

## END OF LIFE CARE DATA RESOURCES



This document contains links to end of life care data resources from the EDELE (Epidemiology of Dying & End-Of-Life Experience) site. Information is listed in alphabetical order by organization with a brief description of the data and the web address. Click on the organization name in the table below to go directly to the resources from that organization.

<a href="#"><u>AARP</u></a>	<a href="#"><u>FedStats</u></a>	<a href="#"><u>The Dartmouth Atlas of Healthcare</u></a>
<a href="#"><u>Agency for Healthcare Research &amp; Quality</u></a>	<a href="#"><u>Kaiser Family Foundation</u></a>	<a href="#"><u>The Robert Wood Johnson Foundation</u></a>
<a href="#"><u>Brown Medical School</u></a>	<a href="#"><u>MedPac</u></a>	<a href="#"><u>University of Michigan</u></a>
<a href="#"><u>Center to Advance Palliative Care</u></a>	<a href="#"><u>National Alliance for Caregiving</u></a>	<a href="#"><u>University of Wisconsin</u></a>
<a href="#"><u>Centers for Disease Control &amp; Prevention</u></a>	<a href="#"><u>National Cancer Institute</u></a>	<a href="#"><u>US Census Bureau</u></a>
<a href="#"><u>Centers for Medicare &amp; Medicaid Services</u></a>	<a href="#"><u>National Hospice &amp; Palliative Care Organization</u></a>	<a href="#"><u>US DHHS</u></a>

Organization and Report Title	Description	URL for Web Page
<b>AARP</b>		
State Health Care Briefs 2009: Why Healthcare Reform is Important	This set of 2009 State Health Care Briefs provides a one-page overview of facts on health care data for each of the 50 states and the District of Columbia. Information is provided about each state's older population, the uninsured, Medicare beneficiaries, hospital readmissions among Medicare beneficiaries, the distribution of Medicaid long-term care funds, and prescription drug spending.	<a href="http://www.aarp.org/health/health-care-reform/info-06-2009/state_hcb_09.html"><u>http://www.aarp.org/health/health-care-reform/info-06-2009/state_hcb_09.html</u></a>
State Profiles 2005: Reforming the Health Care System	This compilation of state profiles offers readers a snapshot of each state's health care landscape by providing comparable state-level and national data for nearly 100 indicators. This includes state profiles, recent data on state demographics, expenditures and financing, health status, health coverage and the uninsured, available resources, Medicare, Medicaid, utilization of services, and key trends.	<a href="http://assets.aarp.org/rgcenter/health/d18258_reform_05.pdf"><u>http://assets.aarp.org/rgcenter/health/d18258_reform_05.pdf</u></a>
Valuing the	This report, part of the Valuing the Invaluable series on the economic	<a href="http://assets.aarp.org/rgcenter/ppi/ltc/i"><u>http://assets.aarp.org/rgcenter/ppi/ltc/i</u></a>

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Invaluable: The Economic Value of Family Caregiving, 2011 Update	value of family caregiving, updates national and individual state estimates of the economic value of family care using the most current available data.	<a href="#">51-caregiving.pdf</a>
<b>AHRQ</b>	<b>Agency for Healthcare Research &amp; Quality</b>	
Advance Care Planning: Preferences for Care at the End of Life	Findings resulting from research funded by the Agency for Healthcare Research and Quality (AHRQ) are discussed. This research can help providers offer end-of-life care based on preferences held by the majority of patients under similar circumstances. Forty-nine studies/publications are reviewed and results are presented. Figures and Tables can be downloaded.	<a href="http://www.ahrq.gov/research/endliferia/endria.htm">http://www.ahrq.gov/research/endliferia/endria.htm</a>
End of Life Care Outcomes and Summary	This report addresses the following key questions: 1. What outcome variables are valid indicators of the quality of the end-of-life experience for the dying person and for the surviving loved ones? 2. What patient, family, and health care system factors are associated with better or worse outcomes at end of life? 3. What processes and interventions are associated with improved or worsened outcomes? 4. What are future research directions for improving end-of-life care?	<a href="http://www.ahrq.gov/clinic/epcsums/eolsum.htm">http://www.ahrq.gov/clinic/epcsums/eolsum.htm</a>
<b>Brown Medical School</b>	<b>Center for Gerontology and Health Care Research at the Brown Medical School</b>	
Palliative Care/Hospice for Persons with Terminal and/or Chronic Progressive Illness	This study's intent was to expand our understanding of how state policies/practices influence access to and quality of palliative care/hospice for persons needing long-term care services, in order to clarify the advocacy and research needed to better inform policy debates as well as state long-term care initiatives.	<a href="http://www.chcr.brown.edu/JEHT_4_FINALREPORT_JULY_7.PDF">http://www.chcr.brown.edu/JEHT_4_FINALREPORT_JULY_7.PDF</a>
Facts on Dying (Site of death)	State and US data on 12 indicators related to end-of-life care including site of death, pain management, advance directive use, DNR, artificial hydration and nutrition, and feeding tube use. Except for site of death, all other data is for nursing home patients. This URL links to deaths at home, NH, hospital - detailed data by state	<a href="http://www.chcr.brown.edu/dying/BROWNATLAS.HTM">http://www.chcr.brown.edu/dying/BROWNATLAS.HTM</a>

