

Advanced Illness Care: Key Statistics

12-10-12

The Coalition to Transform Advanced Care (C-TAC) is a nonprofit, nonpartisan organization dedicated to transforming advanced illness care by empowering consumers, changing the health care delivery system, improving public and private policies and enhancing provider capacity.

<http://thectac.org>

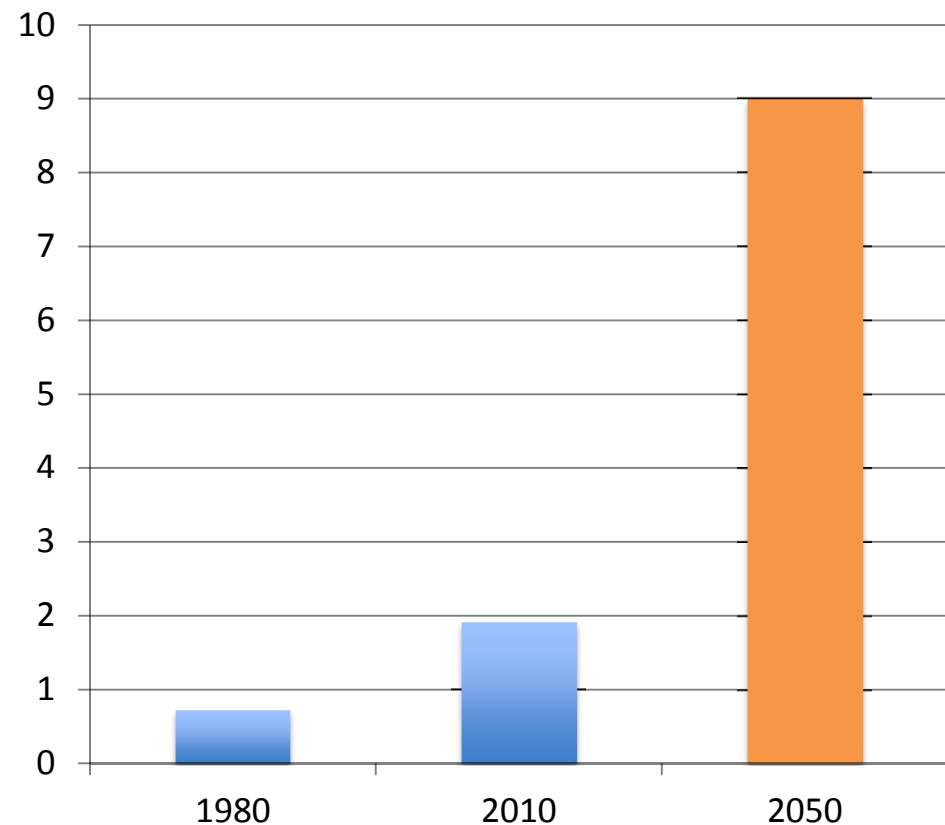
**Coalition to Transform
Advanced Care** 

United States Age and Demographic Trends

While anyone can have advanced illness, it disproportionately affects older adults.

- By 2030, **9 million Americans will be over the age of 85** and will suffer from substantial disability and chronic conditions as a result of their advanced age.
 - By way of comparison, only 4.2 million Americans were 85 or older in 2000. (RAND, 2007)
- Beneficiaries with **5+ chronic conditions represent the fastest growing segment** of the Medicare population.
 - In 2005 they represented 23% of Medicare beneficiaries and 68% of Medicare spending. (Health Affairs, 2010)

Projected growth: Number of Americans age 90 and Over (millions)

