



# The Status of Quality Measure Development in Hospice

## From HIS and CAHPS to HOPE and Claims: Hospice Quality Measurement Today and Tomorrow

### Overview

Throughout the hospice movement's 40-year history, providers have offered personalized care to patients at the end of life, combining science and compassion to meet each individual's own wishes. This movement has grown significantly since its inception. In the past two decades alone, hospice enrollment has nearly tripled, increasing from about 530,000 patients in 2000 to more than 1.5 million in 2018.<sup>1,2</sup> By 2014, nearly half of all Medicare beneficiaries who died used hospice care<sup>3</sup> – care that was provided by 4,300 U.S. hospice agencies.<sup>4</sup>

As the movement has grown, however, hospice leaders have faced the challenge of defining and ensuring the delivery of quality care across the board. Recognizing this need, the federal government mandated the Hospice Quality Reporting Program (HQRP) in the Affordable Care Act of 2010.<sup>5</sup>

Since that time, however, the effort to establish effective, validated quality measures for hospice care has been going through an evolutionary process. In a 2016 issue brief from RTI International, an organization that worked with the Centers for Medicare and Medicaid Services (CMS) on the development of certain quality measures, the authors stated:

*“Defining and measuring the quality of hospice care is challenging, given its strong ties to patient preferences, the terminal health status of patients, and the challenges of an interdisciplinary team delivering services in various settings, including patients’ homes and residential care settings.”*<sup>6</sup>

Throughout the past decade, a number of organizations have issued reports or published studies that identified the need for quality improvements and consistent, effective quality measurement in hospices: assessments from the U.S. Department of Health and Human Services Office of Inspector General,<sup>7</sup> studies published in the *Journal of the American Medical Association*,<sup>8</sup> a wide-ranging investigative series of articles in *The Washington Post* entitled “The Business of Dying,”<sup>9</sup> and a collaborative effort by the American Academy of Hospice and Palliative Medicine and the Hospice & Palliative Nurses Association, whose findings were reported in 2015 in the *Journal of Pain and Symptoms Management*.<sup>10</sup>

This white paper summarizes the work of CMS and partnering organizations, particularly during the past five years, to develop and validate consistent hospice quality measures. Their goal is to ensure that patients and policy makers have meaningful information to help them distinguish between high- and low-quality providers and to make important choices for their care.<sup>11</sup> The paper also provides resource information about how interested hospice leaders can stay up to date on the process and share their points of view.

## Hospice Compare: The Challenges with Process Measures and “After-the-Fact” Experience Surveys

In 2017, CMS launched its Hospice Compare website, which helps consumers compare hospice providers on certain measures of performance to assist them in making important healthcare decisions.<sup>12</sup> The information provided on Hospice Compare comes from two sources: the Hospice Item Set (HIS), which measure the interdisciplinary team's activities at patient admission and discharge, and the Hospice Consumer Assessment of Healthcare Providers and Systems (CAHPS®) Hospice Survey.<sup>13</sup>

Unfortunately, the HIS data set has limitations, as documented in the MedPAC's 2019 Report to Congress.<sup>14</sup> The HIS data set does not provide valuable insights into care provided throughout a patient's hospice experience or any meaningful insights into differences between hospices.<sup>15</sup>

While the CAHPS survey focuses on experience, it is administered after a patient's death, gathering the family caregivers' perspective on their experience with hospice care after the fact. CAHPS questions revolve around communication, respect, getting timely help, and willingness to recommend.<sup>16</sup>

“The challenge with the HIS data set, in particular, is that it measures care processes, not patient outcomes,” said Katherine Ast, MSW, LCSW, Director of Quality and Research at the American Academy of Hospice and Palliative Medicine. “Process measures solely look at if a certain process was done (e.g., pain assessment) but not whether the process was actually helpful to the patient. It remains difficult to define positive outcomes in hospice at all, since patient goals most likely differ from patient goals in other settings. If goals have been defined, then the challenge becomes where to find that documentation in the patient record. With all the challenges, the actual data collected may not offer consumers useful information about how hospices differ from one another.”

