Advance Directives:
Are We Expecting More Than They Can Deliver?

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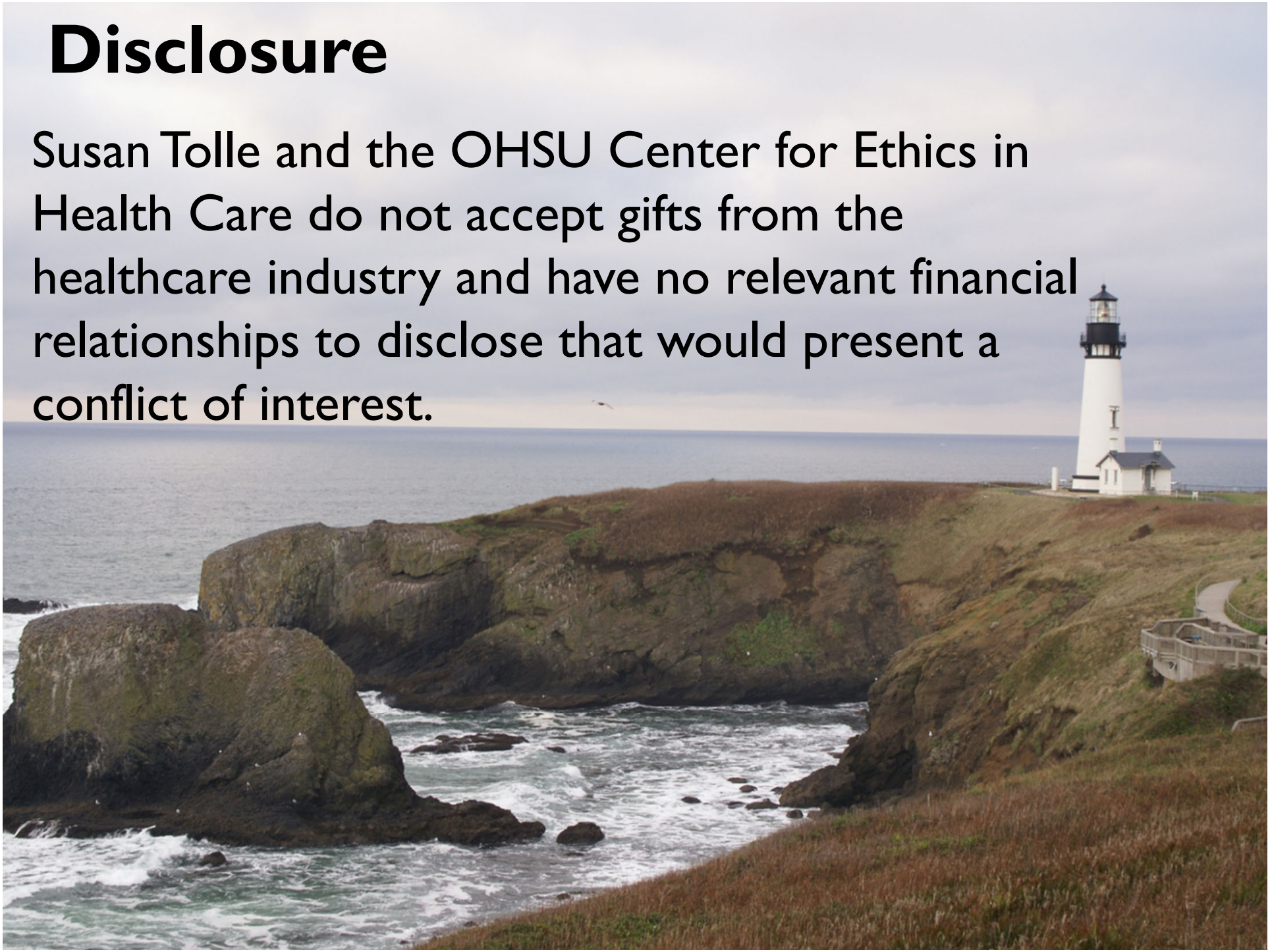
Disclosure

Susan Tolle and the OHSU Center for Ethics in Health Care do not accept gifts from the healthcare industry and have no relevant financial relationships to disclose that would present a conflict of interest.



Objectives:

1. Examine ways that advance directives are effective
2. Review data about the short comings of advance directives
3. Explore data about changing perceptions of quality of life as people adapt to living with disabilities

Differences between Advance Directive & POLST

	Advance Directive	POLST (Portable Orders for Life Sustaining Treatment)
Who is it for?	Everyone 18 and older.	People with a serious illness or who are very old and frail.
What kind of document is it?	It is a legal document.	It is a medical order.
Who signs it?	You fill it out and sign it. Also, your health care representative signs it and witnesses or a Notary.	Your doctor* fills it out with your input. Then signs it.
Do I need a lawyer?	No.	No.
Who keeps the form?	You keep the original where loved ones can find it. You give a copy to your health care representative and your doctor.	Your doctor's office keeps it and enters it into the electronic Oregon POLST Registry. They give you a copy that you post at home in a visible place like the fridge.
Can I change the form if I change my mind?	Yes. You can tear up the old one. Then write a new one where loved ones can find it. You give a copy to your health care representative and your doctor.	Yes. You can ask for an appointment with your doctor to change it.
What if there is a medical emergency and I cannot speak for myself?	Your health care representative speaks for you and honors your wishes.	The ambulance staff, hospital staff and doctors look for the medical orders in the electronic data base and follow them.

*Doctor means anyone who can sign a POLST form (MD, DO, NP, PA, ND).