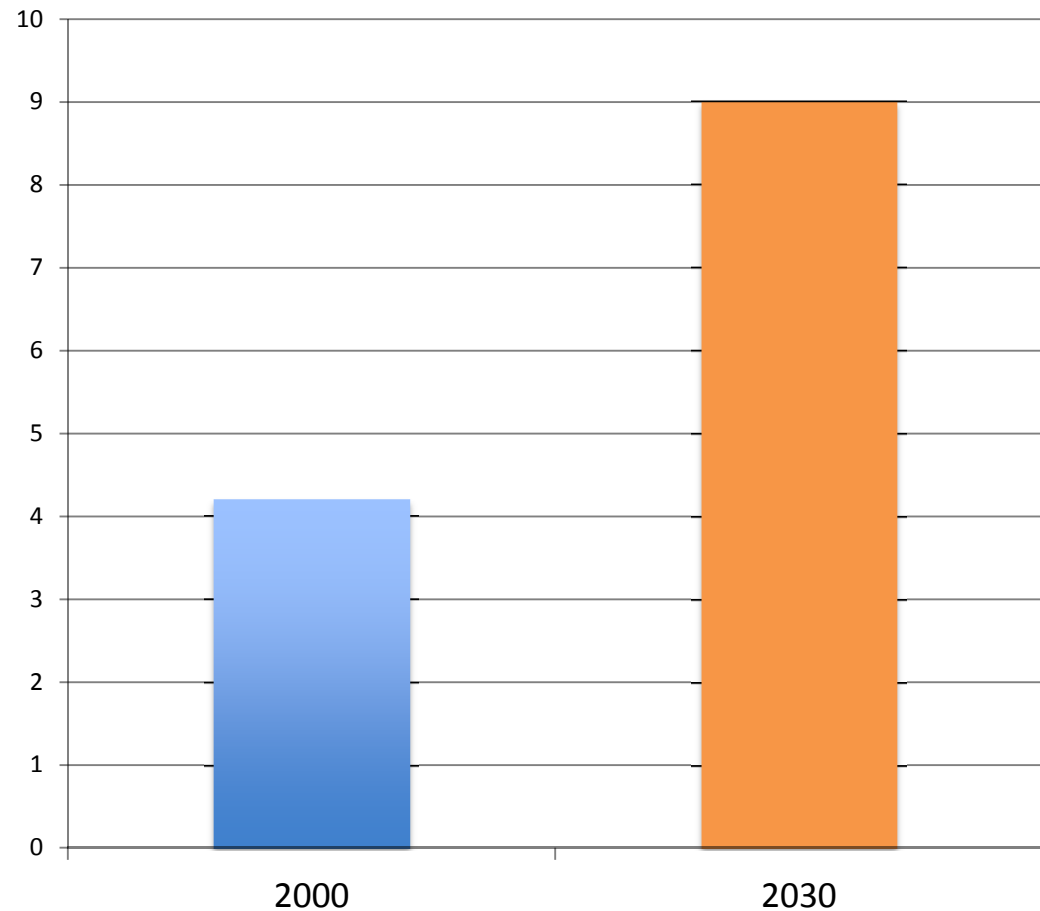


Utilization Trends for the Chronically Ill Elderly

As the health of those with advanced illness declines, they suffer increasingly frequent downturns that lead to avoidable hospital admissions; comorbidities among this population also lead to increased hospitalizations. Multiple specialists further fragment their treatment.

- Nearly **18%** of Medicare patients age 85 and older with an inpatient hospital stay had a comorbidity of congestive heart failure, compared with roughly **9%** of patients age 65 to 74 (Hartman, 2008)
- Per year, nearly **25%** of seniors visit the emergency department at least once, and 9% visit at least twice. **30% of seniors 75+ visit the emergency room** (Centers for Disease Control & Prevention, 2007)

Projected growth: Americans over 85 suffering from chronic illness (millions)



Personal and Out-of-Pocket Costs

There is significant—and not unjustified—fear among individuals that their life savings and way of life can be swiftly destroyed by a serious illness.

- The **cost of treatment ranked as the highest concern** of Americans when they thought about advanced illness (Cambia Foundation, 2011)
- **25 percent of seniors lose their entire assets** during the last five years of life because of the costs of advanced illness care (Kelley, 2012; see graphic to right)

