

Trends in Palliative Care Delivery and End of Life Care: Where are we headed in 2024?

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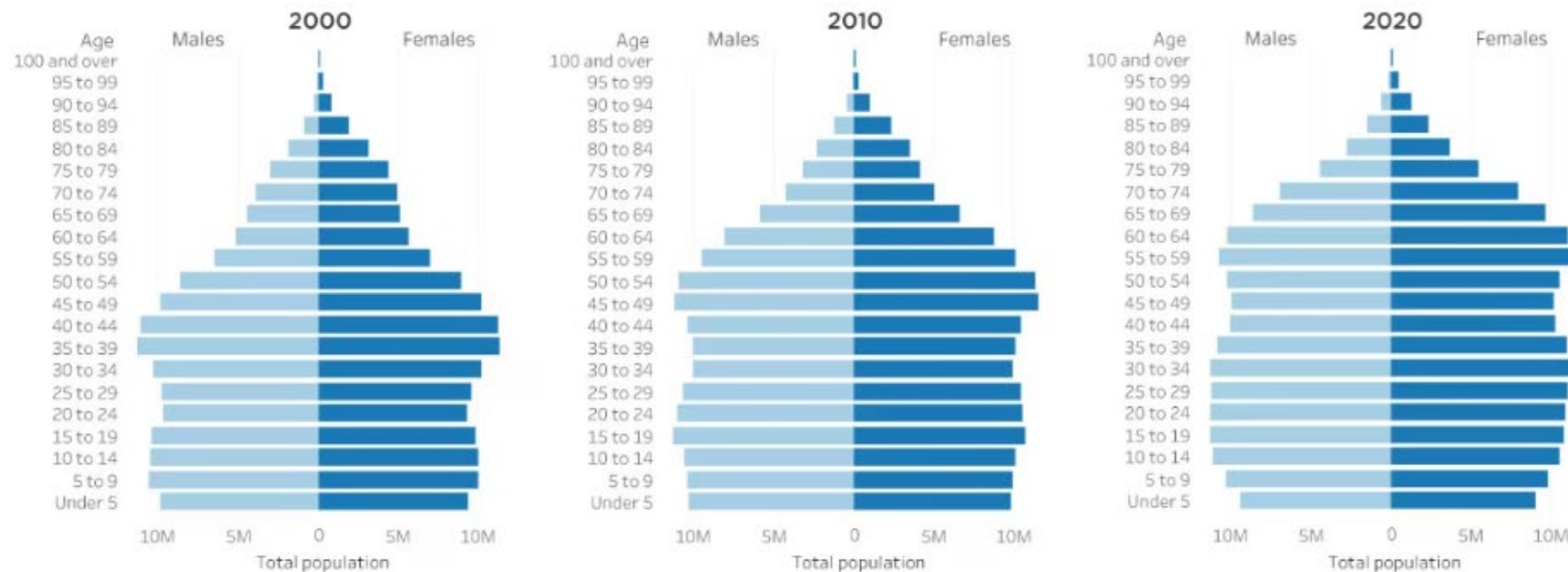
Objectives

After this session, the audience will be able to :

- Discuss the overview of current state of the healthcare landscape and the role of palliative care delivery
- Describe current state of palliative care models and the onramp to hospice in the context of background and recent developments.
- Discuss key quality, compliance and measurement areas in serious illness and end of life care delivery
- Highlight major areas of opportunity and concern, and the role of communities, patients, providers and the inter professional team.

How did we get here?

