N=36 + emailed comments

1. What sector do you represent? (Choose the option that is the best fit.)

Answer Options	Response Percent	Response Count
Primary Care	13.9%	5
Hospital/Clinic	52.8%	19
Government/Public Purchaser	8.3%	3
Employer	2.8%	1
Health Plan	5.6%	2
Consumer/Patient	11.1%	4
Self	5.6%	2
Other (please specify)		14

Other (please specify)

- Washington Advocates for Patient Safety
- Retired pall care RN-EOL Educator as volunteer for PHSW Palliative Care
- State Organization for Hospice & Palliative Care
- Hospice
- Quality Improvement Organization
- Volunteer of WAHA end of life choices and ICU RN
- Hospice and Home-Based Care
- Medical Director of 515 provider CIN
- Nursing Home care
- Health Coalition
- Skilled Nursing Center Advance Care Planning facilitator
- physical medicine and rehabilitation
- Area Agency on Aging....
- UW

2. Do you agree with the definitions? (Pages 5-6)

Answer Options	Response Percent	Response Count
Yes	100.0%	36
No	0.0%	0
Neutral/No Opinion	0.0%	0

3. Do you have any changes, additions, or comments to the definitions?

- In both the definitions and recommendations section the "personal" statement cannot easily be operationalized in most standard documents. The Five Wishes document makes room for values, specific wishes, but this is not generally true.
- Family is tough because it implies biological in any "common sense" definition. Another category might be more beneficial such as "loved ones" or "family and friends."
- The DPOA is 100X more useful than the Directive to Physicians and this MUST receive emphasis.

4. Do you agree with the problem statement? (Pages 7-9)

Answer Options	Response Percent	Response Count
Yes	100.0%	36
No	0.0%	0
Neutral/No Opinion	0.0%	0

5. Do you have any changes, additions, or comments about the problem statement?

- A key problem issue is reimbursement for counseling advisors in a hospital setting. This is later covered in the recommendations.
- Hopefully, the previous work on the WA POLST Registry will be considered. The perception is that the previous registry was not adequately funded and staffed. There would be value in not "reinventing the wheel." The Oregon registry is a wonderful example of how well it could work.
- I agree, but it mainly focuses on the physician/patient relationship. This problem statement should expand to the problem that arises with attorneys having access to advance directives and not families, of having availability of advance directives but them not being in a centralized location so that they cannot be honored, and should discuss the issue of the short length of stay of hospice/low hospice utilization. This is way too targeted toward health systems and not ancillary LTSS providers.
- Yes
- We need to encourage people to realize death is normal

6. Do you agree with the recommendation to "Increase awareness of advance care planning, advance directives, and POLST in Washington State?" (Pages 11-12)

Answer Options	Response Percent	Response Count
Yes	100.0%	36
No	0.0%	0
Neutral/No Opinion	0.0%	0

7. Do you have any changes, additions, or comments to this recommendation?

- Recognize that conversations need to start early in life; incorporate into health ed classes, etc. so it becomes viewed as a natural part of life like understanding birth control; getting a driver's license or financial planning. This will help not only with advance care planning but reduce the number of times those plans aren't followed due to emotional stress at the time.
- I agree with this recommendation, but it doesn't seem to have any supporting recommendation for what a statewide collaboration would look like. This concerns me, as it looks like there are a lot of efforts going on already, and there still needs to have an increase in awareness. Has a needs assessment been performed of who has the lowest AD rate? How does culture and language fit into this? What effort will be made to offer the small community efforts to a larger area? What will be done to increase awareness in rural areas? This seems very vague and more like an inventory, less like a recommendation.
- Absolutely!
- As stated under the definitions section, there is no easy way currently to "pull" for a personal statement or guide that task, but it is essential since the most common documents do not adequately address these values and wishes.
- I find many doctors giving healthy young patients POLST forms and not talking about Adv. Directives, More Education to the doctors and staff
- "Yes, please add the Snohomish County community-wide education efforts underway from the Snohomish County Health Leadership Coaltion. Upcoming classes are listed and there's more information at www.snocohealth.org.

