

Patient Rights and Healthcare Decision Making after COVID-19 Transformations & Future Directions

Thaddeus Mason Pope, JD, PhD, HEC-C
QUT Global Law, Science and Technology
Seminar Series (November 20, 2020)

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Thank you

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3

Australian Centre for Health Law Research



Coffee with a Colleague

Online seminar series

<https://www.qut.edu.au/law/research/achlr>

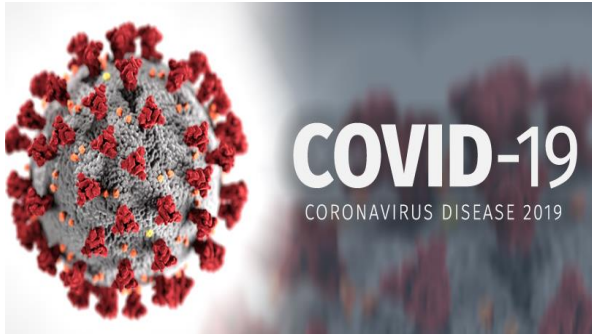
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Introduction

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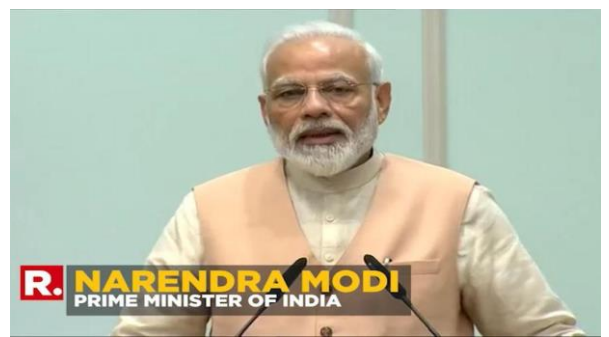
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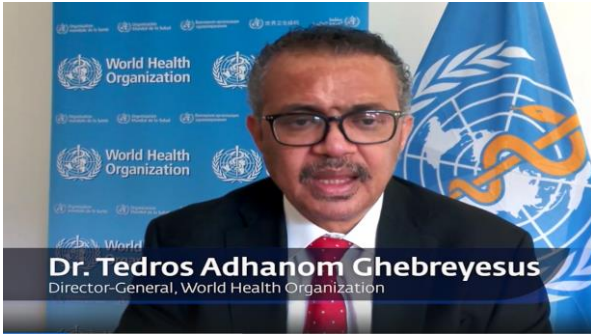
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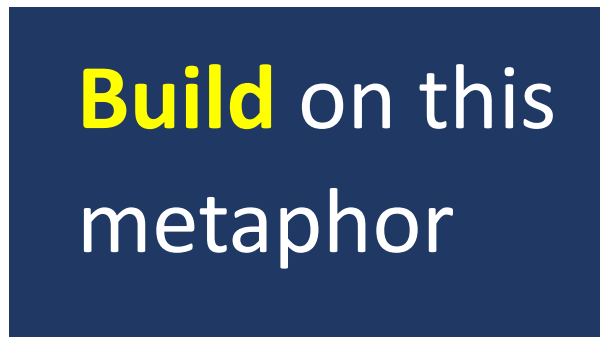
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In what ways has COVID-19 changed how clinicians **communicate** with patients?

21

Ways it changed how patients **make & record** healthcare decisions?

