

Tonight

The Cicely Saunders Institute
Welcomes Dr Joan Teno, for this year's

Mon 7th Oct 2019

17.00 - 18.30 BST

Cicely Saunders Institute
King's College London
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Cicely Saunders International Annual Lecture 2019

'Got quality? The urgent need to focus on quality and not solely costs'

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**Cicely Saunders
International**
Better care at the end of life



KING'S
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LONDON

Got quality?

The urgent need to focus on
quality and not solely on costs

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Disclosure

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 - National Institute of Aging
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- The content of this presentation does not necessarily reflect the views or policies of the Department of Health and Human Services, nor does the mention of trade names, commercial products or organizations imply endorsement by the US Government.

Conclusions

- Embrace the voice of those who live on...
However imperfect, their suffering should not be ignored.
- Process measures are problematic.
- Caution in use of claims-based measures.
- Be wary of unintended consequences.
- We want outcome measures, but...
 - Lacking evidence base
 - Episode of care (short stays)
- Urgent need to arrive at ethical, operationalization of “value” for P4P.

Outline

- US Perspective – Hospice is not a place, but an “insurance benefit”, fraud, and “accountability”
- Importance of the seriously ill person and those who care for that person’s views of the quality of care
- Process measures are problematic
- Concerns with “billing” data quality measures
- Time to focus on quality, NOT COST

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Find a hospice agency

Find hospices that serve your area and compare them based on the quality of care they provide. Hospice agencies most often provide services where you live, whether it's at home, an assisted living facility, or a nursing home.

There are 2 ways to search

Hospice agency name

Full or Partial Hospice Agency Name

and/or

Location

ZIP code or City, State or State

Search

Example: 45802 or Lima, OH or Ohio

Learn more



Family caregivers' survey results

Compare hospices based on results from a national survey that asks a family member or friend of a hospice patient about their hospice care experience. [View more details about the survey.](#)

- The data were collected between 10/01/2016 and 09/30/2018
- Higher percentages are better

Table
Graph

	<u>M J H S HOSPICE AND PALLIATIVE CARE, INC</u>	<u>HOSPICE OF NEW YORK, LLC</u>	<u>CALVARY HOME HEALTH AGENCY AND HOSPICE CARE</u>	National average
Communication with family	70%	76%	77% ⁹	80%
Getting timely help	64%	72%	72% ⁹	78%
Treating patient with respect	81%	87%	87% ⁹	91%
Emotional and spiritual support	84%	85%	87% ⁹	90%
Help for pain and symptoms	62%	70%	71% ⁹	75%
Training family to care for patient	68%	68%	72% ⁹	75%
Rating of this hospice	68%	75%	79% ⁹	81%
Willing to recommend this hospice	73%	79%	85% ⁹	84%

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The Roles of Measurement

- **Clinical Assessment** - measures to guide patient management
- **Research** - assess phenomenon of interest
- **Quality Improvement** - information to reform or shape how care is provided
- **Accountability** - allows the comparison of health care providers

Note: in the US, accountability is a political process.

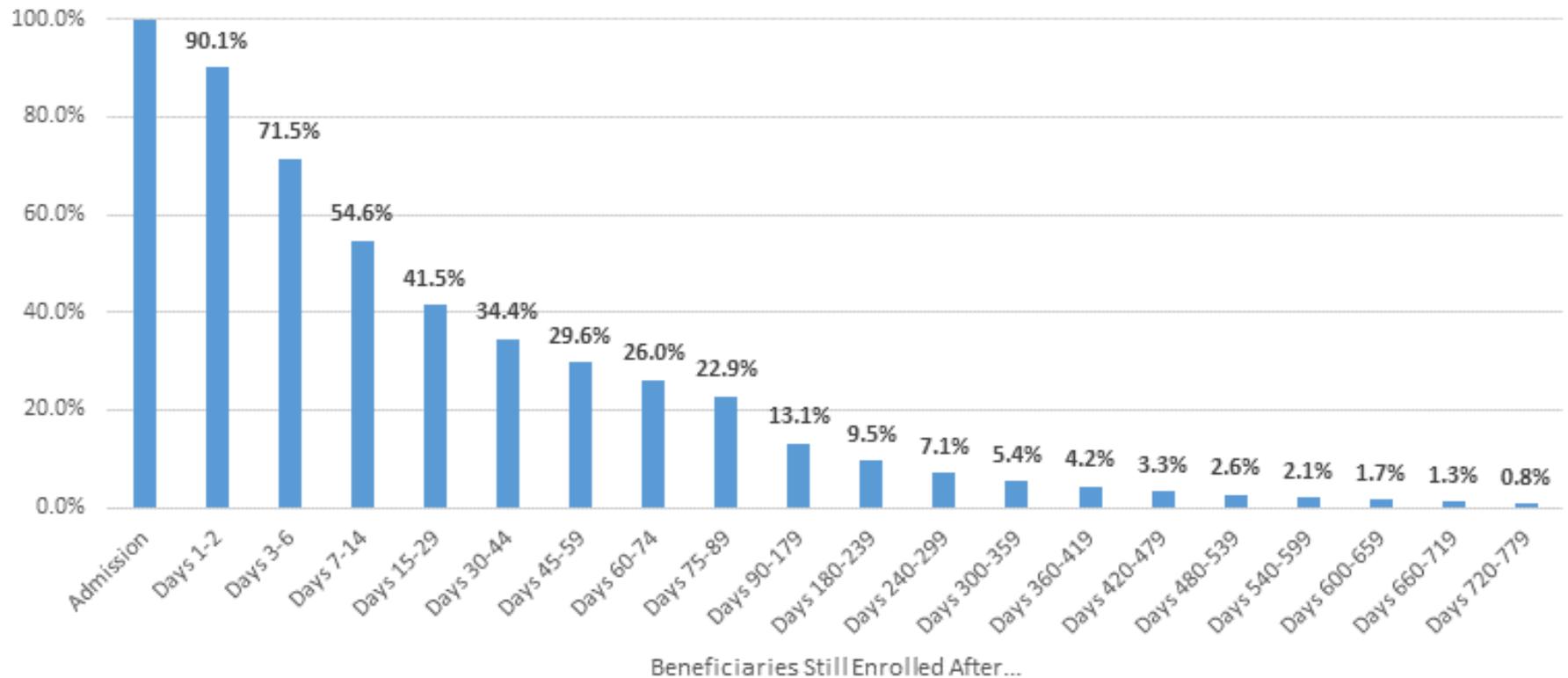
Difference in Measurement Tools

	Clinical Assessment	Research	Improvement	Accountability
Audience	Clinical staff	Science Community	QI team and clinical staff	Purchasers and consumers
Focus	Status of patient	Knowledge	Understand care process	Purchasers and consumers
Evidence base	Face validity	Building off and new knowledge	Building off and developing new knowledge	Domain ought to be under control of health care provider
Importance of psychometric properties	To the individual provider	Extremely important	Important within setting	Extremely important-valid and responsive across settings of care