- The SCHLC has developed a community-based advance care planning initiative which trains an • array of facilitators from senior centers, faith community, YMCAs, service organizations, local hospitals and medical groups and others, using Gunderson Institute certified instruction. An integrated effort by the coalition, made up of an array of leaders from business, healthcare, the faith community, senior services organizations, human services organizations, education and other sectors, has trained 900 consumers and 160 healthcare professionals since June 2013, increasing training from an estimated 9% to 23% of relevant specialist categories. The coalition aims to increase training capacity by 50% in 2015, and to be training 4,500 consumers annually by 2017 (equivalent to the rate at which people reach 65) using a community based volunteer network which minimizes costs on the healthcare system and maximizes opportunities for people to learn in a trusted local atmosphere. Multicultural course offerings are under development including courses for non-English speaking community members. The initiative has worked with community and healthcare advisory council to co-develop and align around a set of community-based uniform desired outcomes, and also promotes a range of curricula with the intent of building diversity and innovation while aligned around a common agenda and shared measurement system. In July 2014, the coalition established a 5-year contract with Gunderson Institute which creates a community-owned consumer curriculum assets based on the Respecting Choices model. More information at www.snocohealth.org."
- As a newcomer to Washington State, it can be confusing to emphasize POLST so much, which is one tool to convey a DNR order. We might be inviting an uphill battle when DNR already has great public recognition.
- Should there be more emphasis on provider education to have effective advance care planning conversations?
- "ADD TO RECOMMENDATION 1/Promote community conversations" section: : "Many Community groups...." Section:
- The SCHLC has developed a community-based advance care planning initiative which trains an array of facilitators from senior centers, faith community, YMCAs, service organizations, local hospitals and medical groups and others, using Gunderson Institute certified instruction. An integrated effort by the coalition, made up of an array of leaders from business, healthcare, the faith community, senior services organizations, human services organizations, education and other sectors, has trained 900 consumers and 160 healthcare professionals since June 2013, increasing training from an estimated 9% to 23% of relevant specialist categories. The coalition aims to increase training capacity by 50% in 2015, and to be training 4,500 consumers annually by 2017 (equivalent to the rate at which people reach 65) using a community based volunteer network which minimizes costs on the healthcare system and maximizes opportunities for people to learn in a trusted local atmosphere. Multicultural course offerings are under development including courses for non-English speaking community members. The initiative has worked with community and healthcare advisory council to co-develop and align around a set of community-based uniform desired outcomes, and also promotes a range of curricula with the intent of building diversity and innovation while aligned around a common agenda and shared measurement system. In July 2014, the coalition established a 5-year contract with Gunderson Institute which creates a community-owned consumer curriculum assets based on the Respecting Choices model. More information at www.snocohealth.org."

care planning in the clinical and community settings?" (Pages 12-17)			
Answer Options	Response Percent	Response Count	
Yes	100.0%	36	
No	0.0%	0	
Neutral/No Opinion	0.0%	0	

8. Do you agree with the recommendation to "Increase the number of patients who participate in advance care planning in the clinical and community settings?" (Pages 12-17)

9. Do you have any changes, additions, or comments to this recommendation?

- I think this recommendation, and the sub-recommendations, are very appropriate. However, they are so vague that they may even verge on the side of too vague to be useful. Without any specific recommendations for evidence-based ACP tools, it would assume providers have time and interest (and funding) to solve this problem themselves. This, in turn, could cause larger health systems to have an advantage over smaller systems or clinics that do not have capacity or resources. S0257 is a great code--I would also add the new E&M codes approved by the AMA to make this list more comprehensive. How is this increase going to be evaluated? How will you know everyone is evaluating it in the same way and that you can document a change? In addition, providers who are reimbursed for S0257 really should be trained in having the conversation, and this should be documented somewhere. This would mitigate risk of a provider having an ACP conversation but skewing it toward their own values and not the values of the individual.
- PeaceHealth Vancouver has four individuals who were trained at Gundersen Lutheran as INSTRUCTORS and we have approximately 50 trained ACP Last Steps FACILITATORS who have been trained within the past three years
- Funding who can help with funding these projects.
- Yes, please add the Snohomish County community-wide education efforts underway from the Snohomish County Health Leadership Coaltion. Upcoming classes are listed and there's more information at www.snocohealth.org.
- On page 12, last paragraph, patients do not complete DNR orders, LIPs do. We want to avoid confusion here.
- P. 13 ""Encourage use of evidence-based acp programs..."" references the Honoring Choices effort which is in the planning stage. Please add content about a program which has moved beyond planning stage and is already being implemented in Snohomish County: ""Examples of efforts already being implemented include an initiative of the Snohomish County Health Leadership Coalition. The coalition contracted in mid-2014 with Gunderson Health and Respecting Choices to develop a community-owned consumer curriculum asset made available at no charge to any interested coalition affiliates in Snohomish County. The curriculum, now in active use, is promoted countywide by The Herald of Everett and other local media, and utilizes certified facilitators, docents and administrative volunteers, minimizing cost impact to the healthcare system. The initiative has increased the capacity of qualified volunteer facilitators in the county, and is led by local senior centers, churches and YMCAs in addition to hospitals and medical groups. Participant post-course surveys identify effectiveness of curriculum in achieving community-based uniform set of desired outcomes, and follow-up counseling assists participants with actions including designation of a personal advocate, conversations with family