22

Will these changes **persist after** the pandemic

23

Roadmap

24

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25

World War II
innovation

26

COVID-19
innovation

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ACP
PDA

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Making it
permanent

29

World War II

30



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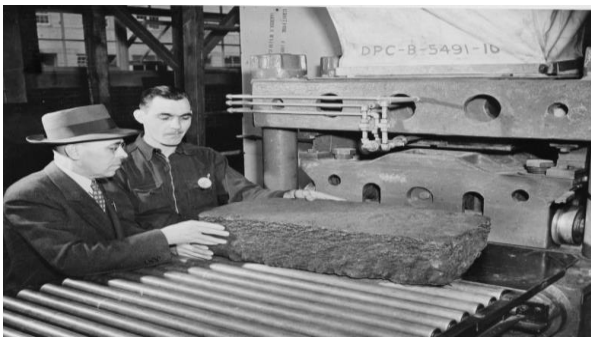
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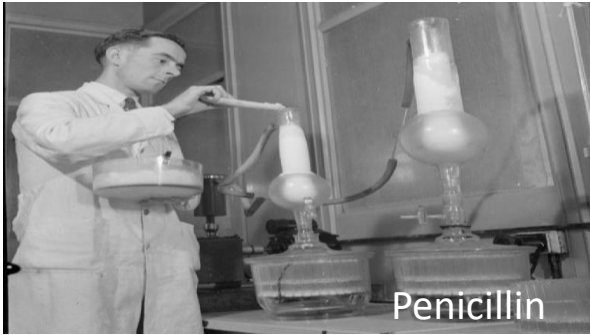
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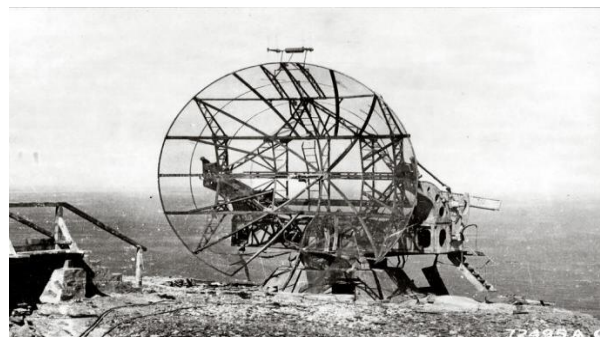
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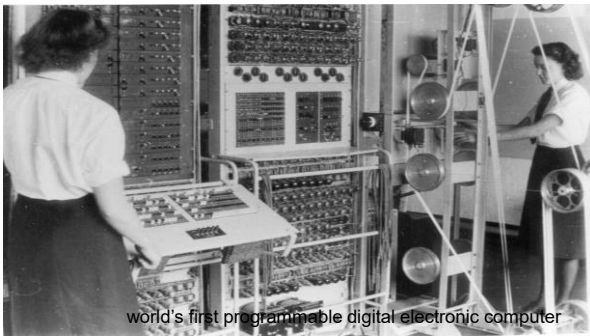
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43



44



world's first programmable digital electronic computer

45



46



47



48



49



50

“necessity is the mother of invention”

51

AND

52

WWII innovations
still used today

53

COVID-19

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Same
true?

55

Innovations?
Will they persist?

56



57

BUT

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Telehealth

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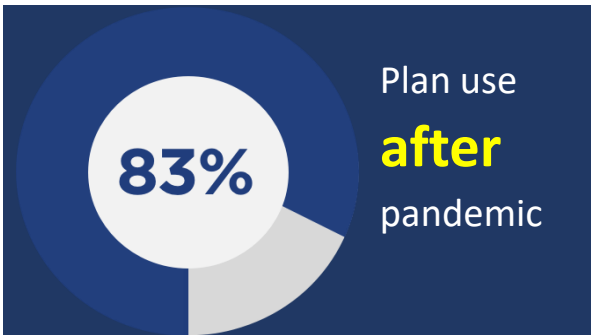
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Persist

64



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Telehealth

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67

Tools for medical
decision-making

68

COVID-motivated
innovations

69

Persist **after**
pandemic

70

Value
discordant
healthcare

71

1. Get treatment that
do **not** want
- or*
2. Don't get treatment
that **do** want

72

Overtreatment
Undertreatment

73

Happens to patients
with decision-
making capacity

74

Happens **more**
with **in**capacitated
patients

75

Cannot tell us
what they want
and do not want

76



77

Key **tool** to mitigate
value discordant
treatment for
incapacitated patients

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Advance
directive

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Advance
Directives

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Before
COVID-19

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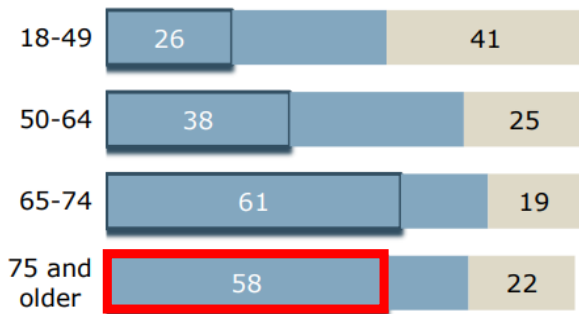
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NOV. 21, 2013