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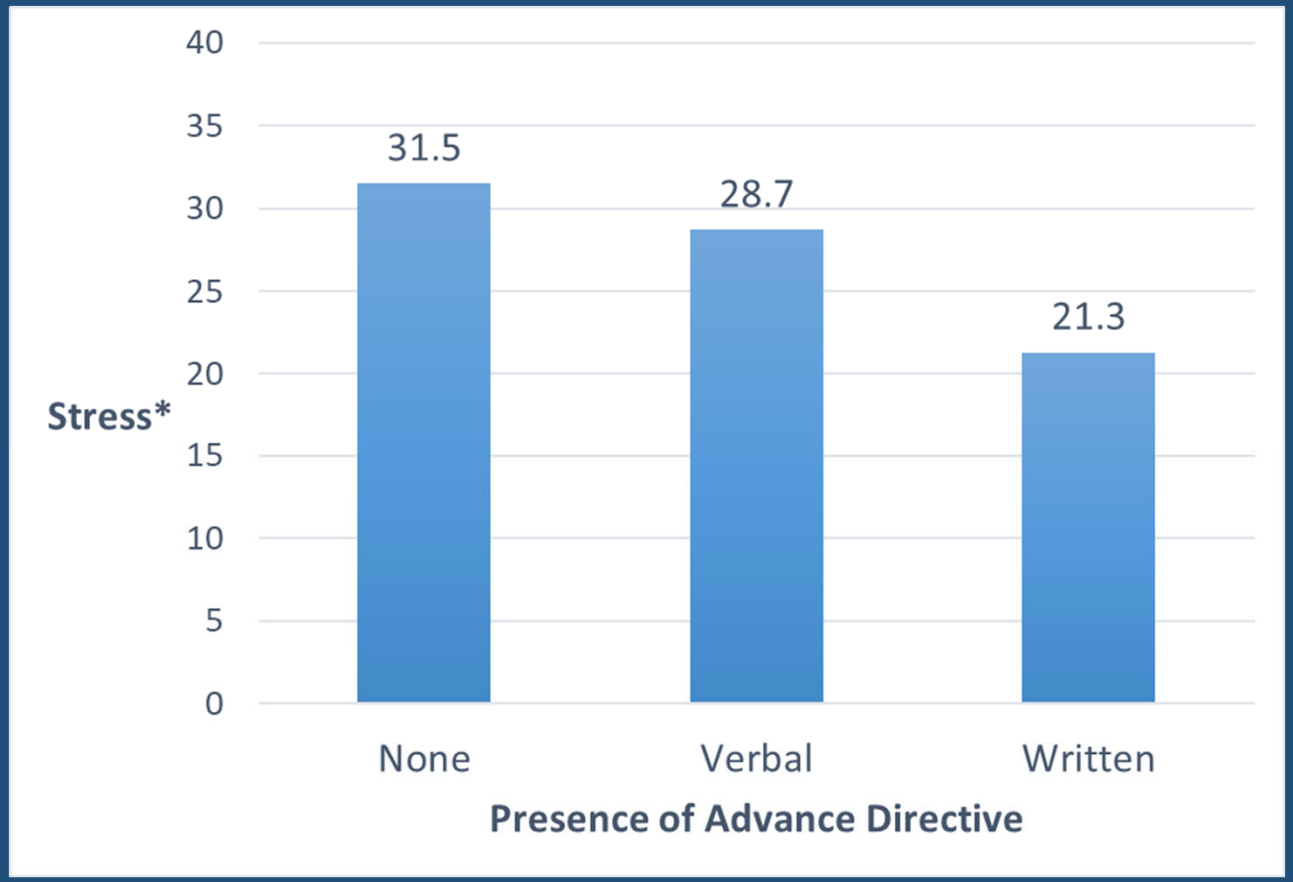
In What Ways are Advance Directives Effective?

Effect of Advance Directives on Family Stress



*Stress measured on Horowitz Impact of Events Scale (Higher score = more stress)

Tilden VP, Tolle SW, Nelson CA, Fields J. (2001). **Family Decision-Making to Withdraw Life-Sustaining Treatments From Hospital Patients**. *Nursing Research*. March/April 2001.

Advance Care Planning Decreases:

1. Anxiety
2. Grief
3. Post-Traumatic Stress

And…

4. Burden on Surrogate Decision Makers

McMahan RD, Tellez I, Sudore RL. (2021). **Deconstructing the Complexities of Advance Care Planning Outcomes: What Do We Know and Where Do We Go? A Scoping Review**. *J Am Geriatr Soc*. 69: 234-244. doi:10.1111/jgs.16801

Advance Directives Allow the Appointment of a Surrogate (Health Care Representative/POA)

Shortcomings of Advance Directives

Advance Directives/Care Planning: Clear, Simple, and Wrong

R. Sean Morrison

Journal of Palliative Medicine
Vol. 23, No. 7
June 9, 2020

doi:10.1089/jpm.2020.0272

A 2018 Review of 80 Systematic Review
(1600 original articles)

Conclusions:

- ✓ No evidence of influence on medical decision making
- ✓ No association with goal concordance

Jimenez G, Tan, WS, Virk AK, Low CK, Car J, Yan Ho, AH. (2018). **Overview of Systematic Reviews of Advance Care Planning: Summary of Evidence and Global Lessons.** *Journal of Pain and Symptom Management*. 16 May 2018. Vol 56, Issue 3. doi:10.1016/j.jpainsymman.2018.05.016

A 2020 Scoping Review of 62 Recent High-quality Articles

- ✓ No evidence that ACP influenced goal concordant care
- ✓ No association with subsequent health care use (ED visits, hospitalization or critical care)

