Shared Decision Making & Advance Care Planning: Using Decision Aids to Improve Patient Safety

Michigan ACP Conference
Lansing, MI ● Oct. 11, 2018

Thaddeus Mason Pope, JD, PhD

Disclosures

I have **no** conflict of interest to report.

I will **not** discuss any off-label use of any product.

I have received **no** commercial support for this presentation.

Objectives

1. Identify the limitations of traditional advance care planning.
2. Distinguish informed consent from shared decision-making.
3. Describe the advantages of patient decision aids (PDAs) over traditional informed consent.
4. State the importance of shared decision making for advance care planning.

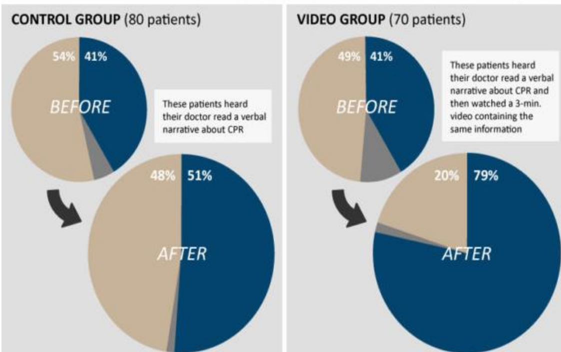
Time

8:45 - 9:45

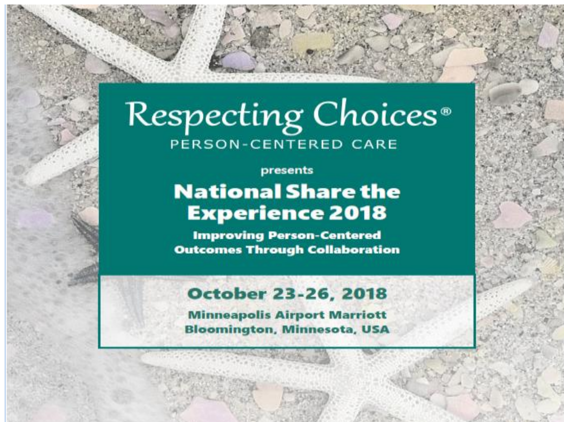
Break: 9:45 – 10:00

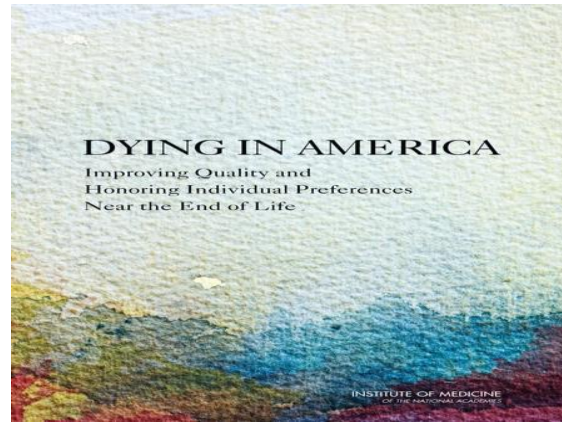
Core thesis

Powerful



Why use **more** PDAs in ACP

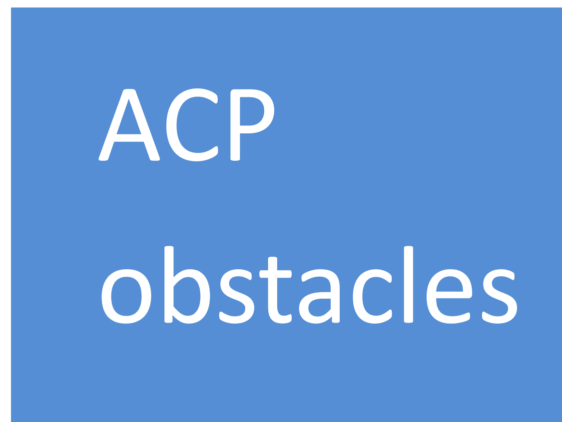

Respecting Choices®
PERSON-CENTERED CARE
presents
National Share the Experience 2018
Improving Person-Centered Outcomes Through Collaboration
October 23-26, 2018
Minneapolis Airport Marriott
Bloomington, Minnesota, USA


DYING IN AMERICA
Improving Quality and Honoring Individual Preferences Near the End of Life
INSTITUTE OF MEDICINE

2014
ACP PDA now

Roadmap

4


ACP
obstacles

Promise of PDAs

PDAs for ACP

PDA certification

ACP Obstacles

Breakout Sessions by Topic

PACE Pre-Conference
This pre-conference workshop will bring together interdisciplinary staff from PACE organizations throughout the state for the purpose of:
- Knowledge sharing in Advance Care Planning work
- Education in Advance Care Planning
- Standardizing ACP Implementation
- Building community and fun, fun, fun!

Ethics:
- Competency, Capacity, and Caregiving; Oh My!
- Just One Word: Simple Tools for Healthcare Professionals that Can and Will Positively Impact Outcomes for Patients and Caregivers Experiencing Health Challenges
- Ethical Dilemmas in ACP
- The Grey Areas of ACP: The Collision of Law Versus Medicine

Disease-Specific/Chronically Ill
- "I" Matter: Influences of Integrating Advance Care Planning for Those with Insistent Illness
- Dementia, Withholding Food and Water, and Overcoming Barriers to VSED by Advance Directive
- Destigmatizing Mental Health Advance Directives
- [illegible]ementia and [illegible]regivers

Conversation skills
- ACP conversation[illegible] A Gift to Your Loved Ones
- [illegible] [illegible]nging the Cultural Conversation about Death
- Michigan Physician Orders for Scope of Treatment (MI-POST): New Form
- Dying to talk about it…

Faith, Culture and Self-Care
- The Miracles of ACP: How 3 Fa[illegible]-Based [illegible] [illegible]ith and Spirituality in the ACP process
- Care of the Arab/Muslim Patient
- Staying Fresh: Building Resiliency Into Your Practice

Implementation
- ACP in the [illegible]H: A Perfect Fit
- CMS Utiliz[illegible]ion: ACP Reimbursement
- A Program th[illegible] "OPTIMISTIC" abo[illegible]ACP
- Building Infrastructure [illegible] in the Skilled Nursing Home
- ACP in the Community: The Experience of ACP Programs on What it Takes to Engage Others