Views on End-of-Life Medical Treatments

Growing Minority of Americans Say Doctors Should Do Everything Possible to Keep Patients Alive

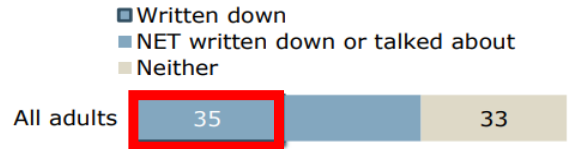
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Preparation for End-of-Life Treatment, By Age

% who say they have written down or talked with someone about their wishes



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RESPECTING PATIENTS' PREFERENCES

By Kuldeep N. Yadav, Nicole B. Gabler, Elizabeth Cooney, Saida Kent, Jennifer Kim, Nicole Herbst, Adjoa Mante, Scott D. Halpern, and Katherine R. Courtright

DOI: 10.1377/hlthaff.2017.0175
HEALTH AFFAIRS 36,
NO. 7 (2017): 1244-1251
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The People-to-People Health
Foundation, Inc.

Approximately One In Three US Adults Completes Any Type Of Advance Directive For End-Of-Life Care

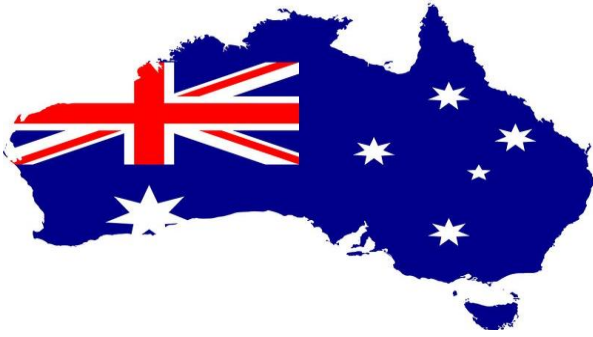
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Systematic review
of 150 studies
800,000 people

89

37%

90



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92



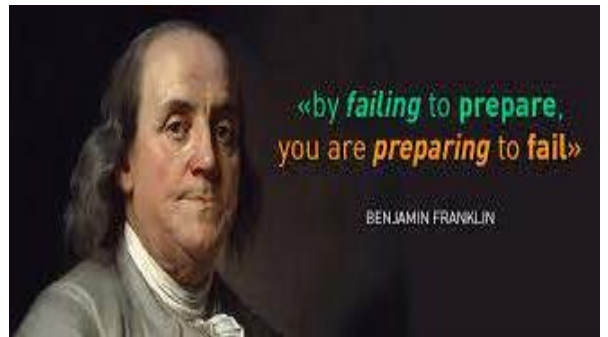
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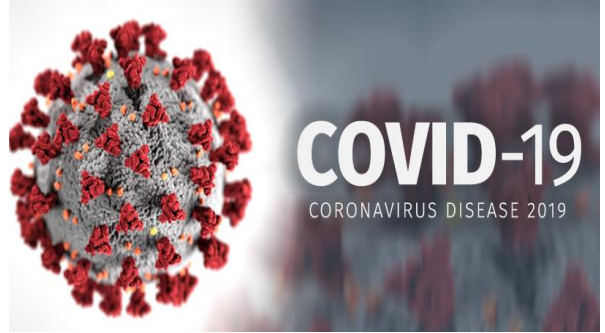
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Advance directive completion



103



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THE INDIANA LAWYER

Life and death decisions: Pandemic increases focus on estate planning, health care advance directives

May 26, 2020 | Olivia Covington

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JOURNAL OF BUSINESS Serving Spokane & Kootenai Counties

Advance directive demand

More clients seek end-of-life plan guidance during pandemic, Spokane attorneys say

■ Virginia Thomas September 24th, 2020

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Vol. ■ No. ■ 2020

Journal of Pain and Symptom Management 1

How COVID-19 Changed Advance Care Planning: Insights From the West Virginia Center for End-of-Life Care

