Updates in ACP Measurement and Evidenced-based, Patient-Facing Tools

Rebecca Sudore, MD, Professor of Medicine, UCSF
www.PrepareForYourCare.org

Disclosures: None

• No financial disclosures
Objectives

- Defining ACP
- Defining ACP Metrics of Success
- Survey to Measure ACP Engagement
- Patient-facing ACP Tools
Delphi Panel → ACP Measurement

• Delphi convened to identify & rate ACP outcomes.
• Unable to agree on a definition → halted

“We are on the same page, yet we can’t seem to agree on anything.”

European White Paper

• Judith Rietjens & Ida Korfage

• Delphi: Elements, roles/tasks, timing, policy, & evaluation of ACP

• → had to first define ACP
Standardizing ACP Definition

- No formal prior definition
- Most often life sustaining treatments & advance directives
- 2014 IOM report: various descriptions
- A consensus definition needed to standardize research & guide policy, quality metrics

<table>
<thead>
<tr>
<th>Delphi Characteristics, n=52</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Country:</strong></td>
<td></td>
</tr>
<tr>
<td>Unites States</td>
<td>80%</td>
</tr>
<tr>
<td>Canada</td>
<td>12%</td>
</tr>
<tr>
<td>Netherlands</td>
<td>4%</td>
</tr>
<tr>
<td>Australia</td>
<td>4%</td>
</tr>
<tr>
<td><strong>Women</strong></td>
<td>63%</td>
</tr>
<tr>
<td><strong>Expert:</strong></td>
<td></td>
</tr>
<tr>
<td>Research</td>
<td>71%</td>
</tr>
<tr>
<td>Clinician/Policy expert</td>
<td>25%</td>
</tr>
<tr>
<td>Law</td>
<td>4%</td>
</tr>
<tr>
<td><strong>Discipline:</strong></td>
<td></td>
</tr>
<tr>
<td>Physician</td>
<td>73%</td>
</tr>
<tr>
<td>PhD</td>
<td>15%</td>
</tr>
<tr>
<td>Nurse</td>
<td>8%</td>
</tr>
<tr>
<td>Lawyer</td>
<td>4%</td>
</tr>
<tr>
<td>Population</td>
<td></td>
</tr>
<tr>
<td>------------</td>
<td></td>
</tr>
<tr>
<td>1. Populations to include? Adults, children, parents?</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Scope</th>
</tr>
</thead>
<tbody>
<tr>
<td>2. Prescriptive or broad?</td>
</tr>
<tr>
<td>3. Focus on patient or clinician behaviors?</td>
</tr>
<tr>
<td>4. Include surrogates, family and friends?</td>
</tr>
<tr>
<td>5. Used for healthcare audiences and the public?</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Purpose – What constitutes ACP?</th>
</tr>
</thead>
<tbody>
<tr>
<td>6. On a continuum or a one-time event (directive/order)?</td>
</tr>
<tr>
<td>7. Appropriate when healthy or only in serious illness/EOL?</td>
</tr>
<tr>
<td>8. Focus on preparing a surrogate or the individual?</td>
</tr>
<tr>
<td>9. Focus on discussions or documentation?</td>
</tr>
<tr>
<td>10. Address life goals/values or medical treatments?</td>
</tr>
<tr>
<td>11. Focus on future or current in-the-moment decisions?</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>How to Conduct ACP</th>
</tr>
</thead>
<tbody>
<tr>
<td>12. Assess readiness to engage in ACP?</td>
</tr>
<tr>
<td>13. Include a discussion of prognosis?</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Semantics</th>
</tr>
</thead>
</table>

---

**Original Article**

**Defining Advance Care Planning for Adults: A Consensus Definition From a Multidisciplinary Delphi Panel**

Rebecca L. Sudore, MD, Hillary D. Lum, MD, PhD, John J. You, MD, Laura C. Hanson, MD, MPH, Diane E. Meier, MD, Steven Z. Pantilat, MD, Daniel D. Matlock, MD, MPH, Judith A.C. Rietjens, PhD, Ida J. Korfage, MSc, PhD, Christine S. Ritchie, MD, MSPH, Jean S. Kutner, MD, MSPH, Joan M. Teno, MD, MS, Judy Thomas, JD, Ryan D. McMahan, BS, BA, and Daren K. Heyland, MD, MSc
• **Definition:** “ACP is a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care.

