

# Postoperative Sleep as a Patient-Centered Outcome After Hospital Discharge – Implications for QOL and Safety

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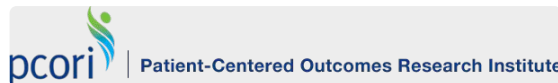
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**“Why me? I’m a critical care  
anesthesiologist and palliative  
care physician and  
researcher...”**

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**“But you are an expert in patient-centered outcomes research (PCOR) and we want to know more about PCOR!”**



Krish Ramachandran, MD  
Beth Israel Deconess Medical Center

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## **Objectives**

- Define patient-centered outcomes research (PCOR)
- Empower you to consider incorporating PCOR through examples from my own research portfolio

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**What is patient-centered outcomes research?**



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## What is the Patient-Centered Outcomes Research Institute?

- Founded in 2010 through the Patient Protection and Affordable Care Act
- Goal to promote comparative effectiveness research to:

*“Assist patients, clinicians, purchasers, and policy-makers in making informed health decisions by advancing the quality and relevance of evidence concerning the manner in which diseases, disorders, and other health conditions can effectively and appropriately be prevented, diagnosed, treated, monitored, and managed through research and evidence synthesis.”*

Selby JV, Beal AC, Frank L. JAMA 2012

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## What is patient-centered outcomes research?



- Research centered on decisions and outcomes *important to patients and family members*
- Trans-disciplinary teams are essential
- Diverse stakeholders (including patients and family members) are integrated into the team throughout all stages of research

Selby JV, Beal AC, Frank L. JAMA 2012  
Krumholz HM, Selby JV. Ann Intern Med 2012  
Fleurence R et al. Health Affairs 2013  
Frank L, Basch E, Selby JV. JAMA 2014

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VIEWPOINT

# The PCORI Perspective on Patient-Centered Outcomes Research

**Lori Frank, PhD**  
Patient-Centered Outcomes Research Institute, Washington, DC.

**Ethan Basch, MD**  
Lineberger Comprehensive Cancer Center, University of North Carolina, Chapel Hill.

**Joe V. Selby, MD, MPH**  
Patient-Centered Outcomes Research Institute, Washington, DC.



The Patient-Centered Outcomes Research Institute (PCORI) was established as part of the US Patient Protection and Affordable Care Act of 2010 to fund patient-centered comparative clinical effectiveness research, extending the concept of patient-centeredness from health care delivery to health care research. In the United States, patient-centered outcomes research is new and not defined in the legislation, and the rationale is unclear to many. In this Viewpoint, we address 2 related questions: What does patient-centeredness in research mean? Why conduct patient-centered outcomes research?

The essence of the PCORI definition of patient-centered outcomes research is the evaluation of questions and outcomes meaningful and important to patients and caregivers. The definition rests on the axiom that patients have unique perspectives that can change and improve the pursuit of clinical questions.

Relevant to both the definition and rationale is the hypothesis that including the perspectives of end users of the research, which include patients, physicians, and other health care stakeholders, will enhance the rel-

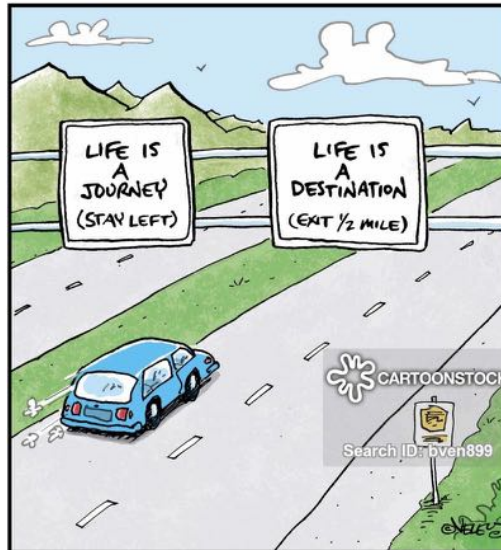
of patients in research is limited but evolving and shows both positive and negative effects. Beneficial outcomes of engagement include improved relevance of study results to patients,<sup>2</sup> improved research recruitment and retention rates,<sup>4</sup> and improved content and construct validity of measures.<sup>5</sup> Negative consequences include added financial and staff resources needed to establish and maintain engagement and a sense of work burden among patient participants.<sup>6</sup> PCORI intends to contribute to this evidence through evaluation of the effects—whether positive, negative, or neutral—of engaged models of research.