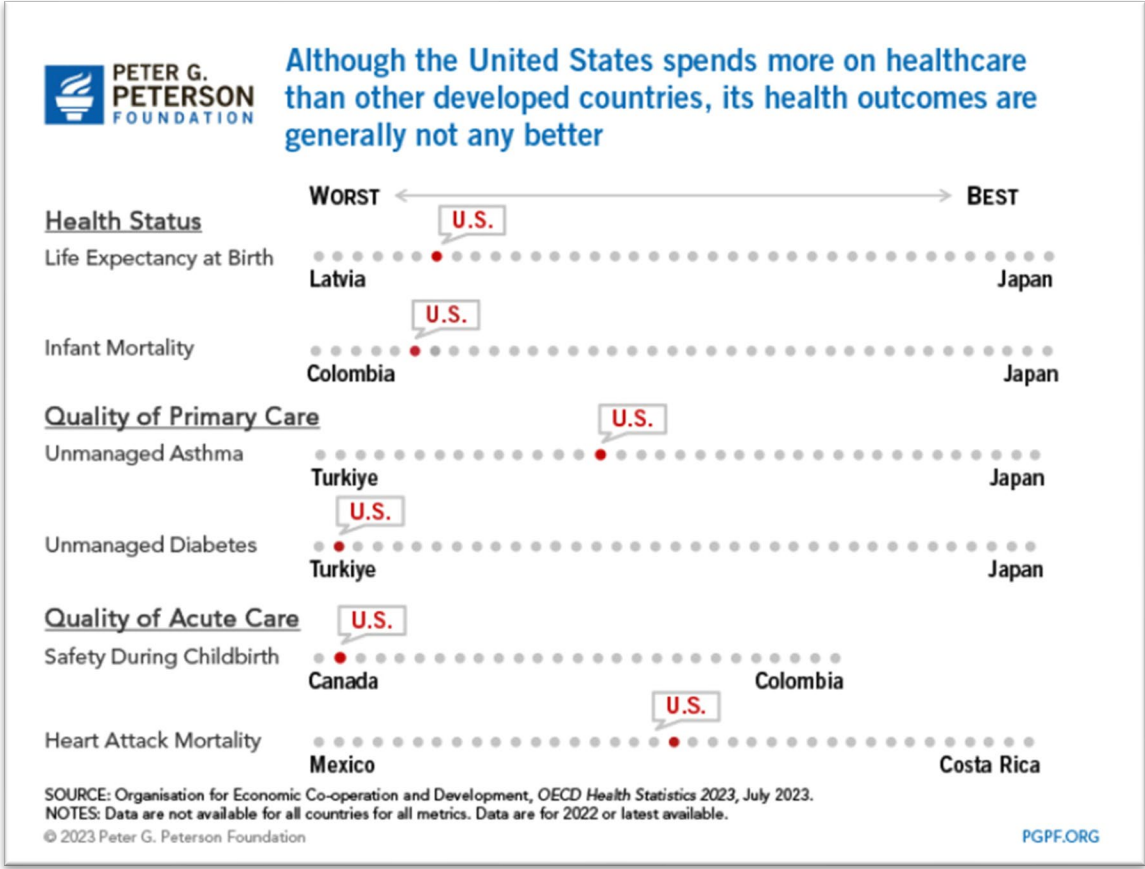
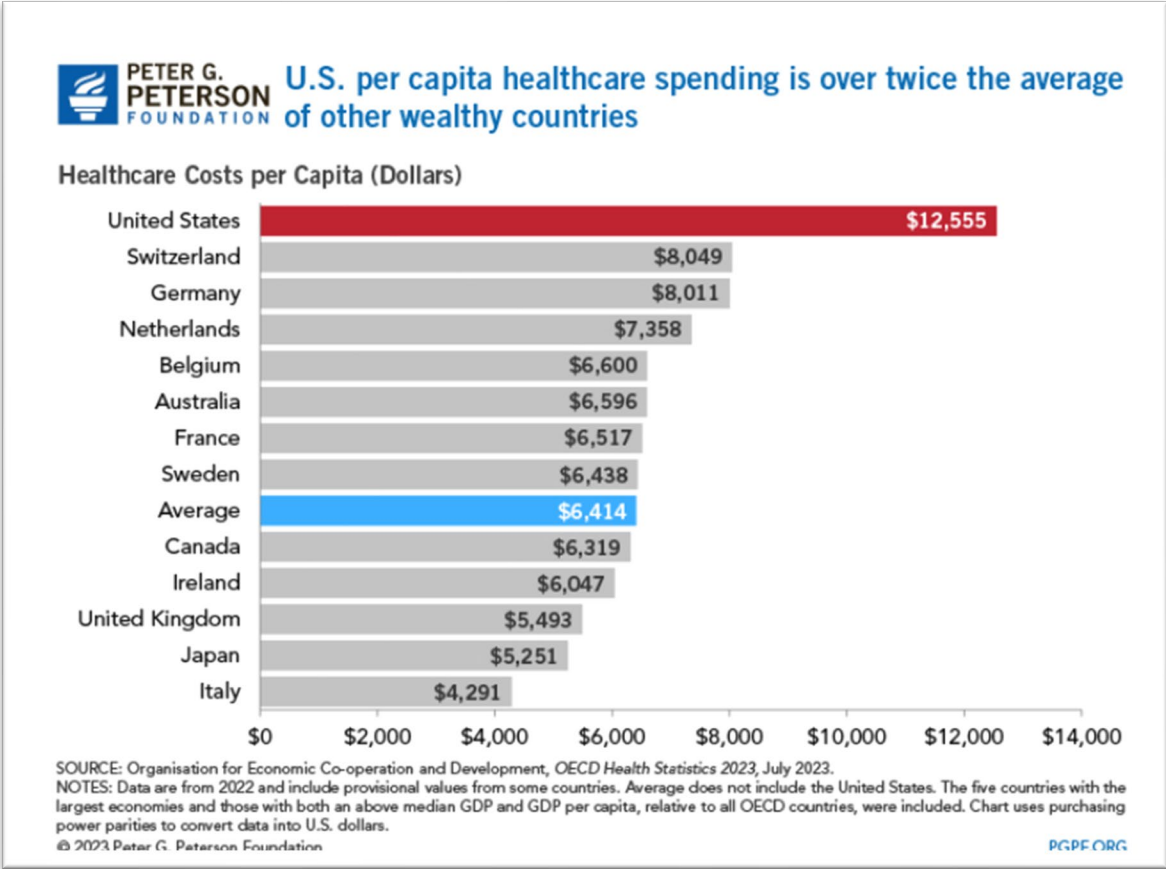
Figure 2.
Population Pyramids for the United States: 2000, 2010 and 2020
(In millions)



Source: U.S. Census Bureau, Census 2000 Summary File 1 (SF1), 2010 Census Summary File 1 (SF1) and 2020 Census Demographic and Housing Characteristics File (DHC).

- The US population was larger in 2020 than it was in either 2010 or 2000
- The US population also aged since 2000
- The baby boom cohort moved up the pyramid
- The base of the pyramid reflects a recent decrease in the number of births in the United States.

Facts – does healthcare spend equal outcomes?



Quality of Death and Dying in the United States (2021)