• **Goal:** The goal of ACP is to help ensure that people receive medical care that is consistent with their values, goals and preferences during serious and chronic illness.”

---

**Lancet Oncology, Sept 2017**

N=109, 14 countries, 82% from Europe
5 Delphi Rounds

**Definition and recommendations for advance care planning: an international consensus supported by the European Association for Palliative Care**

Judith A C Bielemans, Rebecca L. Sudore, Michael Connolly, Johannes J van Delden, Margaret A Drickamer, Mirjam Drooger, Agnes van der Heide, Daren K Heyland, Dirk Houtteker, Daisy J A Janssen, Luciano Orsi, Sheila Payne, Jane Seymour, Ralf J Joo, Ida J Korfage, on behalf of the European Association for Palliative Care
European White Paper Definition

**Brief definition:** ACP enables individuals to define goals & preferences for future medical treatment & care, to discuss these goals & preferences w/ family & health-care providers, & to record and review these preferences if appropriate.

- + 41 recommendations
  - Elements, roles/tasks, timing, policy, evaluation

Similarities

- Any age or stage in health
- Match readiness & information preferences
- Revisit over time and when health changes
- Target, focus on goals & surrogates → specific plan
- Decisions based on shared understanding of prognosis
- If desired, wishes recorded, retrieve, updated
Implications

• Now have standardized definitions
  – Both focus on discussions & not just documentation

• Living definition, evolve over time

• With a definition can focus on measurement

Objectives

• Defining ACP

• Defining ACP Metrics of Success

• Survey to Measure ACP Engagement

• Patient-facing ACP Tools
Outcomes that Define Successful Advance Care Planning: A Delphi Panel Consensus

Rebecca L. Sudore, MD; Daren K. Heyland, MD, MS; Hillary D. Lum, MD, PhD; Judith A.C. Rietjens, PhD; Ida J. Korfage, MSc, PhD; Christine S. Ritchie, MD, MSPH; Laura C. Hanson, MD, MPH; Diane E. Meier, MD, FACP; Steven Z. Pantilat, MD; Karl Lorenz, MD; Michelle Howard, PhD; Michael J. Green, MD; Jessica E. Simon, MD FRCPC; Mariko A. Feuz, BS; John J. You, MD, MSc

JPSM, Aug 2017

Background

- Without a shared understanding of standardized quality metrics that define successful ACP, difficult to compare across systems & populations
RS10  Put a text box that covers logo
Rebecca Sudore, 2/17/2017
Objective

- To convene a large, multi-disciplinary, international Delphi panel of ACP experts to:
  - Create an **Organizing Framework** of patient-centered ACP outcomes
  - Identify, rate, and rank these outcomes

Methods

- Literature & 5 international conferences
- Delphi rounds with 52-member panel of researchers, clinicians, legal experts, and policy makers
Methods: Delphi Instructions

• “We would like to come to consensus about the outcomes that define successful ACP.”

• “How do we know, for research and quality improvement purposes, that ACP interventions are successful?”

Methods: Data Collection

• Focus on overarching ACP outcome domains & constructs, not individual questionnaires

• 7-pt “not-at-all” to “extremely important” scale

• Open-ended text boxes to comment and suggest new ACP domains or constructs
Delphi Flowchart

**Round #1:** Identify and rate initial ACP outcome constructs & Organizing Framework → 33 → 108 constructs

---

**Round #2:** Refine ratings by Organizing Framework domains → 137 constructs
Delphi Flowchart

**Round #1:** Identify and rate initial ACP outcome constructs & Organizing Framework → 33 → 108 constructs

**Round #2:** Refine ratings by Organizing Framework domains → 137 constructs

**Round #3:** Further refine → 121 constructs

**Round #4:** Rank overall → 121 constructs
Delphi Flowchart

**Round #1:** Identify and rate initial ACP outcome constructs & Organizing Framework → 33 → 108 constructs

**Round #2:** Refine ratings by Organizing Framework domains → 137 constructs

**Round #3:** Further refine → 121 constructs

**Round #4:** Rank overall → 121 constructs

**Round #5:** Refine ratings & rankings → 60 constructs

---

**Organizing Framework for ACP Outcomes**

**MODERATOR VARIABLES**
- Non-modifiable
  - Demographics
  - Acculturation
  - Social support
  - Religious/spiritual
  - Past ACP experiences
- Modifiable
  - Perceptions
    - Racism, ageism
    - Trust, satisfaction
    - Decision control
    - Barriers, facilitators
  - Mental & health status
- Community
  - Public health
  - Community initiatives
  - Legal support
  - Policy
  - Media
- ACP system
  - Documentation
  - Training
  - Facilitators
  - Palliative care