Why can researchers or clinicians alone not provide the patient perspective? Experiences and training determine a person's worldview,<sup>7</sup> and patient-centeredness is at its heart a question of including the worldview of patients. Because of their training and orientation, researchers and clinicians can be at a disadvantage for representing the patient perspective. Patients—individuals whose worldview about health is centered on the experience of health care—may more accurately and comprehensively capture the patient per-

Frank L, Basch E, Selby JV. JAMA 2014

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## How do you do PCOR?



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## What is palliative care?

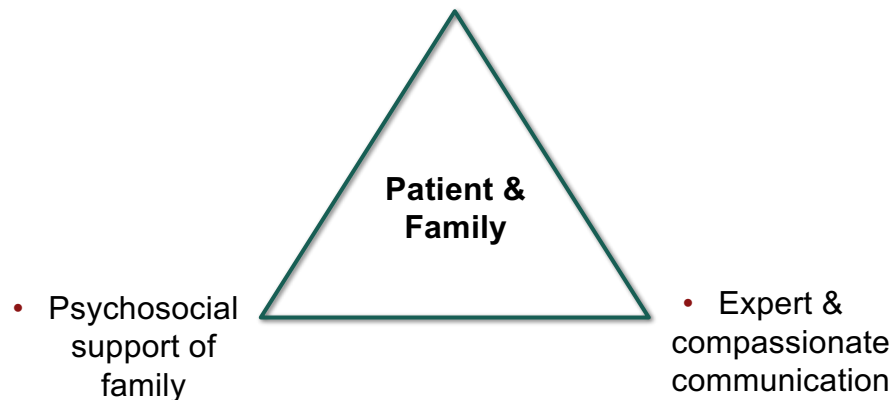
- Specialized medical care
- For patients with serious illness and their family members
- Goal is to improve quality of life
- Appropriate at any age and at any stage of serious illness
- Can be provided together with curative illness

Center to Advance Palliative Care. <http://www.capc.org/>  
Kelley AS & Morrison RS. NEJM 2015.

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## What is palliative care?

- Aggressive symptom management



Center to Advance Palliative Care. <http://www.capc.org/>  
Kelley AS & Morrison RS. NEJM 2015.

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## Our task from the Patient-Centered Outcomes Research Institute (PCORI):

- To develop and test a *patient and family-centered advance care planning instrument* for patients and families preparing for major pancreatic cancer surgery.
- Team of patients, family members, surgeons, SICU intensivists and nurses, anesthesiologists, palliative care providers, and health care quality experts.
- \$2.15 million contract: July 2013 – Nov 2017

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*An Environmental Scan of Advance Care Planning Decision Aids for Patients Undergoing Major Surgery: A Study Protocol*