Country Score : 71.47

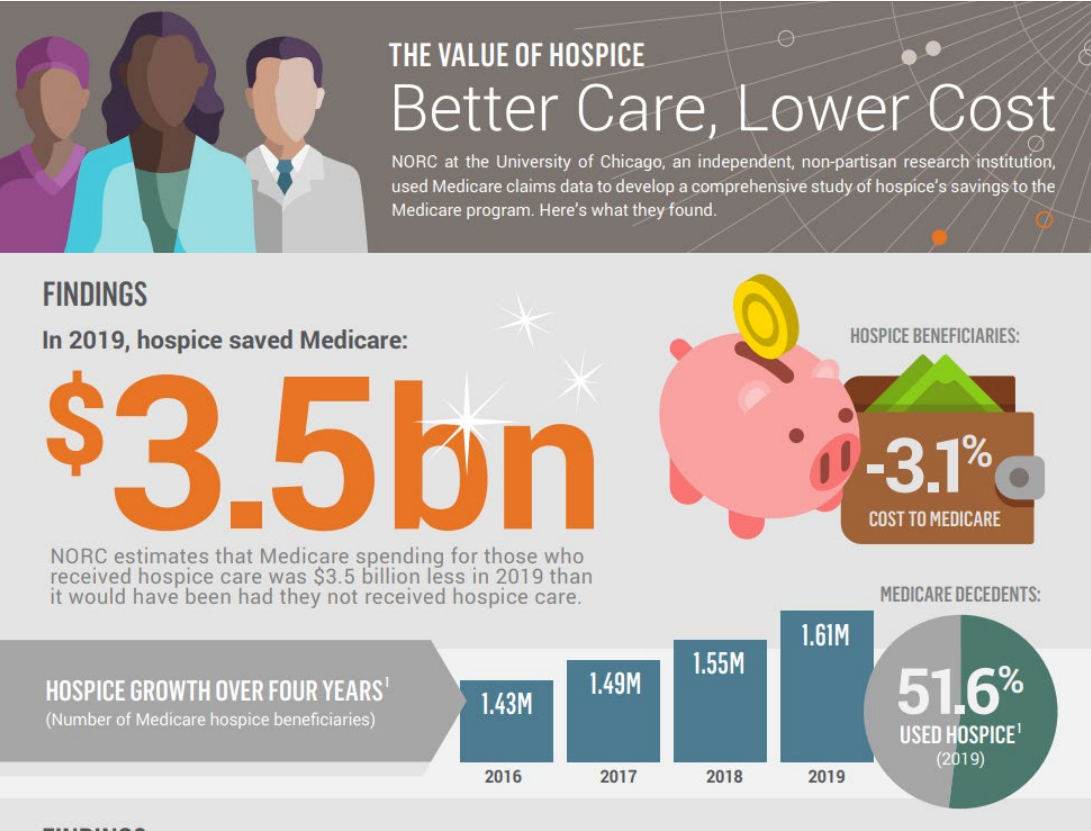
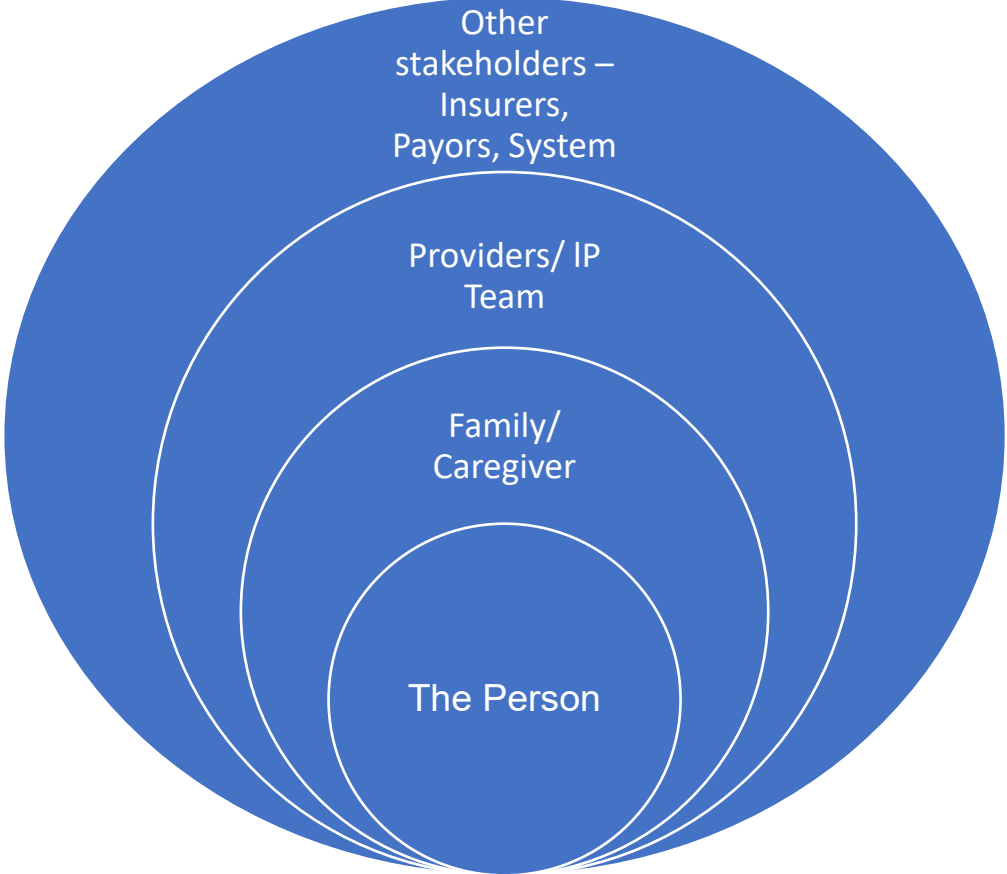
Leading causes of death (2019)

Source: Institute for Health Metrics and Evaluation

- 1 Ischemic heart disease
- 2 Lung cancer
- 3 COPD
- 4 Stroke
- 5 Alzheimer's disease
- 6 Chronic kidney disease
- 7 Colorectal cancer
- 8 Lower respiratory infect.
- 9 Diabetes
- 10 Cirrhosis

<https://www.duke-nus.edu.sg/lcpc/quality-of-death/country-reports/USA>

Barriers to getting to ideal state



Definitions

Hospice Care

“a comprehensive set of services described in 1861(dd)(1) of the Act, identified and coordinated by an interdisciplinary group to provide for the physical, psychosocial, spiritual, and emotional needs of a terminally ill patient and/or family members, as delineated in a specific patient plan of care.”

Palliative Care

“patient and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering. Palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social, and spiritual needs and to facilitate patient autonomy, access to information, and choice.”

<https://www.ecfr.gov/current/title-42/chapter-IV/subchapter-B/part-418>

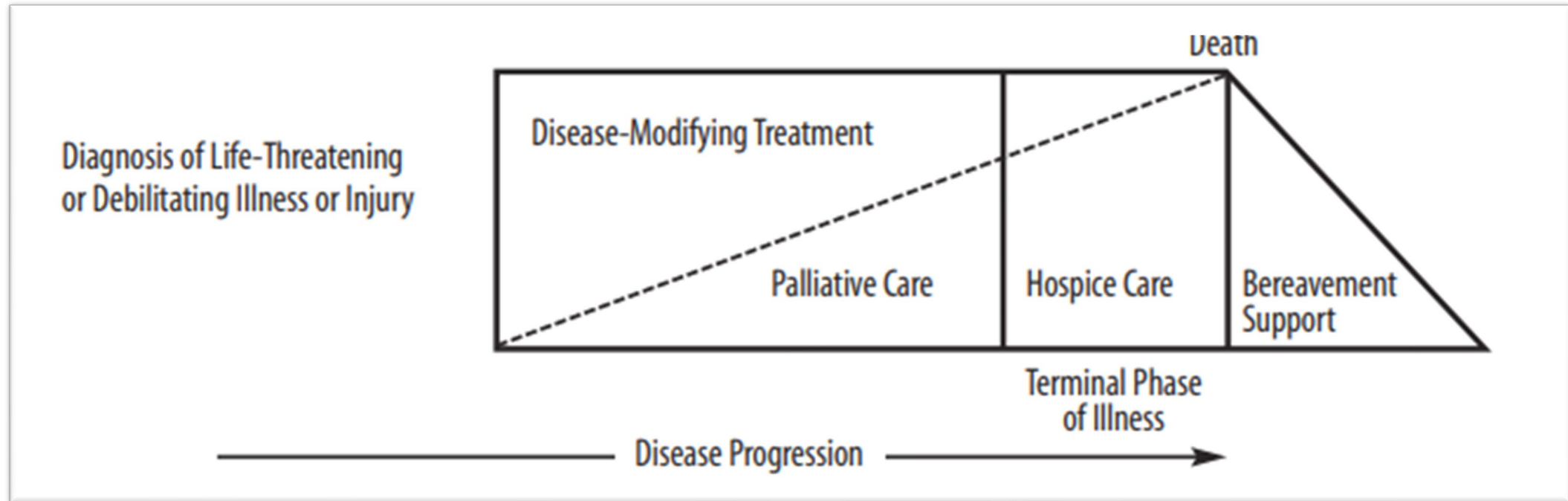
<https://www.caringinfo.org/types-of-care/what-is-the-difference-between-palliative-care-and-hospice-care/>

Where/ When does end of life planning begin?