**UNIT OF ANALYSIS**
- Patient
- Surrogate & Family
- Clinician
- Healthcare System

**PROCESS OUTCOMES**
- Behavior Change
  - Knowledge
  - Self-efficacy
  - Readiness
- Perceptions
  - Barriers, facilitators
  - Attitudes
  - Prognostic awareness

**ACP ACTION OUTCOMES**
- Communication
  - Surrogates
  - Values/preferences
- Documentation
  - Surrogates
  - Values/preferences
- Care consistent with goals
- Satisfaction with care
- Decision making
- Communication

**QUALITY OF CARE OUTCOMES**
- Health Status
- Mental Health
- Care Utilization

**HEALTHCARE OUTCOMES**

Bidirectional arrows represent the interconnectivity between people, surrogates, clinicians, and the healthcare system.

Dashed lines represent moderators or outcomes that may pertain to more than one unit of analysis: people, surrogates, and clinicians.
Organizing Framework for ACP Outcomes

### Process
- Behavior change (e.g., readiness)

### Action
- Discussing/documenting wishes

### Quality of Care
- Satisfaction

### Healthcare
- Utilization

---

**Top 10 Constructs Overall: 1-5**

<table>
<thead>
<tr>
<th>Rank</th>
<th>Outcome</th>
<th>Mean (SD) 7 pt scale</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Care consistent with goals</td>
<td>6.71 (0.04)</td>
</tr>
</tbody>
</table>
### Top 10 Constructs Overall: 1-5

<table>
<thead>
<tr>
<th>Rank</th>
<th>Outcome</th>
<th>Mean 7-pt (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Care consistent with goals</td>
<td>6.70 (0.04)</td>
</tr>
<tr>
<td>2</td>
<td>Surrogate designation</td>
<td>6.55 (0.45)</td>
</tr>
<tr>
<td>3</td>
<td>Surrogate documentation</td>
<td>6.50 (0.11)</td>
</tr>
<tr>
<td>4</td>
<td>Talk w/ surrogates @ goals</td>
<td>6.40 (0.19)</td>
</tr>
<tr>
<td>5</td>
<td>Documents/wishes available</td>
<td>6.27 (0.28)</td>
</tr>
</tbody>
</table>

### Top 10 Constructs Overall: 6-10

<table>
<thead>
<tr>
<th>Rank</th>
<th>Outcome</th>
<th>Mean (SD) 7 pt scale</th>
</tr>
</thead>
<tbody>
<tr>
<td>6</td>
<td>Identify what brings value to patient’s life</td>
<td>6.20 (0.12)</td>
</tr>
<tr>
<td>7</td>
<td>POLST/Scopes of treatment</td>
<td>6.13 (0.17)</td>
</tr>
<tr>
<td>8</td>
<td>Discuss w/ clinicians</td>
<td>6.08 (0.24)</td>
</tr>
<tr>
<td>9</td>
<td>Document values</td>
<td>6.02 (0.25)</td>
</tr>
<tr>
<td>10</td>
<td>Advance directives</td>
<td>6.01 (0.21)</td>
</tr>
</tbody>
</table>
## Top 10 constructs overall: 6-10

<table>
<thead>
<tr>
<th>Rank</th>
<th>Outcome</th>
<th>Mean (SD) 7 pt scale</th>
</tr>
</thead>
<tbody>
<tr>
<td>6</td>
<td>Identify what brings value to patient’s life</td>
<td>6.20 (0.12)</td>
</tr>
<tr>
<td>7</td>
<td>POLST</td>
<td>6.13 (0.17)</td>
</tr>
<tr>
<td>8</td>
<td>Discuss w/ clinicians</td>
<td>6.08 (0.24)</td>
</tr>
<tr>
<td>9</td>
<td>Document values</td>
<td>6.02 (0.25)</td>
</tr>
<tr>
<td>10</td>
<td><strong>Advance directives</strong></td>
<td>6.01 (0.21)</td>
</tr>
</tbody>
</table>

**Care Consistent w/ Goals: Hard to Measure**

- “While this outcome is extremely important, I am not currently aware of an instrument or method to reliably measure this, especially a method that would be amendable to most ACP studies, including quality improvement studies.”
Conclusion

- A large, multidisciplinary Delphi panel came to consensus about an **Organizing Framework** and important outcomes to define successful advance care planning.