**Rebecca A. Aslakson, Anne L. R. Schuster, Judith Miller, Matthew Weiss, Angelo E. Volandes & John F. P. Bridges**

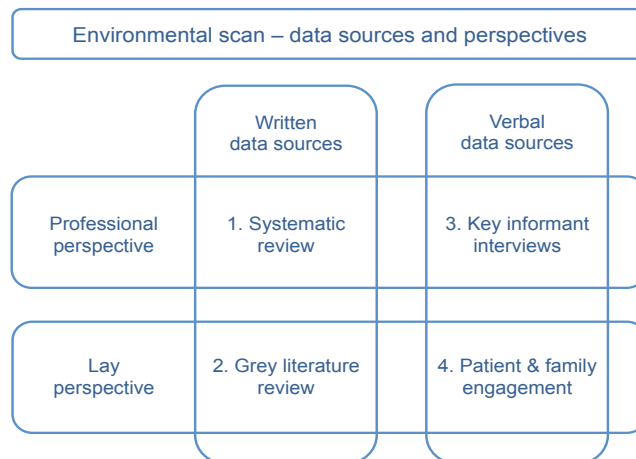
The Patient - Patient-Centered Outcomes Research  
 ISSN 1178-1653  
 Patient  
 DOI 10.1007/s40271-014-0046-3

ONLINE FIRST

**The Patient**  
 Patient-Centered Outcomes Research

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## Conceptual Approach



Aslakson et al, The Patient 2014

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## Promoting perioperative advance care planning: a systematic review of advance care planning decision aids

Journal of Comparative Effectiveness Research

This systematic review identifies possible decision aids that promote perioperative advance care planning (ACP) and synthesizes the available evidence regarding their use. Using PubMed, EMBASE, Cochrane, SCOPUS, Web of Science, CINAHL, PsycINFO and Sociological Abstracts, researchers identified and screened articles for eligibility. Data were abstracted and risk of bias assessed for included articles. Thirty-nine of 5327 articles satisfied the eligibility criteria. Primarily completed in outpatient ambulatory populations, studies evaluated a variety of ACP decision aids. None were evaluated in a perioperative population. Fifty unique outcomes were reported with no head-to-head comparisons conducted. Findings are likely generalizable to a perioperative population and can inform development of a perioperative ACP decision aid. Future studies should compare the effectiveness of ACP decision aids.

**Keywords:** advance care planning • decision-making • decision support techniques • patient-centered care • perioperative care

Rebecca A Aslakson<sup>1\*</sup>, Anne LR Schuster<sup>2</sup>, Jessica Reardon<sup>3</sup>, Thomas Lynch<sup>4</sup>, Catalina Suarez-Cuervo<sup>5</sup>, Judith A Miller<sup>6</sup>, Rita Moldovan<sup>7</sup>, Fabian Johnston<sup>8</sup>, Blair Anton<sup>9</sup>, Matthew Weiss<sup>9</sup> & John FP Bridges<sup>1</sup>

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<sup>3</sup>The Johns Hopkins Evidence-based Practice Center, Pennsylvania State University

Aslakson et al, J Comparative Eff Research 2015

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## Websites

- American Cancer Society
- American Geriatrics Society
- The American Academy of Hospice and Palliative Medicine
- The Center to Advance Palliative Care
- The National Palliative Care Research Center
- National Institute of Health-National Institute for Aging
- The Coalition to Transform Advanced Care
- The Informed Medical Decisions Foundation
- The Center for Shared Decision Making
- The International Patient Decision Aids Standards
- National Quality Forum
- Family Caregiver Alliance, Gerontological Society of America
- Medline Plus (NIH)
- National Cancer Institute
- American Association of Retired Persons
- National Hospice and Palliative Care Organization
- Heart Failure Society of America
- Agency for Healthcare Research and Quality
- Mayo Clinic
- Pancreatic Cancer Action Network
- American Society of Clinical Oncology

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## Grey Literature search

### Newspaper articles

- >400 articles, didn't yield much

### Ongoing studies

- Found many of the researchers from the systematic review

### PhD dissertations and abstracts

- Unpublished – not much of interest

### YouTube – “advance care planning”

- LOTS!