Value and Alternative Payment Model (APM)

- A Center for Medicare and Medicare Services (CMS) alternative to the traditional fee-for-service (FFS) payment model which is based on volume incentives rather than value.
- Incentivizes providers to develop their own strategies to delivery **high-quality care** and **hit spending targets**

Length of Stay





FRAUD

[Updated] \$75 Million FCA Settlement is Largest-Ever for a Hospice

By **Maggie Flynn** | November 14, 2017

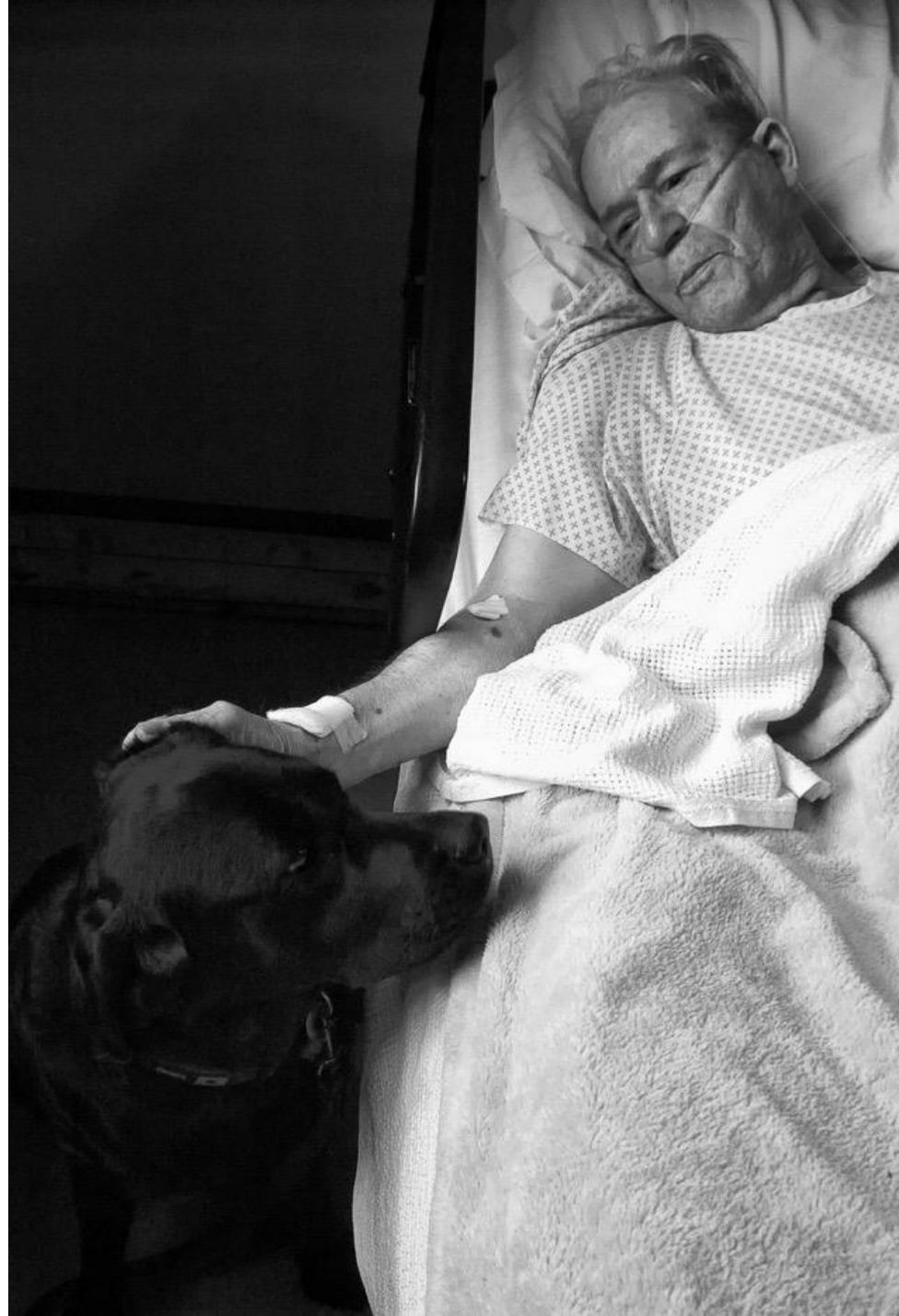
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The largest for-profit hospice chain in the nation and its parent company have agreed to pay [\\$75 million](#) to resolve false claims allegations for hospice services, the Department of Justice announced. The resolution is the largest amount recovered from a provider of hospice services under the False Claims Act, according to the DOJ.