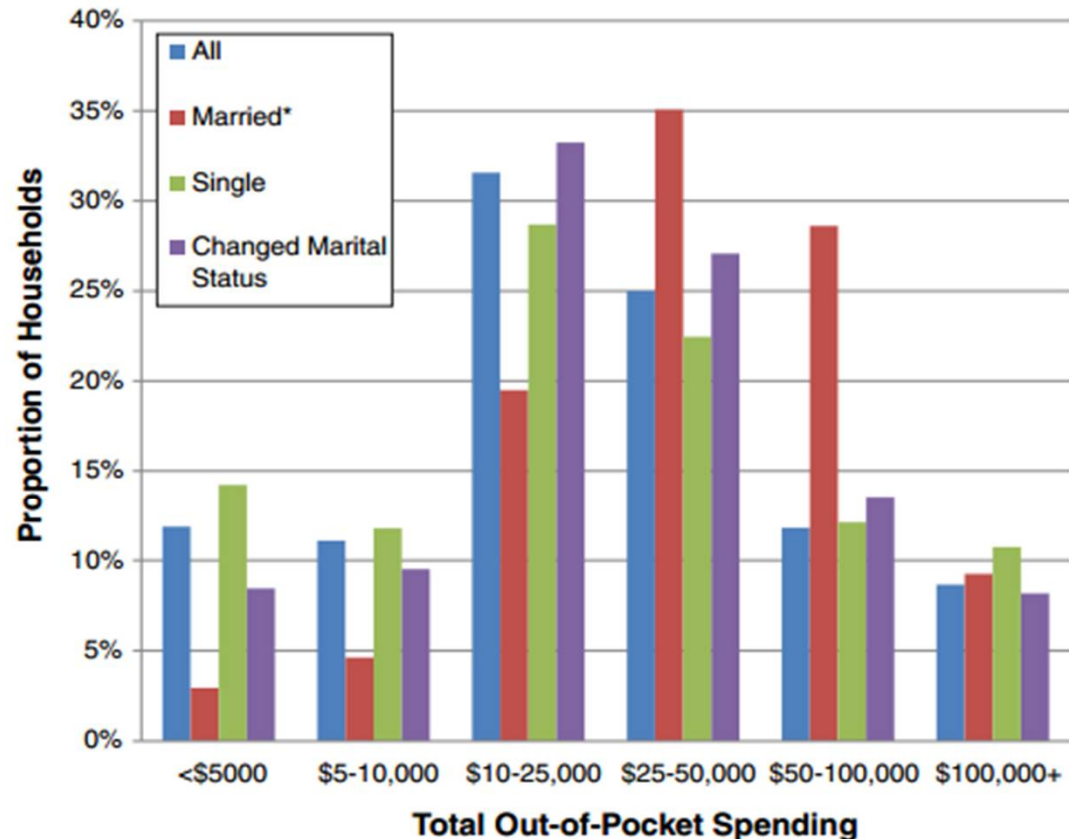
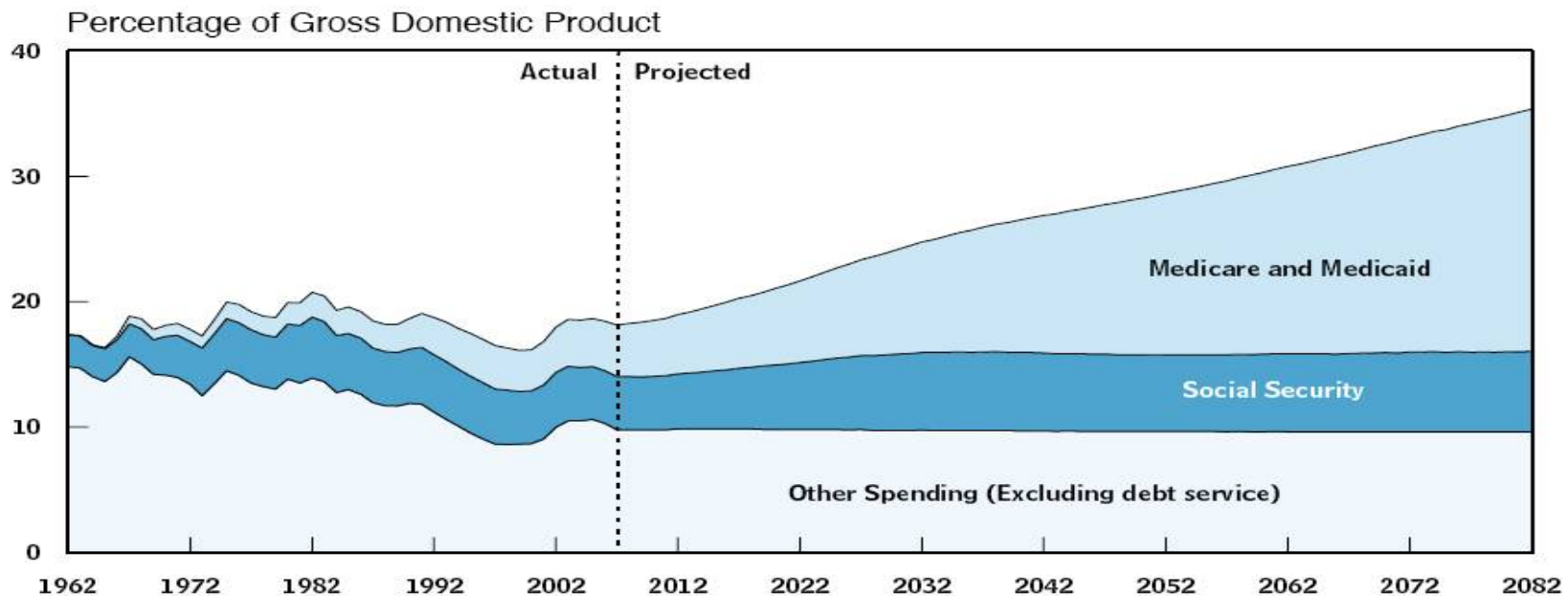