Post-Conference Workshop: Art & Design of Successful ACP Implementation
This workshop will walk attendees through designing an ACP Program specific to your individual setting. At the end of the workshop, attendees will be able to:
- Describe the current state and address regulatory issues related to advance directives, treatment decisions, standing orders and code status in various healthcare work settings
- Design dyads with identification of needed partnerships for successful implementation of ACP programs and MI-POST
- Explore education plans, outreach and engagement techniques, and conversation challenges of ACP in various healthcare settings and communities.
- Identify at least three tools and or templates that would be adaptable to ACP and MI-POST in present work setting

5

Not completed

Not found

Not understood

Not followed

Not i-actionable

Not completed

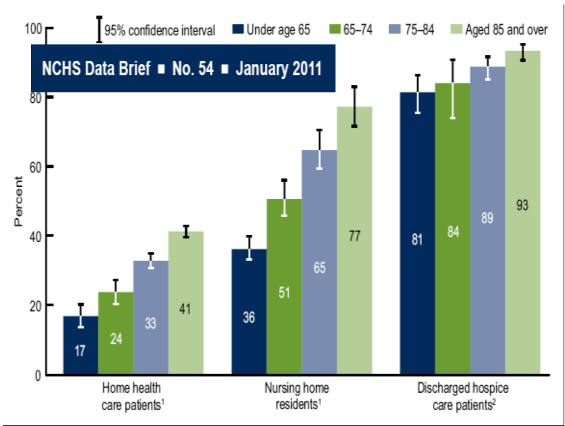
37%

Systematic review of 150 studies
(800,000 people 2011 to 2016
Health Aff 2017 36(7):1244

70%

Older Americans

Even higher



Higher still

99497

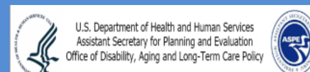
99498

BUT

Even if completed

Not found

76% of physicians whose patients **have** ADs do not know they **exist**



Completed

≠

Have

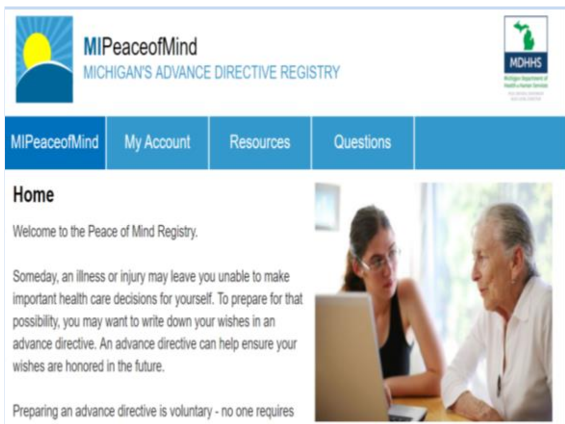
Fail to make & distribute copies

- Primary agent
- Alternate agents
- Family members
- PCP
- Attorney
- Clergy
- Online registry

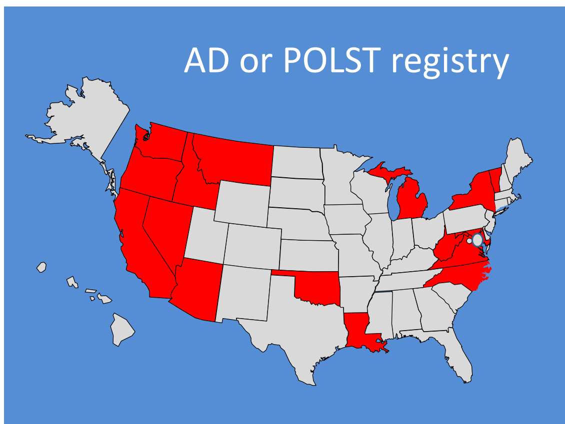
Not enough to "write it down"

Must be **available**

Only **1/3** advance directives used



AD or POLST registry



BUT

Even if completed & found

Not understood

Not clear

if ____,

then ____

If

triggering condition

"Reasonable expectation of recovery"

75%

51%

25%

10%

?

Then

“No ventilator”

Ever?

Even if temporary

Vague

Ambiguous

Limits

Enough

The Failure of the Living Will

by Angela Fagerlin and Carl E. Schneider

Hastings Center Report March-April 2004

Annals of Internal Medicine | Perspective

Controlling Death: The False Promise of Advance Directives

Henry S. Perkins, MD

Ann Intern Med. 2007;147:51-57.

Even worse

TRIAD research

The
Realistic
Interpretation of
Advance
Directives

ELSEVIER

The Journal of Emergency Medicine, Vol. 42, No. 5, pp. 511–520, 2012
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0736-4679/$ - see front matter

doi:10.1016/j.jemermed.2011.07.015

Original Contributions

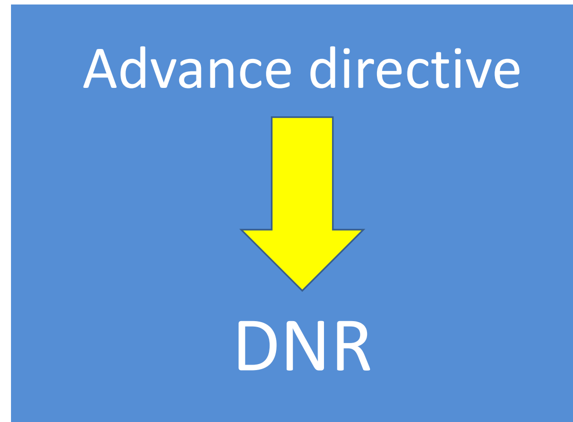
TRIAD III: NATIONWIDE ASSESSMENT OF LIVING WILLS AND DO NOT RESUSCITATE ORDERS

Ferdinando L. Mirarchi, DO, FAAEM, FACEP, Erin Costello, DO, Justin Puller, MD, FACEP, Timothy Cooney, MS, and Nathan Kottkamp, JD, MA (BIOETHICS)

TRIAD IX: Can a Patient Testimonial Safely Help Ensure Prehospital Appropriate Critical Versus End-of-Life Care?

