Our NEJM Catalyst Insights Council survey on palliative care reveals an interesting dichotomy: While the great majority of organizations have a palliative or end-of-life care program, 60% of patients who would benefit from such services don’t receive them.

What percentage of your organization’s patients who would benefit from palliative/end-of-life care do you estimate receive it?

<table>
<thead>
<tr>
<th>Those who would benefit who DO NOT receive it</th>
<th>Those who would benefit who DO receive it</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>60%</td>
</tr>
</tbody>
</table>

Base: 458 (Among those who have palliative or end-of-life care programs)
NEJM Catalyst (catalyst.nejm.org) © Massachusetts Medical Society

"Palliative care helps patients live their best lives with the time they have left, and hospice care helps patients have the death they want consistent with their values. Palliative care should be as ubiquitous as hospice care within the health care industry. If 60% of patients who would benefit aren't receiving it, there's a real disconnect," says Amy Compton-Phillips, MD, Executive Vice President and Chief Clinical Officer at Providence St. Joseph Health in Seattle and NEJM Catalyst’s Care Redesign Theme Leader.

The efforts of health care providers, says NEJM Catalyst Clinical Editor Namita Seth Mohta, MD, “should be focused on improving access to these critical services for the patients who need them.” Across the board, Insights Council members – a qualified group of U.S. executives, clinical leaders, and clinicians who are directly involved in health care delivery – quantify the impact of palliative care as a net improvement. Nearly all respondents (97%) say palliative and end-of-life care boosts patient experience, along with quality of care (94%), clinician work satisfaction (88%), and cost of care (79%).
“Patients understand that the circle of life includes death, and survey after survey shows that patients want to be in control of their lives, maintain autonomy, and retain dignity until the end. Technology’s ability to prolong death has challenged this and the [health care] industry is feeling the struggle more acutely,” Compton-Phillips says.

The survey finds that nonprofit health care delivery organizations are well ahead of for-profit organizations in the maturity of their palliative care programs. For instance, a higher incidence of respondents from nonprofit organizations (60%), compared to those from for-profits (36%), report that their program has been in existence for more than six years.

An important factor in scaling up palliative care services is the alignment of payment incentives, according to Mohta. She believes that value-based health care will support broader implementation of palliative care.

Compton-Phillips agrees. “We have data that shows palliative care costs less and increases patient satisfaction. When we start paying for outcomes rather than inputs, access to palliative care should change rather quickly,” she says.

The palliative care field faces significant challenges, including a shortage of skilled, trained providers. While nearly half of the survey respondents say finding and hiring trained palliative/end-of-life care specialists is difficult, just over a third report that retaining them is equally challenging.

One way to address this challenge is to integrate appropriate palliative care services into primary care, Mohta says. For example, many primary care physicians now routinely prioritize goals of care conversations with their patients (for which some payers now compensate providers). This goal goes a long way toward aligning treatment decisions with patient values, but Mohta would like to see efforts like these even more integrated in primary care settings and given adequate resources. Survey respondents are a bit more bold, with a third saying primary care providers should deliver the majority of palliative/end-of-life care and 77% ranking additional training for primary care physicians as their number-one suggested area of investment.

Insights Council members have seen success with fellowships, mentoring, and train-the-trainer programs to learn about pain treatment and other palliative care skills. In a written comment, one clinical leader respondent says, “We have recently received a grant to educate primary physicians on palliative discussions and had a program on the basics of the conversation at our annual staff meeting. There has been significant increase in awareness of the value of these conversations.” Another clinical leader says his community hospital “offers a Palliative Academy to train non-palliative clinicians in communicating with families.”

To expand access to palliative care services, some health care organizations are turning to technology, using telemedicine, artificial intelligence, and other advances to fill gaps
in human resources. It’s a move that makes Compton-Phillips wary. “Yes, we need to match the demand, but we also need to keep the compassion in care,” she says.

She and Mohta recommend that health care organizations involve patients in the development of palliative care programs. Only 16% of respondents cite patient involvement in the development of their programs.

Ultimately, palliative and end-of-life care has the potential to reshape health care. One clinician reports that “Having advanced palliative care in our organization has been transformative. The patients receive better care, the physicians have gained a new skill set, and the organization is a more just place to work.”

The Power of Palliative Care

Charts and Commentary

We surveyed members of the NEJM Catalyst Insights Council — who comprise health care executives, clinical leaders, and clinicians — about palliative and end-of-life care. Respondents were asked about the start of their organizations’ palliative/end-of-life care program, the position in charge of their organizations’ palliative/end-of-life care program, and the extent of patient involvement in their organizations’ palliative/end-of-life care program. The survey also explores the impact of palliative/end-of-life care, providers of palliative/end-of-life care, the average percentage of patients who would benefit from palliative/end-of-life care, the difficulty in hiring, firing, and retaining palliative/end-of-life care specialists and staff, and additional palliative care services provider organizations should invest in. Completed surveys from 572 respondents are included in the analysis.