Danielle Christina Funk, MS, Alvin H. Moss, MD, and Atticus Speis, MS

West Virginia University, Morgantown, West Virginia

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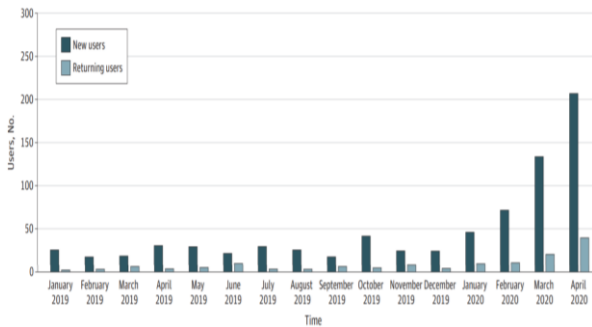
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Research Letter | Geriatrics

Completion of Advance Directives and Documented Care Preferences During the Coronavirus Disease 2019 (COVID-19) Pandemic

Catherine L. Auriemma, MD; Scott D. Halpern, MD, PhD; Jeremy M. Asch, BA; Matthew Van Der Tuyn, MA; David A. Asch, MD, MBA

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111



J Med Internet Res. 2020 Aug; 22(8): e21385.

Published online 2020 Aug 11. doi: 10.2196/21385

PMCID: PMC7423389

PMID: [32716900](#)

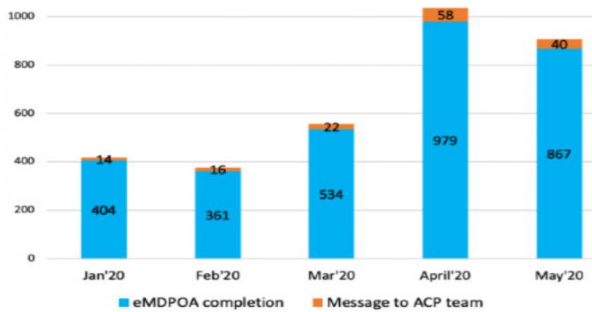
Advance Care Planning Among Users of a Patient Portal During the COVID-19 Pandemic: Retrospective Observational Study

Monitoring Editor: Gunther Eysenbach

Reviewed by Emmanuelle Belanger and Prasad Padala

[Jennifer D Portz](#), PhD,^{1†} [Adreanne Brunogard](#), MM, MT-BC,² [Prajakta Shanbhag](#), MPH,² [Elizabeth W Staton](#), MSTC,³ [Sevil Bose-Billi](#), MD,⁴

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114



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Care and Choice at the End of Life

**COVID-19 Advanced Directive
Addendum: Documenting Your
Preferences**

Please attach this form to your advance directive and date and sign. Then have it signed by witnesses in accordance with witness signature requirements for your state's Advanced Directives. Please note, this Advance Directive is only intended to provide instructions in the event that this person has COVID-19.

- If your oxygen levels are dropping, do you want to go to the hospital or would you prefer to try to get non-invasive respiratory care at home?

119



120



121



122

Innovation

123



124

Witnesses:

1. I am a competent adult who is not named as the agent. I witnessed the patient's signature on this form. _____
Signature of witness number 1

2. I am a competent adult who is not named as the agent. I am not related to the patient by blood, marriage, or adoption and I would not be entitled to any portion of the patient's estate upon his or her death under any existing will or codicil or by operation of law. I witnessed the patient's signature on this form. _____
Signature of witness number 2

This document may be notarized instead of witnessed:

125



126

Who can witness
How can witness

127

Who

128



129

None of the following persons may act as a witness ... the patient's health care provider ..."