- ✓ In primary care
- ✓ When health status changes
- ✓ When any life situation changes (retirement, financial loss, family transitions)
- ✓ At diagnosis of chronic or acute disease – self or family
- ✓ At every healthcare interaction



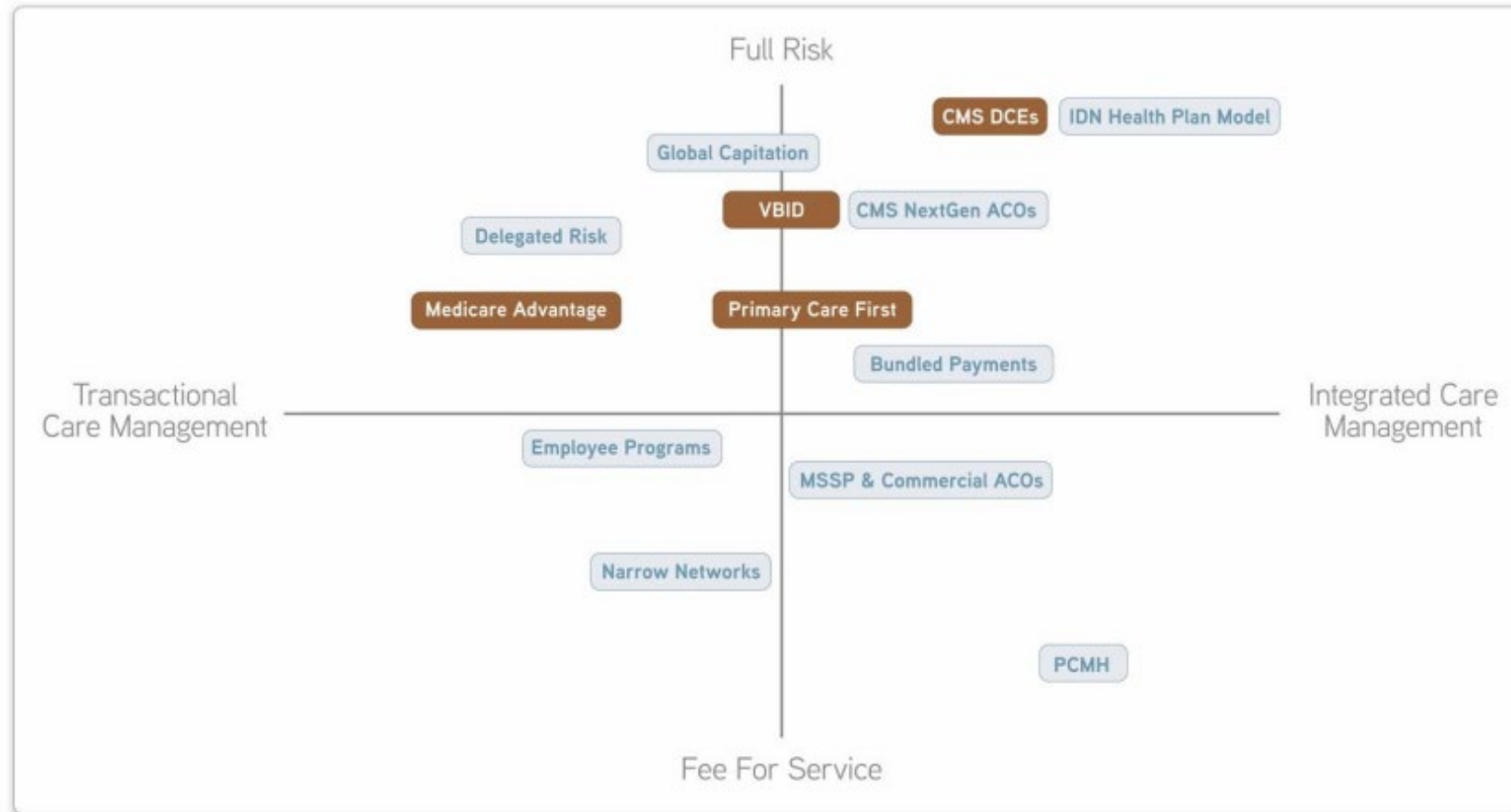
Seamless transitions – Dream or Model?



The Continuum of Care

Adapted from National Quality Forum Consensus Report : A National Framework and Preferred Practices for Palliative and Hospice Care Quality, 2006

Diversity in Payment Models: Serious Illness and End of Life Care



https://www.nhpco.org/wp-content/uploads/Serious_Illness_x_Hospice.pdf

Existing Models of Palliative Care Delivery

❖ Hospice – Medicare eligibility criteria is used by:

- ✓ Medicare
- ✓ Medicaid
- ✓ Most private insurance plans

❖ Hospital Palliative Care

- ✓ Interdisciplinary consultation teams
- ✓ Inpatient units

❖ Newer models of palliative care

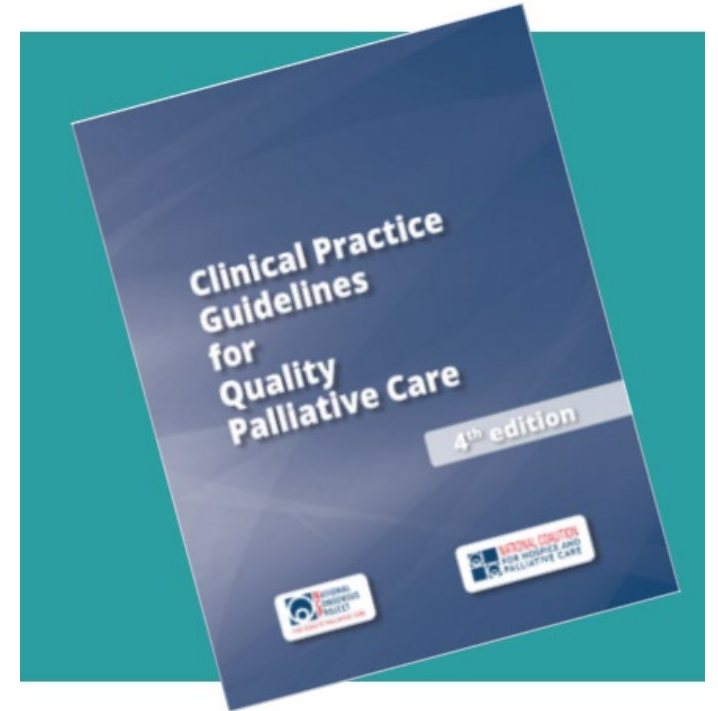
- ✓ Community Based Palliative Care
- ✓ Ambulatory Consultation Clinics
- ✓ Capitated Managed Care Plans

This is where it gets interesting.....and complicated !

