The number of hospice providers is steadily increasing, as more Americans are using hospice care in the last stage of life. In 2010, more than 5,000 hospices will care for almost 40 percent of all dying patients and their families. In many communities, there are multiple hospices to choose from, but there is no system in place to help consumers make informed choices among alternative providers. Nor is there reliable data on hospice performance available to doctors and other referring health professionals, as they help their patients make decisions about hospice care.

Recognizing that there is a lack of publicly available hospice performance information, and that variations in quality exist, the 2010 Patient Protection and Affordable Care Act mandates hospice public reporting on quality by 2014, with measures to be selected by 2012. The Centers for Medicare and Medicaid Services has initiated a study of candidate measures, and those selected will be forwarded to the National Quality Forum (NQF) for possible endorsement for public reporting, to be considered alongside already endorsed measures.

Leading the movement toward hospice public reporting, the American Hospice Foundation has developed a model ‘Hospice Report Card’ with a consumer-friendly format and quality measures that are important to dying patients, their families and referring professionals. A national demonstration conducted by the Foundation revealed meaningful variations in many of these measures. Thus, the American Hospice Foundation’s report card can be used both by consumers as an aid in choosing among hospices, as well as by hospice providers in quality improvement efforts.

As federal and state regulators move toward hospice public reports, they can build on this model and the results of the Foundation’s demonstration, which confirm the importance of:

- Including patient/family-centered measures
- Presenting comparative data in a format that increases usability by both consumers and providers
- Incorporating an educational component to help consumers understand the basics of hospice.

“Hospice is essential to caring appropriately for people who are approaching the end of life. But not all hospice programs and companies are equal. It is important to choose the hospice program that can best meet the needs of yourself and your family. A Hospice Report Card based on reliable information can help a lot!”

--- Ira Byock, M.D.
Director of Palliative Care and Professor at Dartmouth Medical School; Author of Dying Well and The Four Things That Matter Most
Creating a Consumer-Driven Hospice Report Card

In creating its Hospice Report Card, the American Hospice Foundation's goal was to design an evidence-based, consumer-driven tool that is useful for patients and referring professionals as they make hospice choices. To these ends, the Foundation sponsored a systematic, three-year study led by a nationally renowned principal investigator with expertise in designing public quality reports in a variety of health care sectors. The study included focus groups with consumers, physicians and geriatric care managers who were asked what they need to know when selecting a hospice, and how they would like that information delivered to them. For the findings of the consumer focus groups, see: “Addressing the Need for Public Reporting of Comparative Hospice Quality: A Focus Group Study.”

To select the measures that best match the information needs revealed in this study, the American Hospice Foundation convened a diverse technical expert panel to identify nationally endorsed measures that:

- Reflect information that consumers and referring professionals need to compare hospices
- Were scientifically developed and tested
- Have been endorsed by leading national organizations, including the NQF and the National Hospice and Palliative Care Organization (NHPCO)
- Are already in use by a large percentage of hospices
- Pose a minimal burden of data collection and submission on the part of hospice providers.

In all, 26 measures were selected and organized into 10 domains:

- Pain and symptom management
- Communication with patients and families
- Information to support family caregivers
- Availability of hospice staff
- Coordination of patient care
- Emotional and spiritual support
- Following the patient’s end-of-life instructions
- Number of visits to patients by hospice staff
- Hospice and staff accreditation
- Overall ratings of hospice quality

Testing the Hospice Report Card: A National Demonstration

To ensure maximum utility of the Hospice Report Card, a prototype was designed to include three components:

- Comparative data about hospice quality based on measures which are important to key users
- Easy-to-understand explanations about the way the data for each measure was derived
- Comprehensive information that helps consumers better understand hospice care.

This prototype underwent cognitive testing with consumers to assess whether the substance of the measures and the display of the comparative data would help them make informed decisions about hospice care. The cognitive testing revealed that consumers found the interactive format of the Hospice Report Card easy to navigate, and the content helpful in making hospice choices.

Confirming that consumers have widespread misconceptions about hospice, it became clear in the cognitive tests that this knowledge gap needs to be addressed if the comparative quality data are to be helpful in making informed hospice decisions.

“It is important that any public report on hospice performance and quality includes patient and family experience measures which are thoroughly tested and broadly implemented. Unlike some other projects, the American Hospice Foundation’s Hospice Report Card does this.”

— Melanie Merriman
Founder of Touchstone Consulting in North Bay Village, Fla.
To test the feasibility of collecting and reporting the data in the report card for hospice providers, the Foundation conducted five state-wide demonstrations, which revealed that:

- The required data collection and reporting created a minimal burden for the 130 participating hospices;
- Some of the participating hospices used the Hospice Report Card in performance improvement efforts; and
- There is meaningful variation in many of the measures, e.g., Overall Quality of Hospice Care.