Mirarchi, Ferdinando FACEP, FAAEM; Cammarata, Christopher DO; Cooney, Timothy E. MS; Juhasz, Kristin DO; Terman, Stanley A. PhD, MD

Journal of Patient Safety: Post Author Corrections: June 16, 2017



TRIAD finds patient safety **problems**

Also identifies **solutions**

TRIAD VIII: Nationwide Multicenter Evaluation to Determine Whether Patient Video Testimonials Can Safely Help Ensure Appropriate Critical Versus End-of-Life Care

"adding a **video testimonial/message** . . . significant . . . achieving interpretive consensus"

MIDEO™ Resuscitation Card (v)RSS

Thaddeus M. Pope
Code Status: Full Code
Organ Donation: Yes DOB: 08/02/1969
Living Will: Yes, with Appointed Agent
HealthCare Agent: Linda Pope (310)
POLST: Not Indicated

Validated by

Scan my video message:
Password: 911

Issued: 12/08/2017
Expires: 12/08/2027

More
obstacles

Even if
completed
found, **and**
understood

Not followed

Compliance with Advance Directives

Holly Fernandez Lynch J.D., M.Be. , Michele Mathes J.D. & Nadia N. Sawicki J.D., M.Be.

Version of record first published: 28 May 2008.

The Journal of Legal Medicine, 29:133–178

The New York Times

The Patients Were Saved. That's Why the Families Are Suing.

Paula Span

THE NEW OLD AGE APRIL 10, 2017

$1,000,000

(plus appeal to SCOGA)

Last

obstacle

Even if completed, found, understood, **and** followed

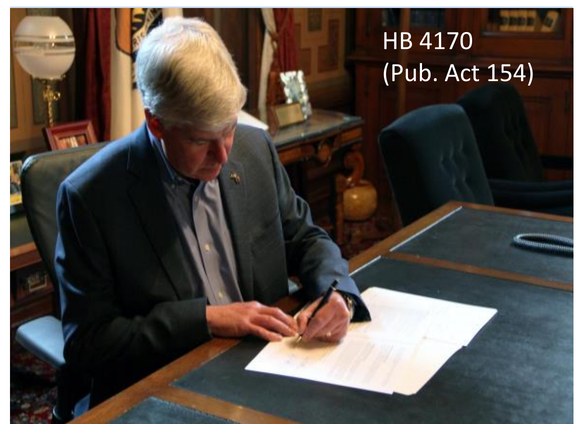
Not

i-actionable

e.g. EMS **cannot** follow

Must "translate" ADs to **orders**

MI-POST



Immediately actionable

Recap

5 obstacles

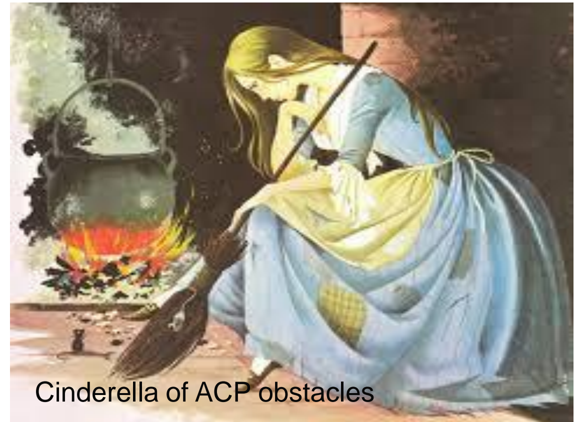
Not completed
Not found
Not understood
Not followed
Not i-actionable

Working on overcoming **these** obstacles

One more

Comparatively

neglected


Cinderella of ACP obstacles

Not

informed

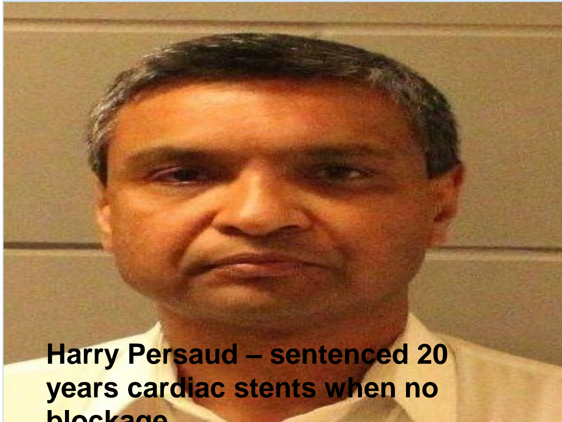
Long time most infamous MI doctor

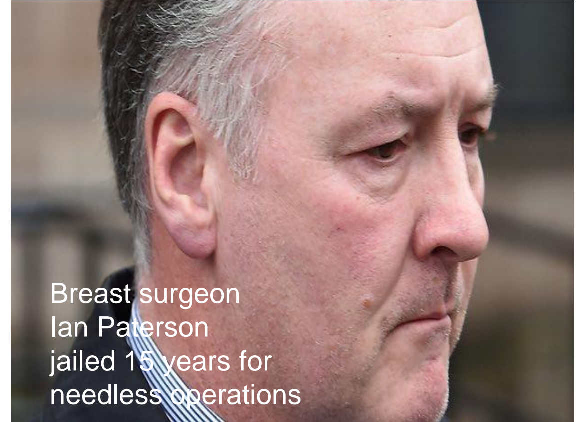
Know this guy?