*“We have never lost sight of the values that were so important to David: commitment to openness, openness to challenge, and **the absolute priority of patients’ own views on what they need.**”*

- Dame Cicely Saunders

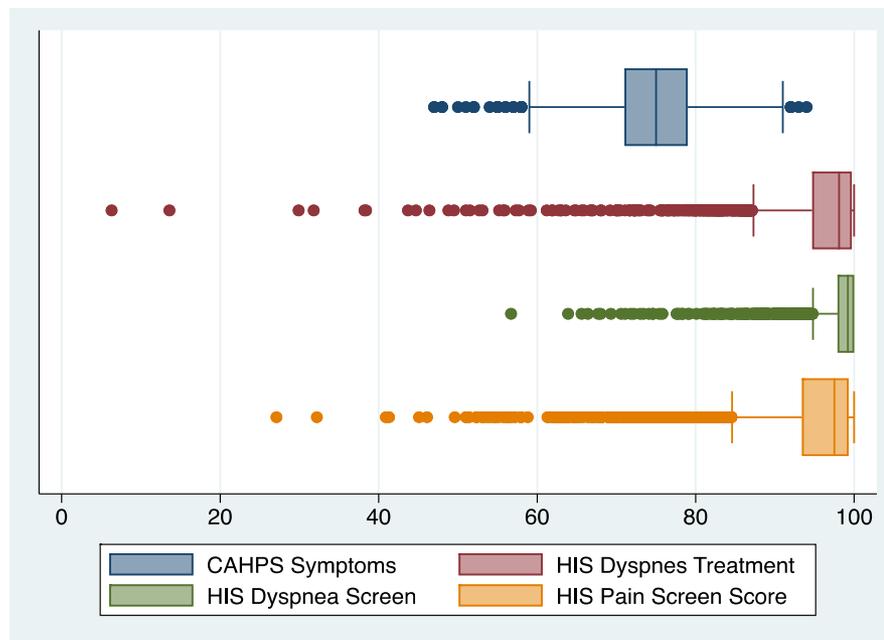






Perils of Process Measures

The Hospice Item Set, the initial measure of hospice quality measures in the US, relied on process measures that became “topped out” with little variation in performance.



Liverpool Care Pathway – become a “tick box” exercises which did not take into account the individual patient circumstances into account

- Baroness Julia Neuberger

“Tick boxes are not a substitute for thoughtful care...”

- Dame Barbara Monroe

Critical
Thinking

Type of Measures

Task	Comments
“If X, then Y” (opiate, then bowel regimen)	Concern with ceiling effect from EMR order sets
Claims-based measure (e.g., referral to hospice in the last 3 days of life vs. rate of hospice live discharges)	Interpretation and thresholds
Patient/family-reported outcomes (e.g., bereavement)	Hindsight bias Misperceptions

Views of Bereaved Family Members

“How people die remains in the memory of those who live on...”

-Dame Cicely Saunders



Why Bereaved Family Members?

- In the US, so many persons are referred “too late” that for the purpose of accountability it would be difficult to rely on patient, only measure.
- Dying persons and family are the unit of care. As the persons dies the family are more involved in care and bear witness. They survive.
- A distressing misperception, such as Cheyne-stokes respiration for shortness of breath, causes suffering. We should not ignore it. It is a quality concern.
- Time frames are clear.
- Captures events in the last week of life where symptoms escalate and in the US, problematic or burdensome transitions occur.

Focus Group Participant

- A focus group participant's response to the question, what was important to measuring the quality of hospice care?

“you know what to expect, how you can help, and what you can expect.”

*"I only want
what is
in your
heart and
in your
mind"*

-David Tasma



Patient-Focused, Family-Centered Medical Care

- Key is medical care that is Competent, Coordinated Compassionate, and Centered:
 - **Competent** – understands disease trajectory, treatment options, and works with the patient to arrive at medical care that meets the patient goals and expectations (within the constraints that society imposes)
 - **Coordinated** - ensures care is seamless with transitions across health care providers, settings of care, and disease trajectory
 - **Compassionate** – treat with respect, provide holistic care
 - **Centered** - focus on the needs of the seriously ill person and those who care for them

Clinical Translation: A High Quality Hospice...

- Keeps the primary caregiver informed and listens to their concerns
- Provides timely help when needed
- Provides the desired help for treatment of symptoms, emotional, and spiritual support
- Treats the patient with respect
- Attends to the needs of the caregiver for information and training to safely care for the patient at home

Advantages of Mortality Follow- back Approach

- Denominator is clearly defined regardless of patient being defined as terminally ill or receiving formal services
- Time frames are clear – allowing comparison of settings of care
- Examines the entire episode of care
- Allows examination of the “big picture”, especially the transitions in health care in the weeks of life
- Majority of dying persons are unable to be interviewed in the last days of life. Allows for data to be collected on the care of the sickest persons, often with important unmet needs
- Concerns about respondent burden in prospective surveys for dying persons and their family

Use of MFB Survey

ORIGINAL CONTRIBUTION

Family Perspectives on End-of-Life Care at the Last Place of Care

Joan M. Teno, MD, MS
Brian B. Claridge, PhD
Virginia Casey, PhD, MPH
Lisa C. Welch, MA
Terrie Weis, PhD
Renae Shield, PhD
Vincent Mor, PhD

OVER THE PAST CENTURY, DYING has become increasingly institutionalized. In the early 1900s most people died at home, but by the middle of the 20th century the majority of deaths in industrialized nations occurred in health care institutions. With recent changes in health care, society is struggling with the role that governmental and nongovernmental regulatory structures should play in assuring that the health care system provides competent, coordinated, and compassionate care at life's end.

Early efforts to define a "good death" were based on expert opinions.¹⁻³ Recent attempts have used focus groups and in-depth interviews to capture patient and family perspectives.⁴⁻⁶ Several authors of the current study developed a conceptual model of quality of end-of-life care⁷ with input from dying patients, their families, structured review of professional guidelines, and experts. This research indicates that high-quality end-of-life care results when health care professionals (1) ensure desired physical comfort and emotional support, (2) promote shared decision making, (3) treat the dying person with respect, (4) provide information and emotional support to family members, and (5) coordinate care across settings. Outcome

Context Over the past century, nursing homes and hospitals increasingly have become the site of death, yet no national studies have examined the adequacy or quality of end-of-life care in institutional settings compared with deaths at home.

Objective To evaluate the US dying experience at home and in institutional settings.

Design, Setting, and Participants Mortality follow-back survey of family members or other knowledgeable informants reporting 1576 decedents, with a 2-stage probability sample used to estimate end-of-life care outcomes for 1.97 million deaths from chronic illness in the United States in 2000. Informants were asked via telephone about the patient's experience at the last place of care at which the patient spent more than 48 hours.

Main Outcome Measures Patient- and family-centered end-of-life care outcomes, including whether health care workers (1) provided the desired physical comfort and emotional support to the dying person, (2) supported shared decision making, (3) treated the dying person with respect, (4) attended to the emotional needs of the family, and (5) provided coordinated care.