## Filling the Gap: HOPE and Claims-Based Measures

To address this issue and to fill the gaps in the measurement of hospice patients' outcomes and experiences, CMS is working on two fronts. First, it is developing a new standardized patient assessment tool called HOPE: Hospice Outcomes & Patient Evaluation (HOPE) tool, which when finalized, will assess the clinical, psychosocial, spiritual, and emotional status and needs of hospice patients during the course of their care.<sup>17</sup> Second, CMS is also developing a Hospice Care Index based on claims data.<sup>18</sup>

HOPE is an evolving standardized hospice patient assessment that stands for Hospice Outcomes & Patient Evaluation (HOPE) tool. It will assess the clinical, psychosocial, spiritual, and emotional status and needs of hospice patients during the course of their care.<sup>19</sup> When finalized and adopted, HOPE will help consumers select a hospice for their care.<sup>20</sup>

The HOPE tool will collect individual assessment items at specific points during a patient's care, including detailed clinical information, updates on the patient's functional status, and the preferences of the



## The Status of Quality Measure Development in Hospice

patient, family, and caregivers. According to the CMS website on HOPE, this new tool will provide “an opportunity to collect information on patients’ holistic needs and experiences of care. When standardized, a patient assessment tool allows for the measurement of quality in a way that can be compared across hospice providers and used to inform future payment refinements.”<sup>19</sup>

Very importantly for hospice providers, a standardized patient assessment tool like HOPE is designed to enhance continuous quality improvement because patient-reported data is collected in real time, able to influence care immediately, Ast said. Hospices will be able to compare their performance on each quality measure against other hospices and to the national average.<sup>20</sup>

When HOPE is adopted, CMS plans to replace the Hospice Item Set with data collected through HOPE.<sup>21</sup> The CAHPS Hospice Survey on patient and family caregiver experience, however, will not be affected by HOPE.<sup>22</sup>

CMS has completed the early development and Alpha testing phases for HOPE and is currently moving into Beta testing. Twenty Medicare-certified hospice providers participated in the Alpha testing phase, representing the diversity of hospices nationwide in terms of size, business model, geographic location, and their use of an electronic or paper-based system of data collection.<sup>23</sup>

The Hospice Care Index is a claim-based measurement system that is also designed to fill the “measurement gap” related to the care provided during a patient’s stay with hospice. Currently, HQRP is the only CMS Quality Reporting Program in health care that does not use any claims-based measures.<sup>24</sup>

The objectives of the claim-based measures initiative are to:

- Capture wide-ranging aspects of hospice care with a broad, holistic set of claims-based quality measures.
- Identify indicators based on caregiver and provider feedback.
- Align the index with family and caregiver perspectives from CAHPS®.<sup>25</sup>

Potential indicator topics include skilled visits, service utilization, access to all levels of care, transitions, and readmission.<sup>26</sup>

During a Hospice Quality Reporting Program forum held on August 5, 2020, presenters from both CMS and Abt Associates, the quality measure developing organization, shared information about how they determined that claims-based data would help bridge hospices’ quality measures gap.

*“Claims data is the best available data for measuring care during the hospice stay. Claims data is readily available, reducing provider burden for implementation. Claims also account for care delivery decisions and actions as they occur, giving consumers a more timely reflection of care quality than other existing measures.”<sup>27</sup>*

A full transcript of the forum, including the questions and answers from participating hospice leaders, can be found online. (See the Resources list at the end of this white paper.)

## Input and Advocacy: Hospice Leaders’ Opportunity to Guide the Process

Given that both of these initiatives – the creation of the HOPE tool and

the Hospice Care Index claim-based measures – are currently under development, CMS is providing a number of opportunities for hospice leaders to learn more and to participate.

“I cannot emphasize enough how important it is to become involved in the process as these programs evolve,” Ast said. “CMS holds regularly scheduled calls for providers, and CMS must answer questions and respond to all comments. It is our responsibility as providers and educators to advocate for what we want and need – consistent quality measures that are manageable, encourage continuous improvement, and will be of value to patients and families making healthcare choices.”

## Resources

### Centers for Medicare and Medicaid Services

#### Hospice Quality Reporting:

<https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/Hospice-Quality-Reporting>

#### Hospice Outcomes & Patient Evaluation Tool (HOPE)

<https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/Hospice-Quality-Reporting/HOPE>

#### Hospice Care Index: Claims Based Measures

<https://www.cms.gov/files/document/hqrp-forum-august-2020-slides.pdf>

#### Hospice Quality Reporting Program Forum on Claims-Based Measures: Transcript from August 5, 2020 Meeting:

<https://www.cms.gov/files/document/hqrp-forum-august-2020-transcript.pdf>

#### National Hospice and Palliative Care Organization – HOPE Tool

<https://www.nhpco.org/regulatory-and-quality/quality/hope-tool/>

## References

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- 5 <https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/Hospice-Quality-Reporting>
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## The Status of Quality Measure Development in Hospice

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## About National Hospice Cooperative

Our mission is to provide world-class, business support services, maximizing financial and process efficiencies to empower community-based, not-for-profit hospice providers to focus their resources on the delivery of quality care.

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