Palliative Care and Quality

National Consensus Project for Quality Palliative Care (2018):

- ✓ structures and processes of care;
- ✓ physical aspects of care;
- ✓ psychological and psychiatric aspects of care;
- ✓ social aspects of care;
- ✓ spiritual, religious, and existential aspects of care;
- ✓ cultural aspects of care;
- ✓ care of the imminently dying patient; and
- ✓ ethical and legal aspects of care.



<https://www.nationalcoalitionhpc.org/ncp-guidelines/>

Palliative Care and Quality

The Palliative Care Quality Measure Project

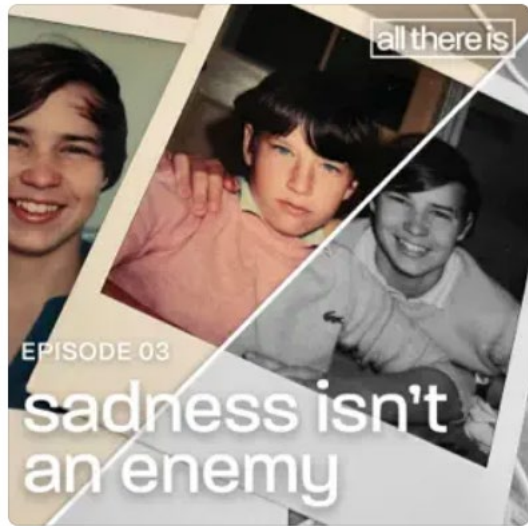
Two measures were developed and tested (2019)

- ❖ The adequacy and appropriateness of symptom management (particularly pain)
- ❖ The experience of feeling heard and understood (by palliative care providers)

- Both patients & caregivers were included in measure development
- Patient reported measures
- Tested in the ambulatory palliative care setting

<https://www.nationalcoalitionhpc.org/qualitymeasures/>

When care planning does occur – success stories



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Sadness Isn't An Enemy
All There Is with Anderson Cooper



Looking Ahead with Parkinson's

A Guide to Future Care Planning

President Carter's many months on hospice highlight a surprising truth

DIANA FRANCHITTO



Celine Dion's sister says 'There's Little We Can Do' to alleviate singer's pain

The Facts

- Hospice Care is underutilized
- Advance care planning decreases life-sustaining treatment, increases use of hospice and palliative care and prevents hospitalization. Complex advance care planning interventions increase compliance with patients' end-of-life wishes.
- Oncologists and general practitioners have an important role in the delivery of primary palliative care, and in facilitating timely referral of patients to specialist palliative-care teams
- Patient referral to specialist palliative care is associated with improved quality of life, symptom control, patient and caregiver satisfaction, illness understanding, end-of-life care, costs of care, and, potentially, survival
- Data regarding completion of advance directives in the United States are inconsistent and of variable quality.
- Approximately one in three US adults completes any type of advanced directive for End-Of-Life Care

Brinkman-Stoppelenburg A, Rietjens JA, van der Heide A. The effects of advance care planning on end-of-life care: A systematic review. *Palliative Medicine*. 2014;28(8):1000-1025. doi:10.1177/0269216314526272

Hui, D., Bruera, E. Integrating palliative care into the trajectory of cancer care. *Nat Rev Clin Oncol* 13, 159–171 (2016). <https://doi.org/10.1038/nrclinonc.2015.201>

<https://doi.org/10.1377/hlthaff.2017.0175>

What is hospice care?

- A model for quality, compassionate care for people facing a serious or life-limiting illness or injury
- Congress created the Medicare Hospice Benefit in 1982, and it was implemented in 1983.
- Involves a team-oriented approach to expert medical care, pain management, and emotional and spiritual support expressly tailored to the patient's needs and wishes.
- Support is provided to the patient or beneficiary's loved ones as well.
- Families of hospice patients are more likely than non-hospice patients to report that their loved ones had their end-of-life wishes fulfilled.

What is hospice care?

- Hospice care starts with a goals-of-care conversation that shapes an individual care plan for each patient, which is implemented by an interdisciplinary team.
- Patients who receive hospice care cost Medicare less in the last three months of life than their counterparts who don't receive hospice care. *DOI: 10.1001/jamahealthforum.2021.5104*
- There are 4 levels of hospice care:
 - ✓ Routine Home Care
 - ✓ Continuous Home Care
 - ✓ General Inpatient Care (GIP)
 - ✓ Inpatient Respite Care

Hospice Care - Figures

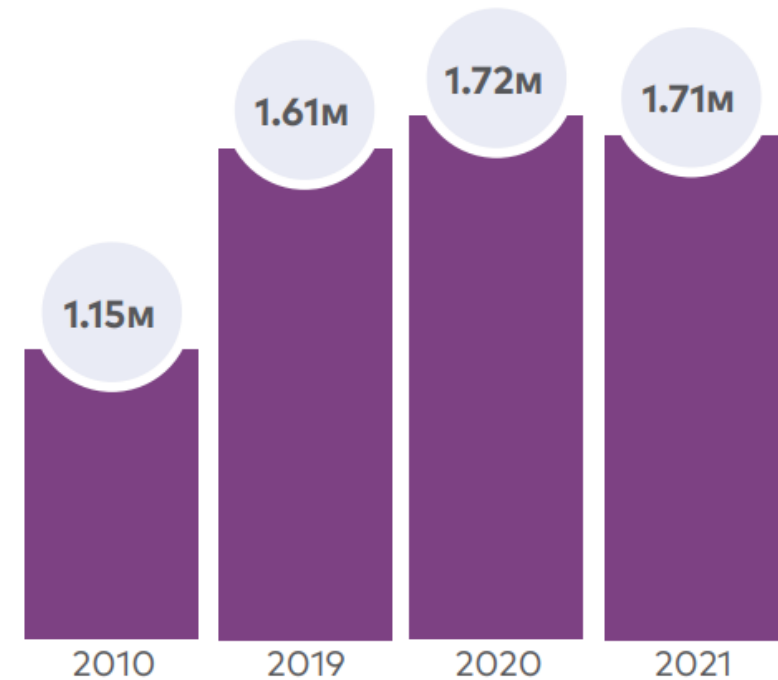
Who received Hospice Care in 2021?

1.71 million Medicare beneficiaries were enrolled in hospice care for one day or more in calendar year (CY) 2021.

This was flat from 2020 (trend wise).