Results For 1059 of 1576 decedents (67.1%), the last place of care was an institution. Of 519 (32.9%) patients dying at home represented by this sample, 198 (38.2%) did not receive nursing services; 65 (12.5%) had home nursing services, and 256 (49.3%) had home hospice services. About one quarter of all patients with pain or dyspnea did not receive adequate treatment, and one quarter reported concerns with physician communication. More than one third of respondents cared for by a home health agency, nursing home, or hospital reported insufficient emotional support for the patient and/or 1 or more concerns with family emotional support, compared with about one fifth of those receiving home hospice services. Nursing home residents were less likely than those cared for in a hospital or by home hospice services to always have been treated with respect at the end of life (68.2% vs 79.6% and 96.2%, respectively). Family members of patients receiving hospice services were more satisfied with overall quality of care: 70.7% rated care as "excellent" compared with less than 50% of those dying in an institutional setting or with home health services ($P < .001$).

Conclusions Many people dying in institutions have unmet needs for symptom amelioration, physician communication, emotional support, and being treated with respect. Family members of decedents who received care at home with hospice services were more likely to report a favorable dying experience.

JAMA. 2004;291:68-74

www.jama.com

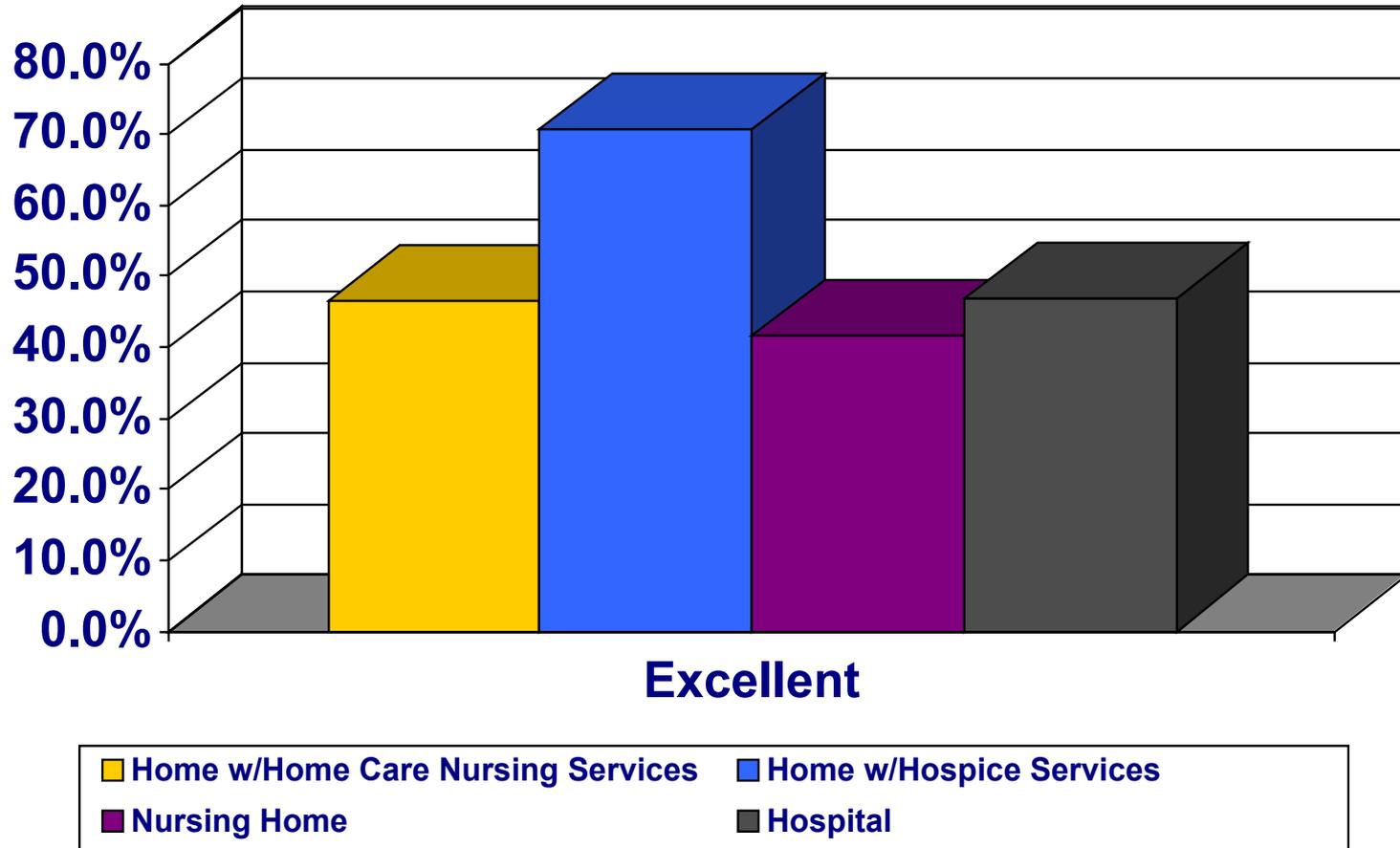
measures based on each of these domains have been developed and validated.⁸ The goal of this study was to use these measures to provide national estimates of the dying experience and to examine whether family members' perceptions of the quality of end-of-life care differed by the last place of care.

Author Affiliations: Center for Gerontology and Health Care Research, Brown Medical School (Dr Teno, Casey, Welch, and Weis), the Veterans Affairs Center of Community Health, Brown University (Dr Teno), the Center for Survey Research, University of the

Center for Survey Research, University of the Pacific (Dr Claridge), and the Center for Gerontology and Health Care Research, Brown Medical School (Dr Teno, Casey, Welch, and Weis), the Veterans Affairs Center of Community Health, Brown University (Dr Teno), the Center for Survey Research, University of the Pacific (Dr Claridge), and the Center for Gerontology and Health Care Research, Brown Medical School (Dr Teno, Casey, Welch, and Weis).