Treatment not

clinically

indicated



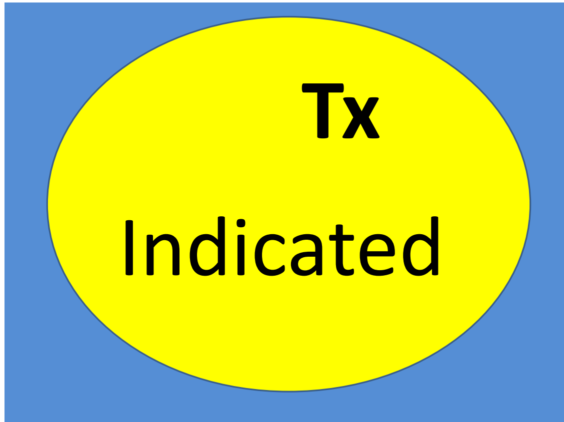


Unwanted
medical
treatment

Tx
Indicated

No patient
would want

2nd type
UMT



Clinical **basis**

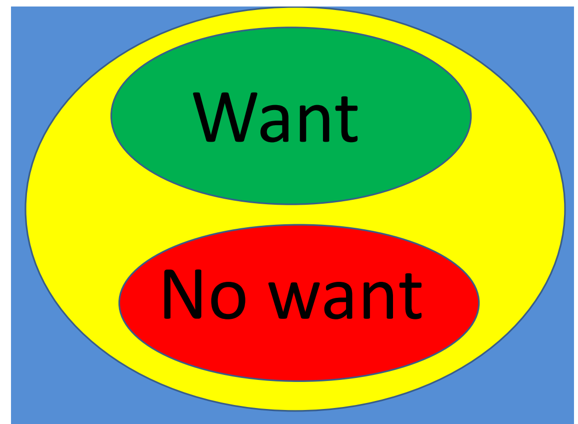
for treatment

BUT

Treatment not

preference

indicated



Reasonable patient **might** want this

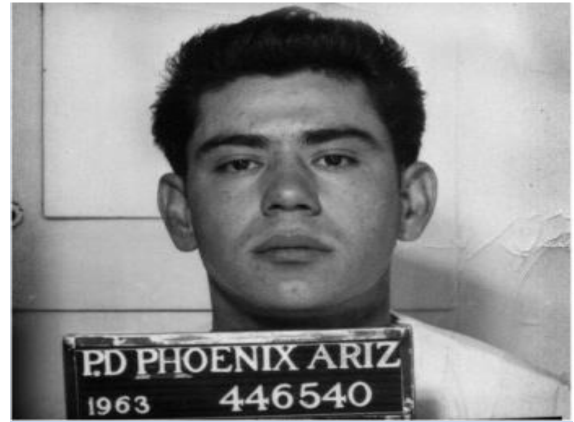
But . . .

this patient does not

Too little to help patients avoid this UMT

Medical consent

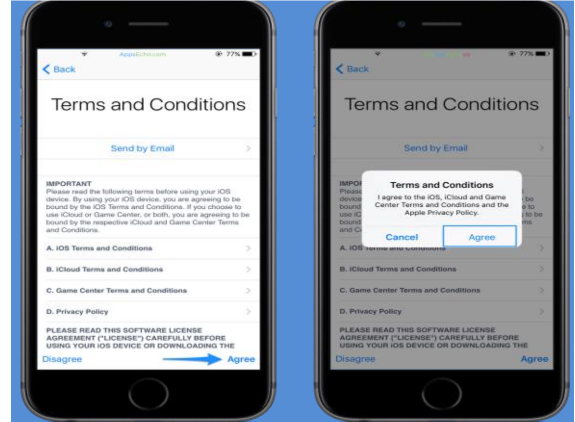
Bad Processes



Informed consent not done **with** patients

It is done **to** patients

"Consent the patient!"

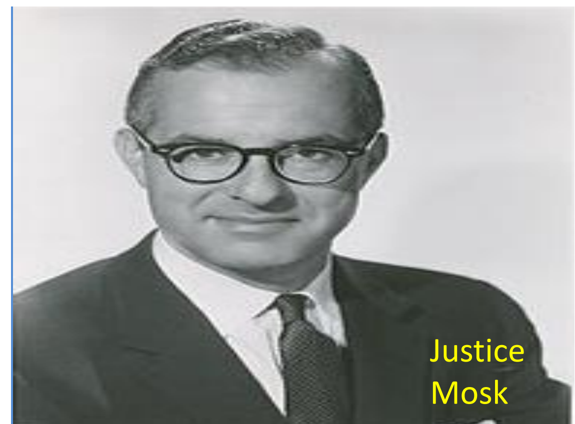


Disclosure was supposed to be a **means** to the goal of understanding

Today, disclosure **is** the goal

1972

Doctrine of informed consent



"lengthy polsyllabic discourse"

2018

"lengthy polsyllabic discourse"

Still

Stalled

50 years

Not only

bad **processes**

Medical consent

Bad

Outcomes

No

disclosure

Some patients

totally

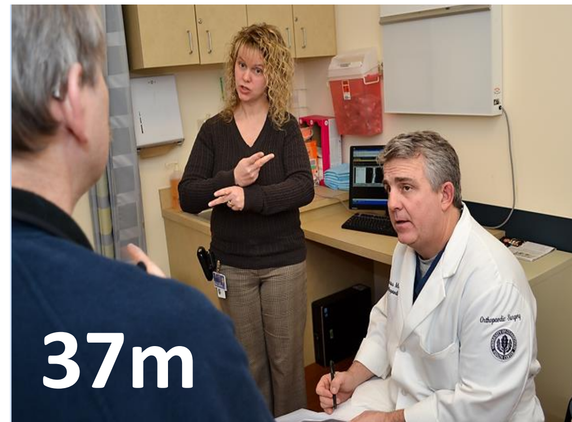
uninformed

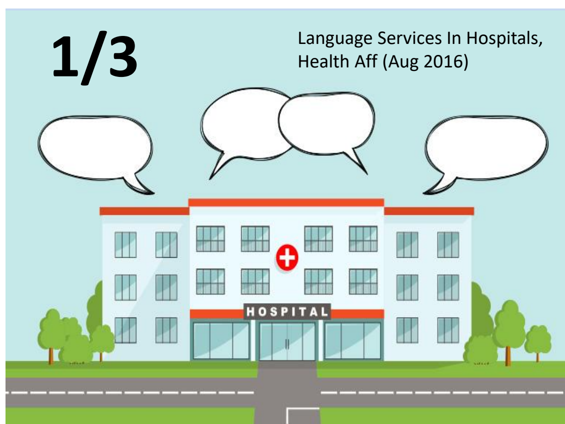
Health Care Costs in the Last Week of Life

Only 31% advanced cancer had EOL discussions

Results: Of 603 participants, 188 (31.2%) reported EOL discussions at baseline. After propensity score matching, the remaining 415 patients did not differ in socio-

Arch Intern Med. 2009;169(5):480-488

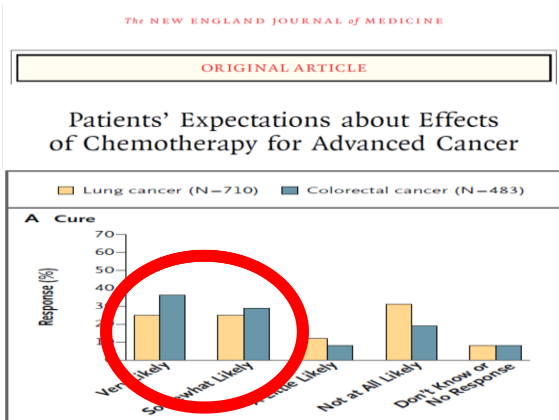




Ineffective disclosure

Whether

How



1000 audiotaped encounters

9%

JAMA 282(24):2313

Not meaningfully **conveyed**

Not understood

The role of informed consent in patient complaints: Reducing hidden health system costs and improving patient engagement through shared decision making

By Karen L. Posner, PhD, Julie Severson, PhD, JD, and Karen B. Domino, MD, MPH

Introduction: Patient complaints about physicians are strongly a
ciated with malpractice risk. Physicians at high risk for lawsuits

38 JOURNAL OF HEALTHCARE RISK MANAGEMENT • VOLUME 35, NUMBER 2

"potential risk of harm . . . **included**"

"but . . .
not clearly
understood"

"Risk of
dental injury
. . . disclosed"

"not **appreciate**
implications . . .
appearance . . .
(front teeth). . ."