This includes patients who:

- ✓ Died while enrolled in hospice
- ✓ Were enrolled in hospice in 2020 and continued to receive care in 2021
- ✓ Left hospice care alive during 2021 (live discharges)



Source: MedPAC March 2023 Report to Congress, 10-4

Trends in Hospice Care – Quality and Outcomes

Hospice Quality Reporting Program (HQRP)

Three sources of data are used:

- Hospice Item Set (HIS) data collection & submission -> Transition to Hospice Outcomes and Patient Evaluation (HOPE)
- CAHPS Hospice Survey submission
- Administrative data (Medicare claims) – Hospice Visits in Last Days of Life (HVLDL) and Hospice Care Index (HCI)

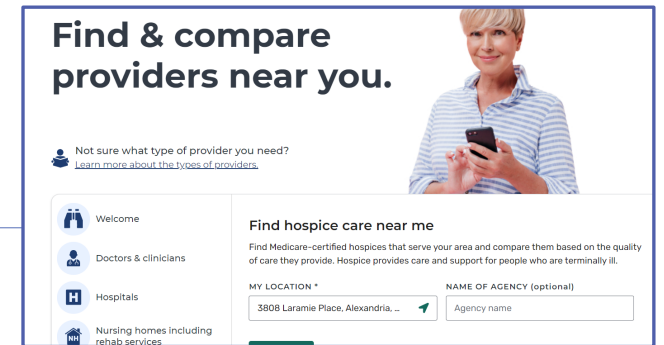
All Medicare certified hospice providers **MUST** comply with quality reporting requirements

- This rule is payer agnostic
- ***Failure to comply results in payment reduction of 4%***

CMS Hospice Care Compare

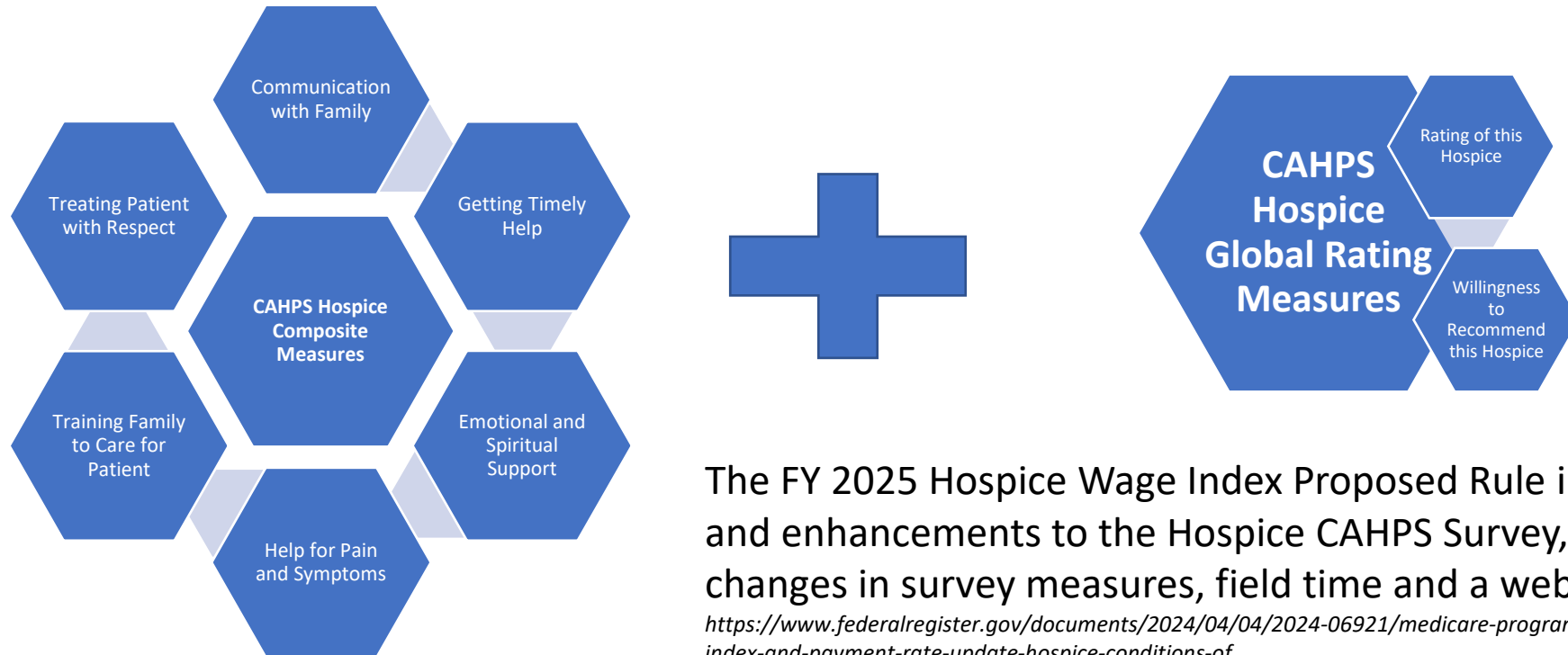
- Hospice Quality Measures are publicly reported on Care Compare
- Consumers may select and compare multiple hospices on similar quality measures
- Comparisons include the Hospice Item Set (HIS), Consumer Assessment of Healthcare Providers and Systems (CAHPS) Hospice Survey, and Claims-based measure scores
- Data from Quarter 1 and Quarter 2 of calendar year 2020 are excluded due to COVID impact
- State averages are also displayed for each measure.

<https://www.medicare.gov/care-compare/>



Trends in Hospice Care – Quality and Experience of Care

CAHPS Hospice Measures – changes are on the way



The FY 2025 Hospice Wage Index Proposed Rule includes changes and enhancements to the Hospice CAHPS Survey, including changes in survey measures, field time and a web-mode option
<https://www.federalregister.gov/documents/2024/04/04/2024-06921/medicare-program-fy-2025-hospice-wage-index-and-payment-rate-update-hospice-conditions-of>

So What?



- ✓ Missing CAHPS Hospice Survey Data
- ✓ Standardization
- ✓ Weighting and Final Output
- ✓ Public Reporting and Special Focus Program
- ✓ CAHPS Hospice Survey Response Rates

CAHPS Hospice Survey Response Rates (July 1, 2021- June 30, 2023)

Region	Response Rate	Number of Hospices Reporting
National	29%	3022
Wisconsin (H)	39%	67
Puerto Rico (L)	21%	18