Implications

- **1st step** to allow researchers, healthcare organizations, & policy makers to standardize ACP outcomes to be compared across sites.

- More research is needed to:
  - Standardize #1: Care Consistent with Goals
  - Define from patients & caregivers perspective
  - Define a set of quality metrics
Objectives

• Defining ACP
• Defining ACP Metrics of Success
• Survey to Measure ACP Engagement
• Patient-facing ACP Tools

Measuring Advance Care Planning: Optimizing the ACP Engagement Survey

Rebecca Sudore, MD  Daren K. Heyland, MD, MSc
Deborah E. Barnes, PhD, MPH  Michelle Howard, PhD
Konrad Fassbender, PhD  Carole A. Robinson, RN, PhD
John Boscardin, PhD  John J. You, MD

JPSM, Dec 2016
Prior Research

• Developed & validated the “ACP Engagement Survey” to detect behavioral change processes and actions for a full range ACP behaviors

• High validity and reliability & able to detect change in response to an ACP intervention

Sudore RL et. al., J Pain and Symptom Management, 2013

Survey Measures the Process of ACP

- Modifiable Mediators = Process Measures
  - Knowledge & beliefs
  - Contemplation & outcome expectations
  - Self-efficacy
  - Readiness

- 5-point Likert

- Yes/no

- Engagement in ACP behaviors = Actions
  - Surrogates: ask, discuss, document
  - Quality of Life: ask, discuss, document
  - Flexibility for Surrogates: ask, discuss, document
  - Ask Providers Questions: ask, discuss
Feasibility Not So Good

- 82 items: 57 process & 25 action measures
- ~ 50 minutes
- Hard to use in research & clinical studies

Objective

- To validate progressively shorter, feasible versions of the ACP Engagement Survey
Feasibility: Shortening the Survey

• Phase 1 item reduction: 4 Canadian, 3 US sites
  • Face validity - item non-response
  • Redundancy - ceiling effects
  • factor analysis

• Phase 2 construct validity: 3 US trials
  • internal consistency
  • cross-sectional correlations
  • detect change

Phase 1: Item Reduction

82 items
  Face validity, item non-response, redundancy
  Ceiling effects
  55 items
  Factor analysis
  Systematic removal
  55, 34, 15, 9, and 4-items

25 Action items
  1 Process item

1 Process item
Results: Phase 2 Construct Validity

• Internal consistency

• Correlations to original

• Associations with prior planning

• Correlation of change

High Internal Consistency
Cronbach’s Alpha, $\geq 0.70 = \text{good}$

<table>
<thead>
<tr>
<th>Survey</th>
<th>Overall (n=664)</th>
<th>English (n=431)</th>
<th>Spanish (n=233)</th>
</tr>
</thead>
<tbody>
<tr>
<td>82-item</td>
<td>0.97</td>
<td>0.97</td>
<td>0.96</td>
</tr>
<tr>
<td>55-item</td>
<td>0.97</td>
<td>0.97</td>
<td>0.96</td>
</tr>
<tr>
<td>34-item</td>
<td>0.96</td>
<td>0.95</td>
<td>0.95</td>
</tr>
<tr>
<td>15-item</td>
<td>0.92</td>
<td>0.92</td>
<td>0.91</td>
</tr>
<tr>
<td>9-item</td>
<td>0.89</td>
<td>0.89</td>
<td>0.87</td>
</tr>
<tr>
<td>4-item</td>
<td>0.84</td>
<td>0.86</td>
<td>0.74</td>
</tr>
</tbody>
</table>
**High Correlation to Original Correlation Coefficient** \( \geq 0.70 = \text{good} \)