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Schuster et al. *BMC Palliative Care* 2014, **13**:32  
<http://www.biomedcentral.com/1472-684X/13/32>



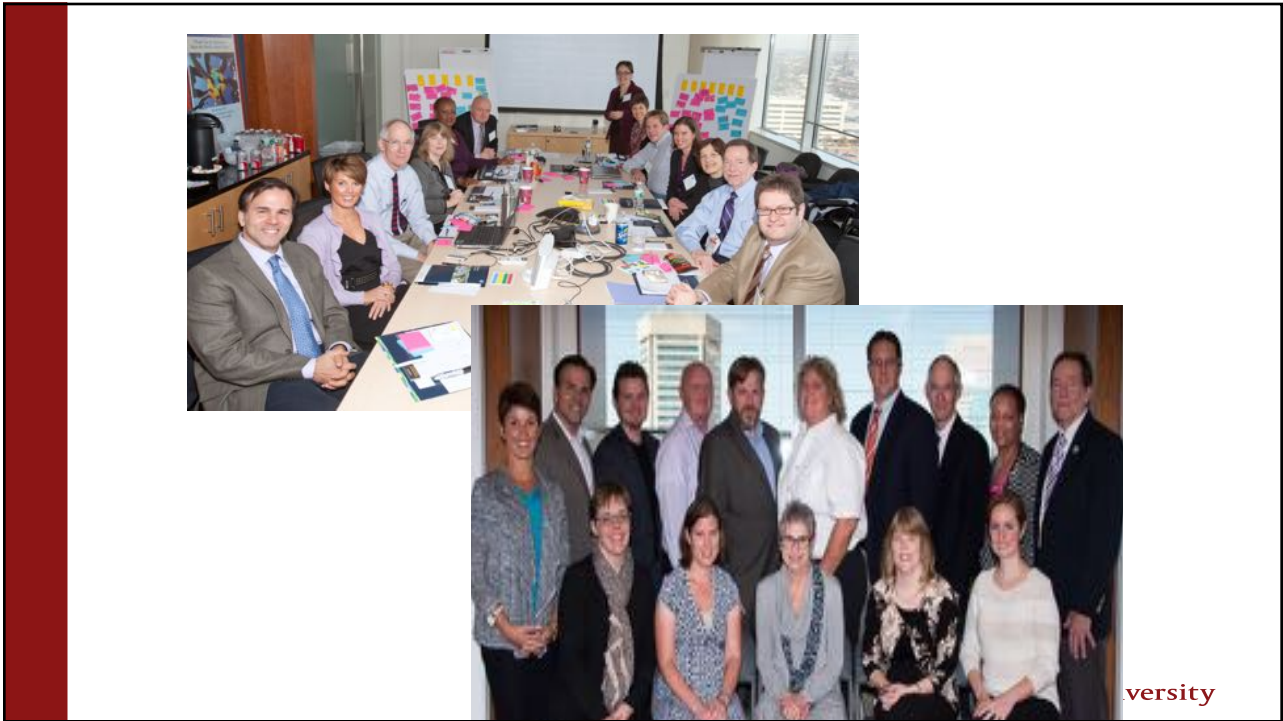
RESEARCH ARTICLE

Open Access

## Creating an advance-care-planning decision aid for high-risk surgery: a qualitative study

Anne LR Schuster<sup>1</sup>, Rebecca A Aslakson<sup>2</sup> and John FP Bridges<sup>1\*</sup>

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## Stakeholder Summit – Findings

### Content

- Vignettes – real stories
- Less “death/dying” more about “how you want to live”
- Specific to surgical population

### Style

- Upbeat
- Involving younger and older subjects
- Involving multiple ethnicities

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Downloaded from <http://spcare.bmj.com/> on July 30, 2015 - Published by group.bmj.com

