

# HOSPICE ANALYTICS

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Hospice Analytics is an information-sharing research organization whose mission is to improve hospice utilization and access to quality end-of-life care through analysis of Medicare and other national datasets. Please contact Hospice Analytics with any questions or ways we may assist you.

## Hospice Data for 2013 Show Shifts in Utilization

Hospice Analytics has recently received the Medicare Claims Data from 2013. Very shortly, this data will be available to all InfoMAX subscribers, well ahead of summary reports from any other organization. What we're seeing in the data so far includes shifts in hospice utilization, nationally and state by state.

National hospice utilization overall has increased: In 2013, **45.4 percent of Medicare beneficiaries were served by hospice**, up from 44.4 percent. Most states gained in utilization, but a few lost ground (see table at right).

Ranging from 48 days (WY) to 91 (AL), **average (mean) length of stay (LOS) in hospice continued its downward trend from 71 days to 70**. Mean LOS dropped in 38 states, from 1 to 18 days (the latter in DE) and increased in only 8, from 1 to 10 days (the latter in HI). Ranging from 14 days (CT) to 44 (ID), **median LOS also dropped one day from 25 days to 24**. In all, median LOS dropped in 33 states, from 1 to 12 days (the latter in DE), and increased in only 7, from 1 to 3 days (the latter in HI).

States* where % hospice utilization increased (5% or greater change)			
State	2012	2013	%Chg
AK	20%	25%	27%
WY	28%	30%	6%
KY	36%	38%	6%
IN	41%	43%	6%
MS	35.5%	37.5%	6%
HI	38%	40%	5%
AR	41.5%	44%	5%
NC	43%	45%	5%
*All but North Carolina have utilization rates below the national median.			
States where % hospice utilization decreased (all)			
SD	45%	35%	-23%
MT	42%	40%	-5%
DE	55%	54%	-2%
IA	55%	54%	-1%
CO	52%	51.5%	-1%
Note: All figures rounded.			

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## Lower Utilization Among African Americans—Why?

In 2013, hospice utilization was 47.4% among Caucasians, but only 34.8% among African Americans. **Why would rates be 10% lower among African Americans?**

Kim Johnson, MD, a geriatrician researcher at Duke University, has obtained NIH funding to explore how to increase hospice utilization among African Americans. Dr. Johnson is seeking to interview (by short online and telephone

survey) hospices in AL, AR, CA, DE, FL, GA, IL, IN, LA, MD, MI, MS, NY, OH, OK, PA, TN, TX, VA, and DC.

Participants will receive a small honorarium and free access to two webinars, on outreach to African Americans, informed by the results of the study. If your hospice would be interested in participating, please contact Dr. Johnson at (919) 660-7531 or e-mail kimberly.s.johnson@dm.duke.edu.

# Decision Aids for Advance Care Planning: Potentially Powerful Tools in Need of Validation and Expansion

Patient-targeted decision aids can support the advance care planning (ACP) process by helping patients begin to prioritize their values and care goals, consider their choices, and communicate their preferences. But although decision aids are fairly widely available, few have been formally evaluated for effectiveness in the empirical literature.

That is according to the authors of a review of the evidence on decision aids, which was commissioned by the federal Agency for Healthcare Research and Quality (AHRQ) Effective Health Care Program, led by Mary Butler, PhD, MBA, of the University of Minnesota School of Public Health in Minneapolis, and published in *Annals of Internal Medicine*.

“Ultimately, decision aids can help patients to thoughtfully consider and document their preferences and assess important relationships,” write the authors. “A well-considered and well-communicated preference helps physicians feel comfortable about the ethics of providing or withholding treatments that affect survival.”

## KEY COMPONENTS OF A HELPFUL ACP DECISION AID INCLUDE:

- Education about anticipated conditions and care options
- A structured approach to clarifying choices
- A behavioral prompt for communicating preferences

Investigators assessed the “state of the science” on decision aids by searching the empirical literature from January 1990 to May 2014 and by interviewing “key informants”: clinicians, advocates, and experts in the field. They identified only 16 published studies that tested decision aids, most of which were found to be proprietary or not publicly available.

General decision aids — those aimed at predominantly healthy older adults — are more likely to be publicly available than are condition-specific aids, but are usually less helpful. “One notable exception is PREPARE, an interactive online resource that helps patients deliberate and communicate their decisions while providing considerable information and video examples for each decision,” note the authors.

New decision aids should be designed to be “responsive to diverse philosophical perspectives and flexible enough to change as patients gain experience with their personal illness courses,” suggest the authors. “Better interactive or patient-specific tools are needed to help patients and clinicians estimate probabilities of intervention benefits in various circumstances near the end of life.”

