



National Hospice and Palliative Care Organization
Palliative Care Resource Series

**METRICS AND MEASUREMENT
FOR PALLIATIVE CARE**

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INTRODUCTION

Measurement is an activity in which all palliative care (PC) programs must engage. Program leaders need to be able to describe what their services do for patients and families and the outcomes that flow from those efforts. But measurement can be difficult, for many reasons. Palliative care has a broad and far-reaching scope and, as a result, there are literally hundreds of metrics that might be used to assess care quality. Just sorting through all of the possibilities can be overwhelming.

Stakeholders – individuals or groups who have an interest in the palliative care program – often have different priorities and interests, meaning that it will probably not be possible to measure all of the things that are important to all of the stakeholders. Choices will need to be made. Further, because palliative care is a relatively new and evolving field, there is tremendous variation in care settings, scopes of practice, staffing models, and patient populations. All of this variation means that there is no single set of metrics that is appropriate for all palliative care services.

Programs need to identify the measures that meet their specific needs, given their scope of practice, patient population and the resources that are available to gather and analyze data.

This paper will describe a five-step process that can be utilized to guide selection of a meaningful, balanced, feasible portfolio of metrics:

1. Review best practices in the palliative care field;
2. Elicit and appreciate stakeholder interests and priorities;
3. Identify potential structure, process and outcome metrics;
4. Assess feasibility – consider data collection burden and data accessibility;
5. Select your portfolio of feasible measures.

1. REVIEW BEST PRACTICES IN THE PALLIATIVE CARE FIELD

Before selecting metrics, it's a good idea to spend some time reflecting on what good palliative care looks like. While there are many documents that describe PC best practices, a good one to start with is *Clinical Practice Guidelines for Quality Palliative Care*, developed by the National Consensus Project for Quality Palliative Care (NCP)¹. The 27 guidelines and supporting criteria reflect expert consensus, informed by an extensive body of published evidence. The guidelines address eight domains of palliative care:

1. Structures and Processes of Care
2. Physical Aspects of Care
3. Psychological and Psychiatric Aspects of Care
4. Social Aspects of Care
5. Spiritual, Religious and Existential Aspects of Care
6. Cultural Aspects of Care
7. Care of the Patient at the End of Life
8. Ethical and Legal Aspects of Care

¹National Consensus Project for Quality Palliative Care Clinical Practice Guidelines for Quality Palliative Care, 3rd edition (March 2013). Available at: http://nationalconsensusproject.org/Guidelines_Download2.aspx

Identify metrics that monitor the extent to which the structures of your PC program and the processes it uses are aligned with best practices, for all eight domains.

2. ELICIT AND APPRECIATE STAKEHOLDER INTERESTS AND PRIORITIES

Consider the interests and priorities of stakeholders when making choices about which aspects of care you want to address in your metrics portfolio. Many groups and individuals will have an interest in what your palliative care program does: patients, families and caregivers; clinical and administrative leaders such as the Chief Medical Officer and Chief Financial Officer of a health system; referring providers; contractual partners like health plans or medical groups; and the members of the clinical palliative care team, to name a few. Some PC programs will also need to consider the interests of philanthropic organizations or individual donors who have supported (or might support) the PC program.

How do you find out what your stakeholders are interested in? The best way is to simply ask; most will be more than happy to share their priorities and needs. It is not unusual for program sponsors (like a health system) or contractual partners (like a health plan or medical group) to describe their priorities during contract negotiations or strategic support discussions. Surveys and interviews are the most commonly used method for gathering information about what patients, families and referring providers value.

3. IDENTIFY POTENTIAL STRUCTURE, PROCESS AND OUTCOME METRICS

The next step is to identify metrics that might be right for your program. There are three types of metrics to choose from; structure metrics, process metrics and outcome metrics.

Structure metrics: Describe what is in place to serve patients and families, and usually focus on issues like team composition, team training, service availability, and scope of practice.

SAMPLE STRUCTURE METRICS

- Proportion of PC team members who have advanced training in palliative care
- The days of week and times of day the service is available to patients, families and referring providers

Process metrics: Describe what was done by whom and when, with emphasis on the extent to which those actions were aligned with best practices.

SAMPLE PROCESS METRICS

- Proportion of patients seen by the PC service who received a comprehensive assessment;
- Proportion of patients who had a documented discussion about hospice or PC within 2 months of death.

