



PRIORITIES UNDER SECTION 1013 OF THE MEDICARE PRESCRIPTION DRUG, IMPROVEMENT AND MODERNIZATION ACT OF 2003

Thank you for the opportunity to provide input on the priorities for research, demonstrations, and evaluations under Section 1013 of the Medicare Prescription Drug, Improvement, and Modernization Act of 2003 (MMA). The Medicare program, which serves persons age 65 and older and those with disabilities, is the most important source of health insurance for Americans at the end of their lives. Medicare spending for decedents accounts for over one-quarter of Medicare's total annual spending, a share that has remained constant over time. Death in America is, for the most part, a Medicare issue. Of the approximately 2.5 million Americans who die each year, 75 percent are over the age of 65. When the disabled population is included, Medicare covers over 80 percent of decedents.¹ Therefore, Medicare's rules and payment structure have a significant impact on access to and quality of end-of-life care.

End-of-life care is one of the most neglected public policy issues facing us today; however, we lack the most basic details of how Americans spend their final months and days. In addition, the demographic shift that is occurring will increase the number of seriously ill and dying people at the same time that the number of caregivers decreases. The nation's elderly population will continue to grow—fueled by the baby boomers who will start to turn 65 in 2011. Careful consideration and study of the current state of end-of-life care for Medicare beneficiaries is a first and crucial step in moving towards improving the way we care for the dying in America.

Last Acts Partnership is a national, not-for-profit organization dedicated to improving care and caring near the end of life. We represent individual members, national, state, and local organizations, and nearly 400 grassroots coalitions committed to our shared goals of educating the public, informing medical and health care professionals, and promoting policy reforms that will create more options and better care for people nearing the end of life.

As requested, our comments focus on the three questions noted in the request for input.

Suggested Topics for Study Under MMA Section 1013

Medicare has been the subject of intense debate and periodic reform since its passage 33 years ago. Medicare primarily covers acute care costs. Its skilled nursing facility and home health care benefits are intended as short-term coverage for post-acute care following a beneficiary's hospitalization. Medicare's hospice benefit provides access to palliative care only for terminally ill beneficiaries who are willing to forgo curative treatment. To elect the Medicare hospice benefit, beneficiaries must have a statement from their physician that certifies that they have a life expectancy of six months or less (if the disease runs its normal course). Medicare coverage and payment for palliative care is complex and often poorly

understood by providers and program beneficiaries. This complexity prevents many individuals from accessing comprehensive, quality care at the end of life.

Last Acts Partnership believes that careful consideration and study of various aspects of end-of-life care in the Medicare population, as well as the Medicaid and SCHIP populations, is an essential step to public health system reform. End-of-life topics include:

- ?? Health-related decision making (advance directives, awareness of hospice, satisfaction with provider communication, decision making style, knowledge or perception of available options);
- ?? Health care utilization and financing (utilization of services including last place of care, length of stay in hospital, nursing home, or hospice, intensity and types of medical treatment, number of health care transitions in last month of life, payment sources, insurance coverage);
- ?? Quality of health care (provision of desired physical comfort and emotional support, pain and other symptom management, decedent and family treated with respect, family needs attended to, overall assessment of quality and unmet needs, bereavement support);
- ?? Health and illness variables (diagnosed medical conditions, health behaviors, cognitive status, problem behaviors, mental health status, functional status);
- ?? Palliative care (including coverage of prescription pain medications used at the end-of-life, and broadening Medicare coverage of prescription drugs to include self-administered medications used at home and coverage for palliative care services outside the hospice benefit).

Structure of the Priority Lists

The need for serious efforts to determine how best to care for dying people and their loved ones is fast becoming more urgent. A large aging population, increases in the incidence of chronic disease, and the reduced availability of paid and unpaid caregivers, among other factors, will soon demand that more attention be paid to improving access to quality palliative care for those near the end of life.

Why people die is also a complicated and not clearly answered question. The two leading causes of death—heart disease and cancer—account for 57 percent of Medicare beneficiary deaths.¹ This statistic, however, does not provide a clear picture of end-of-life care because decedents are likely to have multiple medical problems, averaging about four diagnoses in the last year of life. Moreover, 25 percent of decedents have dementia in their last year of life, but rarely is dementia listed as a cause of death.