<table>
<thead>
<tr>
<th>Survey</th>
<th>Overall (n=664)</th>
<th>English (n=431)</th>
<th>Spanish (n=233)</th>
</tr>
</thead>
<tbody>
<tr>
<td>82 items</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>55 items</td>
<td>0.97</td>
<td>0.97</td>
<td>0.97</td>
</tr>
<tr>
<td>34 items</td>
<td>0.94</td>
<td>0.94</td>
<td>0.94</td>
</tr>
<tr>
<td>15 items</td>
<td>0.91</td>
<td>0.90</td>
<td>0.90</td>
</tr>
<tr>
<td>9 items</td>
<td>0.89</td>
<td>0.89</td>
<td>0.87</td>
</tr>
<tr>
<td>4 items</td>
<td><strong>0.85</strong></td>
<td><strong>0.85</strong></td>
<td><strong>0.80</strong></td>
</tr>
</tbody>
</table>

**Higher Scores Associated with Prior Advance Directives (ADs)**

<table>
<thead>
<tr>
<th>Survey</th>
<th>Average 5-point Likert scores</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Prior AD, n=148</td>
<td>No AD, n=505</td>
</tr>
<tr>
<td>82 items</td>
<td>3.5</td>
<td>2.3</td>
</tr>
<tr>
<td>55 items</td>
<td>3.6</td>
<td>2.6</td>
</tr>
<tr>
<td>34 items</td>
<td>3.9</td>
<td>2.8</td>
</tr>
<tr>
<td>15 items</td>
<td>4.0</td>
<td>2.9</td>
</tr>
<tr>
<td>9 items</td>
<td>4.0</td>
<td>2.9</td>
</tr>
<tr>
<td>4 items</td>
<td><strong>3.8</strong></td>
<td><strong>2.4</strong></td>
</tr>
</tbody>
</table>
## Correlation of Change with Original Correlations ≥ 0.70 = good

<table>
<thead>
<tr>
<th>Survey</th>
<th>Overall (n= 664)</th>
<th>English (n=431)</th>
<th>Spanish (n=233)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Correlation</td>
<td>Correlation</td>
<td>Correlation</td>
</tr>
<tr>
<td>82 items</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>55 items</td>
<td>0.93</td>
<td>0.93</td>
<td>0.94</td>
</tr>
<tr>
<td>34 items</td>
<td>0.89</td>
<td>0.88</td>
<td>0.90</td>
</tr>
<tr>
<td>15 items</td>
<td>0.82</td>
<td>0.82</td>
<td>0.82</td>
</tr>
<tr>
<td>9 items</td>
<td>0.74</td>
<td>0.75</td>
<td>0.75</td>
</tr>
<tr>
<td>4 items</td>
<td>0.68</td>
<td>0.66</td>
<td>0.70</td>
</tr>
</tbody>
</table>

## 4-Item: How ready are you to (5pt Likert):

1. Sign official papers naming a person or group of people to make medical decisions for you?

2. Talk to your decision maker about the kind of medical care you would want if you were very sick or near the end of life?

3. Talk to your doctor about the kind of medical care you would want if you were very sick…?

4. Sign official papers putting your wishes in writing?

Readiness → Stage of Change

- Never thought @ it/not ready = Pre-contemplation
- Thinking @ doing it in next 6 mo = Contemplation
- Planning to do it in next 30 days = Preparation
- Already did it w/in 6 months = Action
- Did it > 6 months ago = Maintenance

Adapted from Fried, et al, JAGS 2010

Conclusion

- Shorter versions of the ACP Engagement Survey in English & Spanish are:
  - valid
  - internally consistent
  - able to detect change across a broad range of ACP behaviors
Implications

- Shorter ACP Engagement Surveys can efficiently & effectively measure ACP in research & clinical settings
- May be used for screening purposes
- Using the 4-item version in a large pragmatic trial

Objectives

- Defining ACP
- Defining ACP Metrics of Success
- Survey to Measure ACP Engagement
- Patient-facing ACP Tools
Background

- Barriers to ACP include lack of clinician time and healthcare system resources

- It is unknown if easy-to-use, patient-facing ACP interventions can overcome barriers to ACP in busy primary care settings
**Background**

ACP

- Clinician or Facilitator
- Patient
- Healthcare System

**Objective**

- To compare the efficacy of:
  - an interactive, patient-centered, ACP website: [www.PrepareForYourCare.org](http://www.PrepareForYourCare.org)
  - to an easy-to-read advance directive (AD)

  to increase ACP documentation & engagement
Design and Setting

• DESIGN:
  – Single blind, comparative effectiveness randomized trial
  – April 2013 – July 2016