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	with maps; 1989, 1997, 2001.	
Facts on Dying (Site of death over time - state and county)	Percentage of people in each state(with county data) that died in NH, Hospital, home, 1989, 1997, 2001 - maps to compare as well.	<a href="http://www.chcr.brown.edu/dying/factsondyingstate.htm">http://www.chcr.brown.edu/dying/factsondyingstate.htm</a>
Facts on Dying (State Maps and Rankings)	Compare state information and rankings on 12 indicators of end-of-life care including site of death, pain management, advance directive use, artificial nutrition and hydration, and feeding tube use. Most of the data are for nursing home patients.	<a href="http://www.chcr.brown.edu/dying/MAPSRANKINGS.HTM">http://www.chcr.brown.edu/dying/MAPSRANKINGS.HTM</a>
Facts on Dying (Feeding Tube Use - NH)	Data on feeding tube use among nursing home residents 1999-2001. US map and narrative report on each state.	<a href="http://www.chcr.brown.edu/dying/feedingtubes.htm">http://www.chcr.brown.edu/dying/feedingtubes.htm</a>
Facts on Dying (Pain and Symptom Mgmt - Nursing Home)	Data on severe and persistent pain among nursing home residents 1999-2001. US map and narrative report on each state.	<a href="http://www.chcr.brown.edu/dying/severepain.htm">http://www.chcr.brown.edu/dying/severepain.htm</a>
Facts on Dying (State Profiles)	For each state a profile is provided of 12 end-of-life indicators including: site of death, advance directive use, DNR, artificial nutrition and hydration, and feeding tube use.	<a href="http://www.chcr.brown.edu/dying/stateprofiles.htm">http://www.chcr.brown.edu/dying/stateprofiles.htm</a>
Facts on Dying (Change in Indicators Over Time)	Change in 12 indicators of end-of-life care over 1999-2001, by state. Patients are primarily though not exclusively nursing home residents. Indicators include site of death, pain management, advance directive use, DNR, artificial hydration and nutrition, and feeding tube use.	<a href="http://www.chcr.brown.edu/dying/CHANGEOVERTIME.HTM">http://www.chcr.brown.edu/dying/CHANGEOVERTIME.HTM</a>
Facts on Dying (Advance Directive Use by State)	Use of advance directives by state: A US map shows AD use 1999-2001 and narrative information is provided for each state.	<a href="http://www.chcr.brown.edu/dying/mapadall.htm">http://www.chcr.brown.edu/dying/mapadall.htm</a>
Facts on Dying - Family reports on last place of care	Reported in the January 7, 2004 issue of JAMA are concerns of bereaved family members about the quality of care received while their loved ones were dying. Since percentages and rates may not adequately convey the concerns of family members, as part of this study in-depth interviews were conducted with over 100 of	<a href="http://www.chcr.brown.edu/dying/FAMILYREPORTS2004.HTM">http://www.chcr.brown.edu/dying/FAMILYREPORTS2004.HTM</a>

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	the <u>survey participants</u> .	
Facts on Dying - Home, NH, and Hospital deaths by state	Proportion of deaths at home, hospital, and nursing home 1989, 1997, and 2001 - for each state and nationally.	<a href="http://www.chcr.brown.edu/dying/usASTATISTICS.HTM">http://www.chcr.brown.edu/dying/usASTATISTICS.HTM</a>
<b>CAPC</b>	<b>Center to Advance Palliative Care</b>	
A State-by-State Report Card on Access to Palliative Care in Our Nation's Hospitals	A State by State Report Card on Access to Palliative Care in our Nation's Hospitals	<a href="http://www.capc.org/reportcard/data/domain">http://www.capc.org/reportcard/data/domain</a>
<b>CDC</b>	<b>Centers for Disease Control &amp; Prevention</b>	
2007 National Home & Hospice Care Survey - Public Use Data Set	The 2007 National Home and Hospice Care Survey (NHHCS) is one in a continuing series of nationally representative sample surveys of U.S. home health and hospice agencies. It is designed to provide descriptive information on home health and hospice agencies, their staffs, their services, and their patients. NHHCS was first conducted in 1992 and was repeated in 1993, 1994, 1996, 1998, and 2000, and most recently in 2007.	<a href="http://www.cdc.gov/nchs/nhhcs.htm">http://www.cdc.gov/nchs/nhhcs.htm</a>
Characteristics and Use of Home Health Care by Men and Women Aged 65 and Over	This report (April 2012) presents national estimates on differences in the use of home health care between men and women aged 65 years and over. Estimates are based on data from the 2007 National Home and Hospice Care Survey, conducted by the Centers for Disease Control and Prevention's National Center for Health Statistics.	<a href="http://www.cdc.gov/nchs/data/nhsr/nhsr052.pdf">http://www.cdc.gov/nchs/data/nhsr/nhsr052.pdf</a>
NNHS Linked Mortality Files	NCHS has conducted mortality linkages of the 1985, 1995, 1997, and 2004 National Nursing Home Surveys (NNHS) to death certificate data found in the National Death Index (NDI). The NNHS Linked Mortality Files provide mortality follow-up data from the date of NNHS interview through December 31, 2006. Mortality ascertainment is based primarily upon the results from a probabilistic	<a href="http://www.cdc.gov/nchs/data_access/data_linkage/mortality/nnhs_linkage.htm">http://www.cdc.gov/nchs/data_access/data_linkage/mortality/nnhs_linkage.htm</a>

