



# National Quality Partners Case Study: Integrating Personal Preferences in Advanced Illness Care

MARCH 2017



NATIONAL  
QUALITY FORUM

IN NOVEMBER 2016, National Quality Partners (NQP) released the issue brief, **A Collaborative Journey to Transform Advanced Illness Care**. NQP's Advanced Illness Care Action Team—which includes more than 25 patient advocates, physicians, hospital systems, and other stakeholders from the public and private sectors—identified six key preferences of individuals with advanced illness: purpose and connection, physical comfort, emotional and psychological well-being, family and caregiver support, financial security, and peaceful death and dying. The issue brief explores these key preferences in depth and includes snapshots of organizations that have embraced one or more of these preferences. By placing individuals at the center as the guiding North Star of all healthcare decisions, this initiative calls on the nation to transform advanced illness care and to engage patients, families, and caregivers as true partners in care planning.

This issue brief supplement offers a case study example of how the care plan can integrate an individual's preferences and how measures can provide a tool to guide and improve person-centered care delivery across different care settings. This case study, therefore, focuses on the measures that may best correspond to the individual's personal goals of care, many of which also meet federal reporting requirements.

## Background

Hazel is a 63-year-old woman recently diagnosed with advanced lung cancer. She has a history of chronic obstructive pulmonary disease (COPD), diabetes, major depression, and anxiety. She lives in a suburban community outside of a major metropolitan area with her daughter Judy, a 44-year-old who also has multiple chronic conditions. Hazel takes an active role in supporting Judy's care, as worsening kidney disease due to diabetes has limited Judy's activities. Judy has been unable to work for several years, and as a result is now covered by Medicaid. Hazel has health coverage through an employer-sponsored health insurance plan, but her premiums and co-pays have risen over the past few years. She worries that she will have to dip into her modest retirement savings to help cover her medical expenses. Because her condition has been relatively stable over the past six months, Hazel hopes to continue to be able to work and earn an income and to care for Judy, with additional support from family and close friends. Hazel currently receives care from multiple providers across several care sites, including primary care, specialty care, and pharmacy services.

This case study follows Hazel as she transitions across the healthcare system. This path is just one illustrative example of the settings of care and transitions an individual may experience, recognizing that every person's experience is unique. At every stage in her journey, having conversations about her priorities and values is the first step in ensuring that her healthcare is person-centered and aligns with her personal goals.

The following scenarios illustrate Hazel’s journey through the healthcare system, from inpatient and post-acute care to palliative and hospice care.



## Primary/Specialty Care

### Description

Hazel currently receives primary care from an internist, specialty care from an oncologist, pulmonologist, and endocrinologist, and consultation from her local pharmacist. Her oncologist plays the primary coordinating role for her care, which has become increasingly overwhelming and leads her team of physicians to design a comprehensive plan of care that addresses both her short- and long-term goals. Her oncologist shares information with and integrates information from her primary care physician, pulmonologist, and endocrinologist, while ensuring that the care plan is up to date and addresses the management of her COPD, diabetes, anxiety and depression. On this visit, Hazel’s physician notices signs of potentially worsening depression and stamina. He is also concerned that she has not yet developed an advance care plan to address her preferences should her condition decline.

**Personal Goals**      Hazel would like to feel less depressed and fatigued, miss fewer days of work, and be able to take Judy to her son’s basketball games on weekends.

**NQF-Endorsed Performance Measures**

- **0326** Advance Care Plan\*
- **0701** Functional Capacity in COPD Patients Before and After Rehabilitation
- **0712** Depression Utilization of the PHQ-9 Tool\*
- **0711** Depression Remission at Six Months\*

*\*Measure included in the Center for Medicare & Medicaid Services (CMS) Physician Feedback Program/Value-Based Payment Modifier and Quality and Resource Use Reports*

**Action Plan**      Together, Hazel and her physician discuss the importance of creating an advance care plan with her treatment preferences. Her physician suggests that she use an advance care planning tool such as **Five Wishes**® with Judy between now and her next visit and that she consider how her preferences might affect Judy in both the short- and long- term. He administers the Patient Health Questionnaire (PHQ-9) to gain a baseline understanding of her depression. At Hazel’s request, he offers options for treating her depression and fatigue without medication and plans to re-check her PHQ-9 scores in six months.

## Inpatient Acute Care

### Description

Following a relatively stable six-month period, Hazel's physician admits her to the hospital with an acute exacerbation of COPD. Although her lung cancer has remained stable, her breathing has become more difficult, and her anxiety and depression have increased. Over the course of her hospitalization, the nurses and therapists working with her have noted occasional signs of confusion, and have alerted the discharge team that she is not safe for discharge home.

### Personal Goals

Hazel takes several medications due to her many conditions. She expresses concerns about the cost and potential side effects of adding to her already complex medication regimen. She also notes a decline in stamina while in the hospital and feels that she will not be able to manage well if discharged home. She is concerned about how Judy will manage without her support, but recognizes that she is not strong enough to take care of herself.