“Throughout health care, we need consumer perspectives, buy-in, and help in making sure that providers are accountable. The same goes for transparency in hospice care. We need a hospice public reporting tool which captures the experiences of patients and their families. The Hospice Report Card has the potential to improve quality in end-of-life care and provide important information to consumers to help them make informed end-of-life decisions.”

— Debra L. Ness
President of the National Partnership for Women & Families
Designing a Powerful Online Tool to Compare Hospice Providers

The American Hospice Foundation’s Hospice Report Card uses visual components based on best practices of comparative quality reports in other health sectors. An online template makes it easy to use the Hospice Report Card for learning about hospice care and comparing quality. **Start Comparing Hospice Quality** leads to the 10 domains of quality comparisons.

Among the 10 domains, **Pain and Symptom Management** has four measures. The first measure—*Patient-reported comfort within 48 hours of admission*—is shown in a graph displaying the scores of all of the hospices in the comparison group, as well as the state and national averages. Users can easily see which hospices do the best job in managing pain soon after admission. Below the graph, there are instructions on how to read the graph and explanations about the data sources and calculations. To learn more about the hospice of interest, the viewer can place the mouse over a hospice name and view more information.
Building Hospice Knowledge

Consumers cannot effectively ask questions about the quality of hospice care unless they know how hospice care is delivered, how it is paid for and what role the family plays in patient care. Having learned from the cognitive tests that some consumers are ill-informed about hospice, the American Hospice Foundation created an educational component with consumer-friendly information about the most salient features of hospice care. Entitled Learn More about Hospice Care, this section of the report card directs the user to a variety of questions and detailed responses that enhance the usability of the comparative hospice performance data.

“When I cared for my dying friend, there were multiple hospices from which to choose. Hospices are different, and each patient’s care needs are different. Based on my professional hospice experience, I was able to piece together suggestions and make assumptions. But it would’ve been comforting to have one good source of information to help us make decisions.”

— Johanna Turner
Former Hospice Professional and Family Caregiver, Washington, D.C.
Earning External Recognition

The National Quality Forum (NQF) views the Hospice Report Card as a potentially instrumental driver toward improved quality in end-of-life care. As a result, NQF is highlighting the Report Card project with a brief article, “Helping Consumers with Hospice Care Decisions,” on its National Priorities Partnership website.

The Agency for Healthcare Research and Quality (AHRQ) has posted graphics from the Hospice Report Card prototype on its new “Talking Quality” website as an example of emerging public reports. To illustrate an effective example of self-explanatory bar charts, the AHRQ website displays the Hospice Report Card bar graph design and also cites several of the measures selected by the Foundation as examples of quality measures that are useful for consumers.

Understanding Why the Hospice Report Card Matters

A public Hospice Report Card is timely and important because:

- The quality of hospice care varies among providers, and there are real opportunities for improvement now.
- When addressing health care quality, what gets measured gets improved.
- Consumers and referral sources need comparative quality information to guide their decisions.

“While most hospices deliver high-quality care for their patients, no hospice provider wants to rank at the bottom of the list with competing hospices. Comparative quality data that is available to the public will drive the quality improvement efforts of most hospices, which is good for patient care and good for the hospice industry.”

— Carla Braveman
President and CEO of Big Bend Hospice in Tallahassee, Fla.
Many groups will benefit from the Hospice Report Card

- **Policymakers** need this tool to ensure that precious government resources are spent on high-quality hospice care that effectively meets the needs of patients and their families.
- **Patients and their families** need this tool to learn more about hospice in general and make decisions based on quality.
- **Hospice providers** need this tool to know where their care can be improved and to track the quality of their services against competing hospices.

The American Hospice Foundation hopes that its model Hospice Report Card will set the stage for others to build upon this effort, offering an evidenced-based model that can be used for the dual purposes of informed consumer decision-making and hospice quality improvement. The measures selected for this Hospice Report Card are patient-centered and feasible to report, making it useful for dying patients and their families, public and private payers, federal and state regulators and hospice providers.

**Contact Us to Learn More**

The American Hospice Foundation welcomes opportunities to discuss its Hospice Report Card. Please contact Marsha Nelson at mnelson@americanhospice.org.

To view the Hospice Report Card, and learn more about the project, visit the Foundation’s website at www.americanhospice.org.

“Thus far, hospice quality improvement has been driven by national regulators, but that doesn’t mean that state regulators don’t have a role. In order to improve quality reporting at home, state regulators need to know where hospice reporting is going, and what consumers need and want from hospice.”

— **Jennifer Hale**
State Executive, Georgia Hospice and Palliative Care Organization