"**Nerve injury**
. . . disclosed"

"**not understand**
. . . manifest as
pain or weakness
in an extremity"

Who's been out
to **dinner** in past
few weeks?

Too much

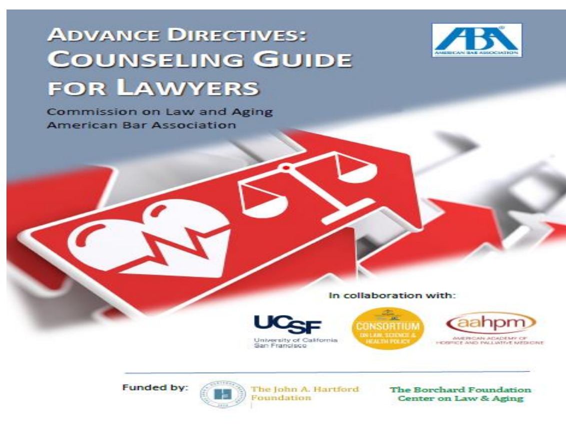
Too fast

Too complex

Also in medicine

Also in ACP

ACP



Older Adults More Likely to Discuss Advance Care Plans With an Attorney Than With a Physician

Gerontology & Geriatric Medicine
Volume 3: 1–5
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DOI: 10.1177/2333721417741978
journals.sagepub.com/home/ggm
SAGE

Mercedes Bern-Klug, PhD[1]
and Elizabeth A. Byram, MSW[1]

Attorney 38%

Physician 23%

Naming agent

Attorney

=

Physician

Less sure

about

goals of care

POLST

Problems

Physician Orders for Scope of Treatment (POST)
Executive Summary

Completion of a POST form **requires shared decision making** between the health care professional . . . and the patient, or . . . representative.

Physician Orders for Scope of Treatment (POST)
Executive Summary

"**must be a discussion** of . . . diagnosis and prognosis . . . available treatment options"

BUT

2 worrying reports

(summer 2018)

Architects & leaders

1

Health Affairs

Counting POLST Form Completion Can Hinder Quality

Susan W. Tolle, Joan M. Teno

JULY 19, 2018 DOI: 10.1377/hblog20180709.244065

"health plans . . . **measure the frequency** of POLST form completion"

Research Letter

January 2018

Palliative Care Eligibility, Symptom Burden, and Quality-of-Life Ratings in Nursing Home Residents

Caroline E. Stephens, PhD, GNP-BC[1]; Lauren J. Hunt, MSN, FNP, RN[2]; Nhat Bui, MSN, AGNP,RN[3]; et al

Author Affiliations

JAMA Intern Med. 2018;178(1):141-142. doi:10.1001/jamainternmed.2017.6299

98.5% completion

"**few patients** or their family members recalled being counselled on . . .POLST"

2

Bifocal

A Journal of the ABA Commission on Law and Aging

POLST:
Avoid the Seven Deadly Sins

By Charlie Sabatino

Signing a POLST form **without** meaningful discussion

Providing **incentives** for completing more POLST forms.

Recap

ACP suffers **same** patient understanding **problems**

ACP benefit same **solutions**

Solution

Problems

Patient decision aids

PDAs

What are PDAs?

Evidence based educational tools

2

Before encounter

During encounter

Present options clearly & graphically

THAI CUISINE

SOUP

1. Tom Yum
   Chicken or Vegetable (S) 2.95 (L) 4.95
   Seafood or Shrimp (S) 3.95 (L) 6.95
   Thai hot & sour soup with pepper, lime juice, mushroom , onion, lemongrass.
2. Tom Kar
   Chicken or Vegetable (S) 2.95 (L) 4.95
   Seafood or Shrimp (S) 3.95 (L) 6.95
   Thai hot & sour soup in coconut milk, lime juice, lemongrass, mushroom, onion & pepper.

APPETIZER

3. Thai Spring Roll (4) 4.95
   Crispy Siamese spring roll with vegetable filling, served with unique sweet sour dipping sauce
4. Satay Chicken (4) 6.95
   Grilled chicken skewered fillets accompanied by peanut dipping sauce and mini salad of cucumber and onion in vinaigrette dressing
5. Duck Salad 9.95
   Roast duck in Thai salad sauce (pineapple, red onion, scallion, green pepper)
6. Beef Salad 9.95
   Grilled beef, red onion, tomatoes, cucumber, lime juice and special Thai sauce

STIR FRIED

Traditional dishes, seasoned and herb dressed

CURRY ENTREES

Traditional Thai curry each one:
Unique each one can be ordered mild, medium or hot

Shrimp or Beef $11.95
Chicken, Vegetable or Tofu $9.95

11. Green Curry
    Green chili paste in coconut mil, pepper, basil, and eggplant.
12. Red Curry
    Red curry paste in coconut milk, pepper, basil, and eggplant.
13. Panange Curry
    Panange curry paste in coconut milk, string beans, basil, pepper
14. Yellow Curry
    Yellow curry paste in coconut milk, potatoes and onion
15. Massamen Curry
    Massamen curry paste in coconut milk, potatoes and onion & peanuts

