. Medicaid Reimbursement - Nursing Homes

- a. *File Name:* Medicaid_reimbursement_nh.xlsx
- b. *Description of Data:* The dataset details final annual Medicaid reimbursement rates for various nursing homes by state from 2012-2019 (time frames vary by state due to data availability).
- c. *Data Source:* State agency datasets on reimbursement rates by facility, requested directly from the states.
- d. *Variables*
 - i. Year = year
 - ii. State = state
 - iii. NH = Nursing home name
 - iv. Final Rate = Final Medicaid reimbursement rate

10. Physician Ordered Life Sustaining Treatment (POLST)

- a. *File Name:* Phys_ordered_life_sus_treatment.dta
- b. *Description of Data:* This dataset catalogs monthly state-level attributes and regulations pertaining to Physician Orders for Life-Sustaining Treatment (POLST) programs from 1999-2016. This includes requirements on the forms' structure, portability, and execution.
- c. *Data Source:* Information was collected from state statutes, as well as reports and websites on POLST policy characteristics.
- d. *Variables:*
 - i. state = state
 - ii. year = year
 - iii. month = month
 - iv. polst = Does the state have a POLST program?
 - v. ntnlpolst = Status of the POLST program according to the National POLST Paradigm

- vi. statutorypolst = Does the state have a statutory program?
- vii. formreq = Does the state require the original form?
- viii. sigreq = Does the state require the provider's signature?
- ix. notmd = May NP/APRN/PAs sign in lieu of MD?
- x. patient_sig = Does the state require patient signature?
- xi. surrogate_sig = Does the state require surrogate signature?
- xii. verbal_orders = Does state include verbal orders in the POLST?
- xiii. formsend = Does the form state send with patient when transferred/discharged?
- xiv. portability = Does the form have portability provisions?
- xv. ad_conflict = Does the state address conflict w/ ADs?
- xvi. oospolst = Does the state expressly recognize out-of-state POLSTs?
- xvii. med_ineffective = Does the state allow objections for medically ineffective care?
- xviii. obj_conscience = Does the state allow objections for conscience?
- xix. ems_polst = Expressly applies to EMS personnel?
- xx. fulltreat = Does the state presume that incomplete sections imply full treatment?
- xxi. registry = Is there a POLST registry?
- xxii. adpolst_registry = Is this the same as AD registry?
- xxiii. terminallyill = Does the state have a limit execution to terminally ill, etc?
- xxiv. duty_comply = Express duty of providers to comply with POLST?
- xxv. registry_operated = Is the registry state or privately operated?

11. POLST Forms

- a. *File Name:* Statutory and Legal Data 2.16.2020\POLST Forms
- b. *Description of Data:* Representative POLST forms from each state that has them, with dates ranging from 1995-2019. This does not include exhaustive records of all previous iterations of POLST forms.
- c. *Data Source:* State agencies and healthcare systems' POLST forms from websites.
- d. *Variables:* N/A

12. POLST laws and regulations

- a. *File Name:* Polst_state_policy.xlsx
- b. *Description of Data:* State by state descriptions of POLST history/specific policies/terminology etc. This includes regulations on validity and execution, among other factors. This information overlaps with the data contained in Section 11.
- c. *Data Source:* Information was collected from state statutes, as well as reports and websites on POLST policy characteristics.
- d. *Variables:* N/A

13. State Advance Directive Registries

- a. *File Name:* Advance_directive_registry_state.dta
- b. *Description of Data:* This dataset catalogs on a state-by-state basis if the state provides for Advance Directive registry each month from 1999-2016.
- c. *Data Source:* Information was collected from state statutes.
- d. *Variables:*
 - i. state = state
 - ii. year = year
 - iii. month = month
 - iv. registry = does the state provide for an AD registry?