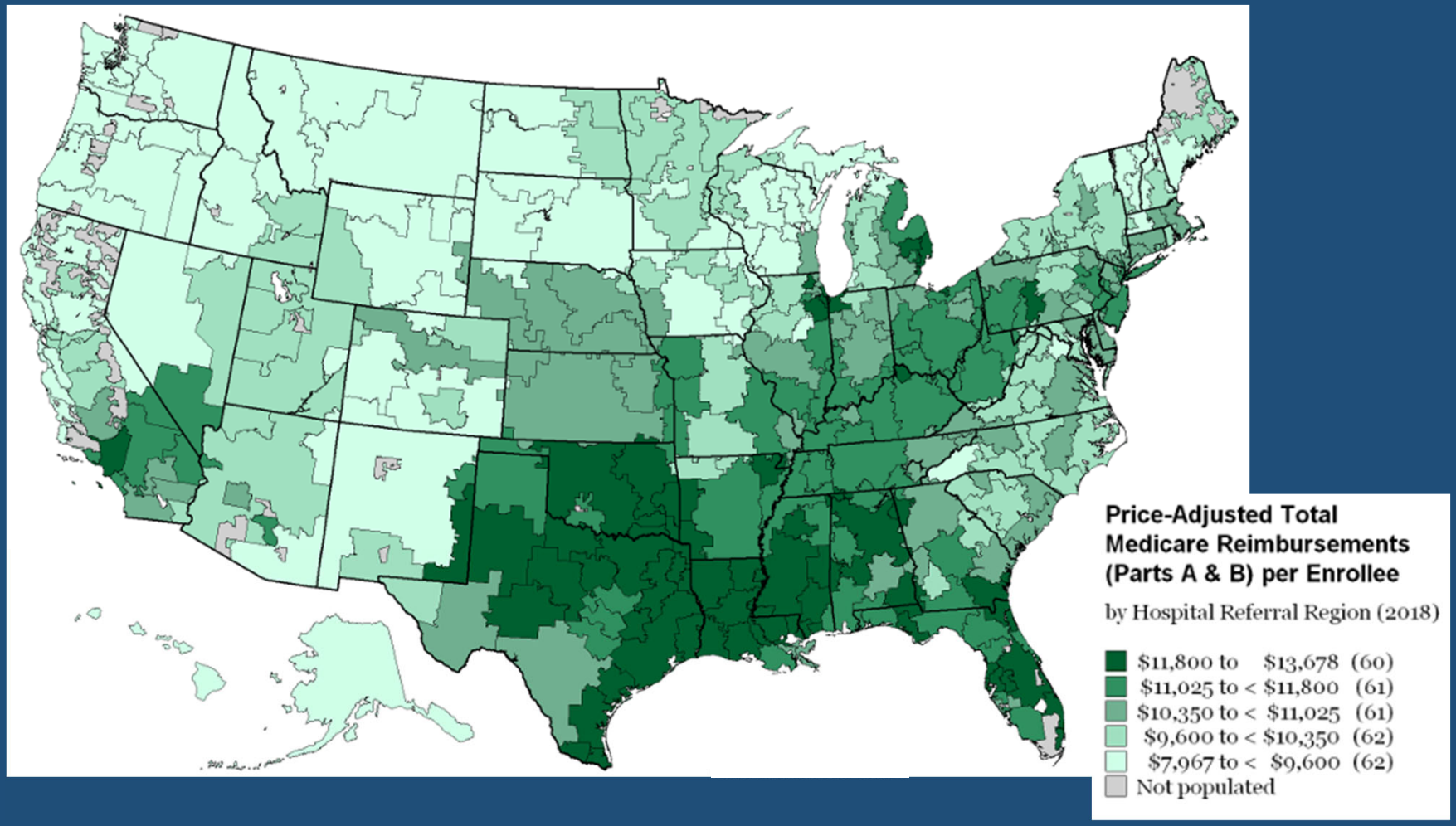
McMahan RD, Tellez I, Sudore RL. (2021). **Deconstructing the Complexities of Advance Care Planning Outcomes: What Do We Know and Where Do We Go? A Scoping Review.** *J Am Geriatr Soc*. 69: 234-244. doi:10.1111/jgs.16801

Advance Directives' Negligible Association on Hospitalizations and Hospital Deaths

- Health and Retirement Study
- N=6,122 age 60 & older at death
- 72% advance directives at time of death 2010

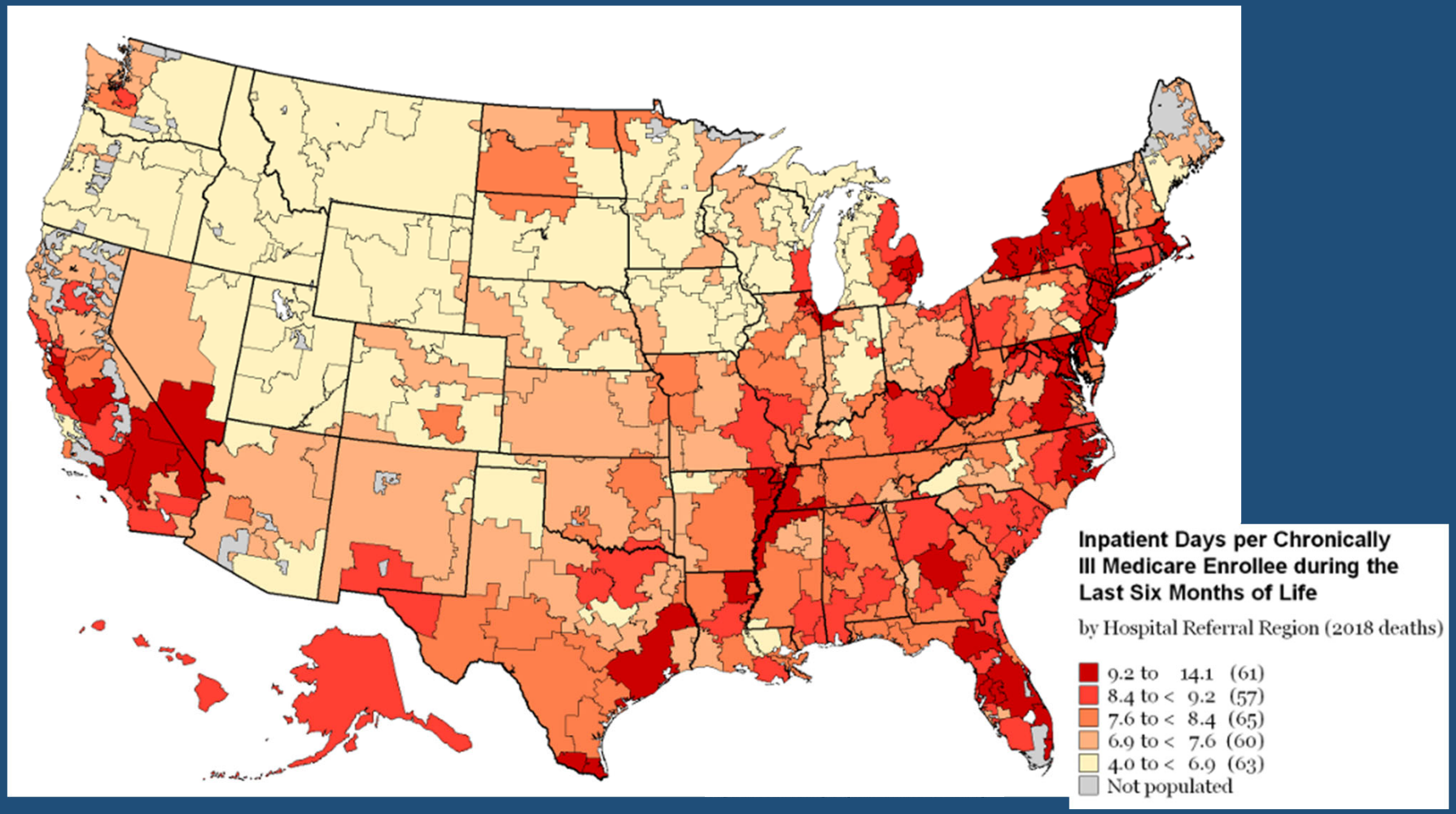
Silveira MJ, Wiitala W, Piette J. (2014). **Advance Directive Completion by Elderly Americans: A Decade of Change A Scoping Review.** 02 April 2014. *J Am Geriatr Soc*. 62:706–710. doi:10.1111/jgs.12736