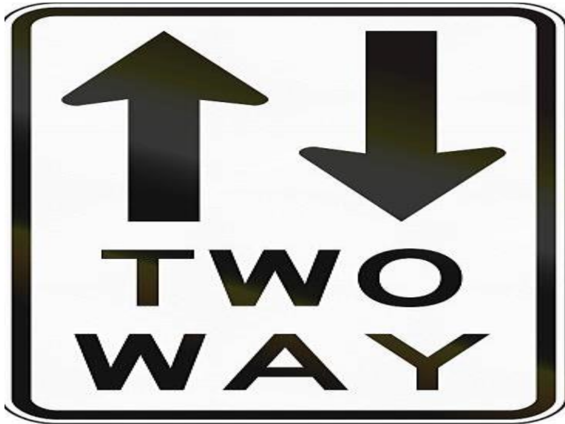
NOODLES

The most famous dish in Thailand

Shrimp or Beef $9.95 / Chicken or Vegetables $8.95

16. Pad Thai
    Sauteed rice noodles with eggs, bean sprouts, scallions and grounded peanuts

The Signature (Mild)
Massaman Beef (Mild)
Classic Pad Thai (Mild)
Toasted Sweet Chili (Mild-Medium)
Red Curry (Medium)
Green Curry (Medium)
Tiger Tear Salad (Mild)
Basil Stir Fried (Mild)
Spring Rolls
Thai Ice Tea/Coffee
Brew it Strong!



Do they work?

Yes

Robust evidence shows PDAs are highly **effective**

> 130 RCTs

30,000 patients

50 conditions

Improved knowledge

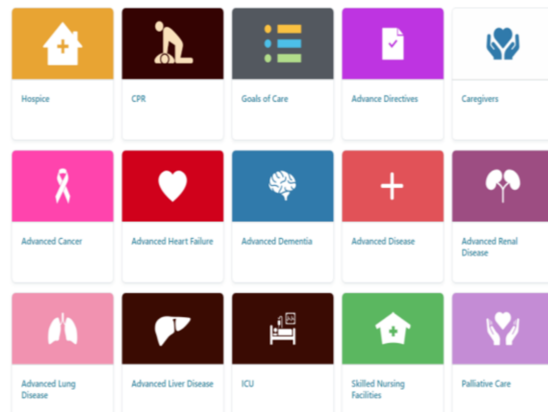
More accurate expectations

Lower decisional conflict
(less uncertainty)

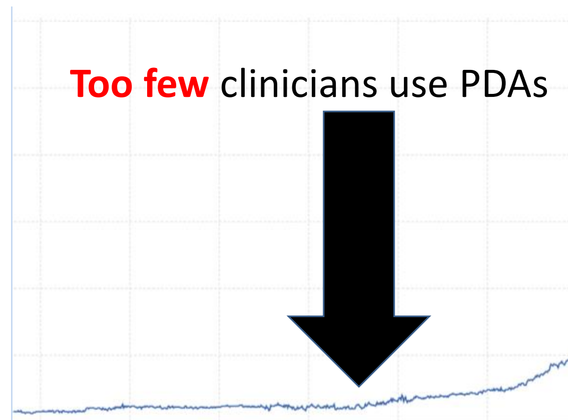
More value congruent choice

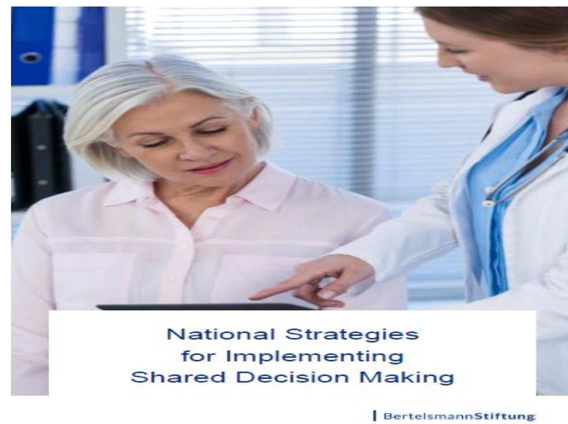
Great evidence

ACP PDAs



What is the problem?





Australia
Canada
Denmark
Germany
Netherlands
Norway
Taiwan
UK
USA

"**More work** has been done on SDM in **the US** than in any other country."

BUT

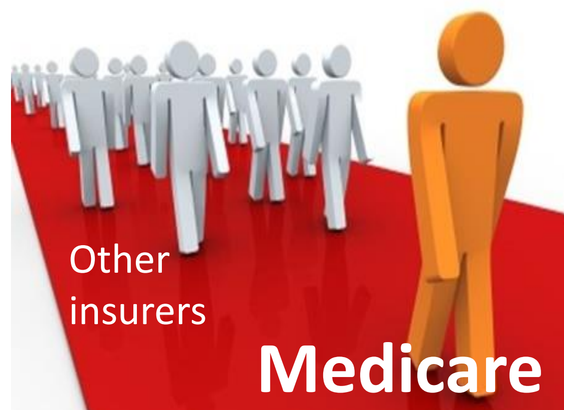
"**not** incorporated into mainstream care"

So:

Move PDAs from research to practice

From lab to clinic

Payment Tools



PDA use = "condition for payment"

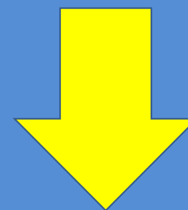
No PDA

Logic

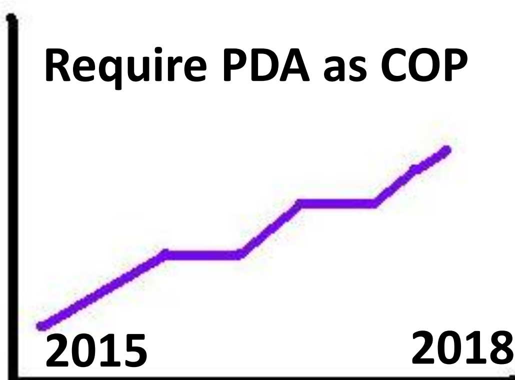
Medicare only pays **"medically necessary"**

"Medically necessity" **not** purely clinical determination

Unwanted



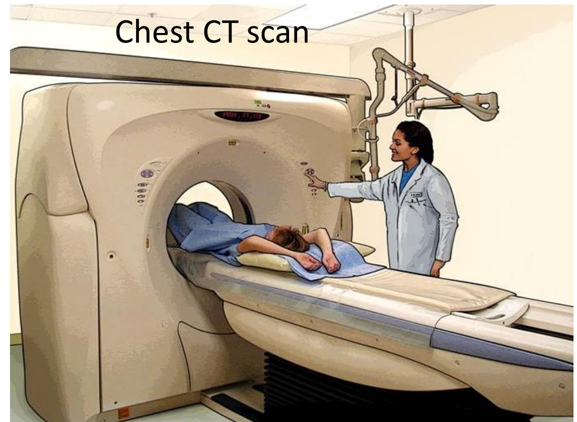
Not med. necc.