and physicians, and creation of advance directives. This community-based initiative aims to minimize direct cost to the healthcare system, promote effective approaches based on evidence, and encourage involvement of trusted local communities of interest.

PAGE 16: Please add in the section beginning with ""Many possible resources...""

More information on Snohomish County Health Leadership Coalition Advance Care Planning initiative: www.snocohealth.org

Page 17: Section: Train qualified advance care planning facilitators: Please insert reference to SnoCo Health Leadership Coalition in the following sentence:

The Snohomish County Health Leadership Coalition, WAHA's End of Life Choices program and the Swedish/Edmonds Advance Care Planning Program currently train advance care planning facilitators and provide this service to their community members."

10. Do you agree with the recommendation to "Increase the number of patients who record their wishes and goals for end-of-life care using documents that: accurately represent their values; are easily understandable by patients, family members, and health care providers; and can be acted upon in the health care setting?" (Pages 17-19)

Answer Options	Response Percent	Response Count
Yes	100.0%	36
No	0.0%	0
Neutral/No Opinion	0.0%	0

11. Do you have any changes, additions, or comments to this recommendation?

- This is extremely important. Families are heavily impacted by lack of such understanding and documentation. This is a vital discussion for all.
- The recommendation of Prepare is really great. What would be the recommendation for implementation? What would be the success criteria/metrics?
- The recommendation for health-literacy adjusted advance directives and promoting availability in multiple languages is an important under-taking for the benefit of our diverse population. This work would benefit our provider programs as well.
- Work with EMR, particularly EPIC, to make ACP documents and POLST easily accessible, especially in the ED. Also we need to have a place in the chart that is portable to each setting to RECORD ONGOING ACP CONVERSATIONS
- Great that section a. mentions culturally appropriate AD, I would say that training needs to incorporate cultural issues / barriers and considerations.
- I think this is right on target and hits all the issues. Nice job.
- Emphasize the DPOA, the lack of need for an attorney, and the POLST. The advance directive is rarely useful

12. Do you agree with the recommendation to "Increase the accessibility of completed advance directives and POLST for health systems and providers?" (Pages 19-21)

Answer Options	Response Percent	Response Count
Yes	100.0%	36
No	0.0%	0
Neutral/No Opinion	0.0%	0

13. Do you have any changes, additions, or comments to this recommendation?

- See comment under problem statement
- These are very concrete recommendations. I would also comment on the ability of the registry to easily link into their EMR. Also, EMR reform would need to be supported with state funding, as many health systems would not have the funds to improve processes.
- The Washington State Living Will Registry was under-utilized and we are not sure if consumers are more motivated to use one that would be contracted for us.
- see above #11
- HIPAA is spelled incorrectly on page 20.
- Very important!!
- I love the idea of tying it into the drivers' license system so it is portable through out the state!

14. Do you agree with the recommendation to "Increase the likelihood that a patient's end-of-life care choices are honored?" (Pages 21-22)

Answer Options	Response Percent	Response Count
Yes	97.2%	35
No	2.8%	1
Neutral/No Opinion	0.0%	0

15. Do you have any changes, additions, or comments to this recommendation?

I am the patient care manager for Volunteer Hospice of Clallam County,
 We are based on the older model for hospices, with paid nursing staff, but no charges for our services.

My comment and concern is that we encounter assisted living facilities and SNF that will not honor the Polst form of a DNR with comfort care only unless the patient is on Hospice services, and even then either ship person's off to the ACF, just to have them sent back.