Price-Adjusted Total Medicare Reimbursements per Enrollee by Hospital Referral Region (2018)



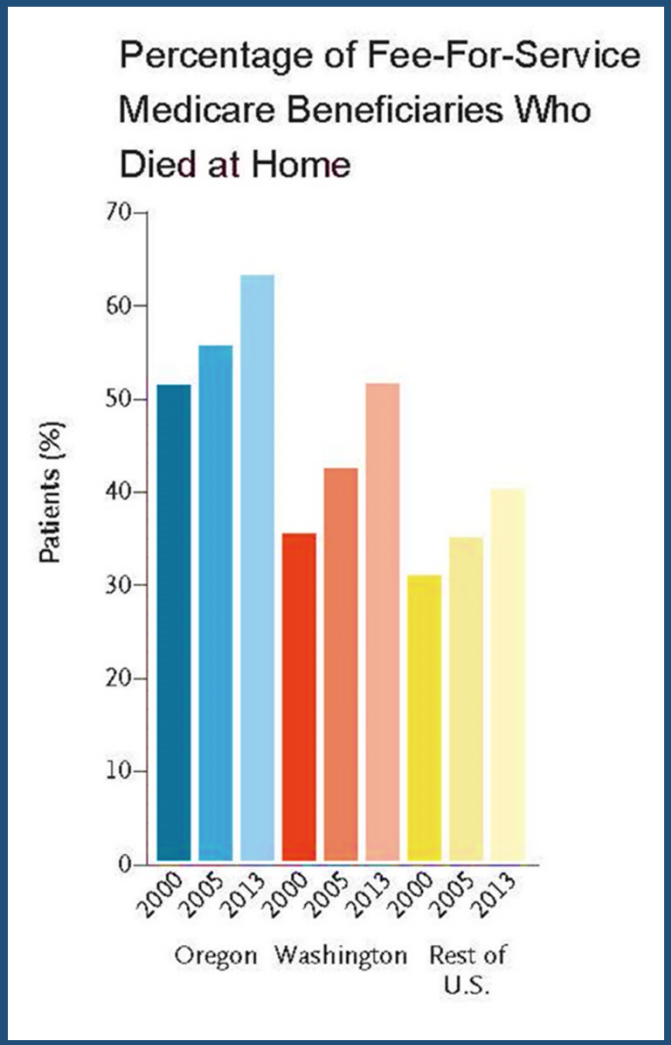
The Dartmouth Atlas of Health Care: 2018 Data Update. Page 3 - Map 1.

Inpatient Days per Chronically Ill Medicare Enrollee during the Last Six Months of Life by Hospital Referral Region (2018 deaths)



The Dartmouth Atlas of Health Care: 2018 Data Update. Page 7 - Map 3.

Deaths among Fee-for-Service Medicare Beneficiaries in Oregon, Washington and the Rest of the United States



Tolle SW, Teno JM. (2017). **Lessons from Oregon in Embracing Complexity in End-of-Life Care.** *New England Journal of Medicine.* 16 March 2017. 376:1078-1082. doi: 10.1056/NEJMsb1612511

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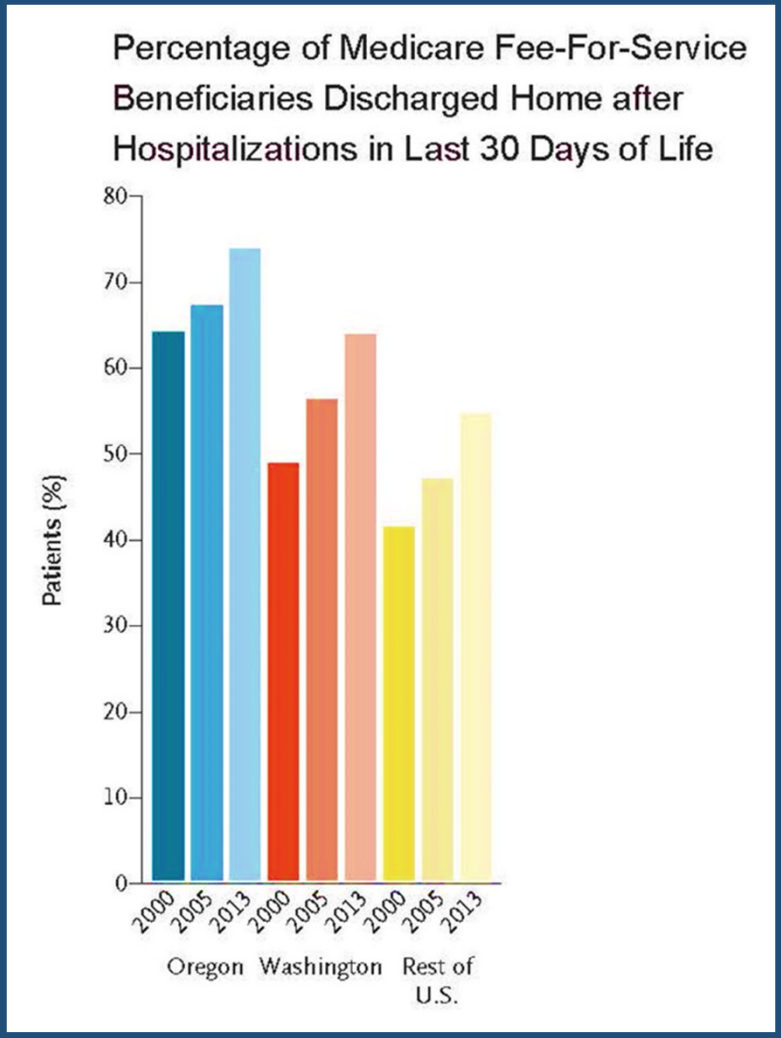