- 2004 article that showed that bereaved family members' perceived higher quality of hospice care at home compared to persons dying at other sites of death

Overall Assessment of Quality of Care



Change in Bereaved Family Member Perceptions

Bereaved family member report	2000	2011-2013
N/Weighted N	622/794,341	586/2,257,759
Unmet need for pain management	15.5	25.2
Unmet need for emotional support	48.9	49.8
Unmet need for help with dyspnea	23.6	21.4
Decision that patient would not want	10.0	11.0
Care-Excellent	56.7	47.0

More ICU, More Repeat Hospitalizations, More Late Hospice Referrals

Care at Life's End

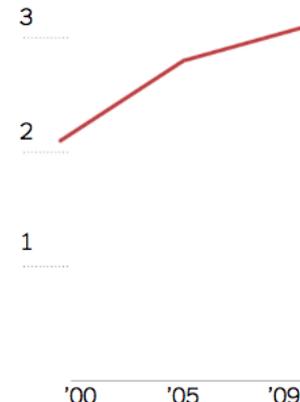
In their last days, older patients are increasingly likely to be shuttled among hospitals, nursing homes and hospices in pursuit of Medicare and Medicaid coverage. Ultimately, most die in an institution, rather than at home.

Among Medicare beneficiaries over 65 who died*

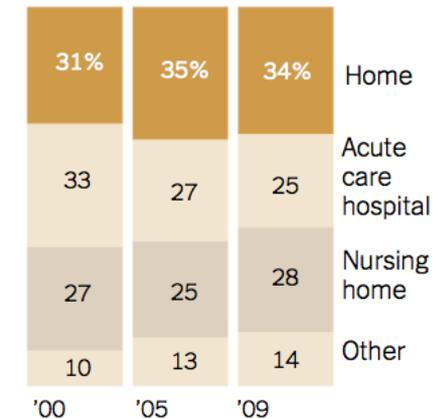
Place of care
Percentage receiving treatment in last days**



Transfers
Among facilities and home, average number in last 90 days



Place of death



*Excludes Medicare Advantage members. **Patients may get care in more than one place. Those receiving hospice care may get it anywhere, not just in a stand-alone hospice.

Source: Journal of the American Medical Association

Do These Patterns of Care Matter?

Bereaved Family Member Perceptions	Did not experience late transition (Weighted n= 3.5 Million)	Late transitions (18%) (Weighted n = 760,690)
Rated Care as Excellent	49.3	43.7 (0.74, 0.5-1.1)
Unmet needs for emotional distress	45.3	56.6 (1.6, 1.0-2.6)
Unmet needs for spiritual support	55.0	69.3 (1.6, 1.1-2.4)
Family not always kept informed about patient's condition	19.0	33.3 (1.9, 1.3-2.7)
Care not consistent with patient preferences	12.2	16.1 (1.3, 0.8-2.1)

Claims-Based Measures: A Word of Caution

- “Quality measures” based on administrative data are proliferating:
 - Chemotherapy in the last 2 weeks of life
 - Hospice live discharges
 - ER visit in the last month of life
 - Terminal hospitalization in the last month of life
- “Burdensome Transitions” – See Teno, JAMA 2018

Concerns
with
Claims-
Based
Measures

What is the right
rate?

Too often they focus
on less care, which
provides the wrong
message

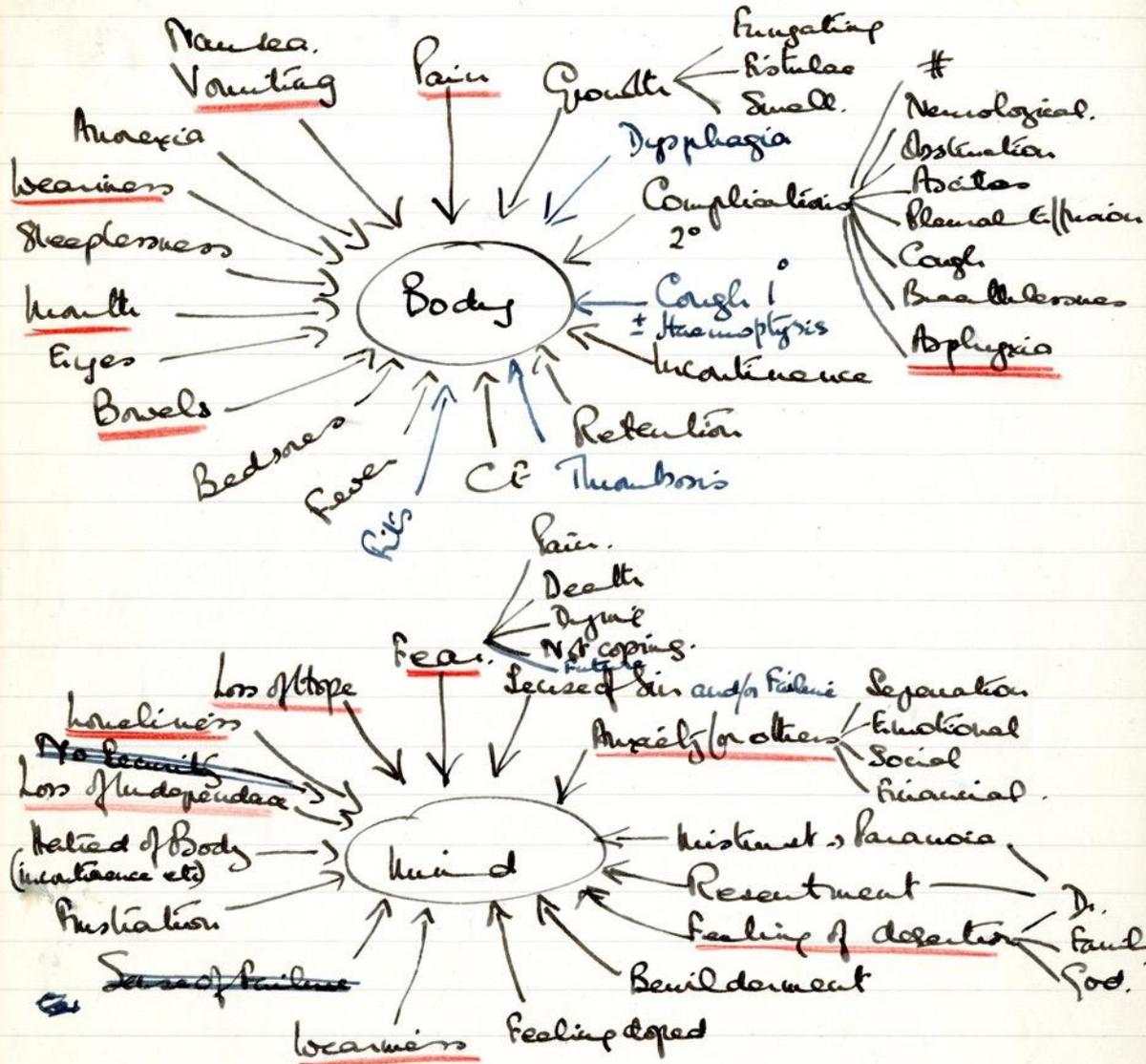
Goal Concordant Care

*“The door of hope must
be shut slowly and
gently...”*

- Dame Cicely Saunders



Attack.