Or the client who has CPR initiated, 911 called by the CNA, or RNA of an assisted living facility,,, and then the body is left on the floor for the family to see them in that way, with hospice eventually being called.

We have also encountered the problem at a local facility for people with disabilities that even though hospice is on board, the POA and all do not want resuscitation,,, it is still initiated. We beg them to get an exception to avoid this for the dying client, and staff, but seem to fall on deaf ears.

This is one of my greatest concerns, what good is a Polst if not honored, Bette Wood RN pcm@vhocc.org

- See comment above.
- I agree with this, though there needs to be the development of an experience of care tool that medical decision makers would be surveyed with post-death. RAND has interest in developing a tool like this. The existing tools are only location-specific, not accurately capturing experience of care. In addition, there needs to be an emphasis on the measurement of how treatment provided matches the most recent AD and/or POLST. This would take an all-payer-all-claims database for health systems to evaluate or a partnership between payers and providers.
- We find the Driver's license feature a novel approach that just might work!

- As an ICU RN I find it very frustrating when a POLST is on file and family over ride the orders. Doctors not having the time or make the time to explain what "do Everyting " means
- Having been a Nurse for 40 years and working both professionally and personally with many end
 of life experiences, what I see as one of the most significant issues that I did not see addressed
 in this entire document is "How to support the patient and family during times of crisis" What I
 mean by this is, when the patients condition changes or deteriorates, it is extremely difficult to
 continue to honour established wishes. When you are exhautsed, in pain, lonely, etc many
 families or patients will turn to the ED or hospital where there ultimate wishes may not be
 honoured. In these situations, if a coach, care giver, friend, Hospice worker etc. can be there to
 support the patient and family in the environment they wished to stay in, their wishes can
 usually be honoured. It is unfortunate that some patients do not choose Hospice Services and
 that reimbursement for Hospice services are being reduced, but having a knowledgible/trained
 support person is critical to this entire program being successful.
- Section: 5 2nd to last paragraph that says, "Encourage providers and facilities to measure family satisfaction with end-of-life care by widespread use of an after-death survey tool similar to that used by hospice agences". Providers and facilities are asked to do quite a bit of correspondence and I think leaving this responsibility to them will underserve the community. Providers are busy, have poor data, and results would prove inconsistent. Not all providers participate in CAHPS. There should be a community-based solution to measure this. Perhaps funeral homes could work with families to provide and help collect and tabulate this information. There should be an oversight entity that helps finalize the results, as well. Perhaps a university or insurance company could help with this.
- The ability for the system to honor a patient's end-of-life care choices bases itself on the criteria that the patent has and understands their choices. These Choices are difficult to understand and quantify for most patients... let-alone to tract and reinforce and honor as time goes by.
- more needs to be done in the hospital at the time of a major change in outcome. many advanced directives are ignored by surrogates at end of life

16. Do you have any changes, additions, or comments to the discussion of end-of-life care improvement efforts in Washington State? (Pages 23-25)

 Thanks for sharing this. Beginning on page 23, there is a list of various programs and efforts in WA State. I did not see the work of the Snohomish County Health Leadership Coalition and also that of Everett Clinic and Edmonds Family Medicine. These organizations use a variation of the Gunderson program called "Your Life, Your Wishes" (TEC may have re-named this, "My Life, My Wishes").

I have passed this along to the folks in our group that lead the patient sessions to see if they have additional comments.

Thank you for supporting this important work, Marcy Shimada

- This is an exceptionally well done DRAFT set of recommendations. Thank you and congratulations to the entire team for thoughtful recommendations that will effect us all.
- "We have several initiatives occurring in Vancouver.
- There is ""Life Transitions, the End of Life Coalition of Southwest Washington. (Swlifetransitions@gmail.com). It consists or community partners including AADSW, PHSW

Palliative Care and Hospice, Community Home Health and Hospice, Glenwood Place Senior Living, Home Instead and Prestige Facilities. We are currently providing ACORN, A quarterly EOL education program for caregivers in SNFs, AFHs and in the home.