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	match between the NNHS and NDI death certificate records.	
Health, United States, 2010 with Special Feature on Death and Dying	The Health, United States series presents national trends in health statistics. The report contains a Chartbook that assesses the Nation's health by presenting trends and current information on selected measures of morbidity, mortality, health care utilization, health risk factors, prevention, health insurance, and personal health care expenditures. This year's Chartbook includes a special feature on death and dying. The report also contains 148 trend tables organized around four major subject areas: health status and determinants, health care utilization, health care resources, and health care expenditures.	<a href="http://www.cdc.gov/nchs/data/hus/hus10.pdf#specialfeature">http://www.cdc.gov/nchs/data/hus/hus10.pdf#specialfeature</a>
Home Health Care and Discharged Hospice Care Patients: United States, 2000 and 2007	This report presents national estimates on home health care patients and discharged hospice care patients. Information on characteristics, length of service, medical diagnoses, functional limitations, service use, advance care planning, and emergent and hospital care use are presented for home health care patients and hospice care discharges. A comparison of selected characteristics for 2000 and 2007 is also provided to highlight changes.	<a href="http://www.cdc.gov/nchs/data/nhsr/nhsr038.pdf">http://www.cdc.gov/nchs/data/nhsr/nhsr038.pdf</a>
2010 National Survey of Residential Care Facilities	The National Survey of Residential Care Facilities (NSRCF) is a first ever survey of residential care providers. Included are residential care facilities; assisted living residences; board and care homes; congregate care; enriched housing programs; homes for the aged; personal care homes; and shared housing establishments that are licensed, registered, listed, certified, or otherwise regulated by a state. NSRCF is designed to produce national estimates of these places and their residents.	<a href="http://www.cdc.gov/nchs/nsrcf.htm">http://www.cdc.gov/nchs/nsrcf.htm</a>
Drug Characteristics and Estimates for	Medication data were collected in the 2007 National Home and Hospice Care Survey. The PDF files accessed through this link provide useful information about how these data were collected and	<a href="http://www.cdc.gov/nchs/nhhcs/nhhcs_medication_data.htm">http://www.cdc.gov/nchs/nhhcs/nhhcs_medication_data.htm</a>

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Medications Taken by Hospice Care Discharges in 2007 NHHCS	provide resources to help data users analyze the medication data.	
Home Health and Hospice Care Agencies Fact Sheet	This fact sheet provides selected data highlights from the 2007 National Home and Hospice Care Survey (NHHCS), one in a continuing series of nationally representative sample surveys of U.S. home health and hospice care agencies.	<a href="http://www.cdc.gov/nchs/data/nhhcs/2007hospicecaresurvey.pdf">http://www.cdc.gov/nchs/data/nhhcs/2007hospicecaresurvey.pdf</a>
Home Health Care Patients and Hospice Care Discharges	This fact sheet provides selected data highlights from the 2007 National Home and Hospice Care Survey (NHHCS), one in a continuing series of nationally representative sample surveys of U.S. home health and hospice care agencies and their patients.	<a href="http://www.cdc.gov/nchs/data/nhhcs/2007hospicecaredischarges.pdf">http://www.cdc.gov/nchs/data/nhhcs/2007hospicecaredischarges.pdf</a>
Comparison of Home Health and Hospice Care Agencies by Organizational Characteristics and Services Provided: United States, 2007	This report presents national estimates of the organizational characteristics of home health and hospice care agencies in 2007. Comparisons of organizational characteristics and provision of selected services are made by agency type. A comparison of selected characteristics between 1996 and 2007 is also provided to highlight changes that have occurred leading to the current composition of the home health and hospice care sector.	<a href="http://www.cdc.gov/nchs/data/nhsr/nhsr030.pdf">http://www.cdc.gov/nchs/data/nhsr/nhsr030.pdf</a>
Use of Advance Directives in Long-term Care Populations (2011)	Percentage of home health care patients, nursing home residents, and discharged hospice care patients with any advance directive, by age: United States, 2004 and 2007.	<a href="http://www.cdc.gov/nchs/data/databriefs/db54.pdf">http://www.cdc.gov/nchs/data/databriefs/db54.pdf</a>
Complementary and Alternative Therapies in Hospice: The 2007 National Home and	This report presents national estimates on the provision and use of complementary and alternative therapies (CAT) in hospice. Comparisons of organizational characteristics of hospice care providers are presented by whether the provider offered CAT. Comparisons of selected characteristics of patients discharged from	<a href="http://www.cdc.gov/nchs/data/nhsr/nhsr033.pdf">http://www.cdc.gov/nchs/data/nhsr/nhsr033.pdf</a>