Figure 1. Distribution of out-of-pocket spending in the last 5 years of life. Legend: *Expenditures for married include expenses of both spouse and household head.

Costs to Society

- The time burdens for caregivers of the frail elderly result in anywhere from **\$17.6-\$33.1 billion in lost productivity**, and approximately 2.5% of caregiving employees left the workforce entirely in 2004 for the health reasons of a frail elderly family member (Health Affairs, 2009)
- **Nearly 30% of Medicare expenditures in a given year are for the 5 percent of beneficiaries who died during that year**, a range that has remained consistent for many years (Lubitz and Riley, Hogan et al, 2010).
- The last year of life represents more than 25 percent of total Medicare spending, a **5 percent reduction in end of life costs** would amount to Medicare savings of **\$6.4 billion in 2010 and \$90.8 billion over ten years** (Berenson, 2011).

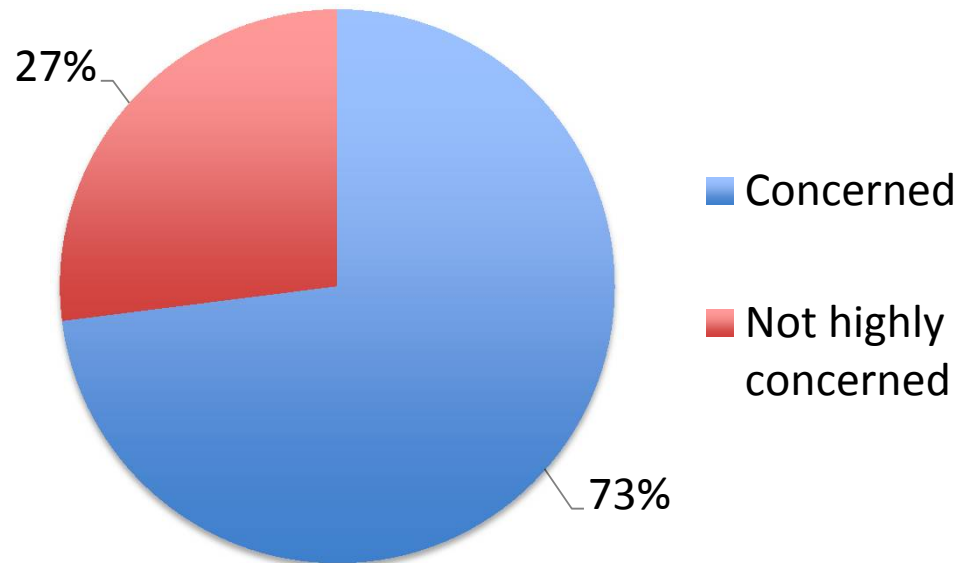


Americans' Perspectives on Advanced Illness

There is no common language of health and medical terms among patients, families and caregivers and even among health professionals, who often assign different meanings and interpretations to the same words. The vast majority of people do not understand their options for care for serious illness (C-TAC Consumer Brief, 2012)