Across the board, Insights Council members – a qualified group of U.S. executives, clinical leaders, and clinicians who are directly involved in health care delivery – quantify the impact of palliative care as a net improvement. Nearly all respondents (97%) say palliative and end-of-life care boosts patient experience, along with quality of care (94%), clinician work satisfaction (88%), and cost of care (79%).
Respondents from nonprofit organizations (85%) outpaced respondents from for-profit organizations (64%) in indicating their organization has one or more programs for palliative or end-of-life care.

**Most Health Care Organizations Have Palliative or End-of-Life Care Programs**

*Does your organization have one or more programs for palliative or end-of-life care?*

- **Yes**: 80%
- **No**: 16%
- **Don’t know**: 3%

Base: 572
NEJM Catalyst (catalyst.nejm.org) © Massachusetts Medical Society

More than half of respondent organizations have had palliative/end-of-life care programs for more than six years.

**Most Palliative/End-of-Life Care Programs Are Well Established**

*When did your organization begin a program for palliative/end-of-life care?*

- **Less than 1 year ago**: 2%
- **1-3 years ago**: 20%
- **4-6 years ago**: 22%
- **More than 6 years ago**: 55%

Base: 458 (Among those who have palliative or end-of-life care programs)
NEJM Catalyst (catalyst.nejm.org) © Massachusetts Medical Society
There is a higher incidence of respondents at for-profit organizations who indicate that the Chief Medical Officer (16%) or clinical leaders (13%) are the positions in charge of palliative/end-of-life care programs, compared to nonprofit programs, at 4% and 6%, respectively.

**Clinicians and Specialists Oversee Palliative/End-of-Life Care Programs**

Who is in charge of palliative/end-of-life care programs at your organization?

<table>
<thead>
<tr>
<th>Position</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Palliative care clinician or specialist</td>
<td>53%</td>
</tr>
<tr>
<td>VP or director of palliative care</td>
<td>14%</td>
</tr>
<tr>
<td>Clinical leaders</td>
<td>7%</td>
</tr>
<tr>
<td>Chief Medical Officer</td>
<td>7%</td>
</tr>
<tr>
<td>Department chair</td>
<td>7%</td>
</tr>
<tr>
<td>Clinicians in general</td>
<td>5%</td>
</tr>
<tr>
<td>Nurses</td>
<td>2%</td>
</tr>
<tr>
<td>Other</td>
<td>6%</td>
</tr>
<tr>
<td>No one is responsible</td>
<td>1%</td>
</tr>
</tbody>
</table>

Base: 458 (Among those who have palliative or end-of-life care programs)

NEJM Catalyst (catalyst.nejm.org) © Massachusetts Medical Society
Patients are more involved in developing palliative/end-of-life care programs at for-profit organizations (45%) than nonprofit organizations (24%), respondents say.

**Patients Are Rarely Involved in Developing Palliative/End-of-Life Care Programs**

Were patients involved in developing your organization’s palliative/end-of-life care program?

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
<th>Don’t know</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>16%</td>
<td>28%</td>
<td>55%</td>
</tr>
</tbody>
</table>

How involved were patients in developing your organization’s palliative/end-of-life care program?

<table>
<thead>
<tr>
<th>Extremely involved</th>
<th>Very involved</th>
<th>Involved</th>
<th>Not very involved</th>
<th>Not at all involved</th>
</tr>
</thead>
<tbody>
<tr>
<td>12%</td>
<td>27%</td>
<td>57%</td>
<td>4%</td>
<td>0%</td>
</tr>
</tbody>
</table>

Base = 75 (Among those whose patients were involved in developing palliative/end-of-life care programs)

Base: 458 (Among those who have palliative or end-of-life care programs)

NEJM Catalyst (catalyst.nejm.org) © Massachusetts Medical Society
Approximately 80% or more of respondents indicate that dedicated palliative/end-of-life care improves patient experience (97%), quality of care (94%), clinician work satisfaction (88%), and cost of care (79%).

**Palliative/End-of-Life Programs Improve Many Aspects of Care**

In general, what is the impact of dedicated palliative/end-of-life care on the patient experience, quality of care, cost of care, and clinical work satisfaction?