Outcome metrics: Describe the impact of clinical contacts. There are three types of outcome metrics to choose from: **clinical / patient reported** outcome metrics; **social** outcome metrics, which address the experiences of families, caregivers and providers; and **cost and utilization** outcome metrics, which describe PC impact on institutions like health systems and payers.

SAMPLE OUTCOME METRICS

- *Clinical / patient reported:* pain score reported at initial encounter compared to pain score reported 30 days later
- *Social:* family satisfaction with care provided to a loved one
- *Cost / utilization:* cost of care in the final six months of life for patients seen by the PC service, compared to costs incurred by similar patients not seen by the service.

Where can you find potential metrics? Several professional organizations have created or endorsed palliative care measures. One of the most important is the National Quality Forum (NQF).² The NQF is a nonprofit, nonpartisan, public service organization that reviews, endorses, and recommends use of standardized healthcare performance measures.

The federal government and many private sector entities use NQF-endorsed measures in payment and public reporting programs. Because of the rigorous process that precedes endorsement, and because NQF endorsement carries weight with many groups nationally, if an NQF-endorsed measure is right for your program, consider using it. Currently there are more than 20 NQF-endorsed measures that address cancer end-of-life care and palliative care generally, all of which can be accessed through NQF's on-line, searchable database, The Quality Positioning System.

Review and consider using the metrics that have been recommended by the Measuring What Matters (MWM) initiative³. MWM was a consensus project sponsored by the American Academy of Hospice and Palliative Medicine and the Hospice and Palliative Nurses Association. The initiative goal was to identify a portfolio of performance measures for all hospice and palliative care programs, which would be applicable across settings and patient populations. Potential measures were first vetted by a Technical Advisory Panel that focused on reliability and validity, and then by a Clinical User Panel, which focused on feasibility, importance, and usefulness. Through this consensus process 9 specific measures addressing 5 NCP domains were recommended, along with a general recommendation that patient and family perceptions of care be assessed. All things being equal, if one of the MWM recommended measures is right for your program you should use it. The initiative home page includes a link to a great paper, *Measuring What Matters: Top-Ranked Quality Indicators for Hospice and Palliative Care*, which describes the recommended metrics, their sources, and a summary of the measure selection process⁴.

²For more information about the NQF go to: <http://www.qualityforum.org/Home.aspx>

³For more information on the MWM initiative go to: <http://aahpm.org/quality/measuring-what-matters>

⁴Dy SM, Kiley KB, Ast K, Lupu D, Norton SA, McMillan SC, Herr K, Rotella JD, Casarett DJ. Measuring What Matters: Top-Ranked Quality Indicators for Hospice and Palliative Care from the American Academy of Hospice and Palliative Medicine and Hospice and Palliative Nurses Association. *Journal of Pain and Symptom Management* (2015), PMID: 25697097 Full text available from: [http://www.jpmsjournal.com/article/S0885-3924\(15\)00073-1/fulltext](http://www.jpmsjournal.com/article/S0885-3924(15)00073-1/fulltext)

The peer-reviewed literature in general and comprehensive review articles in particular are also terrific sources for possible metrics. In *Quality Measures for Palliative Care in Patients with Cancer: A Systematic Review*, Kamal et al. offer a comprehensive summary of several hundred measures relevant to cancer care.⁵ And in *Moving Upstream: A Review of the Evidence of the Impact of Outpatient Palliative Care*, Rabow et al. review the outcomes that were achieved by palliative care programs in various outpatient and community settings.⁶ These and other review articles, and the papers included in their reference lists, include hundreds of metrics that might be right for your program.

4. ASSESS FEASIBILITY (ACCESS AND BURDEN)

Once potential metrics have been identified, determine which ones are actually feasible for your program to use. Two components of feasibility need to be considered; access and burden.

For each potential metric consider which data elements are needed to use the metric, and whether your program has access to those data. For example, if your program does not have access to data describing date of death (regardless of location of death) for the patients you serve you would not be able to use any metrics that require that variable (for example, proportion of patients who receive chemotherapy within 14 days of death).