- **Still, 93% of Americans** say advanced care (including hospice and palliative care) should be a top priority for our health care system.
 - **46% of people** have thought about advanced care issues a great deal
 - **Yet only 24 % consider themselves very prepared for dealing with these issues.** (Cambia Health Foundation, 2011)
- **70% of Californians surveyed said their home is their preferred place of death,** but only **32%** of Californians pass away in their homes. (California Healthcare Foundation, 2012)

Americans highly concerned (on 10-scale) about not having adequate information about treatment options in case of serious illness



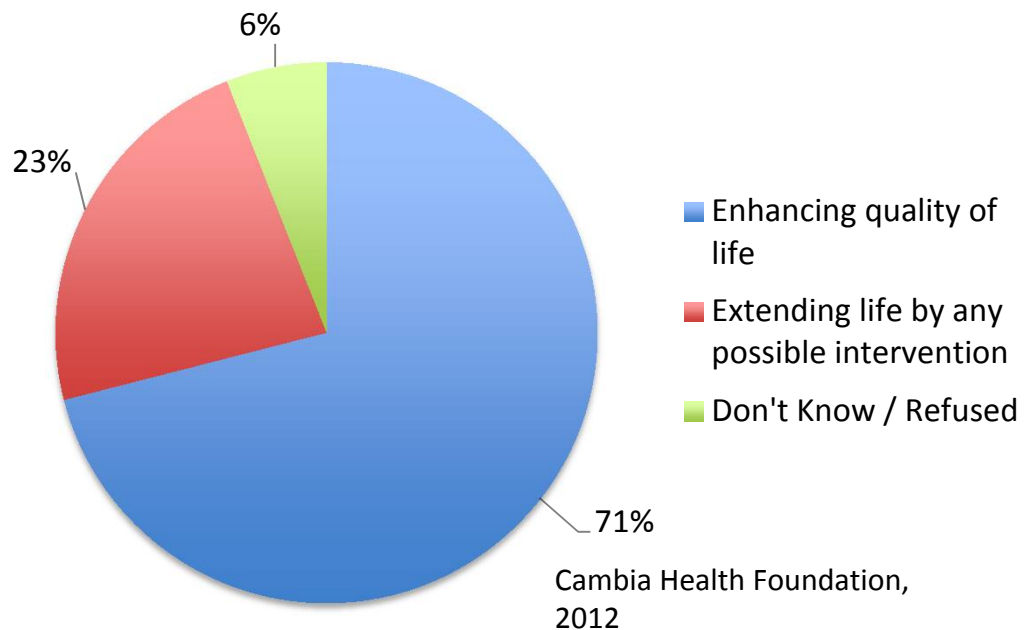
Cambia Health Foundation,
2012

What Do Americans Want During Advanced Illness?

Recent research indicates that people want care that enhances their **quality of life**.

- Most would choose a **enhancing quality of life** over extending life by interventions that would reduce quality of life. (Cambia Health Foundation, 2011)
- They also want **to avoid being a burden to their family** and to have **adequate information** about treatment for advanced illness. (California Healthcare Foundation, 2012)
- For chronic and late-stage illness, the **majority says they prefer to stay in their homes**, rather than in other settings, with the support of their families, who are their most trusted caregivers. (Whitlatch & Feinberg, 2007; Harris Interactive, 2010)

Americans' attitudes toward which is more important



Cultural Issues and Advanced Illness Care

Research shows that cultural and ethnic beliefs affect how people make decisions about care for advanced illness and the end of life.

- Decision-Making. For example: African Americans often value the role of the family or close friend in decision-making whereas Anglo-Europeans emphasize the patient's autonomy in making decisions.
- Advance care planning. For example: African American are more likely than Whites to believe that the completion of an advance directive may result in the withdrawal or withholding of care at times when that is not the wish or desire of the patient.
- Death and Dying. For example: Chinese believe that it is bad luck to talk about death and tend to avoid completing advance directives.
- Communication and Interaction with Clinicians. For example: to Hispanics, bad news may be seen as causing more harm to the patients and families and they may request to withhold information from the patient to allow him or her to maintain hope.
- Preference for Care. For example: Mexican-Americans believe that enduring sickness is a sign of strength. For Latinos, patients start by treating themselves or their family members with home or traditional remedies and/or providers.