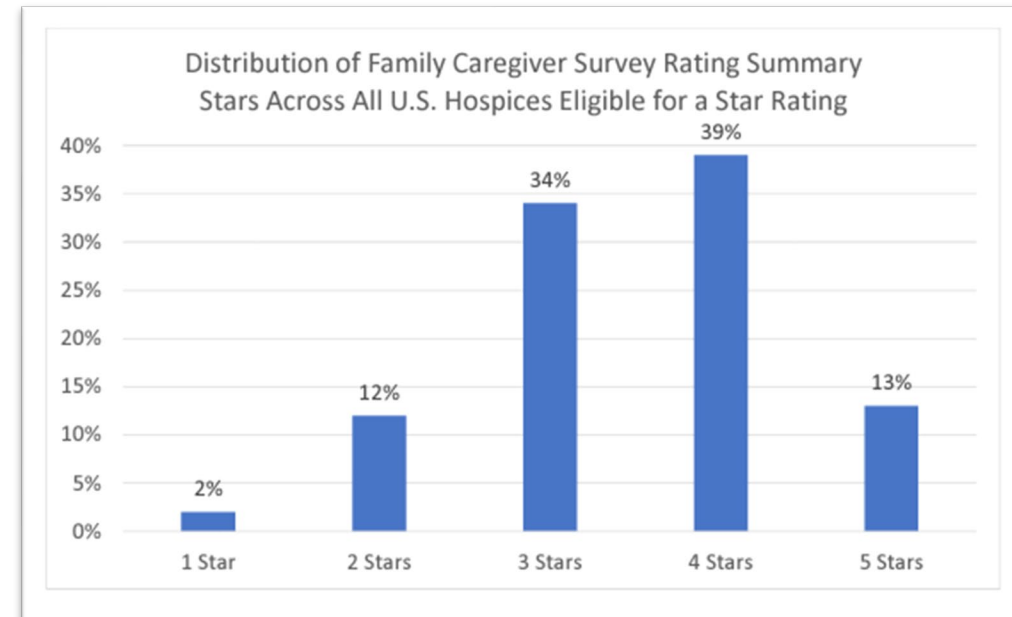
Shooting for the Stars (ratings)



Minimum number of respondents for public reporting – 75 (completed surveys) -> over a given 8-quarter period. If <75 respondents, then Star Rating is not generated

- Measure scores may still be used to determine Star Ratings cut points & may be publicly reported on Hospice Care Compare

Family Caregiver Survey Rating Average (unrounded)	Family Caregiver Survey Rating (rounded)
>_1.00 and <1.50	1
>_1.50 and <2.50	2
>_2.50 and <3.50	3
>_3.50 and <4.50	4
>_4.50 and <_5.00	5



Feb and May 2024 Refresh Periods

<https://hospicecahpssurvey.org>

Shooting for the Stars



Reporting period: April 1, 2021 – March 31, 2023

Distribution of Family Caregiver Survey Rating Summary Stars in Wisconsin

1 Star		2 Star		3 Star		4 Star		5 Star		Total
N	%	N	%	N	%	N	%	N	%	N
1	2%	6	12%	21	43%	18	37%	3	6%	49

<https://hospiceahpssurvey.org>

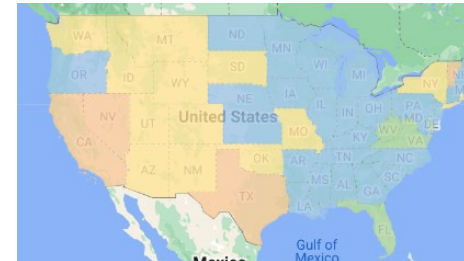
The regulatory / compliance lens

❑ Program Integrity Concerns:

- ✓ 34 recommendations, led by 4 national organizations
- ✓ Grouped into 11 core issues
- ✓ Five key points : limit enrolment of new providers with a targeted moratorium on new hospices, enforcement against non-operational hospices, develop hospice “red flag” criteria, require surveyors to confirm ability of hospices to deliver all four levels of care, add hospice administrator and patient care manager qualifications to Medicare Hospice CoPs.

❑ APU Implications for Non – Submission of Quality Data

❑ Q4 FY 22 Hospice PEPPER released on April 5, 2023 (currently unretrievable)



e: 80-100% 60-79% 40-59% 20-39% 0-19%

[Hospices PEPPER Portal
Retrieval Map \(cbrpepper.org\)](https://cbrpepper.org)

❑ Medicare Special Focus Program

- ✓ Designed to identify low performing hospices for additional oversight, support and possible termination
- ✓ SFP algorithm includes regulatory (survey result deficiencies) and quality (HCI, CAHPS scores) elements
- ✓ Published initially in the CY 2024 Home Health Final Rule

Current Trends – Models and Demonstrations

Announced	Active
Radiation Oncology Model	ACO REACH
States Advancing All-Payer Health Equity Approaches and Development Model (AHEAD)	Enhancing Oncology Model
ACO Primary Care Flex Model	ESRD Treatment Choices (ETC)
Transforming Episode Accountability Model (TEAM)	Primary Care First Model
Medicare Advantage Value Based Insurance Design (VBID)	
Making Care Primary Model (MCP)	
Guiding and Improved Dementia Experience (GUIDE)	

www.cms.gov/innovation/models

Current Trends – CMS Innovation Center Objectives



Measuring Progress:

Drive Accountable Care

- Medicare + Medicaid beneficiaries in value-based arrangements by 2030

Advance Health Equity

- Collect & report demographic data, include patients from historically underserved populations & safety net providers, identify areas for reducing inequities

Support Innovation

- Set Performance targets for patient experience measures & patient reported outcomes

Address Affordability

- Opportunities to include high value care and targets to reduce foregoing of care

Partner to Achieve System Transformation

- Multi-payer alignment, integrate patient perspectives across the life cycle

No One Left Behind – the role of equity

“The attainment of the highest level of health for all people, where everyone has a fair and just opportunity to attain their optimal health regardless of race, ethnicity, disability, sexual orientation, gender identity, socioeconomic status, geography, preferred language, or other factors that affect access to care and health outcomes.”



Health equity is attained when every individual has individualized and person-centered tools, resources and opportunities to achieve optimal health

Health Equity through Transformed Systems of Health

Indicators of meaningful community partnerships:

- Diversity and inclusivity
- Partnerships and opportunities
- Acknowledgment, visibility, and recognition
- Sustained relationships
- Mutual value
- Trust
- Shared power
- Structural supports for community engagement