Sketch of "Total Pain:
-Dame C. Saunders,
from archive at King's
College

Concerns

Evidence base for management of dyspnea in hospice patients is “low quality” – systematic review by RAND and Cochrane review

For many of key interventions, note that the evidence base is problematic

Don't want a QM to result in treatment that is not consistent with patient preferences

Quality Measurement for Dyspnea

Varying etiologies (obstructive lung disease, tumor pressing on trachea, metabolic abnormalities, anemia)

Conservation of energy and ADL assistance are first line non-pharmacological treatment in typical patient admitted to US Hospice program

Opiates and the use of benzodiazepines are not without risk

Evidence is low quality per Cochrane review and starting doses are based on expert opinion

Concern is sedation (refractory dyspnea may need)

WSJ

THE BUSINESS OF BETTER END-OF-LIFE CARE

BY MELINDA BECK

HEALTH-CARE EXPERTS often lament that one-quarter of all Medicare spending—\$150 billion annually—goes to treating patients in their last year of life. But identifying those patients in advance and cutting back on futile care has been difficult. Can an algorithm help?

A startup called **Aspire Health** says that it can predict which patients are likely to die in the next year and reduce their medical bills substantially by offering them palliative care at home, keeping them comfortable while avoiding costly ER visits and hospital stays.

"We can tell which patients will die in one week, six weeks or one year," says former Senate Majority Leader William Frist, a transplant surgeon who co-founded Aspire. "We can say to

health plans, 'How much are these patients costing you? We can care for them for less, and have higher patient satisfaction rates too.'"

The Nashville-based company, which recently won \$32 million in funding from GV (formerly called Google Ventures), has managed the care of more than 20,000 Medicare Advantage patients in 19 states in exchange for a monthly fee. It estimates that it can save health plans \$8,000 to \$12,000 per patient.

Palliative care focuses on easing

symptoms such as pain and shortness of breath that are often overlooked amid aggressive efforts to save seriously ill patients. Unlike hospice, patients receiving palliative care aren't required to forego potentially curative treatments like chemotherapy. But many do, especially if the regimens are unpleasant and unlikely to buy much time.

Hospitals that offer in-house palliative-care programs find that they save an average of \$7,000 per patient, according to the National Palliative Care Research Center. The handful of hospitals that provide palliative care in patients' homes can save even more—as much as \$2,000 a month in one study—by preventing return trips to the hospital.

Many palliative-care experts say that the need for such services is so great that they have no problem with a for-profit business model built around predicting patient's deaths, as long as patients are not pressured to forego care.

Aspire "is filling a huge gap between hospitals and hospice. We need the mainstream health-care systems to step up and do the same thing," says Diane E. Meier, director of the Center to Advance Palliative Care at the Ichan School of Medicine at New York's Mount Sinai Health System.

To identify target patients, Aspire's algorithm sorts through med-

ical claims, looking for diagnoses such as congestive heart failure or late-stage cancer or for a pattern of frequent hospitalizations. Its clinicians also consult with patients' primary care physicians to see if palliative care would be appropriate.



ASPIRE nurse practitioner Amanda Clark and a patient, Pittsburgh, Oct. 2015.

MELINDA BECK/THE WALL STREET JOURNAL

cal claims, looking for diagnoses such as congestive heart failure or late-stage cancer or for a pattern of frequent hospitalizations. Its clinicians also consult with patients' primary care physicians to see if palliative care would be appropriate.

Medical ethicist Arthur Caplan of New York University says that "a private entity snooping around" in patient records and consulting their doctors without prior consent seems like a violation of privacy. Aspire says that working with health plans to coordinate patient care is an approved use of such data under Medicare rules.

Aspire representatives don't men-

initial assessment, the first thing we say is, 'Tell us about your illness,' " says David Thimons, Aspire's lead physician in the Pittsburgh area. "Sometimes they say, 'I've got about four months to live—don't tell my kids.'"

A key part of the program is discussing patients' individual "goals of care," including what treatments they want and don't want. "We emphasize that not wanting to go to the hospital anymore doesn't mean you're giving up," says Tiffany Lunsford, a nurse practitioner and clinical director with Aspire. "And if they do want to want to go to the hospital, we go."

One 64-year-old patient she cared for last spring had stage IV lung cancer, as well as multiple sclerosis, chronic obstructive pulmonary disease and chronic pain.

The patient wanted to continue on chemotherapy, and Ms. Lunsford says that she and other nurses visited frequently for months to adjust her pain medication, manage her nausea and help her to breathe until she switched to hospice care and died at home.

Bill Ellsworth, an 83-year-old former Navy engineer with a long history of heart problems, says that he enjoys the twice-monthly visits from his Aspire nurse practitioner, but he scoffs at the notion that a computer program thinks he'll die in the next year. "They've been giving me two years to live since 2003," he says.

"Occasionally we're wrong, and we couldn't be happier," says Dr. Thimons.

term "palliative care" when they invite patients to enroll. "We help patients understand that they are sick and getting sicker, and we describe what we do, rather than put a label on it," says the company's CEO, Brad Smith. That includes a complete in-home assessment of their physical, emotional and spiritual needs, and then regular visits from nurses and social workers as well as a nurse practitioner on call 24/7—all at no cost to patients.