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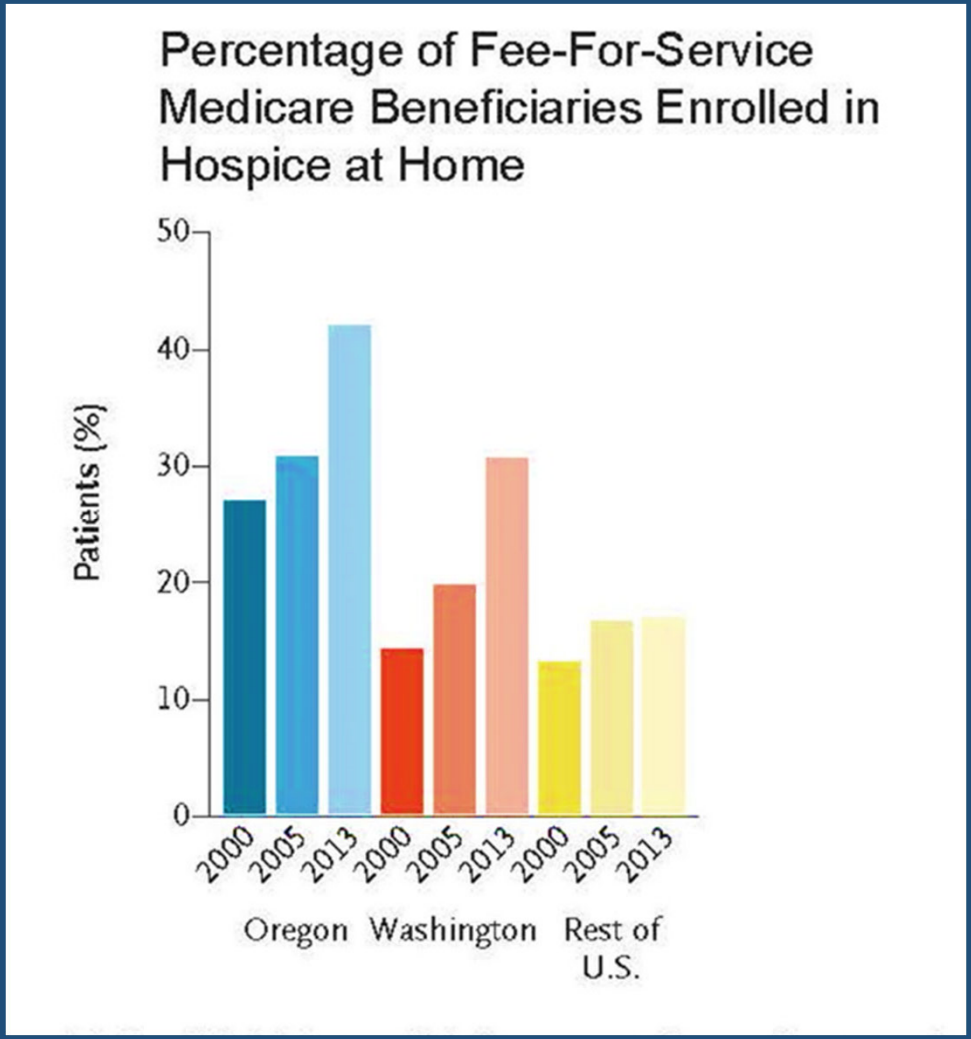

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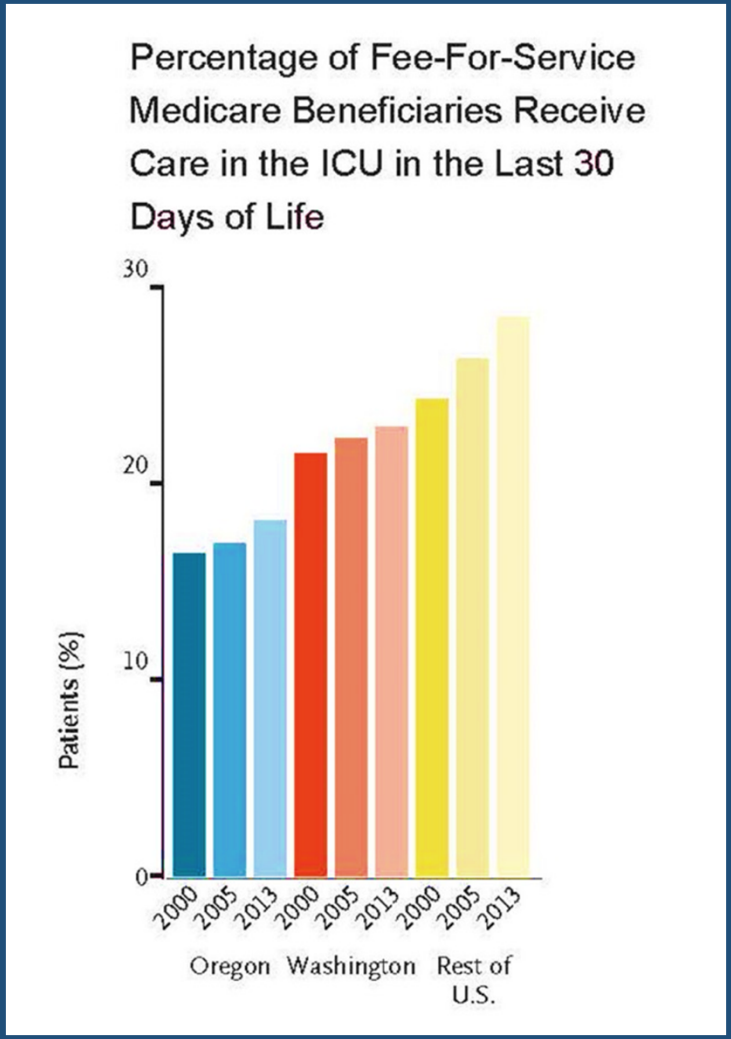