- A team from PHSW Hospice and Palliative Care have been certified at Gunderson to provide 8 hour Respecting Choices Last Steps education to hospital and medical office personnel. We also do quarterly 2 hour Respecting Choices education at PHSW for the Community as well as requested presentations for churches and community groups. We include the video ""Consider the Conversation"" and provide WSMA AD forms, the POLST and Five Wishes documents. we have presentations scheduled in Oct and Nov for the community, for Case Managers at AADSW, and Pulmonary Rehab at PHSW.
- Since 2010, PHSW Bridges Palliative has been providing ELNEC education to staff at PHSW and other hospitals.."
- HICOR is developing an evaluation of provision of palliative care in oncology practices; Northwest Medical Specialties is undergoing a pilot injecting ACP into oncology pathways; Cambia Health Solutions is developing a primary care-based medical home model that would transition individuals from the ambulatory to the home setting; The Everett Clinic and their efforts should also be highlighted.
- POLST form would love to see all information on a ONE SIDED FORM. Physicians seem to 'forget' the second side, or do not fill it out because it is labeled 'optional'. I would like to see ongoing training for physicians on proper POLST completion (such as filling out a new form and not crossing out options when a form is updated.)
- Just to add that The Everett Clinic is an example of pro-active work on advance directives with classes and also they make the videos available to patients (the videos created by the key note speaker at WPSC annual meeting last spring)
- More funding to allow the programs to grow, as in La Crosse Wis posters on buses, at the airport, library,etc. At your annual checkup " Do you have an an advance directive?" if not here is someone to counsel you.
- should be encouraged as a normal topic at healthcare contact points like advanced directives are
- "Please add the following listing on Page 23:
 - Snohomish County Health Leadership Coalition Advance Care Planning Initiative This countywide, community-based collaboration developed and funded by a coalition of the Everett Public Schools, Premera Blue Cross, Verdant Health, Providence Regional Medical Center Everett, The Everett Clinic, Senior Services of Snohomish County, the Economic Alliance of Snohomish County, WSU North Sound, the YMCA of Snohomish County, The Boeing Company, United Way of Snohomish County, and Trinity Lutheran Church; an advisory council of senior centers, faith organizations and others; and healthcare organizations including Edmonds Family Medicine, Providence Medical Group, Puget Sound Kidney Centers and others. The coalition has licensed Respecting Choices curriculum from Gunderson Institute and certifies and deploys a network of volunteer facilitators who teach onsite across Snohomish County. More information: www.snocohealth.org"
- I am truly excited about this! It is a long time coming !!
- "Please add the following: Snohomish County Health Leadership Coalition Advance Care Planning Initiative

This countywide, community-based collaboration developed and funded by a coalition of the Everett Public Schools, Premera Blue Cross, Verdant Health, Providence Regional Medical Center Everett, The Everett Clinic, Senior Services of Snohomish County, the Economic Alliance of Snohomish County, WSU North Sound, the YMCA of Snohomish County, The Boeing Company, United Way of Snohomish County, and Trinity Lutheran Church; an advisory council of senior centers, faith organizations and others; and healthcare organizations including Edmonds Family Medicine, Providence Medical Group, Puget Sound Kidney Centers and others. The coalition has licensed Respecting Choices curriculum from Gunderson Institute and certifies and deploys a network of volunteer facilitators who teach onsite across Snohomish County. More information: <u>www.snocohealth.org</u>"

- 17. Please provide any general comments here:
 - As a patient advocate for my parents in their last days I found it essential to have such documentation in place so family members could discuss in advance. Doing this saved needless heartache and conflicts when the time came to honor my parents choices. This is a vital benefit for all family members and the patient's well being.
 - "First, the WSHPCO applauds the Collaborative for endeavoring to undertake an important yet challenging report on the topic of end of life care in Washington State. We have voiced some concern regarding multiple stakeholder groups with a focus on end of life care, advance care planning and palliative care, without any one group having an over-arching view of the work currently being undertaken within our state.

We believe the Bree's attempt to summarize the project work of organizations across Washington State will help to illuminate good work in progress, better inform all stakeholders, and decrease duplication of efforts. We support broad distribution of the report and its recommendations.

In addition, we fully support the concepts of increasing access to palliative care services through policy changes within the Health Care Authority for HCPCS code S0257. Our providers welcome the opportunity to assist with advocacy for the recommended changes and subsequent education of providers. Further, we are grateful for your recognition of the value of hospice care and services, in addition to the recommendation to promote awareness and enhance opportunities for hospice referrals. We appreciate the inserted link to our WSHPCO website and only regret that our website upgrade is still a work in progress.