There are a number of promising ways to improve the care and management of chronically and terminally ill people. For example, DHHS could fund demonstration projects that test the use of modified benefit designs for meeting the various needs of dying patients, depending on their medical characteristics and acuity level. Patients with chronic obstructive pulmonary disease, for instance, may be managed better if they receive a combination of home health and hospice care services, or if they are admitted to hospice programs without a life-expectancy restriction. Another opportunity for DHHS to support research on palliative care is through the Agency for Healthcare Research and Quality (AHRQ). This agency currently funds an initiative designed to promote best practices of clinical care through the synthesis of published research, focusing on health issues common to the Medicare and Medicaid populations. If AHRQ selected palliative care as a focus topic, then it could investigate issues such as pain management, quality assurance, and length of stay in hospice and produce a nationally-available report on best practices in palliative care.

The specific, prioritized research questions that could be addressed include:

- ?? Classification of decedents, costs, and treatment trajectories by category of condition (for example, sudden death, terminal illness, organ failure, and frailty);
- ?? Rates of disability, chronic illness, and utilization of long-term care;
- ?? Medicare utilization and costs for various medical conditions and demographics (ethnicity, race, gender, years of disability after age 65 years, etc.);
- ?? Projections of chronic illness, disability, and long-term care for current and future cohorts;
- ?? Medicare spending patterns for those dually eligible (for Medicare and Medicaid) versus those eligible only for Medicare, by disease status, demographic characteristics, etc.;
- ?? Years of life and Medicare spending patterns before and after entering the Medicare hospice program;
- ?? Differentials in end-of-life care by socioeconomic status, race or ethnicity, and geography² (as recommended in the recent Agency for Healthcare Research and Quality National Healthcare Disparities Report (2003));
- ?? Factors associated with the spend-down to Medicaid eligibility;
- ?? Consequences of changes in public policy such as the recent changes in financing home health care;
- ?? Health care consequences of prior behaviors, such as cigarette smoking, drug and alcohol abuse, and obesity.

Methods to Answer these Questions of Safety and Effectiveness as Quickly and Efficiently as Possible

Many of these topics and issues could be addressed through a revitalized National Mortality Followback Survey (NMFS). The NMFS was last conducted in 1993 by the Centers for Disease Control and Prevention's National Center for Health Statistics and proved to be a rich source of information that gave insight into aspects of living and dying in America. The survey provided policymakers with data concerning disparities among socioeconomic and racial groups, the association of disability and the use of formal health services, lifetime use of nursing home care, and the characteristics of persons dying of varying health causes. However, the last NMFS was conducted over 10 years ago. This old data cannot describe the experiences of people dying **today** or allow us to anticipate the needs for care in the future. Because the NMFS utilizes interviews with the next of kin (or someone close to the decedent) for a sample of people who died in the previous year, the followback survey is the most cost effective and efficient way to gather information on end-of-life care and quality of life. **(A summary of this recommendation to conduct another NMFS is attached).**

Thank you for your consideration of our comments. Significant improvement in end-of-life care is a large and ambitious goal that requires a shift in social and cultural orientation toward illness, caregiving, dying, death, and grief. We lack reliable and continuous descriptions of the dying experience and the care given to people who are approaching death. We cannot overestimate the importance of continued research, which creates the underpinning for evidence-based change. Systemic improvement in Medicare and other public and private programs relies on publicly funded quality research.

Last Acts Partnership believes that *now* is the time to prioritize research into better ways to deliver quality end-of-life care. The information gained through a National Mortality Followback Survey would help shape Medicare and Medicaid policy, and could lead not only to more humane care, but possibly to more cost-effective approaches to treating the chronically and terminally ill.

For further information on end-of-life care issues, please see the following Last Acts Partnership publications:

- ?? ***Expanding Prescription Drug Coverage in Medicare: Issues for End-of-Life Care*** (www.lastacts.org/files/publications/medicarerx.pdf)
- ?? ***Medicare and End-of-Life Care*** (www.lastacts.org/files/publications/medicare.pdf)
- ?? ***Medicaid and End-of-Life Care*** (www.lastacts.org/files/publications/medicaid.pdf)
- ?? ***Means to a Better End: A Report on Dying in America*** (www.lastacts.org/files/misc/meansfull.pdf)
- ?? ***On the Road from Theory to Practice: Progressing Towards Seamless Palliative Care Near the End of Life*** (www.lastacts.org/files/publications/pp1.pdf)

Should you have any questions about this submission, please contact Judith Peres, Vice President, Policy and Advocacy, at 202.296.8071, x108 or jperes@lastactspartnership.org.

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¹ Hogan C et al. "Medicare Beneficiaries' Costs of Care in the Last Year of Life." *Health Affairs*. 20(4): 188-195. 2001.

² Agency for Healthcare Research and Quality, "National Healthcare Disparities Report", Rockville, MD: AHRQ, U.S. Department of Health and Human Services, December 2003.