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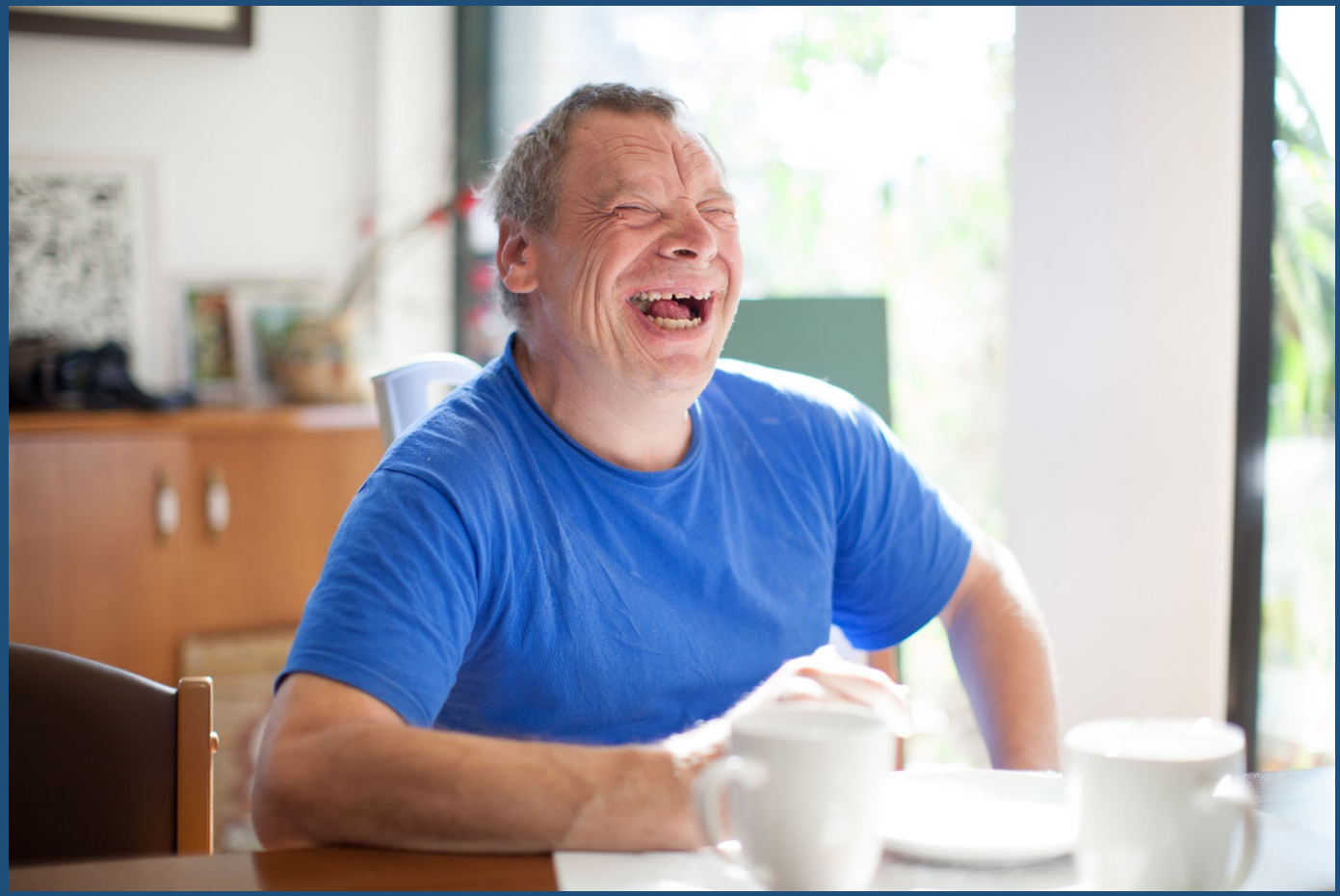
Advance Care Planning and People with Disabilities



Guarding Against Bias in the Care of People with Disabilities

Physician Perception of People with Disabilities and Their Health Care

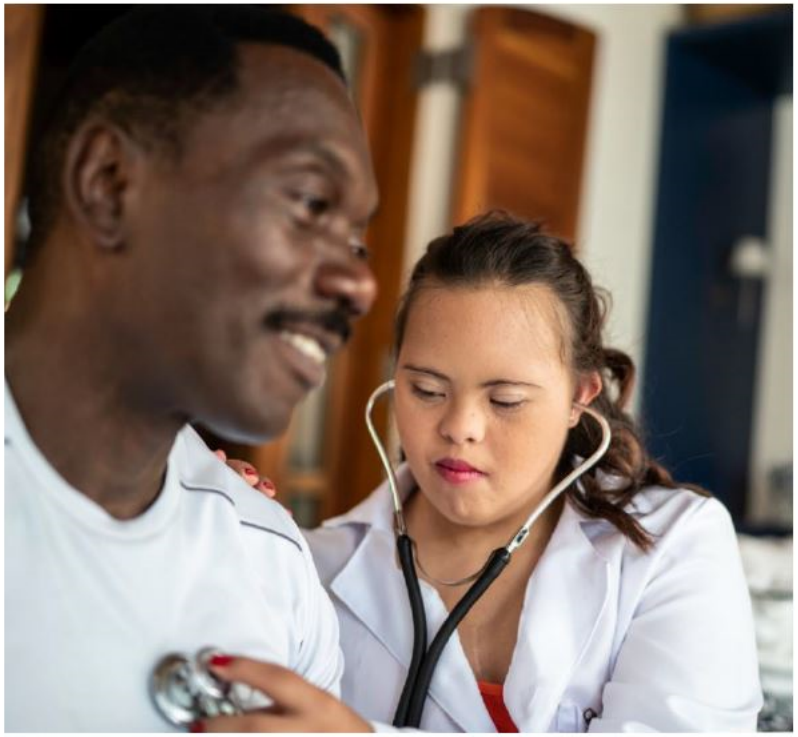
"82.4% of physicians report that people with significant disabilities have a lower quality of life than non-disabled people."

Iezzoni LI, Rao SR, Ressalam J, Bolcic-Jankovic D, Agaronnik ND, Donelan K, Lagu T, Campbell EG. (2021). **Physicians' Perceptions Of People With Disability And Their Health Care.** *Health Affairs*. Feb 2021. 40, No. 2. doi:10.1377/hlthaff.2020.01452

Portable Orders for Life-Sustaining Treatment (POLST®):

Guidelines on POLST Use for Persons with Significant Disabilities who are Now Near the End of Life

Developed by the Oregon POLST Coalition
and approved by its Education Committee in July 2020



Who is POLST for?