The recommendation for health-literacy adjusted advance directives and promoting availability in multiple languages is an important under-taking for the benefit of our diverse population. This work would benefit our provider programs as well.

Lastly, we appreciate the recognition for our Family Evaluation of Hospice Care (FEHC) survey that our provider programs have been using for years to measure satisfaction and benchmark with other programs across the nation. The new survey process (CAHPS), will be operational in 2015 as stated in the report. We fully support the recommendation that all programs providing end of life care need to have a formal process to measure satisfaction and outcomes. Thank you for the opportunity to provide formal comments and feedback! Lisa Butler, MN, RN-BC, Director of Public Policy/Outreach"

• "I would like to see more representation from Vancouver and Southwest Washington,

Also I think that partnering with the Oregon POLST registry would make the most sense, and I would love to see this happen."

- This is very important for both improving patient goal definition, appropriate care & to have the care be cost effective.
- Nice work over all. What I found missing was the 1) provider training in having "conversations" with patients and family members. I think this is a big need by all disciplines from MD's to nurses and all settings, clinic, hospital, SNF, etc. 2) some beginning work on when and who are appropriate for these conversations. I find that a lot of "dodging" is based on a belief that it is someone else's job. 3) How will the recommendations be quantified in terms of making progress? I think this comes after the recommendations are vetted perhaps.
- Thank you for taking this challenge on.
- Thank you for this excellent work. I look forward to this intiative moving forward.
- "I too have seen my fair share of ""bad deaths"" and poor EOL planning. As a result, I too am an advocate for improvement. For the past several years I have used and and promoted the concept of ""Allow Natural Death"" (AND). The concept originated within the nursing profession probably 20 years ago, but for some reason has gained little traction. The approach puts the patient and his/her family back in control. It SO simplifies the discussion, and has revolutionized the conversation I have when a seriously ill and/or terminal patient is facing yet another hospital admission or a potentially fatal condition.

Here's an example of how it goes: ""Mr. Jones, you are very ill and have been in the hospital several times in the past year. While I'm confident that we can help you pull through this situation once again, I need to ask you a question. If, while you are here in the hospital this time, your heart stops or your breathing stops AND YOU DIE A NATURAL DEATH, do you want us to do anything about that?""

The usual response is ""Of course not. I have always hoped I would die a natural death. I don't want to die hooked up to a bunch of tubes and machines.""

I've yet to meet a patient OR family who did not aspire to a ""natural death,"" regardless of what their attorney-written ""advance directive"" or POLST form might say when the time comes.

My own hospital's medical staff recently revised our DNR policies. It states something like ""I do not wish to be resuscitated. I prefer be allowed to die a natural death.""

I encourage you to consider this approach.

Below are some of my favorite references on the subject.

Chuck Pilcher MD FACEP

chuck@bourlandweb.com

206-915-8593

- My own recent ""Comment"" on an article in ACEP's ""eNow"" publication. Simple Language Eases End-of-Life Care Discussions http://www.acepnow.com/article/end-lifecare-discussions-benefit-simple-language/
- A 2009 article in USA Today on ""AND"": http://usatoday30.usatoday.com/news/health/2009-03-02-DNR-natural-death_N.htm
- Article in KevinMD by Virginia Seno: What does it take to have successful end of life conversations?. http://www.kevinmd.com/blog/2012/04/successful-lifeconversations.html Excerpt: ""Everyone suffers when communication fails at the end of

life. Though we may "know in our hearts" what to do in difficult situations; anxiety and bias close us down.