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Hospice Care Survey	hospice are presented by whether they received care from a provider that offered CAT, and whether they received a CAT service.	
Mortality Statistics – Publications and Key Statistics	Mortality data from the National Vital Statistics System (NVSS) are a fundamental source of demographic, geographic, and cause-of-death information. This is one of the few sources of health-related data that are comparable for small geographic areas and are available for a long time period in the United States. The data are also used to present the characteristics of those dying in the United States, to determine life expectancy, and to compare mortality trends with other countries	<a href="http://www.cdc.gov/nchs/deaths.htm">http://www.cdc.gov/nchs/deaths.htm</a>
NCHS Data Warehouse - Mortality Tables	This site presents detailed mortality tables prepared by the Division of Vital Statistics, National Center for Health Statistics, includes data on age, race, sex, cause-of-death, life expectancy, and infant mortality. Some of the tables present national-level data, others feature State-level data.	<a href="http://www.cdc.gov/nchs/nvss/mortality_tables.htm">http://www.cdc.gov/nchs/nvss/mortality_tables.htm</a>
CDC Wonder - Mortality Statistics	Mortality and morbidity statistics from the National Vital Statistics System	<a href="http://www.cdc.gov/mmwr/distrnds.html">http://www.cdc.gov/mmwr/distrnds.html</a>
The National Nursing Home Survey: 2004	Links to survey reports and products.	<a href="http://www.cdc.gov/nchs/nnhs/nnhs_products.htm">http://www.cdc.gov/nchs/nnhs/nnhs_products.htm</a>
An Overview of Home Health Aides: United States, 2007	This report presents national estimates of home health aides providing assistance in activities of daily living (ADLs) and employed by agencies providing home health and hospice care in 2007. Data are presented on demographics, training, work environment, pay and benefits, use of public benefits, and injuries. Estimates are based on data collected in the 2007 National Home Health Aide Survey.	<a href="http://www.cdc.gov/nchs/data/nhsr/nhsr034.pdf">http://www.cdc.gov/nchs/data/nhsr/nhsr034.pdf</a>
Hospice patients by services provided,	This is one of thirteen tables that present hospice discharge data by various variables, such as age, race, functional status, length of stay,	<a href="http://www.cdc.gov/nchs/data/nhhcsd/curhospicecare00.pdf">http://www.cdc.gov/nchs/data/nhhcsd/curhospicecare00.pdf</a>

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treatments, locations of care, functional status, living arrangements: United States, 2000	living arrangements, caregiver status, etc. Open up the bookmarks to view a listing of all the tables.	
Trends in Health and Aging: All Tables	This site contains tables that describe trends in health and aging. Health Data Interactive presents tables with national health statistics for infants, children, adolescents, adults, and older adults. Tables can be customized by age, gender, race/ethnicity, and geographic location to explore different trends and patterns.	<a href="http://www.cdc.gov/nchs/hdi.htm">http://www.cdc.gov/nchs/hdi.htm</a>
The Longitudinal Study of Aging Wave II Decedent Interview	This site has raw data on trends in health, health care utilization and expenditures, mortality, and risk factors.	<a href="http://www.cdc.gov/nchs/isoa/isoa2.htm">http://www.cdc.gov/nchs/isoa/isoa2.htm</a>
<b>CMS</b>	<b>Centers for Medicare &amp; Medicaid Services</b>	
Hospice Center	This resource has been developed to incorporate all Medicare Fee-for-Service Hospice information in one place. We will continue to add information to this page as it becomes available.	<a href="https://www.cms.gov/Center/Provider-Type/Hospice-Center.html">https://www.cms.gov/Center/Provider-Type/Hospice-Center.html</a>
Medicare Hospice Cost Reports	Healthcare Cost Report Information System (HCRIS) Dataset – Hospice Release Date, April 16, 2012 - the data included with this release includes all years (from FY1999 through FY2011) of HOSPICE Cost Reports (CMS-Form 1984-99) received by HCRIS through March 31, 2012. There are a total of 18,554 cost reports.	<a href="https://www.cms.gov/Research-Statistics-Data-and-Systems/Files-for-Order/CostReports/Hospice.html">https://www.cms.gov/Research-Statistics-Data-and-Systems/Files-for-Order/CostReports/Hospice.html</a>
Medicare Hospice Data Trends 1998-2009	Includes the 20 most frequent diagnoses, the number of patients, average length of stay, and trends over time in length of stay, by diagnosis.	<a href="https://www.cms.gov/Medicare/Medicare-Fee-for-Service-Payment/Hospice/Medicare_Hospice_Data.html">https://www.cms.gov/Medicare/Medicare-Fee-for-Service-Payment/Hospice/Medicare_Hospice_Data.html</a>
Medicare Current Beneficiary Survey – Cost and Access	Medicare Current Beneficiary Survey (MCBS), which is sponsored by the Centers for Medicare & Medicaid Services (CMS), is the only comprehensive source of information on the health status, health care	<a href="http://www.cms.gov/Research-Statistics-Data-and-Systems/Research/MCBS/">http://www.cms.gov/Research-Statistics-Data-and-Systems/Research/MCBS/</a>