- Greatly improves
- Moderately improves
- No change
- Moderately worsens
- Greatly worsens

<table>
<thead>
<tr>
<th>Area</th>
<th>Greatly improves</th>
<th>Moderately improves</th>
<th>No change</th>
<th>Moderately worsens</th>
<th>Greatly worsens</th>
<th>Net improves</th>
</tr>
</thead>
<tbody>
<tr>
<td>The patient experience</td>
<td>69%</td>
<td>28%</td>
<td>2%</td>
<td></td>
<td></td>
<td>97%</td>
</tr>
<tr>
<td>Quality of care</td>
<td>61%</td>
<td>32%</td>
<td>6%</td>
<td>1%</td>
<td></td>
<td>94%</td>
</tr>
<tr>
<td>Clinician work satisfaction</td>
<td>49%</td>
<td>39%</td>
<td>10%</td>
<td>1%</td>
<td></td>
<td>88%</td>
</tr>
<tr>
<td>Cost of care</td>
<td>37%</td>
<td>42%</td>
<td>17%</td>
<td>3%</td>
<td>1%</td>
<td>79%</td>
</tr>
</tbody>
</table>

Base = 572

NEJM Catalyst (catalyst.nejm.org) © Massachusetts Medical Society

60% of respondents agree that palliative care specialists are who should provide the majority of palliative/end-of-life care.

**Specialists Should Provide Most Palliative/End-of-Life Care**

Who should provide the majority of palliative/end-of-life care?

- Primary care physicians and other non-palliative clinicians or specialists: 31%
- Palliative care specialists: 60%
- Other: 9%

Base: 572

NEJM Catalyst (catalyst.nejm.org) © Massachusetts Medical Society
Council members indicate that 60% of those who would benefit from palliative/end-of-life care at respondents’ organizations do not receive it.

Many Patients Who Would Benefit from Palliative/End-of-Life Care Do Not Receive It

What percentage of your organization’s patients who would benefit from palliative/end-of-life care do you estimate receive it?

<table>
<thead>
<tr>
<th>Those who would benefit who DO NOT receive it</th>
<th>Those who would benefit who DO receive it</th>
</tr>
</thead>
<tbody>
<tr>
<td>60%</td>
<td>40%</td>
</tr>
</tbody>
</table>

Base: 458 (Among those who have palliative or end-of-life care programs)
NEJM Catalyst (catalyst.nejm.org) © Massachusetts Medical Society

"Palliative care helps patients live their best lives with the time they have left, and hospice care helps patients have the death they want consistent with their values. Palliative care should be as ubiquitous as hospice care within the health care industry. If 60% of patients who would benefit aren’t receiving it, there’s a real disconnect."
Some organizations are using internal resources to train staff in palliative care. For instance, one clinician says, “The Palliative Service offers a Palliative Academy to train non-palliative clinicians in communicating with families and patients.”

Organizations Have Moderate Difficulty in Filling Palliative/End-of-Life Care Positions

Has your organization experienced difficulties in finding, hiring, and retaining palliative/end-of-life care specialists and staff?

<table>
<thead>
<tr>
<th>Finding and hiring trained palliative/ end-of-life care specialists</th>
<th>Yes</th>
<th>Don’t know</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>45%</td>
<td>29%</td>
<td>26%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Finding and hiring trained palliative/ end-of-life care staff</th>
<th>Yes</th>
<th>Don’t know</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>38%</td>
<td>32%</td>
<td>30%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Retaining palliative/end-of-life care specialists</th>
<th>Yes</th>
<th>Don’t know</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>31%</td>
<td>31%</td>
<td>39%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Retaining palliative/end-of-life care staff</th>
<th>Yes</th>
<th>Don’t know</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>27%</td>
<td>38%</td>
<td>36%</td>
</tr>
</tbody>
</table>

Base = 458 (Among those who have palliative or end-of-life care programs)

NEJM Catalyst (catalyst.nejm.org) © Massachusetts Medical Society

"The palliative care field faces significant challenges, including a shortage of skilled, trained providers. While nearly half of the survey respondents say finding and hiring trained palliative/end-of-life care specialists is difficult, just over a third report that retaining them is equally challenging."
There is a higher incidence of respondents from nonprofit organizations (58%) than from for-profit organizations (38%) who indicate investments should be made in additional training for dedicated palliative care outpatient clinics.

**Substantial Room for Growth in Palliative Care Services**

What additional palliative care services should provider organizations invest in?

- Additional training for primary care physicians: 77%
- Additional patient populations (e.g., chronic disease, non-oncology): 67%
- Additional training for specialty non-palliative care providers (e.g., surgeons, cardiologists): 63%
- Dedicated palliative care outpatient clinics: 53%
- Additional training for palliative care specialists: 37%

Base: 572 (Multiple responses)

NEJM Catalyst (catalyst.nejm.org) © Massachusetts Medical Society

*To expand access to palliative care services, some health care organizations are turning to technology, using telemedicine, artificial intelligence, and other advances to fill gaps in human resources.*
Verbatim Comments from Survey Respondents

What type of palliative/end-of-life care program at your organization has had the most impact, and why?