- Post in KevinMD by Elaine Waples: 4 perfect questions when facing an end of life situation. http://www.kevinmd.com/blog/2012/04/4-perfect-questions-facing-lifesituation.htmllt references a talk by Atul Gawande. There's a link to a video of the talk in the article.
- ""Code Sunset"" article by Jeanette Wolfe in EP Monthly: http://www.epmonthly.com/features/current-features/code-sunset/
- ""Old Patients, Ancient Questions"" by Greg Henry in EP Monthly: http://www.epmonthly.com/departments/columns/oh-henry/old-patients-ancientquestions/
- A great article called ""Physicians Really DO Die Differently."" http://www.zocalopublicsquare.org/2012/07/23/doctors-really-do-diedifferently/ideas/nexus/It has LOTS of references to excellent studies on end-of-life issues and preferences. A couple excerpts below.
- My sense that there's a yearning among ordinary patients to have more peaceful deaths has been echoed in the research of University of Wisconsin-Madison nursing professor Karen Kehl. In an article called "Moving Toward Peace: An Analysis of the Concept of a Good Death," http://www.ncbi.nlm.nih.gov/pubmed/17060291 ehl analyzed a collection of relevant articles and, based on their contents, ranked the attributes of an ideal death as follows: being in control, being comfortable, having a sense of closure, having one's values affirmed, trusting in care providers, and recognizing impending death. Hospitals cannot help with most of these things.
- When applied to a patient in the last stages of a terminal decline, CPR is particularly ineffective. A 2010 study http://www.ncbi.nlm.nih.gov/pubmed/19813029published in the journal Supportive Care In Cancer looked at terminal patients who wanted no CPR but got it anyway. Of the 69 patients studied, eight regained a pulse, but, 48 hours later, all were dead. Well-meaning CPR advocates talk in terms of "survival," but all the term means is that the heart again beats on its own. In the above example, survival was 11 percent, but "survival" as often understood by the public—regaining a reasonable quality of life—was zero.
- \circ $\:$ Just Google ""Allow Natural Death"" and you'll find a wealth of additional reading."
- GREAT WORK!!! You might consider inviting an ethicist to be a part of the collaborative membership. If you decide to do that, I'd be interested in speaking with you: D.W. Donovan, 425-420-0504.
- I wholeheartedly agree with the major recommendations here.
- When recommending reimbursement for the EOL conversation, there must be documentation requirements to assure that providers aren't billing for an EOL conversation, when all they have done is ask the patient, "do you have an advance directive in place?"
- Thank you for providing the opportunity to review and contribute to this report. Don't hesitate to contact me if we can provide further information. Best, Scott Forslund/Director, Snohomish County Health Leadership Coalition and Paula Beatty, Strategic Program Manager, Advance Care Planning Initiative via Coalition Administration Manager Michelle Morford, 425-918-8188

- The idea of having people receive care at home vs hospital or nursing home at the end of life is a great idea, however it depends a large part of whether or not there are paid or informal caregivers willing and able to provide the level of care needed.
- Two comments: One, I would like to see a concerted effort to identify best practices in these areas. It is clear from the data presented that some organization s and some regions are doing a much better job than others. What are the successes and commonalities that could be emulated. Second, we have had a couple of previous attempts to have registries where people could register their choices with respect to advance care plans and end-of-life choices and those registries were very poorly used. We should look more closely at why those did not receive much use and perhaps "go back to the drawing board" to come up with alternative strategies.
- Important work. What are the details of implementation?
- Good plan
- POLST form should be revised- remove feeding tubes as data shows that this hastens death at end of life

Emailed Comments

I am the patient care manager for Volunteer Hospice of Clallam County,
 We are based on the older model for hospices, with paid nursing staff, but no charges for our services.

My comment and concern is that we encounter assisted living facilities and SNF that will not honor the Polst form of a DNR with comfort care only unless the patient is on Hospice services, and even then either ship person's off to the ACF, just to have them sent back.

Or the client who has CPR initiated, 911 called by the CNA, or RNA of an assisted living facility,,, and then the body is left on the floor for the family to see them in that way, with hospice eventually being called.

We have also encountered the problem at a local facility for people with disabilities that even though hospice is on board, the POA and all do not want resuscitation,,, it is still initiated. We beg them to get an exception to avoid this for the dying client, and staff, but seem to fall on deaf ears.

This is one of my greatest concerns, what good is a Polst if not honored, Bette Wood RN pcm@vhocc.org

• WSMA

Thanks for sharing this. Beginning on page 23, there is a list of various programs and efforts in WA State. I did not see the work of the Snohomish County Health Leadership Coalition and also that of Everett Clinic and Edmonds Family Medicine. These organizations use a variation of the Gunderson program called "Your Life, Your Wishes" (TEC may have re-named this, "My Life, My Wishes").

I have passed this along to the folks in our group that lead the patient sessions to see if they ave additional comments.

Thank you for supporting this important work,

Marcy Shimada

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