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to Care	use and expenditures, health insurance coverage, and socioeconomic and demographic characteristics of the entire spectrum of Medicare beneficiaries. This web site is intended to provide information about MCBS that will be of interest to health services researchers, particularly to current and potential users of MCBS data.	
<b>FedStats</b>		
MapStats - United States	Basic demographic data by state, county and city.	<a href="http://www.fedstats.gov/qf/">http://www.fedstats.gov/qf/</a>
<b>Kaiser Family Foundation</b>	<b>State Health Facts</b>	
State Health Facts Online (Providers and Service Use)	Presents state-by state population-based data on health status, health coverage, costs, minority health, women's health, and other health topics. This link includes data about hospitals, nursing homes, federally qualified health and rural health centers, physician demographics, non-physician providers, and health care employment. Updated annually.	<a href="http://www.statehealthfacts.org/comparecat.jsp?cat=8">http://www.statehealthfacts.org/comparecat.jsp?cat=8</a>
State Health Facts Online (Medicare Hospice Days and Patients Served)	Number of Hospices, Number of Persons Served, and Covered Days of Care for Hospice Services Used by Medicare Beneficiaries, 2010	<a href="http://www.statehealthfacts.org/comparabletable.jsp?ind=338&amp;cat=6">http://www.statehealthfacts.org/comparabletable.jsp?ind=338&amp;cat=6</a>
State Health Facts Online (Relative Price of Care)	Distribution of Health Care Expenditures by Service by State of Residence (in millions)	<a href="http://www.statehealthfacts.org/comparebar.jsp?ind=593&amp;cat=5">http://www.statehealthfacts.org/comparebar.jsp?ind=593&amp;cat=5</a>
State Health Facts Online (Health Coverage and HMO Penetration)	This category includes the health insurance status of the state's population (those with various types of health coverage or who are uninsured), and demographic information (such as income, race/ethnicity, age, gender) for those who are uninsured, have employer-based insurance, or Medicaid. Information about Medicaid and Medicare beneficiaries can be found in those respective	<a href="http://www.statehealthfacts.org/comparecat.jsp?cat=3">http://www.statehealthfacts.org/comparecat.jsp?cat=3</a>

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	categories. Updated annually.	
State Health Facts Online (Demographics and the Economy)	This category includes basic information about a state's residents, including demographics (such as population by age, gender, race/ethnicity), income (people in poverty by demographic grouping, and median family income), and employment (employment status and state unemployment rates and layoffs). Updated annually.	<a href="http://www.statehealthfacts.org/comparecat.jsp?cat=1">http://www.statehealthfacts.org/comparecat.jsp?cat=1</a>
State Health Facts Online (Facts at a Glance)	Individual State Profiles – Facts at a Glance. Includes demographics, health costs, health coverage and health status.	<a href="http://www.statehealthfacts.org/profile.jsp">http://www.statehealthfacts.org/profile.jsp</a>
<b>MedPac</b>	<b>Medicare Payment Advisory Commission (MedPac)</b>	
Evaluating Medicare's hospice benefit	Medicare's hospice benefit; Cost of hospice relative to curative care at end of life; Trends in hospice utilization; Characteristics of hospices exceeding the payment cap; Effects of the cap on access to hospice care; Incentives in Medicare's hospice payment system; Medicare has insufficient information on the hospice care it purchases; Measuring and reporting quality of hospice care.	<a href="http://www.medpac.gov/documents/Jun08_EntireReport.pdf">http://www.medpac.gov/documents/Jun08_EntireReport.pdf</a>
Healthcare Spending and the Medicare Program - A Data Book - June 2009	The Medicare Payment Advisory Commission (MedPAC) is an independent federal body established by the Balanced Budget Act of 1997 (P.L. 105-33) to advise the U.S. Congress on issues affecting the Medicare program. This report discusses the Medicare Hospice Benefit and how its use and costs have changed over time.	<a href="http://www.medpac.gov/documents/Jun10DataBookEntireReport.pdf">http://www.medpac.gov/documents/Jun10DataBookEntireReport.pdf</a>
<b>National Alliance for Caregiving</b>		
Caregiving in the US - A Focused Look for Those Caring for the 50+ (November 2009)	The purpose of this analysis is to determine how many caregivers age 18 and over are providing assistance to someone age 50 years and older in the U.S. We want to know who they are, what they do for the person they assist, and how caregiving affects their lives. The first national profile of caregivers was published in 1997 in Caregiving in the U.S. An updated version of the study was fielded in 2003 and reported in 2004. This report describes the findings from the third wave of this important study and begins to trend the findings. Each of	<a href="http://www.caregiving.org/data/2009/CaregivingAARP_Full_Report.pdf">http://www.caregiving.org/data/2009/CaregivingAARP_Full_Report.pdf</a>