Cal. Prob. Code 4674

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CONFLICT OF INTEREST

131

BUT

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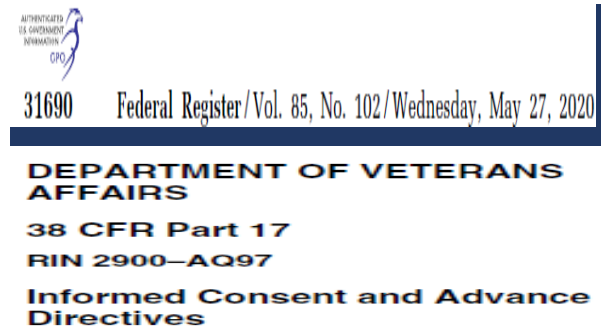
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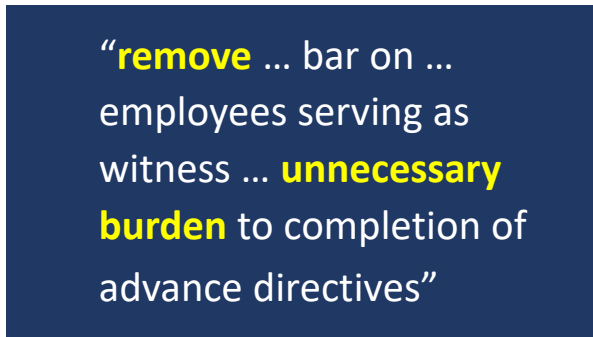
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How

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BUT

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So...

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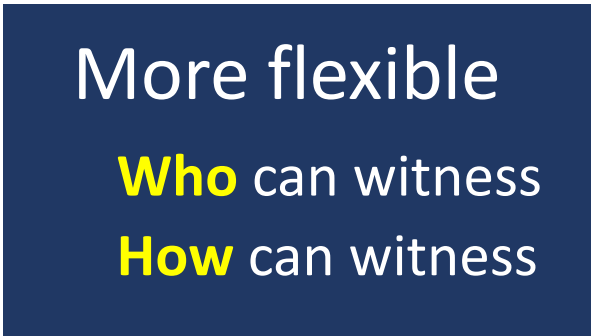
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Advance Care Directive Form

By completing this Advance Care Directive you can choose to:

1. Appoint one or more Substitute Decision-Makers and/or
2. Write down your values and wishes to guide decisions about your future health care, end of life, living arrangements and other personal matters and/or
3. Write down health care you do not want in particular circumstances.

Part 1
You must fill in this Part.

Part 1: Personal details
Name: Serena Primrose
(Full name of person giving Advance Care Directive)
Date of birth: 21 / 1 / 1952

Part 2a
Only fill in this Part if you want to appoint one or more Substitute Decision-Makers.

Part 2a: Appointing a substitute decision-maker(s)
I appoint: Amelia Sherlock
(Name of appointed Substitute Decision-Maker)
Ph: 8000 8000 Date of birth: 2 / 7 / 1968
Amelia Sherlock

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Validity Meaning

170

Validity

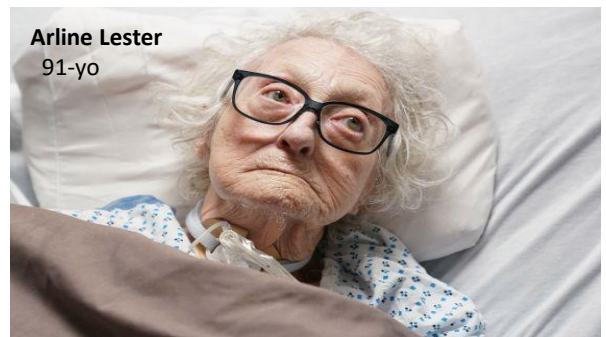
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Someone claims
patient **lacked capacity**
to complete the AD

172



173



174



Kyle

175

Wants mother **removed** from life-sustaining treatment per her **1991 advance directive**

176



Edward Lester
Son of hospitalized mother

177

Says mother **executed a new** advance directive on Nov. 13, 2019 and wants to live

178

Later in time
ADs **revoke**
earlier ADs

179

But ... is the
newer AD
valid?

180

Did Arline have **capacity** to complete?

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video helped

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Sumner Redstone
92yo

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September 3

AD names agent "companion"

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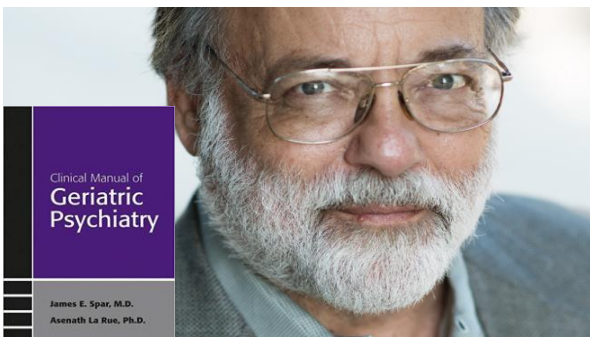
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Validity requires not
only capacity but also
voluntariness

193

Someone claims
patient **coerced**
to sign AD

194



195

Videos
help prove
AD **validity**

196

Capacity
Voluntariness

197

Meaning

198

What did the patient want?