Research

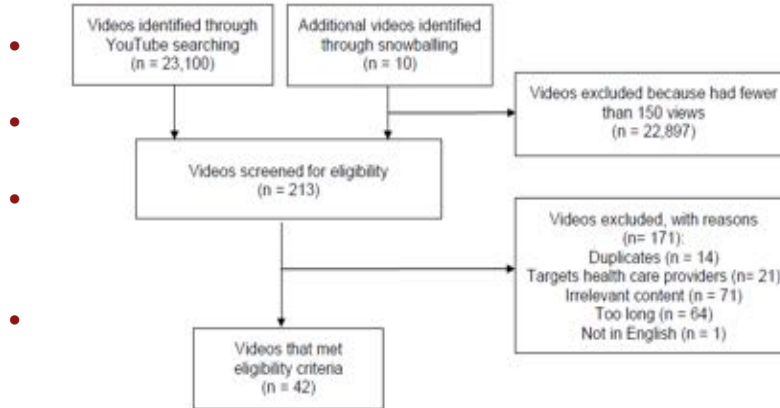
## Why don't end-of-life conversations go viral? A review of videos on YouTube

Imogen A Mitchell,<sup>1,2</sup> Anne L R Schuster,<sup>2</sup> Thomas Lynch,<sup>3</sup>  
Katherine Clegg Smith,<sup>4</sup> John F P Bridges,<sup>2</sup> Rebecca A Aslakson<sup>3</sup>

Mitchell IA, et al. *BMJ Supportive & Palliative Care* 2015;0:1–8. doi:10.1136/bmjspcare-2014-000805

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## Systematic Review of YouTube “advance care planning”



Mitchell et al., *BMJ Supportive & Palliative Care* 2015

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## Developing the video – conceptual model

| Basic Design Phase      | Purpose  | Stakeholder Involvement   | Media Development                                 |
|-------------------------|--|---|---|
| 1. Environmental Scan   | Gather and analyze pre-existing ACP instruments of all media types.                                  | Discuss merits and drawbacks of ACP instruments.                                  | Determine scope of and gaps in available content. |
| 2. Content Synthesis    | Determine communication goals and content of new ACP video.  | Participate in Stakeholder Summit to discuss and identify relevant video content. | Generate video concepts.                          |
| 3. Prototype Production | Translate content elements into provisional ACP video design and storyline.                          | Contribute to and critique ACP video script and storyboards.                      | Develop ACP video script and storyboards.         |
| 4. Evaluation           | Evaluate provisional ACP video design and storyline.   | Participate in evaluation of the storyboards.                                     | Revisions, if applicable                          |
| Decision                | Determine whether revisions are necessary or if moving to the video production stage is appropriate. | Participate directly in final decision.   | Revisions, if applicable                          |
| Approve storyboard      |  |   |   |

*Note: A vertical arrow labeled "Revisions" points from the Evaluation and Decision phases back to the Content Synthesis and Prototype Production phases.*

Aslakson et al, *J Pall Med* 2018  
Isenberg SR et al, *BMJ Pall Supp Care* 2018

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### Scene 3: The Pre-Operative Waiting Area



SCRIPT

Family member: I couldn't have known what to expect. Oh my goodness, the preoperative area had so much activity...like a medical Grand Central Station and nurses going this way and that and I was not sure of who would come. There was a nurse from the preoperative area, a person to start my husband, the anesthesia doctor, and the nurse from the OR.

### Scene 8: Having a Conversation with Family and Friends



SCRIPT

Narrator: Anytime you have surgery, there will be times when you are under anesthesia or are too sick to be able to communicate. For many, those times are brief and are limited to the time when you are having the actual surgery. However, for some, those times can last days to even weeks. We cannot predict exactly who will or will not get very sick after major surgery.

You can prepare for any situation through some simple steps with your family and those closest to you. You can designate the friend or family member who would make decisions for you if you cannot speak for yourself.