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	these three studies has inquired about core elements of caregiving, and each has explored new areas.	
<b>National Cancer Institute</b>		
State Cancer Profiles	The objective of the State Cancer Profiles Web site is to provide a system to characterize the cancer burden in a standardized manner in order to motivate action, integrate surveillance into cancer control planning, characterize areas and demographic groups, and expose health disparities. The focus is on cancer sites for which there are evidence based control interventions. Interactive graphics and maps provide visual support for deciding where to focus cancer control efforts.	<a href="http://statecancerprofiles.cancer.gov/">http://statecancerprofiles.cancer.gov/</a>
US Mortality Data	The Surveillance, Epidemiology, and End Results (SEER) Program of the National Cancer Institute (NCI) is an authoritative source of information on cancer incidence and survival in the United States. SEER currently collects and publishes cancer incidence and survival data from population-based cancer registries covering approximately 26 percent of the US population.	<a href="http://seer.cancer.gov/mortality/">http://seer.cancer.gov/mortality/</a>
<b>NHPCO</b>	<b>National Hospice and Palliative Care Organization</b>	
NHPCO's Facts and Figures: Hospice Care in America (2011 Edition)	This report provides an annual overview of important trends in the growth, delivery and quality of hospice care across the country. This overview provides specific information on: Hospice patient characteristics (e.g., gender, age, ethnicity, race, primary diagnosis, and length of service); Hospice provider characteristics (e.g., total patients served, organizational type, size, and tax status); Location and level of care; Role of paid and volunteer staff.	<a href="http://www.nhpc.org/files/public/Statistics%20Research/2011%20Facts%20Figures.pdf">http://www.nhpc.org/files/public/Statistics Research/2011 Facts Figures.pdf</a>
Comparing Hospice and Nonhospice Patient Survival	The focus of this report is to study the difference of survival periods of terminally ill patients between those using hospices and not using hospices.	<a href="http://www.nhpc.org/files/public/JP%20SM/march-2007-article.pdf">http://www.nhpc.org/files/public/JP SM/march-2007-article.pdf</a>

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Among Patients Who Die Within a Three-Year Window		
Opioid Use and Survival at the End of Life: A Survey of a Hospice Population	To determine whether survival after last opioid dose change is associated with opioid dosing characteristics and other factors, data from the National Hospice Outcomes Project, a large prospective cohort study involving 13 U.S. hospice programs, were analyzed.	<a href="http://www.nhpc.org/files/public/JP/SM/Dec06_Opioid_survival_JPSM.pdf">http://www.nhpc.org/files/public/JP/SM/Dec06_Opioid_survival_JPSM.pdf</a>
African American Bereaved Family Members' Perceptions of the Quality of Hospice Care	This study published in the Journal of Pain and Symptom Management describes data from bereaved family members who the Family Evaluation of Hospice Care. It compares Non-Hispanic Black and Non-Hispanic White participants to determine differences in their perceptions whether they received family centered care.	<a href="http://www.nhpc.org/files/public/JP/SM/Nov07/article.pdf">http://www.nhpc.org/files/public/JP/SM/Nov07/article.pdf</a>
Pediatric Palliative & Hospice Care in America	Pediatric Palliative and Hospice Care in America provides an overview of the landscape of pediatric palliative and hospice care for providers, policy makers, funders and the media. The specific goals of this report are to: 1) Describe the current state of pediatric palliative and/or hospice care in the United States; 2) Identify children who may be in need of pediatric palliative and hospice care support in order to help programs determine which children might benefit most from available services and guide program outreach and design; and 3) Identify gaps in service provision in order to help guide interventions to address those gaps.	<a href="http://www.nhpc.org/files/public/quality/Pediatric_Facts-Figures.pdf">http://www.nhpc.org/files/public/quality/Pediatric_Facts-Figures.pdf</a>
Growth of US Hospice Programs & Hospice Patients	Growth in U.S. Hospice Programs: 1974 to 2009 Patients Served by Hospice in the U.S.: 1984 to 2009	<a href="http://www.nhpc.org/i4a/pages/index.cfm?pageid=5994">http://www.nhpc.org/i4a/pages/index.cfm?pageid=5994</a>
Hospices' Preparation and Practices for	This report contains the results of a survey of 652 NHPCO hospice members. Data was analyzed to describe preparation and practices for quality measurement and research and to examine associated	<a href="http://www.nhpc.org/files/public/JP/SM/JPSM_January_2010.pdf">http://www.nhpc.org/files/public/JP/SM/JPSM_January_2010.pdf</a>