199

Did she want it under **these** circumstances?

200

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

Ferdinando L. Mirarchi, DO, FACEP, Timothy E. Cooney, MS,* Arvind Venkat, MD, FACEP,†
David Wang, MD,‡ Thaddeus M. Pope, JD, PhD,§ Abra L. Fant, MD,|| Stanley A. Terman, PhD, MD,¶*

J Patient Saf 2017;13: 51–61

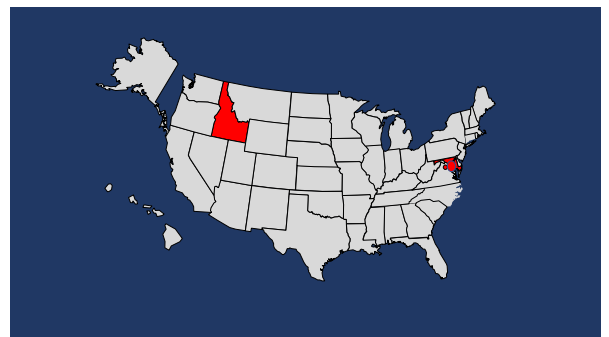
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Value

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BUT

203



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Temporary
↓
Permanent

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206

Patient → clinician
AD
Video AD

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Clinician → patient

208

Patient
Decision
Aids

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What are
PDAs?

210

Evidence based
educational tools

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2

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Before
encounter

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During
encounter

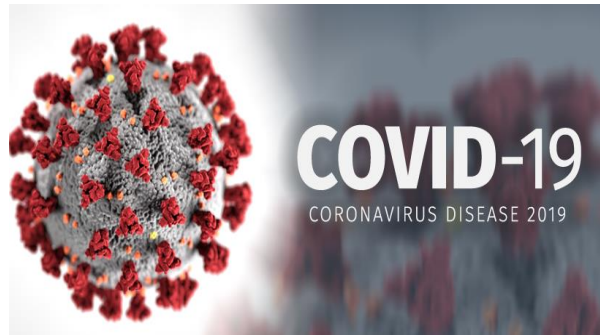
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Present options clearly & graphically

217



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Life Support During the COVID-19 Pandemic

This is an unusual time, with very large numbers of very sick people right now. Some people are getting so sick that they need a life support machine (like a ventilator or breathing machine - see picture).

Because of the current pandemic, there might not be enough life support machines for everyone who needs them. Hopefully, this does not happen.

In this very difficult time, it's really important to be clear about your values and main concerns for your health care.

How would decisions about who gets a life support machine be made?

If there is a shortage, a team of doctors and nurses will review all cases of patients who need life support machines. This team will make tough decisions based on the best medical information available. The team will not be given information about patient race, ethnicity, religion, insurance or other unrelated things.

What are my choices?



221

If you become sick enough to need a life support machine, what would you want?

- I want to be on a life support machine, if a machine is available.
- I want one **if it is available**, but first consider others who may be more likely to survive. I understand this would mean that I am more likely to die.
- I **don't want one**, even if it is available. I understand this would mean that I am more likely to die.

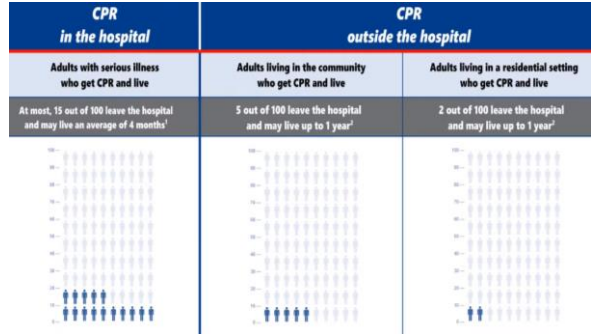
Are you sure that your answer above says what you really want?