• SETTING:
  – Multiple primary care clinics at SF VA

Participants & Recruitment

• PARTICIPANTS:
  – ≥60 years of age, English-speaking
  – ≥ 2 chronic/serious conditions
  – ≥ 2 primary care visits/year
  Excluded: deaf, blind, cog impairment

• RECRUITMENT: Flyers, letters, phone calls, clinic
Intervention: Patient-facing ONLY

www.PrepareForYourCare.org

Easy-to-Read Advance Directive (AD)

Prior RCT:
- Doubled completion rates
- Overwhelmingly preferred
- 10 languages

www.PrepareForYourCare.org

Sudore RL et. al., Patient Educ Couns 2007
Welcome to PREPARE!
PREPARE is a program that can help you:
- make medical decisions for yourself and others
- talk with your doctors
- get the medical care that is right for you

You can view this website with your friends and family.

Click the NEXT button to move on.

---

5-Steps of PREPARE

<table>
<thead>
<tr>
<th>Step</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Choose a Medical Decision Maker</td>
</tr>
<tr>
<td>2</td>
<td>Decide What Matters Most In Life</td>
</tr>
<tr>
<td>3</td>
<td>Choose Flexibility for Your Decision Maker</td>
</tr>
<tr>
<td>4</td>
<td>Tell Others About Your Wishes</td>
</tr>
<tr>
<td>5</td>
<td>Ask Doctors the Right Questions</td>
</tr>
</tbody>
</table>

PrepareForYourCare.org
Creating PREPARE

• Easy to understand: 5th-grade reading level
  – Voice-overs & closed captioning

• Range of video stories:
  – Surrogate availability
  – Decision making preferences

• Videos that **model** ACP behavior

* Sudore RL et. al., J Pain & Symptom Manage, 2012

---

How to Ask a Decision Maker

How to Ask Someone to Be Your Decision Maker

You can watch this video with your friends and family.
How to Talk with Family & Friends

How To Tell Others About Your Wishes

How to Ask Clinicians Questions

How To Ask Doctors the Right Questions
Randomization & Blinding

- Participants were block randomized by:
  - health literacy & race/ethnicity

- Staff blinded for all follow-up assessments
Primary Outcome

• New ACP documentation in the record:
  – Forms and/or discussions at 9 months
  – Chart review by 2 independent coders

Secondary Outcomes

• ACP Engagement Survey: 1wk, 3 mo, 6 mo
  – Behavior Change, 5-point Likert
    • Self-efficacy, Readiness
  – Self-reported Action, score 0-25
    • Discussions & Documentation

Sudore, et. al., Plos One, 2015
Secondary Outcomes

- **Satisfaction**
  - “How easy was it to use this guide?” 1-10 scale
  - “Not-at-all” to “Extremely” 5-point Likert:
    - “How comfortable were you reviewing this guide?”
    - “How helpful was this guide?”
    - “How likely are you to recommend to others?”

- **Depression** (PHQ-2) & **Anxiety** (GAD-2)

Analysis: Intention to Treat

- Mixed effects logistic & linear regression
- All models adjusted for prior ACP documentation and potential clustering by physician
- Interactions: age, gender, US acculturation, race/ethnicity, literacy, health status, surrogate, prior ACP documentation & internet access
### Patient Characteristics, n=414

<table>
<thead>
<tr>
<th></th>
<th>AD-only n=209</th>
<th>PREPARE+AD n=205</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean Age (SD)</td>
<td>72 (8)</td>
<td>71 (8)</td>
</tr>
<tr>
<td>Women</td>
<td>9%</td>
<td>9%</td>
</tr>
<tr>
<td>Non-white</td>
<td>41%</td>
<td>45%</td>
</tr>
<tr>
<td>Fair-to-poor health</td>
<td>27%</td>
<td>32%</td>
</tr>
<tr>
<td>Depression/Anxiety</td>
<td>1%</td>
<td>1%</td>
</tr>
<tr>
<td>Limited health literacy</td>
<td>21%</td>
<td>19%</td>
</tr>
<tr>
<td>Internet access</td>
<td>38%</td>
<td>42%</td>
</tr>
</tbody>
</table>

**PREPARE & Easy-to-Read AD Increased ACP Documentation**

- 6 months before baseline
- Easy-to-Read AD
- AD + PREPARE

*< 1%*
PREPARE & Easy-to-Read AD Increased ACP Documentation in the Medical Record