“Dedicated palliative/end-of-life care program.”
— Clinician at a small for-profit physician organization in the Northeast

“Dedicated team of trained physicians, advanced practice clinicians, social workers, clergy, nurses and support staff – available 24/7/365 – major impact on patient and family satisfaction with symptom control and goal setting.”
— Department chair at a large nonprofit teaching hospital in the Northeast

“Diagnosis agnostic approach, including outpatient centers.”
— Executive at a large nonprofit teaching hospital in the South

“Having a palliative care specialist direct care policy for continuity’s sake.”
— Clinician at a small nonprofit teaching hospital in the South

“Consult service for inpatients with complicated situations – helps to provide another system of support, source of information, and sounding board for the patients/families.”
— Department chair at a nonprofit midsized teaching hospital in the Northeast

“Largely, hospital-based palliative care/end-of-life, but we are now moving to the nursing home setting.”
— Vice President of a large nonprofit health system in the Midwest

“Having advanced palliative care in our organization has been transformative. The patients receive better care, the physicians have gained a new skill set, and the organization is a more just place to work.”
— Clinician at a small nonprofit teaching hospital in the West

“Inpatient palliative care because that is all we really have. We need outpatient palliative care. Problem is staffing, training/education, physician engagement and business model.”
— Chief Medical Officer at a midsized for-profit physician organization in the South

“Counseling and social support services for families and the client.”
— Director of a large nonprofit health system in the West
“Oncology with chronic pain. Perhaps because this is the population with the most needs.”

— Clinician at a large nonprofit teaching hospital in the Northeast

“A new shared decision-making tool we are using for cancer patients at critical decision points. The physician maps out the remaining options for care — including no further treatment. An experienced oncology RN writes down the options and benefits/burdens of each choice in lay language and goes through this with the patient and family after the MD leaves the room. Patients are reporting this is the first time they’ve really understood their situation and prognosis.”

— Director of service line at a large nonprofit community hospital in the West

“Focus on identifying hospice eligible patients and tracking EOL conversations with those patients to hold providers accountable.”

— Vice President of a midsized for-profit physician organization in the Northeast
Methodology

- The Palliative/End-of-Life Care survey was conducted by NEJM Catalyst, powered by the NEJM Catalyst Insights Council.

- The NEJM Catalyst Insights Council is a qualified group of U.S. executives, clinical leaders, and clinicians at organizations directly involved in health care delivery, who bring an expert perspective and set of experiences to the conversation about health care transformation. They are change agents who are both influential and knowledgeable.

- In February 2019, an online survey was sent to the NEJM Catalyst Insights Council.

- A total of 572 completed surveys are included in the analysis. The margin of error for a base of 572 is +/- 4.1% at the 95% confidence interval.

NEJM Catalyst Insights Council

We’d like to acknowledge the NEJM Catalyst Insights Council. Insights Council members participate in monthly surveys with specific topics on health care delivery. These results are published as NEJM Catalyst Insights Reports, such as this one, including summary findings, key takeaways from NEJM Catalyst leaders, expert analysis, and commentary.

It is through the Insights Council’s participation and commitment to the transformation of health care delivery that we are able to provide actionable data that can help move the industry forward. To join your peers in the conversation, visit join.catalyst.nejm.org/insights-council.
Respondent Profile

**Audience Segment**
- Executive: 26%
- Clinician: 46%
- Clinical Leader: 28%

**Organization Setting**
- Hospital: 46%
- Clinic: 18%
- Other: 19%
- Physician organization: 8%

**Type of Organization**
- For profit: 27%
- Nonprofit: 73%

**Number of Beds** (Among hospitals)
- 1 - 50: 5%
- 51 - 199: 13%
- 200 - 499: 32%
- 500 - 999: 32%
- 1000+: 18%

**Number of Sites** (Among health systems)
- 1 - 5: 17%
- 6 - 20: 23%
- 21 - 49: 15%
- 50+: 46%

**Number of Physicians** (Among physician organizations)
- 1 - 9: 12%
- 10 - 49: 18%
- 50 - 99: 5%
- 100+: 66%

**Net Patient Revenue**
- > $5 billion: 12%
- $1 - $4.9 billion: 26%
- $500 - $999.9 million: 12%
- $100 - $499.9 million: 15%
- $10 - $99.9 million: 23%
- < $9.9 million: 13%

**Region**
- 18%
- 24%

Base = 572
NEJM Catalyst (catalyst.nejm.org) © Massachusetts Medical Society
About Us

NEJM Catalyst brings health care executives, clinical leaders, and clinicians together to share innovative ideas and practical applications for enhancing the value of health care delivery. From a network of top thought leaders, experts, and advisors, our digital publication, quarterly events, and qualified Insights Council provide real-life examples and actionable solutions to help organizations address urgent challenges affecting health care.