- Yes, I understand and my answer above says what I really want.
- No, I need to ask questions and talk to a doctor and my loved ones before I can be sure.

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Cardiopulmonary Resuscitation (CPR) Decision Aid		Respecting Choices [®] PERSON-CENTERED CARE
For people with serious illness (like heart or lung disease or cancer) facing a decision about attempting CPR.		
What care do you want if your heart and breathing stop? This decision aid will help you consider your options for CPR and your personal values. You may change your choice at any time. Review the information on both sides of this decision aid. Talk with your doctor about what to expect.		
What are your options?	Attempt CPR	Do Not Attempt CPR
What is it?	CPR is done for you by someone else and can include: • Pressing on your chest • A tube to help you breathe • Electrical shock and drugs	CPR is not provided. You will receive other care to treat your symptoms and keep you comfortable.
What does it do?	CPR attempts to restart your heart and breathing. CPR may restart your heart and breathing. Review the facts (on the back) about the chances of CPR restarting your heart and breathing.	Not attempting CPR allows a natural death. Not attempting CPR avoids machines. Not attempting CPR avoids the burdens of CPR.
What are the benefits?	You will need to be on a breathing machine for a time. You will need to be in the intensive care unit (ICU). You may have damaged or broken ribs.	You will die.
What are the short-term burdens?	You may have mild to severe brain damage. You may no longer be able to live alone.	
What are the long-term burdens?	You may have mild to severe brain damage. You may no longer be able to live alone.	
Which option best matches your values?	Your Values You want the chance to live. You are willing to accept the fact that CPR may not restart your heart and breathing. You are willing to accept the burdens of CPR.	Your Values You prefer a natural death. You are unwilling to accept the fact that CPR may not restart your heart and breathing. You are unwilling to accept the burdens of CPR.

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224

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Coronavirus Disease 2019 (COVID-19) Shared Decision-Making

March 19, 2020

1. What is my, or my loved ones, likelihood of surviving COVID-19?
The most important predictors of survival are age and pre-existing conditions.

AGE ^a	DEATH RATE Confirmed Cases	DEATH RATE All Cases
80+ years old	21.9%	14.8%
70-79 years old	8.0%	8.0%
60-69 years old		3.6%

nhpco.org/coronavirus

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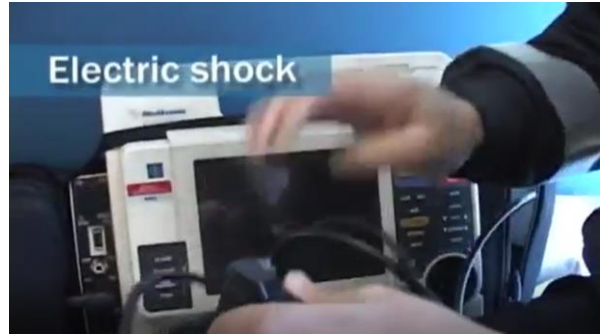
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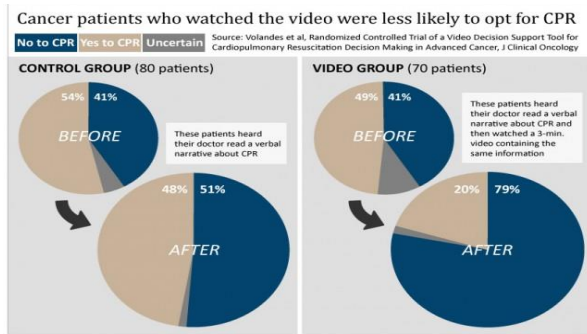
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231

Not only for medical care

232


Where to live

233



During the COVID-19 pandemic, should I go to live elsewhere or stay in my retirement/assisted living home?

234



A COVID-19 DECISION AID: How Do I Choose When to Interact with People or Take Part in Activities Outside My Home During the Pandemic?

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Do PDAs work?