## ONLINE ‘PREPARE’ DECISION AID GETS HIGH RATING

Subsequent to the review by Butler et al, the developers of the PREPARE decision aid reported their findings from a pilot study of the online ACP tool. “PREPARE significantly increased engagement in ACP behavior change within one week,” write

Rebecca L. Sudore, MD, of the Department of Medicine, University of California, San Francisco, and colleagues.

“PREPARE also was rated easy to use and acceptable to older adults from ethnically and racially diverse backgrounds, many of whom had limited health and computer literacy,” the authors report in the *Journal of Pain and Symptom Management*.

The online tool guides people through an easy-to-follow, five-step process focused on building skills in communication and being prepared for future, in-the-moment decision making, rather than requiring individuals to make potentially uninformed hypothetical decisions about specific medical procedures. The interactive program then summarizes the completed steps and asks the participant to make an action plan.

## ‘PREPARE’ STEPS INCLUDE:

1. Choosing a medical decision maker and asking that person to accept the role
2. Deciding what matters most in life and for medical care
3. Choosing flexibility for the surrogate decision maker (i.e., giving permission for decision-making leeway, based on the patient’s best interest)
4. Communicating one’s wishes to others
5. Asking physicians the right questions

For the pilot test of the website, investigators assessed the behavior changes after one week for the multiple steps along the ACP process among 43 participants (mean age, 68.4 years; nonwhite, 65.1%). Although many had never before used a computer and one-third had limited health literacy, all participants viewed the entire interactive program.

## STUDY FINDINGS

1. Mean behavior change scores increased significantly after one week (from 3.1 [ $\pm 0.9$ ] to 3.7 [ $\pm 0.7$ ] on a five-point scale;  $P < 0.001$ ).
2. All scores in behavior change subscales (knowledge, contemplation, self-efficacy, readiness) also increased significantly ( $P < 0.001$  for all).
3. User ease-of-use rating was 9 ( $\pm 1.9$ ) on a 10-point scale.

“This study demonstrates that it is possible to engage people not just in the signing of advance directive forms, but also in a full range of ACP behaviors, such as identifying one’s goals for medical care and communicating with surrogate decision makers and clinicians,” write the authors. “Therefore, PREPARE may help individuals move along the behavior change pathway, begin to engage in ACP on their own, and prompt outpatient discussions with clinicians.”

A clinical trial of the patient-centered website tool is currently underway, note the authors. In addition, because evidence shows that “ACP requires a system-level approach,” the developers plan

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# Feeding Tubes Should Be Withheld or Withdrawn in Advanced Dementia Patients, Professional Society Advises

The placement of feeding tubes — gastrostomy tubes (G-tubes) or other long-term enteral access devices — is not recommended in patients with advanced dementia or other near end-of-life conditions, according to a special report from the International Clinical Ethics Section of the American Society for Parenteral and Enteral Nutrition (A.S.P.E.N.).

“Current scientific evidence suggests that the potential benefits of tube feeding do not outweigh the associated burdens of treatment in persons with advanced dementia,” write the authors of the report, which was published in *Nutrition in Clinical Practice*, the official journal of A.S.P.E.N. “Studies consistently demonstrate a very high mortality rate in older adults with advanced dementia who have feeding tubes.”

Although dementia is a leading cause of death in the U.S., it is under-recognized as a terminal illness, the authors note. Because clinicians frequently care for patients for whom feeding tubes are considered, the report offers strategies for addressing the “practice gap” between evidence-based medicine and G-tube use in patients with advanced dementia and others nearing the end of life.

“This paper recommends a change in clinical practice and care strategy based on the results of a thorough literature review,” write the authors. “Clinical practice needs to address risks, burdens, benefits, and expected short-term and long-term outcomes in order to clarify practice changes.”

The report offers a recommended approach for patients with advanced dementia or other near end-of-life conditions who are being considered for G-tube placement. It also includes tools for clinicians, such as an algorithm for the collaborative process of

decision making prior to G-tube placement, and a checklist for determining whether a patient is an appropriate candidate for the intervention. There is also a table comparing the known risks and burdens of tube feeding with the potential benefits.

Studies have found that two-thirds of all feeding tubes are inserted during an acute care hospitalization, note the authors. The most common primary diagnoses associated with tube insertion are aspiration pneumonia, dehydration, dysphagia, urinary tract infection, malnutrition, and pneumonia, “although no evidence exists that feeding tubes reduce the risk of any of these problems.”

## INCREASING USE OF FEEDING TUBES

There is increasing use of endoscopically placed tubes for long-term feeding, due to:

- The aging population
- Advances in medicine and technology
- Inadequate communication and advance care planning

“The decision for or against tube feeding must *always* be a personal decision for each patient, made together with caregivers, legal custodians, family, health care providers, and therapists,” the authors state. They recommend that clinicians carefully educate the family about the terminal nature of dementia, and address emotional issues concerning the perception of “starving” a loved one.