About 15% of those approached decline because they have home-care already or don't think they need it. Many of those who do enroll are

Operationalization of Value in P4P Payment Models

- Value = Quality + Costs
- Key is how to combine these constructs that can be opposing; e.g., achieving pain control may require expensive medication.
 - Lacking measures of quality, thus costs that is easy to measure drives the definition of value
 - How do you weight low prevalence but important events in measuring the quality of care? This is especially problematic with this based on entire population.
 - Combining and various strategies for weighting of quality and cost measure to come up financial incentive needs careful thought.

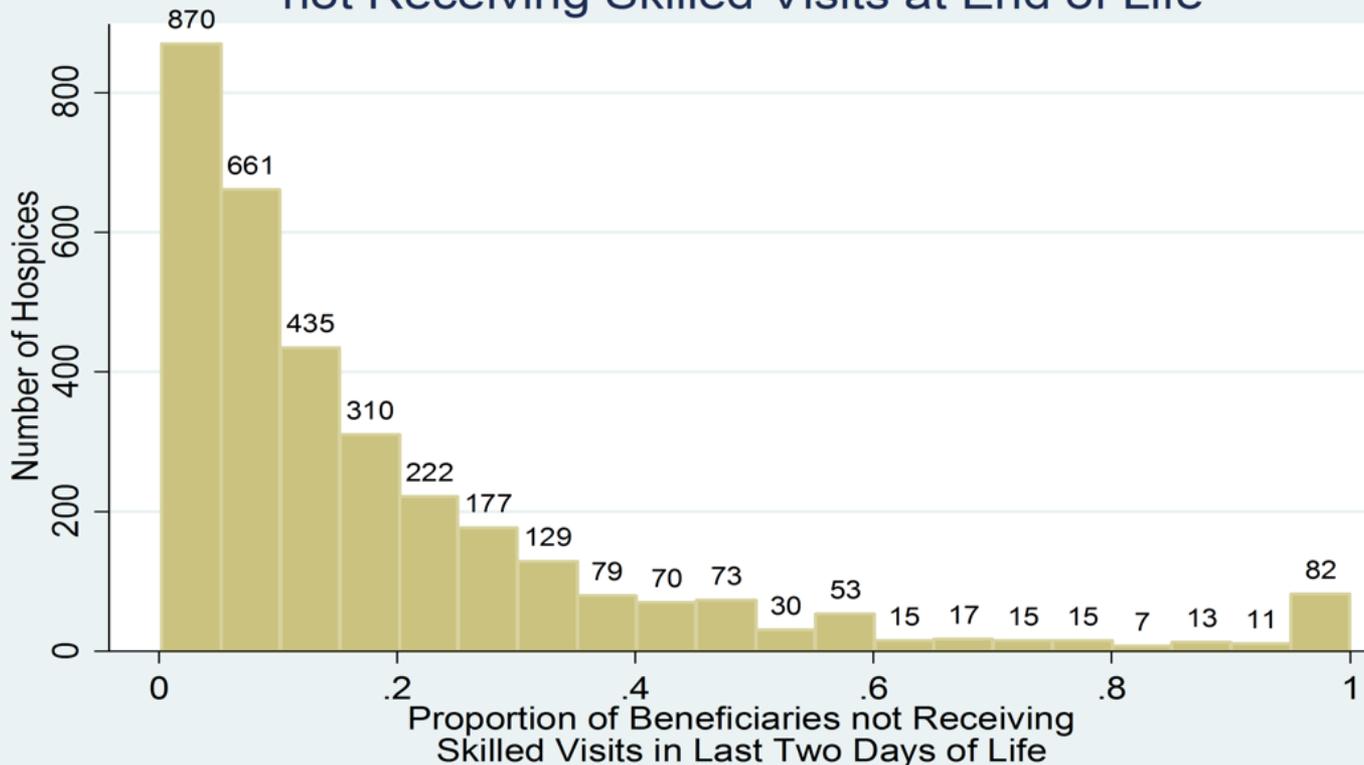
Importance of the IPOS



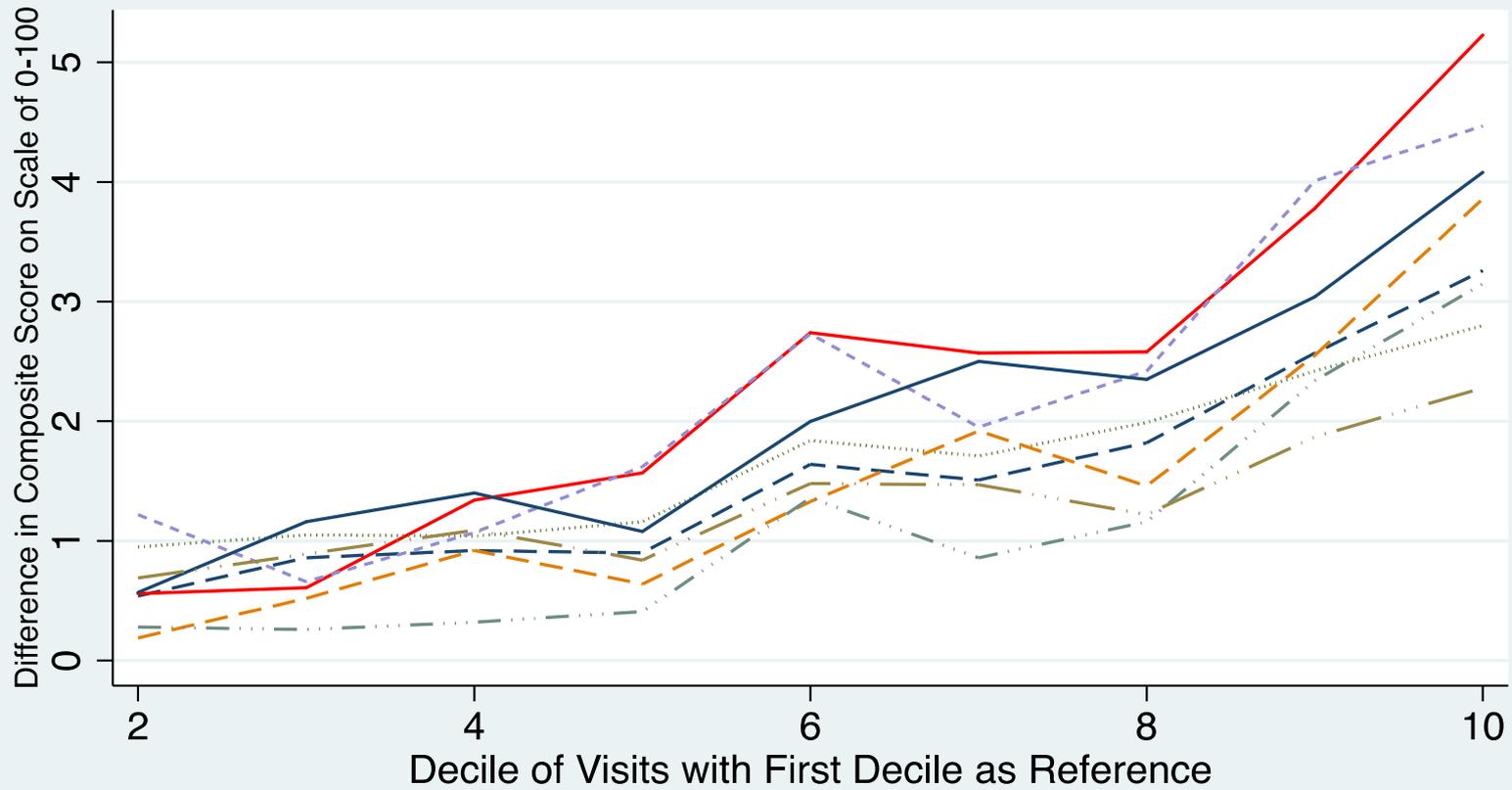
Biddy