3 examples

1

Screening for Lung Cancer with Low Dose Computed Tomography



Before

CT scan

“**must receive**

. . . SDM visit”

“**include** . . .

one or more

decision aids”

NATIONAL CANCER INSTITUTE

CENTERS FOR DISEASE CONTROL AND PREVENTION

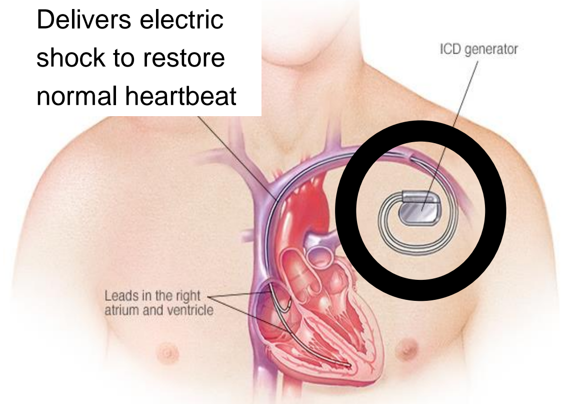
Memorial Sloan Kettering Cancer Center™

WHAT IS IMPORTANT TO YOU WHEN DECIDING ABOUT SCREENING FOR LUNG CANCER?

There are many things to think about when deciding whether lung cancer screening is right for you. Below is a list of questions that may help you decide.

	Favors Screening				Favors No Screening
How important is:	Very Important				Not Important
Finding lung cancer early when it may be more easily treated?	○	○	○	○	○
How concerned are you about:	Not Concerned				Very Concerned
Having a false alarm?	○	○	○	○	○
Having other tests if you have a positive screening test?	○	○	○	○	○
Being exposed to radiation from lung cancer screening?	○	○	○	○	○
Being treated for lung cancer that never would have harmed you?	○	○	○	○	○
Being harmed by the treatments you receive for lung cancer?	○	○	○	○	○

Implantable Cardioverter Defibrillators



Before

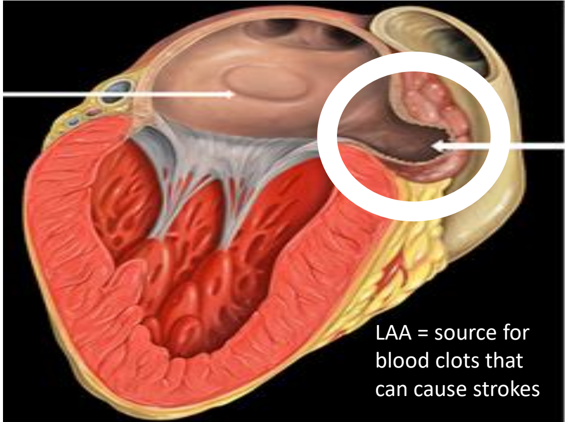
implantation

"formal SDM encounter **must occur**"

"evidence-based **decision tool** "

3

Percutaneous Left Atrial Appendage Closure Therapy



Warfarin NA (Coumad
2mg 90 Tablets
N 67544-0401-60

Warfarin NA (Coumadin)

Thin blood with anticoagulant medication

Mfg. By: Bristol-Myers Squibb Company
Garden City, NY
Repackaged by Aphena Pharma
Cookeville, TN 38506

Batch:
Exp:
Lot:

RX Only

N 67544-0401-60

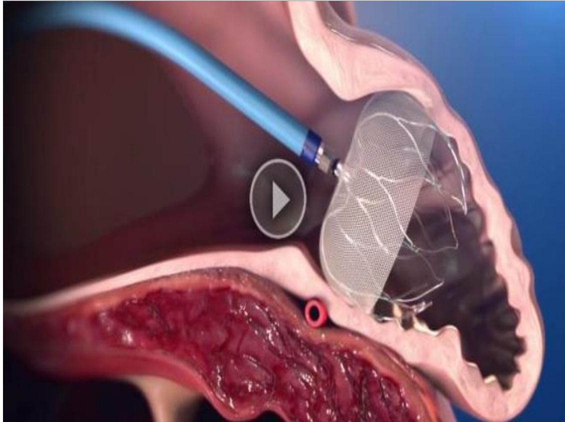
Warfarin NA (Coumadin) 2mg 90 Tablets

Boston Scientific
Advancing science for life™

PROFESSIONALS PATIENTS PRODUCTS ABOUT

THERE'S AN ALTERNATIVE TO WARFARIN

FOR PEOPLE WHO NEED ONE. IT'S CALLED WATCHMAN™.



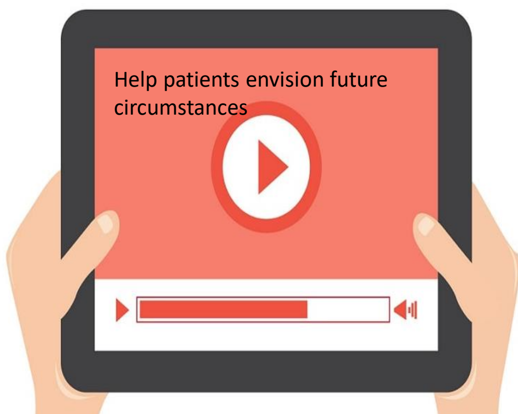
Before

implantation

"formal SDM interaction"

evidence-based **decision tool**"

ACP PDAs



No intubation

Verbal	**Video**
53%	80%

Circulation 134:52

Adv. dementia comfort care

Verbal	Video
50%	89%

Deep 2010

Adv. cancer comfort care

Verbal	Video
22%	91%

El-Jawahri 2010

99497

99498

"formal SDM interaction"

evidence-based **decision tool**"

SENATE, No. 1891

STATE OF NEW JERSEY

218th LEGISLATURE

INTRODUCED FEBRUARY 15, 2018

Sponsored by:
Senator TROY SINGLETON
District 7 (Burlington)

Medicaid will cover advance care planning

BUT

"Advance care planning shall consist . . . **SDM** . . . **decision aids**"

Link ACP reimbursement to PDA use?