### NQF-Endorsed Performance Measures

- **0166** HCAHPS\* (review items related to communication, explanation of medications)
- **0228** 3-Item Care Transition Measure\*
- **0419** Documentation of Current Medications in the Medical Record
- **0553** Care of Older Adults (COA)—Medication Review

*\*Measure included in the CMS Hospital Compare, Hospital Inpatient Quality Reporting, and Hospital Value-Based Purchasing programs*

### Action Plan

While Hazel is hospitalized, her care team initiates a palliative care consultation given the complexities of her medical and social situation. The consultation covers Hazel's unmanaged symptoms, care needs, and the possible benefits of hospice and palliative care now and in the future. Upon discharge, she receives a social work referral from an inpatient physician and consults with a pharmacist to minimize medication changes and obtain assistance with medication management. The physician recommends a short-term subacute rehabilitation stay at a nursing home close to her house. The discharge staff coordinates closely with the post-acute care facility to exchange important information about Hazel's inpatient stay, including her depression and potential cognitive issues.

## Post-Acute/Skilled Nursing Home Facility Care

### Description

Hazel feels weakened by both her illness and hospital stay and is not able to manage activities of daily living. Following the recommendation from the inpatient physician, she enters short-term subacute rehabilitation after discharge.

**Personal Goals** Hazel has a strong desire to regain her independence and to go back home. She continues to worry about Judy and her ability to return to work..

### NQF-Endorsed Performance Measures

- **0326** Advance Care Plan
- **0418** Preventive Care and Screening: Screening for Clinical Depression and Follow-Up
- **0676** Percent of Residents Who Self-Report Moderate to Severe Pain (Short-Stay)
- **2612** CARE: Improvement in Mobility
- **2613** CARE: Improvement in Self Care
- **2775** Functional Change: Change in Motor Score for Skilled Nursing Facilities
- **2769** Functional Change: Change in Self Care Score for Skilled Nursing Facilities
- **2858** Discharge to Community

### Action Plan

As a result of Hazel's complicated medical history and home situation, it is critical that she has an advance care plan. The staff work with her on completing one before discharge. The post-acute care facility coordinates Hazel's return home and recommends a short course of home health care. The discharge staff communicates directly with the home health agency. Prior to discharge, the staff perform a final medication review to make decisions about which medicines to continue at home.

## Home Health Care

### Description

Hazel's primary care provider alerts the home care staff to her ongoing struggles with depression and increased pain, which are likely to prevent her return to work.

**Personal Goals** Hazel is most concerned about how her ongoing illness is affecting her daughter Judy, and wants to avoid another hospitalization or rehabilitation stay. She wants to be able to take care of herself without relying on Judy. Hazel is having trouble coping with her pain and is worried about whether she will be able to return to work even on a limited basis.

### NQF-Endorsed Performance Measures

- **0167** Improvement in Ambulation\*
- **0171** Acute Care Hospitalization During the First 60 Days of Home Health
- **0177** Improvement in Pain Interfering with Activity\*
- **0326** Advance Care Plan
- **0518** Depression Assessment Conducted\*

*\*Measure included in the CMS Home Health Quality Reporting program*

### Action Plan

The home health care team continues to work on helping Hazel regain function so that she can be independent at home. The team continues to monitor her for signs of depression and pain that may adversely impact her quality of life. The agency staff emphasize the importance of knowing about her advance care plan and communicating it to the next care provider, if applicable.

## Hospice Care

### Description

Hazel's prognosis worsens, and her physician discusses with her that her condition is likely terminal. He advises her that she may have as little as three months left to live. He recommends that she receive hospice services to assist her and Judy in preparing for this stage of her life.

**Personal Goals** Hazel recognizes that she is approaching end of life and wishes to remain in her home with Judy. She hopes for spiritual support since she can no longer attend church, and she is concerned about worsening pain and shortness of breath, which cause significant anxiety. She would like to be comfortable and spend as much of her time as possible with her Judy and her grandson.

### NQF-Endorsed Performance Measures

- **0208** Family Evaluation of Hospice Care
- **0209** Comfortable Dying
- **0211** Proportion with more than one emergency room visit in the last days of life
- **1638** Hospice and Palliative Care—Dyspnea Treatment
- **1637** Hospice and Palliative Care—Pain Assessment\*
- **1641** Hospice and Palliative Care—Treatment Preferences\*
- **1647** Beliefs and Values—Discussions of Spiritual/Religious Concerns\*
- **2651** CAHPS® Hospice Survey
- **1623** Bereaved Family Survey

*\*Measure included in the CMS Center for Medicare Hospice Quality Reporting program*

### Action Plan

The hospice staff work closely with Hazel and her family to ensure that her care preferences are clearly documented, communicated, and integrated into all aspects of her care during this difficult time. The staff monitor and adjust Hazel's medication regime to keep her comfortable yet alert so that she can interact with her family. The team offers her specific advice and guidance on what would constitute an appropriate reason to return to the emergency room and whom to contact in the event of a change in her clinical condition. The team makes modifications in her home, including the use of medical equipment, to provide a safe and comfortable environment. The chaplain helps Hazel find comfort through her spiritual beliefs, and the hospice staff have begun working with Judy and Hazel's grandson to address their anticipatory grief. After Hazel passes, the hospice agency offers bereavement counseling and support to Judy and other family members.

## CLOSING NOTE

This case study takes healthcare providers and policymakers, as well as individuals, families, and their caregivers, through a scenario of an individual experiencing advanced illness along the continuum of care. The highlighted NQF-endorsed measures offer options for measuring the quality of care; however, these are not the only measures that could be used, nor are all relevant NQF-endorsed measures included. Hazel's experience demonstrates how an individual can receive care from multiple providers and in many different settings, and illustrates how various providers can best work together to achieve person-centered advanced illness care that reflects an individual's preferences, wishes, and goals.