- Brief, easily administered with visit with published psychometric properties
- Deals with the information about quality that may need to come from family or staff in this population.
- Responsiveness to change
- What we urgently need is evidence base – could come from non-experimental repository using propensity matching.

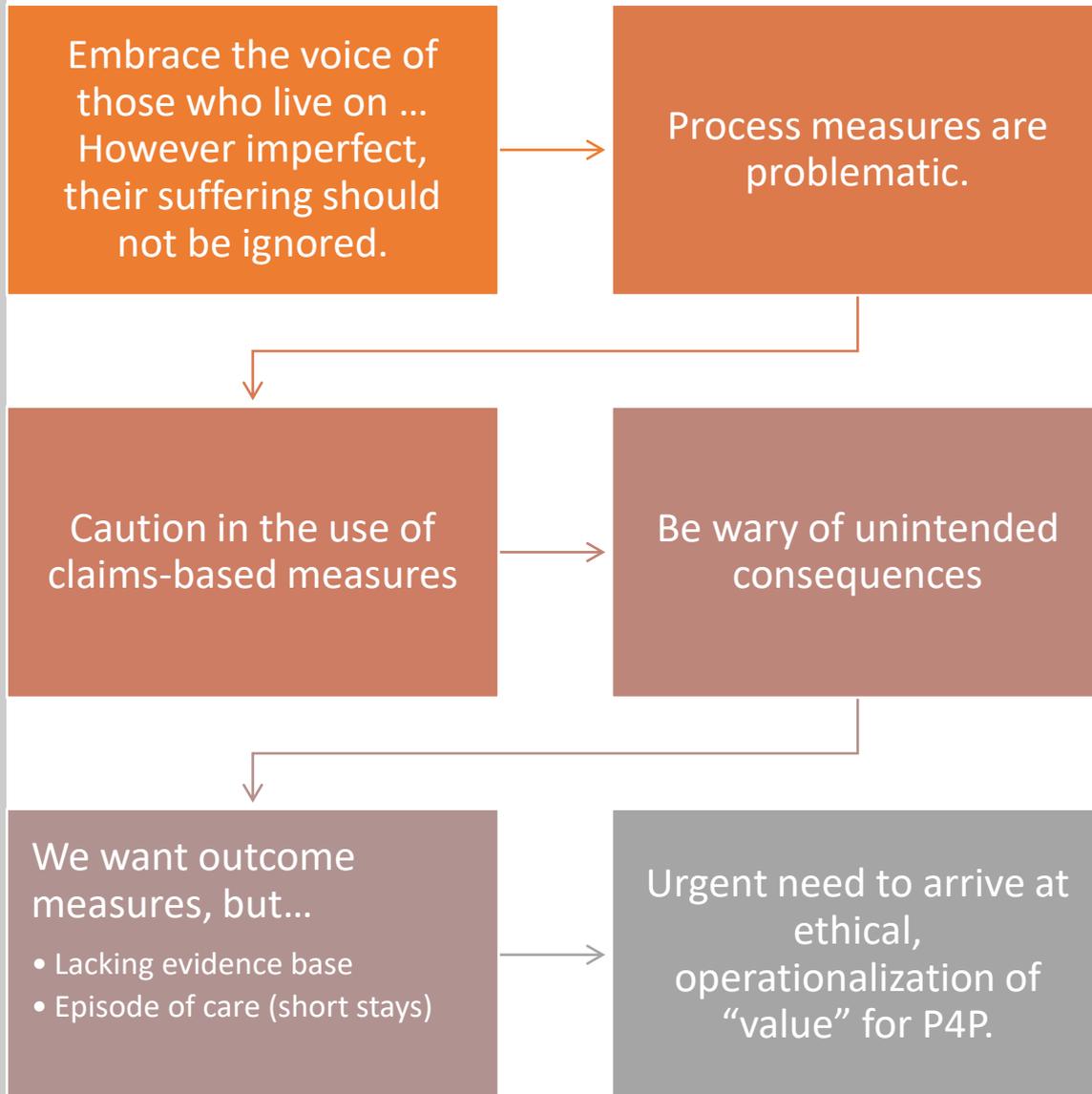
Hospice Level Rate of Beneficiaries not Receiving Skilled Visits at End of Life



- If provider level rates (i.e. the proportion of decedents at a hospice with no skilled visits at the end of life) are calculated, a large degree of variation is found
 - 393 hospices (not shown on the histogram) have a proportion equal to 0
 - 75 hospices have a proportion equal to 1
 - The 75th percentile proportion is 0.22 while the 25th percentile proportion is 0.31



Conclusions





Thank you!