(Bullock 2011; Tulsky, 2005; Thomas, 2011; Searight and Gafford, 2005)

Models that Work

- Sutter Health's Advanced Illness Management (AIM)TM program, **reduced hospitalization rates by over 60%** at 30, 60, and 90 days post program enrollment. Direct inpatient costs were reduced **by \$2,000 per enrollee per month** on average. Over 2/3 of AIM enrollees accepted enrollment in hospice. Patient and physician satisfaction with the program were high. This AIM pilot study was implemented in Sutter's Sacramento region, which was already a Dartmouth Atlas benchmark performer in low Medicare costs for this population. (Health Affairs, 2011)
- The Aetna Compassionate CareSM program coordinates medical care, benefits, and community-based services, and eliminates barriers to continuity of care such as Medicare hospice eligibility constraints and health-plan-imposed day and dollar limits on hospice care. Hospice enrollment rates for Medicare patients averaged 63%. The percentage of enrollees with a hospitalization decreased from 88 to 30%; inpatient days/1000 patients **decreased by 82% and ICU days/1000 were reduced by 86%** (Health Affairs, 2009)
- Home-Based Primary Care (HBPC), developed through the US Veterans Health Administration, has shown to **reduce hospital days by 63%, nursing home days by 83%, and total cost of care by 24%**. At the same time, HBPC received the highest patient satisfaction ratings of any VA survey. (CMS, 2010)

Models that Work

- Gundersen Health System's Respecting Choices® (RC) program is now being implemented at over 55 sites in the US and is in widespread use in Australia and Canada. RC has contributed significantly to the low rates of Medicare inpatient utilization seen in its region of La Crosse County, WI.
 - Dartmouth Atlas data shows that at Gundersen Lutheran, total Medicare reimbursement and hospital days for patients in the **last 2 years of life are 29% and 43% lower respectively than the national average**. A 2010 study in the *Journal of the American Geriatric Society (JAGS)* showed that at Gundersen Lutheran, 99.4% of patients had an advance directive in the medical record at the time of death, and **in 99.5% of cases, medical treatment was in accord with patient wishes**.
- At Ascension Health, the nation's 3rd largest healthcare delivery system, inpatient pilots have seen improved pain and symptom management scores (pain well controlled within 48 hours 92% of the time, dyspnea well controlled w/in 48 hours 98% of the time), spiritual assessments within 24 hours 100% of the time, and a significant increase in the completion of advance directives. Their home health palliative care team has achieved a **30 day readmission rate of 1.2% and increased hospice median LOS to 60 days**. (Health Prognosis, 2011)

Models that Work

- Hospice & Palliative Care of Western Colorado (HPCWC) palliative care includes nursing care coordination, monthly assessment visits, weekly telephone support, social work resources, 24-hour on-call response, and volunteer support.
 - **In 2005 only just over 50 percent of patients had at least one hospitalization over the last six months of life, compared to the U.S. average of a little over 70 percent. Reimbursement per decedent in 2005 covering the last six months of life for inpatient hospitalization was less than \$8,000 while the U.S. average was just under \$14,000 (the savings were \$6,236 per person).**
- A study of a Guided Care enhanced care management program for highest-risk older patients found that over a six-month period, those in the intervention group had fewer hospital admissions, days in the hospital, and ER visits than matched highest-risk patients in the control group.
 - **Admissions to the hospital were 44 percent lower in the intervention group, and hospital days in the intervention group were only one-third as high as in the treatment group.** The rate of ER visits was only about half as high for those participating in the guided care program. Moreover, **total health expenditures were lower for people in the intervention group—\$4,586 versus \$5,964**


The Coalition to Transform Advanced Care (C-TAC) is a national non-profit, non-partisan alliance of patient and consumer advocacy groups, health care professionals and providers, private sector stakeholders, faith-based organizations, and health care payers.

<http://thectac.org>. Members include:



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C-TAC's Action Plan



Doing What Works: promoting best-practice care delivery (the models that work in clinical and community settings) to ensure high-quality, coordinated advanced illness care, across all settings;

Creating Policy Change: developing and advocating for federal and state legislative, regulatory, judicial and administrative initiatives and also private policies to improve care for those with advanced illness.

Educating Health Professionals: to better serve patients and families/caregivers so people know their options, make informed choices, get the care they need and avoid procedures they don't want;

Empowering the Public: helping people to understand and make informed choices for themselves and their families and to call for change in care delivery and in policies;

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