PDAs widely **varying** quality

ACP PDA too

Annals of Internal Medicine | Review

Decision Aids for Advance Care Planning: An Overview of the State of the Science

Mary Butler, PhD, MBA; Edward Ratner, MD; Ellen McCreedy, MPH; Nathan Shippee, PhD; and Robert L. Kane, MD

Cannot attach legal consequences

Assure PDA **quality**

Certification

Accurate

Up to date

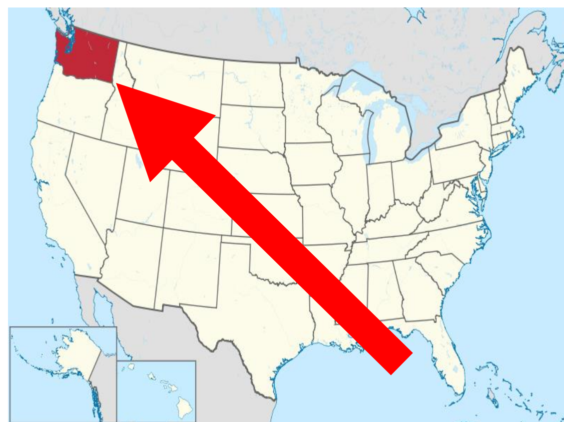
No bias, COI

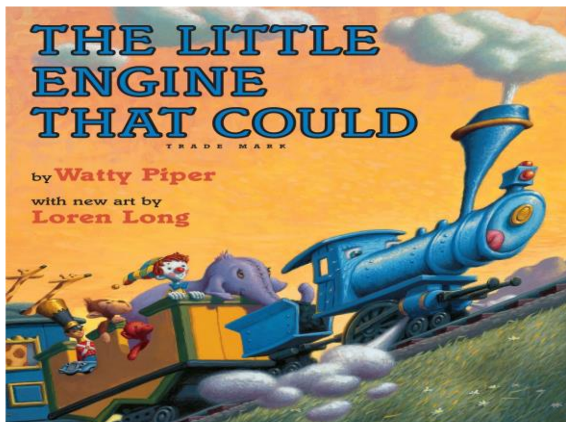
Understandable

No **national** certification entity

2017

Contract with an entity to “synthesize evidence” and establish “consensus based standards”

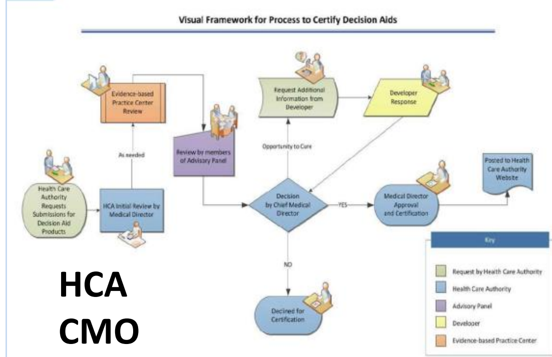




Final Set of Certification Criteria

Does the patient decision aid adequately:	Additional Criteria for Screening and/Testing, if applicable:
1. Describe the health condition or problem 2. Explicitly state the decision under consideration 3. Identify the eligible or target audience 4. Describe the options available for the decision, including non-treatment 5. Describe the positive features of each option (benefits) 6. Describe the negative features of each option (harms, side effects, disadvantages) 7. Help patients clarify their values for outcomes of options by a) asking patients to consider or rate which positive and negative features matter most to them AND/OR b) describing each option to help patients imagine the physical, social (e.g. impact on personal, family, or work life), and/or psychological effects 8. Make it possible to compare features of available options 9. Show positive and negative features of options with balanced detail 10. Provide information about the funding sources for development 11. Report whether authors or their affiliates stand to gain or lose by choices patients make using the PDA 12. Include authors/developers' credentials or qualifications 13. Provide date of most recent revision (or production)	14. Describe what the test is designed to measure 15. Describe next steps taken if test detects a condition/problem 16. Describe next steps if no condition/problem detected 17. Describe consequences of detection that would not have caused problems if the screen was not done 18. Include information about chances of true positive result 19. Include information about chances of false positive result 20. Include information about chances of true negative result 21. Include information about chances of false negative result **Does the Patient Decision Aid and/or the accompanying external documentation (including responses to the application for certification) adequately:** • Disclose and describe actual or potential financial or professional conflicts of interest? • Fully describe the efforts used to eliminate bias in the decision aid content and presentation? • Demonstrate developer entities and personnel are free from listed disqualifications in Attachment A? • Demonstrate that the Patient Decision Aid has been developed and updated (if applicable) using high quality evidence in a systematic and unbiased fashion? • Demonstrate that the developer tested its decision aid with patients and incorporated these learnings into its tool?

Certification Process



In use

23

CPR (6)

Advanced cancer
Advanced disease
Advanced heart failure
Advanced liver disease
Advanced lung disease
Closer look for people with a serious illness

Goals of care (5)

Advanced cancer
Advanced disease
Advanced heart failure
Advanced lung disease
Family meetings in the ICU

Hospice (3)

Advanced cancer
Skilled nursing facility
Introduction

Other

Dialysis for patients 75+
Long-term tube feeding
Help with breathing
Medical care for serious illness
Advanced lung cancer patient

Other vetted ACP PDAs

Conclusion

Medicare does not yet require PDA ACP **yet**

BUT

Look at the WA PDAs

Patient Decision Aid Certification Criteria

Does the patient decision aid adequately:

International Patient Decision Aid Standards (IPDAS) Collaboration

Patient Decision Aids

Patient Decision Aids

For specific conditions

For any decision

Developed in Ottawa

Other KT Tools

A to Z Inventory of Decision Aids

Search all decision aids:

Go

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Mitchell Hamline School of Law
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C 310-270-3618
E Thaddeus.Pope@mitchellhamline.edu
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B medicalfutility.blogspot.com

315

Materials from the cases discussed in this presentation are available at

http://thaddeuspope.com

Medical Futility Blog

Since 2007, I have been blogging, almost daily, to **medicalfutility.blogspot.com**. This blog focuses on reporting and discussing legislative, judicial, regulatory, medical, and other developments concerning end-of-life medical treatment conflicts. The blog has received **over 3 million** direct visits. Plus, it is redistributed through WestlawNext, Bioethics.net, and others.

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