People with serious illness or who are very old and frail and want to set limits on treatment

Advanced Cancer

Advanced Heart Disease

Advanced Dementia

Advanced Frailty

Top 10 Causes of Death with Proportion of Registered POLST Forms at Death

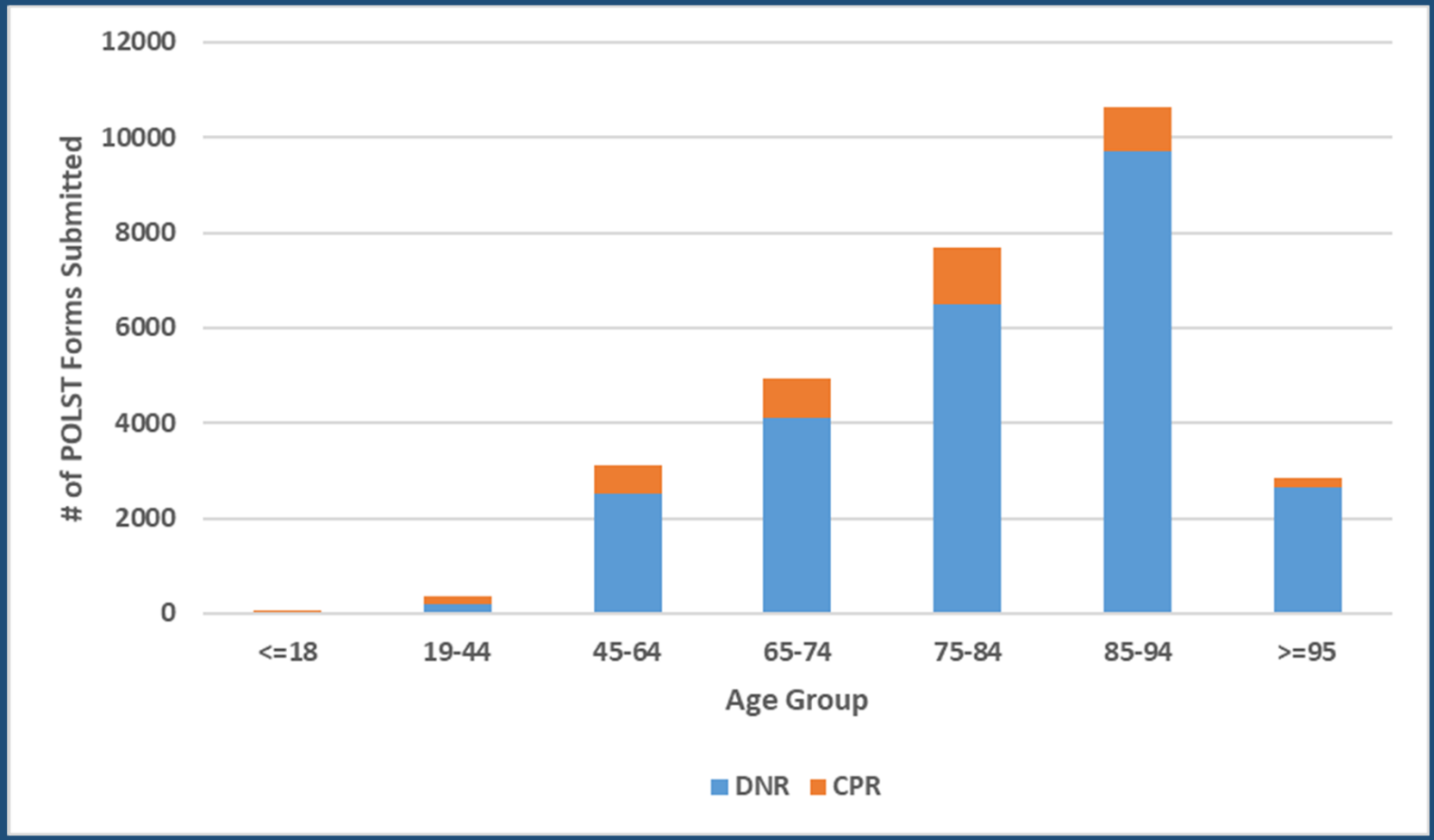
2015-2016 Decedents

Cause of Death	All Natural Deaths (n)	Registered POLST (n)	Registered POLST (%)
Malignant neoplasms	16198	7685	47.4%
Heart Diseases	13656	5689	41.7%
Alzheimer's Disease and Dementia	6850	4246	62.0%
Chronic lower Respiratory diseases	4181	2015	48.2%
Cerebrovascular Diseases	3203	1387	43.3%
Diabetes Mellitus	2381	949	39.9%
Liver Disease	1271	383	30.1%
Influenza and Pneumonia	892	346	38.8%
Parkinson's Disease	871	573	65.8%
Nephritis	793	421	53.1%
All others	15202	6000	39.5%
All causes	65498	29694	45.3%

Zive DM, Jimenez VM, Fromme EK, Tolle SW. (2018). **Changes Over Time in the Oregon Physician Orders for Life-Sustaining Treatment Registry: A Study of Two Decedent Cohorts**. *J Palliat Med*. 2018 Nov 21. doi:10.1089/jpm.2018.0446.

Age of Oregonians with POLST at Death

Number of registered POLST form orders for DNR and CPR by age group 2015-2016.
CPR, cardiopulmonary resuscitation; DNR, do not resuscitate.