236

Yes

237

Robust evidence shows PDAs are highly **effective**

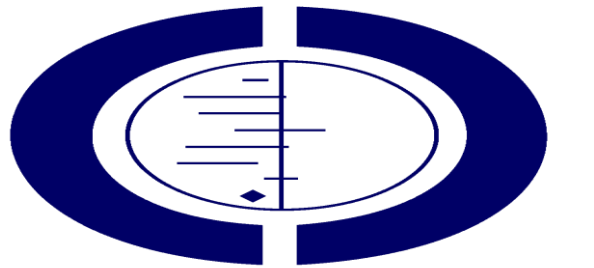
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> 130 RCTs

239

30,000 patients
50 conditions

240



**THE COCHRANE
COLLABORATION®**

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JOURNAL OF SURGICAL RESEARCH • MARCH 2019 (235) 350-366

A Review of Decision Aids for Patients Considering More Than One Type of Invasive Treatment

Kathleen A. Leinweber, BS,^a Jesse A. Columbo, MD, MS,^{a,b,c,d,e}

242

**6 big
benefits**

243

**Improved
knowledge**

244

**More accurate
expectations**

more accurate perception of risks

245

**More value
congruent
choice**

246

Higher
patient
satisfaction

247

Less
decisional
conflict

248

Less
patient
anxiety

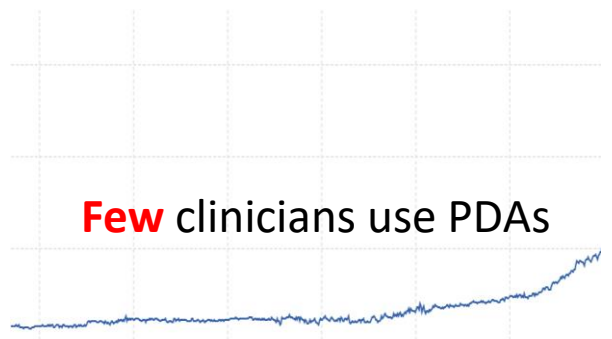
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Great
evidence

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What's the
problem?

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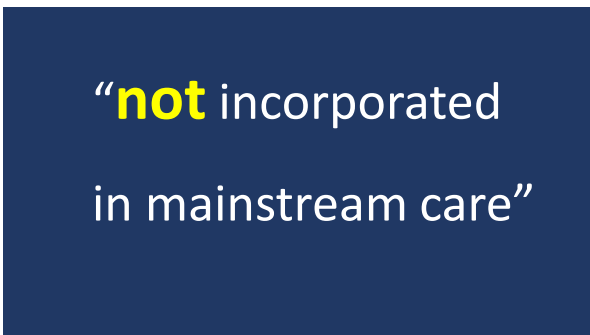
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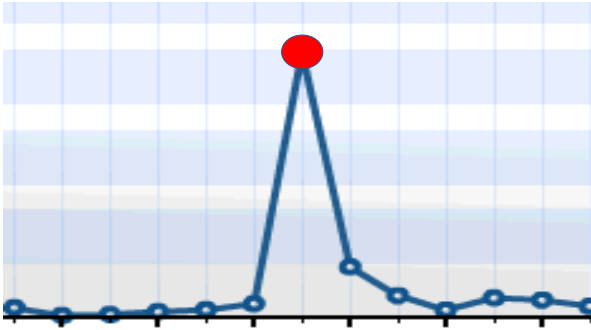
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Legal **incentives** for
clinicians to use PDAs

261

Conclusion

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How has COVID-19
changed how patients
make & record
healthcare decisions?

263

Advance directives

- Allow clinician witness
- Allow remote witness
- Allow remote notary
- More videotaped

264

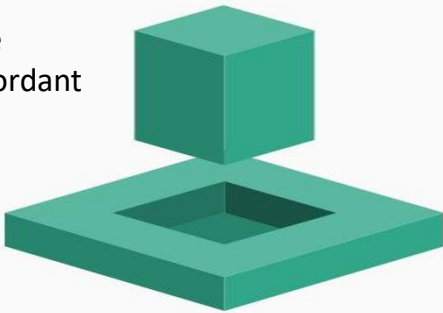
How has COVID-19
changed how
clinicians communicate
with patients?

265

More use
of PDAs

266

Value
concordant
care



267

Just as WWII innovations
persisted after that war,
we must assure these
innovations **persist after**
the pandemic

268

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