

**NICHE Conference April 19, 2017 Roundtable Discussion on  
Summary Results of Progress, Barriers, & Needs in End-of-Life & Serious Illness Care**  
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**National Academy of Medicine Survey**  
March 17-May 16, 2016

**Survey participants:** majority health care providers, nurses, nurse practitioners, physicians and palliative specialists.

<b>Questionnaire Summary Results:</b> <a href="https://nam.edu/wp-content/uploads/2016/06/Assessing-Progress-in-EOL-Serious-Illness-Care-Questionnaire-Summary-Results.pdf">https://nam.edu/wp-content/uploads/2016/06/Assessing-Progress-in-EOL-Serious-Illness-Care-Questionnaire-Summary-Results.pdf</a>	YES	NO	WORSE	NO ANSWER
End-of-Life care in America: improvement	34.2%	53.3%	9%	3.6%
Care delivery Improvements- individual preferences & family involvement	54.2%	38.8%	0%	7.0%
Communication & Planning- improvements in clinician-patient communication & advance care planning (ACP)	59.1%	36.8%	0%	4.1%
Professional Education & Development-improved?	65%	28.9%	0%	6.2%
Policies & Payment Systems: have they improved?	45%	44.7%		10.3%
Public Education & Engagement: has it improved?	63.4%	33.5%	0%	3.1%

**Remaining Barriers to Improvement: top five**

1. Communication between providers, patients & families
2. Understanding of care options and ACP
3. Professional education & training
4. Understanding of palliative care
5. End-of-life issues still “taboo” in conversations

**Top five highest focus areas**

1. Understanding of palliative care, including Hospice benefit
2. Financial incentives to improve quality of life and aligns with patient wishes/family preferences
3. Communication training including sensitivity to cultural differences
4. Improving medical & nursing school curricula & professional guidelines
5. Support for family caregivers/greater interdisciplinary coordination

**Gaps in the Questionnaire**

- Challenges for rural areas & minority populations
- Funding & support for non-physician care providers
- Opportunities for technology to play a role (e.g. electronic health records)

## **Historical Context & References**

**February 1998** Peaceful Death: Recommended Competencies and Curricular Guidelines for End-of-Life Nursing Care <http://www.aacn.nche.edu/el nec/publications/peaceful-death>

**September 2014:** Release of the [\*Dying in America\*](#) National Academy of Medicine report.

**March 2015:** NYU submitted a commitment statement for the National Action Conference: Policies and Payment Systems to Improve End-of Life Care. Organizational commitment statements on the [IOM website](#)

**February 2016:** AACN Endorses Palliative Competencies and Recommendations for Undergraduate Nursing Education. <http://www.aacn.nche.edu/el nec/New-Palliative-Care-Competencies.pdf>

**Updated February 2016:** The End-of-Life Nursing Education Consortium (ELNEC) project is a national education initiative to improve palliative care.

**March 2016:** National Academy of Medicine is conducting a nationwide [survey](#) to track improvements over the past 18 months, discover barriers that have prevented progress, and better understand current areas of need.

**May 23, 2016:** Assessing Progress in End-of-Life and Serious Illness Care-meeting summary <https://nam.edu/meeting-recap-assessing-progress-in-end-of-life-and-serious-illness-care/>

## **IOM Dying in America Report: Recommendations-2014**

- 1. Delivery of Care:** Insurers supporting comprehensive delivery of person/family centered care. Health care delivery organizations improve in access for interdisciplinary palliative care teams. Reporting of quality and cost measures characterized by transparency & accountability.
- 2. Clinician-Patient Communication & Advanced Care Planning:** Measurable, actionable & evidenced based quality standards for clinician-patient communication and advanced care planning that payers and professional societies will support. Payment, licensing and credentialing tied to these standards.
- 3. Professional Education & Development:** Establishment by all key players (educational institutions, credentialing bodies, accrediting boards, state regulatory agencies & health care delivery organizations) appropriate training, certification and/or licensure requirements to strengthen palliative care knowledge & skills
- 4. Policies & Payment Systems:** Integration of insurers (all types) & health care delivery programs financing to support quality of care consistent with the values, goals & informed preferences of people with advanced serious illness nearing the end of life. Need for legislative action. Requirement of public reporting on quality measures, outcomes & costs, interoperable electronic health records with specific advanced care planning communication.
- 5. Public Education & Engagement:** Provision of fact based information on care options using appropriate media channels. Encourage meaningful dialogue; dispel misinformation that may impede informed decision-making.