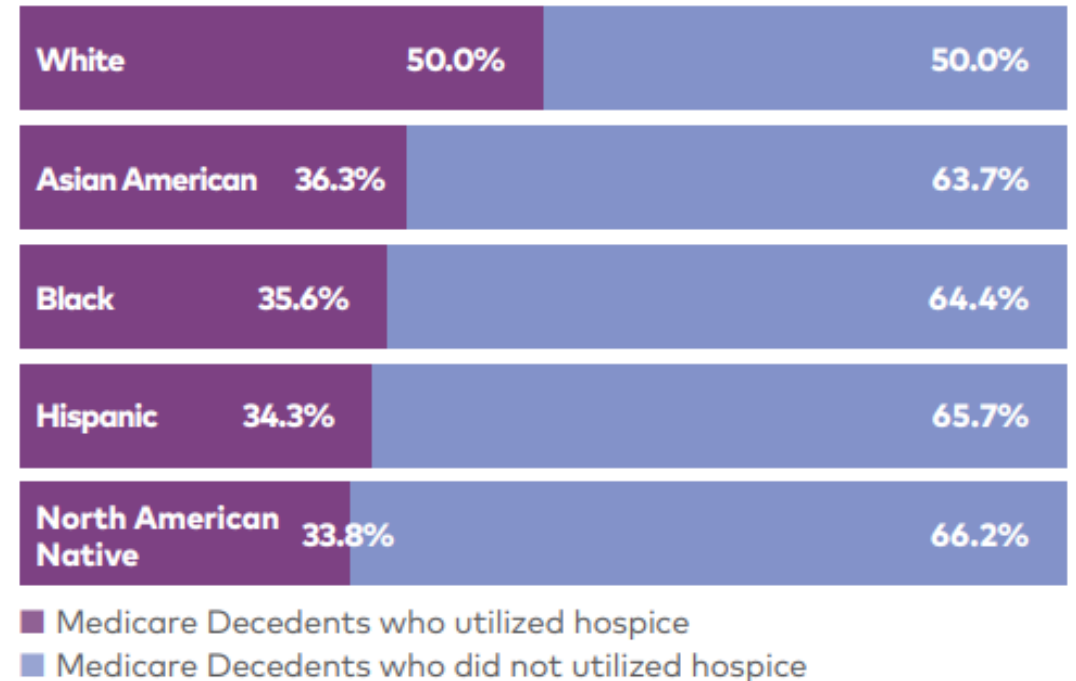


Aguilar-Gaxiola, S., Ahmed, S. M., Anise, A., Azzahir, A., Baker, K. E., Cupito, A., ... & Zaldivar, R. (2022). Assessing meaningful community engagement: a conceptual model to advance health equity through transformed systems for health: organizing committee for assessing meaningful community engagement in health & health care programs & policies. NAM perspectives, 2022.

Equity = Access?

In Calendar Year (CY) 2021,

- 50.0% of White Medicare decedent beneficiaries used the Medicare Hospice Benefit.
- 36.3% of Asian American Medicare decedent beneficiaries. 35.6% of Black Medicare decedent beneficiaries enrolled in hospice.
- 34.3% of Hispanic and 33.8% of North American Native Medicare decedents used hospice.



Source: MedPAC March 2023 Report to Congress, Table 10-3



CMS – Five Health Equity Priorities

- *Expand the collection, reporting and analysis of standardized data*
- *Assess causes of disparities within CMS programs and address inequities to close gaps*
- *Build capacity of the Healthcare Organization and the Workforce*
- *Advance Language Access, Health Literacy and the Provision of Culturally Tailored Services*
- *Increase all forms of accessibility to Healthcare Services and Access*

<https://www.cms.gov/files/document/cms-framework-health-equity-2022.pdf>

Hospice Through The Lens of DEI

➤ Four Key Domains:

- ✓ Location Matters
- ✓ Information Required
- ✓ Finances Necessary
- ✓ Experience with the Healthcare System



Additional Resources

- Equity Where It Matters : DEI Certificate in Hospice and Palliative Care
- NHPCO's Inclusion and Access Toolkit
- Descargar Kit de Herramientas de Inclusión y Acceso - the Spanish language version
- Black and African American Outreach Guide
- Chinese American Resource Guide
- Latino Outreach Guide
- LGBTQ+ Resource Guide
- Hospice Through the DEI Lens : A Report

<https://www.nhpc.org/education/tools-and-resources/diversity>

Additional Resources for Providers

Quality Resources:

- ❖ Charting a Course to Quality – HQRP Guide

<https://www.nhpc.org/wp-content/uploads/Charting a Course to Quality - HQRP Resource Guide.pdf>

- ❖ IDT Hospice Onboarding and Orientation - <https://www.nhpc.org/wp-content/uploads/Interdisciplinary Onboarding and Orientation Guide.pdf>

- ❖ NHPCO Care Planning Primer - <https://www.nhpc.org/wp-content/uploads/NHPCO Care Planning Primer.pdf>

- ❖ QIN / PIP Library - <https://www.nhpc.org/regulatory-and-quality/quality/quality-innovation-network/>

MOE report - <https://www.nhpc.org/regulatory-and-quality/quality/hospice-quality-updates-resources/measure-of-excellence-reports/>

Quality

NHPCO is committed to assisting hospice and palliative care providers in performing continuous quality and performance improvement activity that supports safe, effective, and timely care outcomes for patients and families. Please contact the NHPCO Quality team with any questions:

- General quality inquiries: quality@nhpc.org
- Quality Connections program: qualityconnections@nhpc.org
- Measures of Excellence tool and dashboard: moe@nhpc.org
- STAR survey: star@nhpc.org

MARCH 2023

Charting a Course to Quality:

Quality Reporting
in Comprehensive
Resource Guide



Performance Improvement Project Library

Administrative Operations | Clinical Operations | Documentation and Plan of Care Compliance | Family/Caregiver Satisfaction | Hospice Visits in Last Days of Life | Infection Control | Medication Safety | Patient and Caregiver Safety | Reducing Hospitalizations

Administrative Operations

State	Region	Project Title
IA	Midwest	Improving hospice staff morale
OH	Midwest	Revitalizing hospice quality assurance and performance improvement program
OR	West	Achieving and maintaining state licensure

Clinical Operations

State	Region	Project Title
IA	Midwest	Improving hospice patient symptom management in home and facility settings
IL	Midwest	Improving and expanding bereavement services
IL	Midwest	Reducing preventable live discharges from hospice
MA	Northeast	Increasing response rate for Veteran Specific Questions (VSO) Evaluation of Hospice Care

Additional Resources for Providers

NHPCO Resources:

- ❖ Project ECHO Equity Where It Matters - <https://nhpco.zoom.us/meeting/register/tZEsfu-trz4oGtQeKFw41UEIYNwjSli8QCBF#/registration>
- ❖ NHPCO Equity and Inclusion Resources - <https://www.nhpco.org/resources/access-and-inclusion/>
- ❖ Choosing a Hospice - [Choosing Hospice.pdf \(nhpco.org\)](#)
- ❖ NORC Report - Value of Hospice : [Value of Hospice in Medicare Report | NHPCO](#)
- ❖ Hospice Through the Lens of DEI Report - Hospice DEI Report - <https://www.nhpco.org/resources/access-and-inclusion/hospice-through-the-dei-lens/>

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NHPCO
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Care Organization

Project ECHO

NHPCO PROJECT ECHO 2023

EQUITY WHERE IT MATTERS

About Project ECHO
Extension of Community Health Outcomes

All Teach, All Learn approach → expanding capacity to underserved communities

Case study presentations, key takeaways, and actionable thought starters

Thank You



Questions?

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