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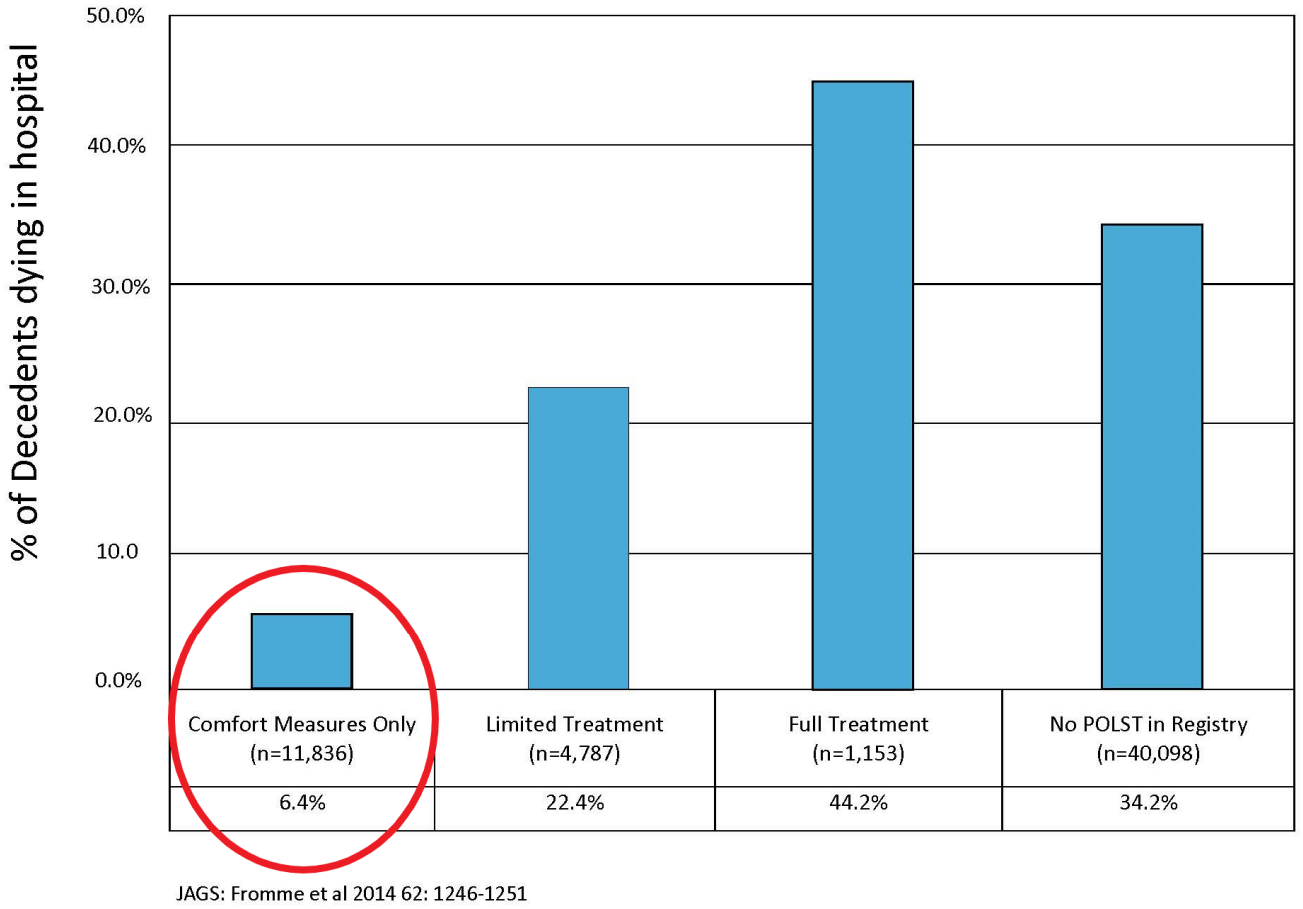
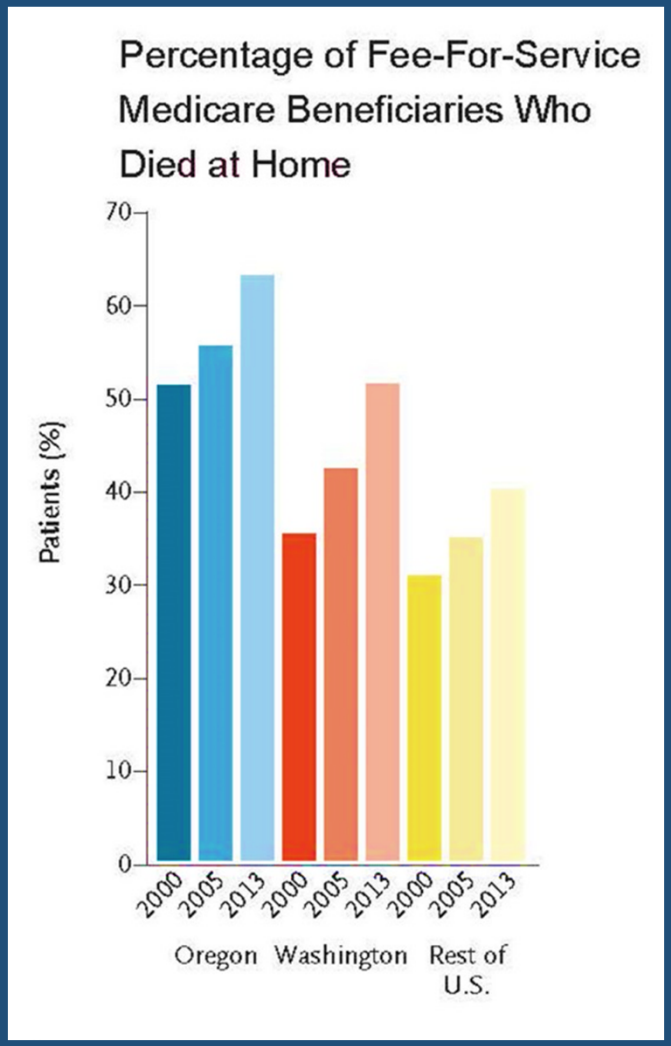
Is POLST Associated with Greater Concordance?

Patient's preferences recorded as medical orders on a POLST Form and how those orders match with death in the hospital



Fromme EK, Zive D, Schmidt TA, Cook JNB, Tolle SW. (2014). **Association Between Physician Orders for Life-Sustaining Treatment for Scope of Treatment and In-Hospital Death in Oregon**. *J Am Geriatr Soc*. 2014 Jul;62(7):1246-51. doi:10.1111/jgs.12889.

Is POLST the Explanation?



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To Have Concordance Takes More Than POLST

- Nimble hospice response
- Options in community-based care
- Systems to locate existing POLST forms

An Ongoing Systems Challenge

Do Not Resuscitate. Limited Treatment.

It takes a lot more than documents to have goal concordant care.

Together

We Can Become More

Trustworthy Care Partners

Thank you

ohsu.edu/center-for-ethics