Next, think about burden. Metrics that place a heavy burden on clinical staff, such as those that require investing significant effort into data collection, might not be good choices if your clinical team is already stretched to the limit. Similarly, metrics that require significant administrative effort (for example, those that require manual chart review) are extraordinarily expensive to utilize, and are probably not worth the effort.

Structure metrics, which are descriptive and static (number of disciplines on the team, number of providers with advanced training, etc.) are the least burdensome to track. Process metrics, which describe actions, can be relatively easy to track if the PC service is supported by a nimble electronic health record, but often require clinical staff to gather and input data. Outcome metrics also require a fair amount of effort, but usually do not increase the burden on the clinical team. For example, assessing PC service impact on health care costs requires significant analyst effort, but places no additional burden on the clinical team.

Be realistic about the resources that are available to your team when assessing feasibility. Metrics that are feasible for a well-funded program that is affiliated with a large health system with a robust and nimble electronic health record might be too burdensome for a small hospice that is providing palliative care in a rural setting.

⁵Kamal AH, Gradison M, Maguire JM, Taylor D, Abernethy AP. Quality measures for palliative care in patients with cancer: a systematic review. *J Oncol Pract*. 2014 Jul;10(4):281-7. PMID: 24917264

<http://jop.ascopubs.org/content/early/2014/06/10/JOP.2013.001212.full>

⁶Rabow M, Kvale E, Barbour L, Cassel JB, Cohen S, Jackson V, Luhrs C, Nguyen V, Rinaldi S, Stevens D, Spragens L, Weisman D. Moving upstream: a review of the evidence of the impact of outpatient palliative care. *J Palliat Med*. 2013 Dec; 16(12):1540-9. PMID: 24225013

5. MAKE YOUR CHOICES

The types and number of metrics in your portfolio will be dictated by the developmental stage of your program and the resources at your disposal to gather and analyze data. New programs or those with relatively few data resources should have modest measurement goals, what we call “Minimal Measuring.” Established programs or those with abundant resources can track more indicators, in particular process and outcome metrics that require more effort. The resulting, more extensive portfolio of metrics is what we call “Maximal Measuring.”

	Minimal Measuring	Maximal Measuring
Structure and process metrics	One structure or process metric for each of the 8 NCP PC Domains, including at least 2 process measures	At least one structure and one process metric for each of the 8 NCP PC Domains
Outcome metrics	4-6 items including any combination of Clinical or patient reported outcome metrics, Social (family /caregiver /provider) outcome metrics, and Cost / utilization outcome metrics	At least 8 metrics addressing some combination of Clinical or patient reported outcomes, Social (family /caregiver / provider) outcomes, and Cost / utilization outcomes, including at least 2 that address clinical or patient reported outcomes
Operational metrics	Items that describe the volume and timing of service delivery and are commonly reported to program sponsors, such as a health system, payer or medical group. The number and type of metrics needed will be negotiated with stakeholders	

Consider using a free resource, the **Palliative Care Measure Menu**, when identifying metrics that your program might use. Developed with support from the California HealthCare Foundation, the Measure Menu is a web-based tool that allows users to consider a wide range of metrics that speak to the quality of and contributions made by a specialty PC service, as well as the quality of palliative and end-of-life care delivered to a population of patients. By using the Menu's filter features, users can leverage the descriptive information provided about each metric to select for specific types of metrics, care settings, and data requirements, and to exclude from consideration metrics that would not be appropriate or feasible. This allows users to narrow the field of candidate metrics, making the process of selecting metrics much more manageable. Users can sequentially consider metrics pertaining to specific domains of palliative care — for example, beginning with metrics that address general structures and processes of care, then moving to metrics that speak to physical aspects of care, and so on. This iterative process will allow for development of a balanced measurement portfolio that only includes metrics that are feasible and meaningful to a particular program or organization. The Menu is available at www.chcf.org/pcmnu

WANT TO LEARN MORE?

The California State University Institute for Palliative Care offers a self-paced, online course, *Metrics and Measurement for Palliative Care* (<https://cspalliativecare.org/organizations/roadmap/#5>) that covers a number of useful topics, including:

- How to apply well-known measurement frameworks in health care to palliative care specifically;
- The five crucial steps for choosing measures wisely;
- How to use the PC Measure Menu to simplify and expedite the process of identifying measures and selecting a balanced, feasible portfolio of metrics;
- Tips for being successful and avoiding mistakes that are commonly made in this area.