## END OF LIFE CARE DATA RESOURCES

Organization and Report Title	Description	URL for Web Page
Quality Measurement	organizational characteristics.	
<b>The Dartmouth Atlas of Healthcare</b>		
Dartmouth Atlas - Data by Topic Interactive Tool	The new site has custom maps, grids, trend reports, charts and fact sheets, databases which allow maps, charts and tables to be created and downloaded for presentations, and search capabilities to compare entities such as states, hospitals, primary care service areas, etc. Additionally, a “key issues” section provides information on “Medicare spending, supply-sensitive care, preference-sensitive care, the physician workforce, end-of-life care, racial disparities, accountable care organizations and more.” Fourteen years of archived media coverage is also included.	<a href="http://www.dartmouthatlas.org/data/topic/">http://www.dartmouthatlas.org/data/topic/</a>
Dartmouth Atlas – Publications (Atlases & Reports)	The reporting of research data from the Dartmouth Atlas Project takes several forms. We have produced twenty book-length editions of <i>The Dartmouth Atlas of Health Care</i> ; several brief reports covering specific topics and/or clinical subject areas; and a number of issue briefs on relevant health policy topics. Atlas investigators also have an extensive bibliography of scientific articles published in peer-reviewed journals.	<a href="http://www.dartmouthatlas.org/publications/reports.aspx">http://www.dartmouthatlas.org/publications/reports.aspx</a>
Dartmouth Atlas – Publications (Research Articles)	The reporting of research data from the Dartmouth Atlas Project takes several forms. We have produced twenty book-length editions of <i>The Dartmouth Atlas of Health Care</i> ; several brief reports covering specific topics and/or clinical subject areas; and a number of issue briefs on relevant health policy topics.	<a href="http://www.dartmouthatlas.org/publications/articles.aspx">http://www.dartmouthatlas.org/publications/articles.aspx</a>
Trends and Variation in End-of-Life Care for Medicare	This report updates to 2007 previous findings regarding regional variations in end of-life care. It also documents trends from 2003 to 2007 in the use of medical resources to treat Medicare beneficiaries at the end of life, both among hospital referral regions and among 94	<a href="http://www.dartmouthatlas.org/downloads/reports/EOL_Trend_Report_0411.pdf">http://www.dartmouthatlas.org/downloads/reports/EOL_Trend_Report_0411.pdf</a>

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Beneficiaries with Severe Chronic Illness	academic medical centers. The data presented in this report show that health systems can change—and are changing—the way they treat patients who are seriously ill with chronic illness. The pace of these changes is strikingly different from region to region and hospital to hospital.	
The Dartmouth Atlas of Health Care 2008 – Tracking the Care of Patients with Severe Chronic Illness	This edition focuses on supply-sensitive care delivered to chronically ill Medicare beneficiaries in the last two years of life (died between 2001 and 2005). Unlike the previous Atlas, this version includes Medicare spending not just on inpatient care, but also the amount spent on ambulatory care, skilled nursing care, long-term care, home health care, and hospice care. The final chapter of this Atlas will outline a proposal for reforming the Medicare payment system, a plan that is intended to simultaneously improve the quality of care for the chronically ill and rein in spending.	<a href="http://www.dartmouthatlas.org/downloads/atlasses/2008_Chronic_Care_Atlas.pdf">http://www.dartmouthatlas.org/downloads/atlasses/2008_Chronic_Care_Atlas.pdf</a>
Quality of End-of-Life Cancer Care for Medicare Beneficiaries	In this report the Dartmouth Atlas Project examines care for Medicare patients over age 65 with cancers that have a poor prognosis and finds that care at the end of life varies markedly across regions and academic medical centers.	<a href="http://www.dartmouthatlas.org/downloads/reports/Cancer_report_11_16_10.pdf">http://www.dartmouthatlas.org/downloads/reports/Cancer_report_11_16_10.pdf</a>
<b>The Robert Wood Johnson Foundation</b>		
Means to a Better End - State Report Card (End-of-life care, 2002)	In this report, <i>Last Acts</i> rates each of the 50 states and the District of Columbia on eight criteria as a basis for assessing the state of end-of-life care in this country. The accompanying interactive feature provides essential information on the quality of end-of-life care on a state-by-state basis. The application looks at state advance directive policies; location of death; hospice use; hospital end-of-life care services; care in ICUs; pain among nursing home residents; state pain policies; and palliative care-certified physicians and nurses.	<a href="http://www.rwjf.org/files/publications/other/meansbetterend.pdf">http://www.rwjf.org/files/publications/other/meansbetterend.pdf</a>
Portrait of Informal Caregiver	This Portrait of Informal Caregivers in America is one of three data portraits produced in 2002 by The Robert Wood Johnson Foundation	<a href="http://www.rwjf.org/files/publications/other/CaregiverChartbook2001.pdf">http://www.rwjf.org/files/publications/other/CaregiverChartbook2001.pdf</a>

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(Caregiver Health)	as part of its National Strategic Indicators Project. This chart book explores the experiences of 1,005 caregivers of the chronically ill surveyed on-line in May 2001. The Robert Wood Johnson Foundation, in collaboration with FACCT The Foundation for Accountability, conducted this survey to learn more about what caregivers are feeling about providing care and what they need from the health care and social services systems.	
<b>University of Michigan</b>		
Changing Lives of Older Couples Study (CLOC): prospective study of spousal bereavement	While primarily a study of spousal bereavement, the dataset also includes a host of other psychosocial and biomedical variables. The combined dataset includes 1532 cases and over 3000 variables that cover every aspect of social, psychological, and physical functioning of older adults. The analysis and distribution of this data set is made possible by a grant from the National Institute on Aging to the University of Michigan (Randolph Nesse, PI). This website provides ready access to the data and codebooks as well as information on projects underway or completed. It is intended to encourage other researchers to make use of this remarkable resource.	<a href="http://www.cloc.isr.umich.edu/codebooks.htm">http://www.cloc.isr.umich.edu/codebooks.htm</a>
<b>University of Wisconsin</b>		
County Health Rankings	This web site provides access to the 50 state reports, ranking each county within the 50 states according to its health outcomes and the multiple health factors that determine a county's health. Each county receives a summary rank for its health outcomes and health factors and also for the four different types of health factors: health behaviors, clinical care, social and economic factors, and the physical environment. Each county can also drill down to see specific county-level data (as well as state benchmarks) for the measures upon which the rankings are based.	<a href="http://www.countyhealthrankings.org/">http://www.countyhealthrankings.org/</a>