- Easy-to-Read AD: 25%
- AD + PREPARE: 35%

* p = 0.04
PREPARE + AD Increased Behavior Change > AD Alone

- Self-efficacy
- Readiness

**Graph:**
- **Mean ACP Engagement Process Scores:**
  - PREPARE+AD
  - AD-only
  - Overall p < 0.001

PREPARE + AD Increased ACP Action > AD Alone

- Discussions
- Documentation

**Graph:**
- **Total ACP Engagement Action Scores:**
  - PREPARE+AD
  - AD-only
  - Overall p < 0.001
Effect Not Moderated by Patient Factors

- No interactions for any patient factor
  - Demographics
  - Literacy
  - Access to the internet
  - Prior ACP

Satisfaction High for AD & PREPARE

<table>
<thead>
<tr>
<th></th>
<th>AD-only</th>
<th>PREPARE+AD</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ease-of-use (0-10)</td>
<td>8.7 (1.7)</td>
<td>9.0 (1.4)</td>
<td>0.31</td>
</tr>
</tbody>
</table>
### Satisfaction High for AD & PREPARE

<table>
<thead>
<tr>
<th></th>
<th>AD-only</th>
<th>PREPARE+AD</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Ease-of-use (0-10)</strong></td>
<td>8.7 (1.7)</td>
<td>9.0 (1.4)</td>
<td>0.31</td>
</tr>
<tr>
<td><strong>Satisfaction (5-pt. Likert)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Comfort reviewing</td>
<td>4.4 (0.8)</td>
<td>4.5 (0.7)</td>
<td>0.57</td>
</tr>
<tr>
<td>Helpfulness</td>
<td>4.3 (0.9)</td>
<td>4.4 (0.8)</td>
<td>0.19</td>
</tr>
<tr>
<td>Recommend to others</td>
<td>4.2 (1.1)</td>
<td>4.4 (0.9)</td>
<td>0.10</td>
</tr>
</tbody>
</table>

### Adverse Events

- No adverse events
- 92% retention rate
- No differences, p>0.05:
  - demographics those who refused
  - reasons for withdrawal
  - depression or anxiety
Conclusion

• Easy-to-use, patient-facing PREPARE tools, with minimal clinician/system-level input, can increase ACP documentation 35-43%

• Combining PREPARE plus an easy-to-read AD resulted in higher ACP documentation and engagement than the AD alone

Implications: Patient-facing ONLY

• PREPARE and the easy-to-read AD may be useful ACP interventions on a population level, especially in resource-poor health systems

• Likely to be synergistic with other clinician/system interventions, more research is needed
Updates & Dissemination

Updated Intro Videos

Click the video above to learn more.
FREE PREPARE Tools

PREPARE QUESTIONS
A guide to help people and their loved ones prepare for medical decision making.

New Easy-to-read ADs for all US States in English & Spanish
PREPARE Group Movie Events

Toolkits for creating movie events for libraries, churches, senior centers, group medical visits

→ NO TRAINING REQUIRED

Journal of Palliative Medicine, 2018

Toolkit Testing

• Senior Centers

• Group Medical Visits
Senior Centers: Easy to Understand

- Strongly Agree: 53%
- Agree: 47%
- I have no opinion: 5%
- Disagree: 2%
- Strongly Disagree: 1%

N=75

Ready to answer questions about preferences for medical care

- Strongly Agree: 38%
- Agree: 55%
- I have no opinion: 2%
- Disagree: 3%
- Strongly Disagree: 2%

N=75
Recommend Session to Others

- Strongly Agree: 68%
- Agree: 29%
- I have no opinion: 3%
- Disagree: 1%
- Strongly Disagree: 0%

N=75

Group Medical Visits, n = 22

- Pre-to-post: 1 week
  - Surrogate designation 48% to 85%, p = 0.01
  - AD form completion 9% to 24%, p = 0.21

Zapata, Wistar, Horton, Sudore
Next PREPARE Steps

- Feasibility of PREPARE among:
  - older adults with cognitive impairment
  - In-Home Supportive Services for elderly

- PCORI Pragmatic trial across 3 UC sites

- Collaborating w/ other programs

Thank You!

www.PrepareForYourCare.org

✉️: rebecca.sudore@ucsf.edu

🐦: @prepareforcare