Aslakson et al, *J Pall Med* 2018  
Isenberg SR et al, *BMJ Pall Supp Care* 2018

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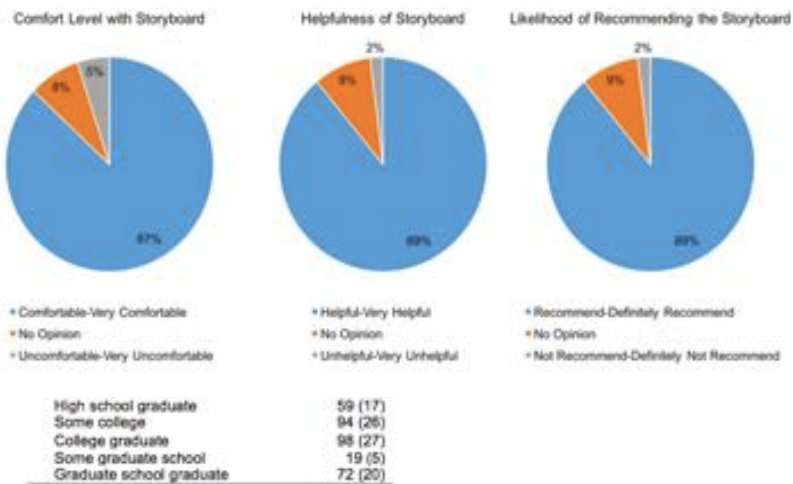
## “Phase I trial” - Maryland State Fair August 22-Sept 1, 2014



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## Storyboards (“Phase I”) study...

Table 1. Demographics of participants who reviewed the storyboards



Aslakson et al. J Palliat Med 2018

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Patient Preference and Adherence Dovepress  
Open Access to scientific and medical research

ORIGINAL RESEARCH

## A patient and community-centered approach selecting endpoints for a randomized trial of a novel advance care planning tool

This article was published in the following Dove Press journal:  
Patient Preference and Adherence

John FP Bridges<sup>1,2</sup>  
Norah L Crossnohere<sup>1</sup>  
Anne L Schuster<sup>1</sup>  
Judith A Miller<sup>1</sup>  
Carolyn Pastorini<sup>1†</sup>  
Rebecca A Aslakson<sup>1,4,5</sup>

<sup>1</sup>Department of Health Policy and Management, The Johns Hopkins Bloomberg School of Public Health, Baltimore, MD, <sup>2</sup>Department of Health, Behavior and Society, The Johns Hopkins Bloomberg School of Public Health, Baltimore, MD, <sup>3</sup>Patient-Centered Outcomes Research Institute (PCORI) Project, Baltimore, MD, <sup>4</sup>Department of Anesthesiology and Critical Care Medicine, The Johns Hopkins School of Medicine, Baltimore, MD, <sup>5</sup>Armstrong Institute for Patient Safety and Quality, The Johns Hopkins School of Medicine, Baltimore, MD, USA

†Carolyn Pastorini passed away on August 24, 2015

**Background:** Despite a movement toward patient-centered outcomes, best practices on how to gather and refine patients' perspectives on research endpoints are limited. Advanced care planning (ACP) is inherently patient centered and would benefit from patient prioritization of endpoints for ACP-related tools and studies.

**Objective:** This investigation sought to prioritize patient-centered endpoints for the content and evaluation of an ACP video being developed for patients undergoing major surgery. We also sought to highlight an approach using complementary engagement and research strategies to document priorities and preferences of patients and other stakeholders.

**Materials and methods:** Endpoints identified from a previously published environmental scan were operationalized following rating by a caregiver co-investigator, refinement by a patient co-investigator, review by a stakeholder committee, and validation by patients and family members. Finalized endpoints were taken to a state fair where members of the public who indicated that they or a loved one had undergone major surgery prioritized their most relevant endpoints and provided comments.

**Results:** Of the initial 50 ACP endpoints identified from the review, 12 endpoints were selected for public prioritization. At the state fair, 359 individuals prioritized the endpoints, the highest ranking of which was having a meaningful conversation with a physician before surgery (57%).

**Conclusions:** Using a novel combination of engagement and research techniques provided the opportunity to understand which endpoints were most important to patients and families and fostered framework development clarifying the differential contributions of engagement and research. Results from this study ultimately changed the content and evaluation of the ACP video.