“Meanings, beliefs, and values related to food should be acknowledged and incorporated into the decision-making processes for artificial nutrition and hydration through a G-tube,” they write. “The decision to place a feeding tube in a patient with advanced dementia is one of the sentinel decisions that family members and healthcare professionals confront.”

Other national health care organizations have issued recent position statements discouraging the use of feeding tubes in patients with advanced dementia. These include the American Medical Association, the American College of Physicians, the American Geriatrics Society, the Academy of Nutrition and Dietetics, and the American Academy of Hospice and Palliative Medicine.

While their special report focuses on patients with advanced dementia or other end-of-life conditions, the authors believe the concepts and tools provided in the paper may be applicable to other patient populations when used in conjunction with the pertinent scientific information.

Source: “Gastrostomy Tube Placement in Patients with Advanced Dementia or Near End of Life,” *Nutrition in Clinical Practice*; Epub ahead of print, October 7, 2014; DOI: 10.1177/0884533614546890. Schwartz DB, et al; Providence Saint Joseph Medical Center, Burbank, California; Atlanta Medical Center, Atlanta; Division of Pediatric Surgery, Ann & Robert H. Lurie Children’s Hospital, Chicago; Clinical Nutrition Service and Nutrition Support Unit, Astral University Hospital, Buenos Aires, Argentina; Christus University School of Medicine, Fortaleza, Ceara, Brazil Baxter Healthcare, Singapore; Intestinal Failure Unit, Sanvite, Zapopan, Mexico; Martin Health System, Stuart, Florida; West Chester University of Pennsylvania, West Chester; Veterans Affairs Boston Healthcare System-West Roxbury Campus, Boston.

## Decision Aids (from Page 2)

to expand the program to target clinicians, surrogates, and the health care system.

PREPARE is available to the public online at [www.prepareforyourcare.org](http://www.prepareforyourcare.org).

Source: “Decision Aids for Advance Care Planning: An Overview of the State of the Science,” *Annals of Internal Medicine*; September 16, 2014; 161(6):408-418. Butler M, Ratner E, McCreedy E, Shippee N, Kane RL; Minnesota Evidence-based Practice Center, University of Minnesota School of Public Health, and University of Minnesota Medical School, Minneapolis. “A Novel Website to Prepare Diverse Older Adults for Decision Making and Advance Care Planning: A Pilot Study,” *Journal of Pain and Symptom Management*; April 2014; 674(4):674-686. Sudore RL, Knight SJ, McMahan RD, Feuz M, Farrell D, Miao Y, Barnes DE; San Francisco Veterans Affairs Medical Center, San Francisco; Division of Geriatrics, Departments of Psychiatry and Epidemiology & Biostatistics, University of California, San Francisco; Health Services Research & Development Service, Veterans Administration, Washington, DC; and People Designs, Inc., Durham, North Carolina.



## Hospice Analytics Can Meet Your Data Needs

Hospice Analytics is your data analyst and research partner in achieving sustainable success. Our online, user-friendly InfoMAX reports translate Medicare claims and cost report data into strategic knowledge of your service area, operations, and market opportunities.

**InfoMAX allows you to pull just the data you need, when you need it.** It provides 25+ report formats on preset variables (such as utilization, patient and market demographics, discharge status, levels of care, admissions and mortality, Medicare reimbursements, etc.), or you can customize reports across counties or years.

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projects on topics of special interest to you in your service environment and education to staff, board members, and leadership on who to interpret and use data to improve patient care.

### ***Cathy Wagner, RN, CHPN, MBA Joins Our Team!***

Cathy Wagner has been active in hospice since 1984 in Ohio and Colorado, serving primarily in executive management and in educational roles. Cathy was most recently the Executive Director of Colorado Community Hospice, now Kindred at Home, in Denver. Cathy will be advising our clients on utilizing data-based information to improve patient care and organizational efficiency.



In addition to her work with Hospice Analytics, Cathy serves as a part-time instructor at Red Rocks Community College, on the RN exam development committee for the National Board for Certification of Hospice and Palliative Nurses, and on the Board of Directors for The Colorado Center for Hospice and Palliative Care. Cathy was a member of the Board of Directors for the Hospice and Palliative Nurses Association (HPNA) for seven years.

## *NEVER underestimate the POWER of data...*

Hospice Analytics is an information-sharing organization whose mission is to improve hospice utilization and access to quality end-of-life care through analysis of Medicare and other national datasets.

More than 50% of the State Hospice Organizations participate in Hospice Analytics' Market Reports Project. These State Hospice Organizations represent over 60% of the hospices serving over 70% of the hospice patients in the country.

Substantial revenue is shared with participating non-profit State Hospice Organizations.

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