14. Advance Directive and Durable Power of Attorney laws and forms

- a. *File Name:* AD_durable_power_attorney.dta
- b. *Description of Data:* This dataset outlines select characteristics of state-specific regulations for advance directives and durable powers of attorney each month from 1999-2016.
- c. *Variables:*
 - i. state
 - ii. year
 - iii. month
 - iv. UHCDA = Adopted Uniform Health-Care Decisions Act?
 - v. effective_condition = Effective on condition other than terminal illness or vegetative state ?
 - vi. oral_directives = State permits oral directives?
 - vii. immediately_effective = State permits oral directives?
 - viii. surrogate = Are there default surrogate laws?
 - ix. combined = Does the state authorize use of combined AD/DPOAs?
 - x. electric_sig = Authorize electronic signatures?
 - xi. prohibited_agents = Are there prohibited agents?
 - xii. ordered_list = Is default surrogate determined through ordered list?-Predicated on AD var
 - xiii. sep_surrogate = Is default surrogate determined through ordered list?-Predicated on AD var
 - xiv. state_only = Does the state only authorize designation of surrogate/agent?
 - xv. favor_life = Is the presumption in favor of life?
 - xvi. med_ineffective = Refusal for medically ineffective care?
 - xvii. conscience_refusal = Refusal for conscience/moral reasons?
 - xviii. ad_accessible = Are ADs and living wills easily accessible?
 - xix. consciencemoral = Refusal for conscience/moral?
 - xx. oral_designation = Does the state permit oral designation of an agent/surrogate?
 - xxi. lw_form = Optional Living Will form provided?
 - xxii. dpoa_form = Optional DPOA form provided?

15. Magnet hospital designation

- a. *File Name:* Magnet_hospital.dta
- b. *Description of Data:* This dataset lists hospitals and the respective years they achieved Magnet designation, which recognizes excellence in nursing.
- c. *Data Source:* This information was collected from the American Nurses Credentialing Center's database of organizations that have achieved Magnet status. This is publicly available at <https://www.nursingworld.org/organizational-programs/magnet/find-a-magnet-organization/>.
- d. *Variables:*
 - i. FacilityName1 = Facility name
 - ii. Address1 = Address
 - iii. City = City
 - iv. State = State
 - v. Zip = ZIP code
 - vi. magnetyear = Year that the hospital first received Magnet designation

16. Aid in dying statutes

- a. *File Name:* Multiple files, including Aid_in_dying (State-Year).xlsx and Aid_in_dying (State-Year-Month).xlsx
- b. *Description of Data:* Code for state-by-state basis of policies surrounding Aid In Dying and Assisted Suicide
- c. *Data Source:* Cannot be found
- d. *Variables:* N/A

17. Hospice: Certificate of Need Laws

- a. *File Name:* Certificate_of_need_laws.xlsx & Certificate_of_need_laws_revised.xlsx
- b. *Description of Data:* State by state descriptions of CON Laws, including definitions, policy design, requirements, impact, etc.
- c. *Variables:* N/A

18. Hospice profit status

- a. *File Name:* 2000-2016_POS_hospice_profit_status.dta
- b. *Description of Data:* This dataset provides information on the for-profit status of hospices from 2000 to 2016.
- c. *Data Source:* Cannot be found
- d. *Variables:*
 - i. prvdr_ctgry_sbtyp_cd : provider subtype category code
 - ii. prvdr_ctgry_cd = provider category code
 - iii. city_name = city name

- iv. fac_name = facility name
- v. prvdr_num – provider number
- vi. zip_cd = ZIP code
- vii. fips_state_cd = Federal Information Processing Standards (FIPS) state code
- viii. fips_cnty_cd = Federal Information Processing Standards (FIPS) county code
- ix. res_hospice = resident hospice?
- x. profit_status = for profit/nonprofit status
- xi. year = year
- e. *Notes:* Please refer to “Profit status breakdown by facility type.docx” for more information on facility type and subtype.

19. Who can pronounce death

- a. *File Name:* 50_state_declare_death.pdf
- b. *Description of Data:* A state-by-state report explaining and describing different state policies on who (Ex: medical providers/clinical professionals/emergency response teams) can legally declare death from 1979-2017.
- c. *Data Source:* Information was collected from state statutes.
- d. *Variables:* N/A

20. State guardianship law

- a. *File Name:* 2003-2015_Medical_guardianship .xlsx
- b. *Description of Data:* A state-by-state report on the regulations surrounding the rights of state-designated medical guardians to make decisions differing from those of healthcare agents between 2003-2015.
- c. *Data Source:* Information on state regulations was taken from the American Bar Association’s Commission on Law and Aging.
- d. *Variables:*
 - i. State = state
 - ii. HC Agent Trumps? = Can a healthcare agent override the decisions of the state-designated guardian?
 - iii. Year = year

21. Medical malpractice caps and limitations

- a. *File Name:* Malpractice_tort_damages.dta
- b. *Description of Data:* This dataset notes the presence of a cap on compensatory damages or medical malpractice claims on a state-by-state basis from 1999-2016.
- c. *Data Source:* Information was collected from state statutes and legal reports.
- d. *Variables:*
 - i. State = state
 - ii. Year = year

- iii. cap_compensatory = Any cap on compensatory damages
- iv. cap_malpractice = Presence of a cap specifically on medical malpractice claims