**Keywords:** patient preference, patient participation, community participation, research design

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## The video

- Collaboration with Angelo Volandes
- Filmed 16 interviews with patients, family members, surgeons, surgical nurses, and anesthesia providers
- Interviews reviewed at stakeholder summit
- Broadened inclusion criteria to any type of major cancer surgery
- Editing took ten months
  - 14 different version of video
  - Reviewed by 70 different stakeholders

JOURNAL OF PALLIATIVE MEDICINE  
 Volume 22, Number 7, 2019  
 © Mary Ann Liebert, Inc.  
 DOI: 10.1089/jpm.2018.0209

## Integrating Advance Care Planning Videos into Surgical Oncologic Care: A Randomized Clinical Trial

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 Norah L. Crossnchere, MHS<sup>2</sup>, Alison M. Conca-Cheng, BS<sup>2</sup>, Madeleine Moore, BS<sup>6</sup>,  
 Akshay Bhamidipati<sup>5</sup>, Silvia Mora, BS<sup>5</sup>, Judith Miller, AID, CDT, LEED, AP<sup>5</sup>,  
 Sarabdeep Singh, PhD<sup>7</sup>, Sandra M. Swoboda, RN, MS<sup>7</sup>, Timothy M. Pawlik, MD, MPH, PhD<sup>8</sup>,  
 Matthew Weiss, MD<sup>7</sup>, Angelo Volandes, MPH, MD<sup>9</sup>, Thomas J. Smith, MD<sup>10</sup>,  
 John F.P. Bridges, MEd, PhD<sup>5</sup> and Debra L. Roter, MPH, DrPH<sup>5</sup>

### Abstract

**Background:** Preoperative advance care planning (ACP) may benefit patients undergoing major surgery.

**Objective:** To evaluate feasibility, safety, and early effectiveness of video-based ACP in a surgical population.

**Design:** Randomized controlled trial with two study arms.

**Setting:** Single, academic, inner-city tertiary care hospital.

**Subjects:** Patients undergoing major cancer surgery were recruited from nine surgical clinics. Of 106 consecutive potential participants, 103 were eligible and 92 enrolled.

**Interventions:** In the intervention arm, patients viewed an ACP video developed by patients, surgeons, palliative care clinicians, and other stakeholders. In the control arm, patients viewed an informational video about the hospital's surgical program.

**Measurements:** Primary Outcomes—ACP content and patient-centeredness in patient–surgeon preoperative conversation. Secondary outcomes—patient Hospital Anxiety and Depression Scale (HADS) score; patient goals of care; patient and surgeon satisfaction; video helpfulness; and medical decision maker designation.

**Results:** Ninety-two patients (target enrollment: 90) were enrolled. The ACP video was successfully integrated with no harm noted. Patient-centeredness was unchanged (incidence rate ratio [IRR]=1.06, confidence interval [0.87–1.31],  $p=0.545$ ), although there were more ACP discussions in the intervention arm (23% intervention vs. 10% control,  $p=0.18$ ). While slightly underpowered, study results did not signal that further enrollment would have yielded statistical significance. There were no differences in secondary outcomes other than the intervention video was more helpful ( $p=0.007$ ).

**Conclusions:** The ACP video was successfully integrated into surgical care without harm and was thought to be helpful, although video content did not significantly change the ACP content or patient–surgeon communication. Future studies could increase the ACP dose through modifying video content and/or who presents ACP. Trial Registration: clinicaltrials.gov Identifier NCT02489799.

**Keywords:** advance care planning; palliative care; patient-physician communication; preoperative care

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## Conclusions

- PCOR involves:
  - › Intense engagement with all stakeholders
  - › Transdisciplinary research teams
  - › Balancing diverse voices with different priorities and perspectives
  
- PCOR enables:
  - › Novel approaches to complicated clinical scenarios
  - › Interventions with “baked in” patient and stakeholder priorities and perspectives

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Any ?'s:  
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