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Organization and Report Title	Description	URL for Web Page
Pain Policy Database of State Laws and Regulations	The purpose of this website is to facilitate public access to information about pain relief and public policy, including material published by the PPSG and other authoritative sources. This link connect the user to a Pain Policy Database and State Laws Regulations.	<a href="http://www.painpolicy.wisc.edu/matrix.htm">http://www.painpolicy.wisc.edu/matrix.htm</a>
Achieving Balance in State Pain Policy (A Progress Report Card 2008)	PPSG has developed a peer-reviewed, validated approach for evaluating state policies that influence pain management and grading each state from A to F depending on the degree their policies enhance or impede pain management.	<a href="http://www.painpolicy.wisc.edu/">http://www.painpolicy.wisc.edu/</a>
<b>US Census Bureau</b>		
Small Area Health Insurance Estimates	2009 Health Insurance Coverage Status by Age, Race, Hispanic Origin, Sex and Income for Counties and States.	<a href="http://www.census.gov/did/www/sahie/data/index.html">http://www.census.gov/did/www/sahie/data/index.html</a>
<b>US DHHS</b>		
<b>U.S. Department of Health and Human Services Office of Inspector General</b>		
Medicare Hospice Care: A Comparison Of Beneficiaries In Nursing Facilities And Beneficiaries In Other Settings	This study describes the characteristics of Medicare hospice beneficiaries who resided in nursing facilities in 2005 and compares this population to Medicare hospice beneficiaries who resided in other settings.	<a href="http://oig.hhs.gov/oei/reports/oei-02-06-00220.pdf">http://oig.hhs.gov/oei/reports/oei-02-06-00220.pdf</a>
Office of Inspector General	Listing of reports and publications from the Office of Inspector General	<a href="http://oig.hhs.gov/search/index-advanced.asp?submitted=submitted&amp;output=xml no dtd&amp;sort=date%3AD%3AL%3Ad1&amp;ie=UTF-8&amp;filter=0&amp;oe=UTF-8&amp;lr=lang_en&amp;client=oig&amp;ud=1&amp;proxystylesheet=oig_test&amp;proxyreload=1&amp;as_q=hospice&amp;site=oig&amp;daterange-start=1995&amp;daterange-end=2012&amp;btnG=Search">http://oig.hhs.gov/search/index-advanced.asp?submitted=submitted&amp;output=xml no dtd&amp;sort=date%3AD%3AL%3Ad1&amp;ie=UTF-8&amp;filter=0&amp;oe=UTF-8&amp;lr=lang_en&amp;client=oig&amp;ud=1&amp;proxystylesheet=oig_test&amp;proxyreload=1&amp;as_q=hospice&amp;site=oig&amp;daterange-start=1995&amp;daterange-end=2012&amp;btnG=Search</a>



## END OF LIFE CARE DATA RESOURCES

Organization and Report Title	Description	URL for Web Page
Medicare's Hospice Benefit: Use and Expenditures, 1996 Cohort	This is a report created by the Department of Disability, Aging, and Long Term Care (DALTCP). This report presents information on Medicare's hospice benefit -- who is using it, how it is being used, what costs are associated with its use, what costs precede hospice enrollment and how these vary by type of enrollee. Also included are snapshot contrasts of two groups of enrollees -- those who were enrolled in HMOs or on Medicaid at least once during the 12 months between July 1995 and July 1996.	<a href="http://aspe.hhs.gov/daltcp/reports/2000/96useexp.htm#section1">http://aspe.hhs.gov/daltcp/reports/2000/96useexp.htm#section1</a>
Hospice Benefits and Utilization in the Large Employer Market	This study, sponsored by the Office of the Assistant Secretary for Planning and Evaluation (ASPE), U.S. Department of Health and Human Services, is part of a larger project exploring the use of hospice benefits and services provided by the Medicare program and to those who are privately insured. The MEDSTAT Group's contribution to the larger study is an examination of hospice benefits in commercial plans and the use of hospice benefits by persons commercially insured. In particular, this report focuses on hospice benefits in plans offered by large employers in the U.S. and the utilization of hospice benefits by the employees of these large companies, their dependents, and in some cases early retirees.	<a href="http://aspe.hhs.gov/daltcp/reports/empmkt.htm#section1">http://aspe.hhs.gov/daltcp/reports/empmkt.htm#section1</a>
Outcomes and Utilization for Hospice and Non-Hospice Nursing Facility Decedents	This comparative study first identifies and describes two cohorts of nursing facility decedents, those that did and did not elect Medicare hospice. Then, using data for up to one year prior to death, the study characterizes utilization and quality of care for these two cohorts. The influence of Medicare hospice on hospital utilization and symptom management at the end of life in nursing facilities is examined through multivariate analyses and findings of these analyses are presented and discussed.	<a href="http://aspe.hhs.gov/daltcp/reports/2000/oututil.htm#section1">http://aspe.hhs.gov/daltcp/reports/2000/oututil.htm#section1</a>