Evaluating Resources for End-of-life Decision-Making

Research on Behalf of
The Coalition to Transform Advanced Care (C-TAC)

Harrison Brown
Consultant, Post-Acute Care Collaborative
202-568-7013
brownh@advisory.com
# Research Overview

## A Mixed-Methods Approach

### Phase #1: Landscape Review

**Methodology:**
- Publicly available literature review
- Collection, review, and categorization of decision-aids identified in literature and recommended by C-TAC members

**Goals:**
- Identify and categorize the landscape of end-of-life decision making resources available in today’s marketplace
- Identify the comparative effectiveness of decision making resources identified (as available in the literature)

**Final Product:**
- Spreadsheet identifying and categorizing decision making resources
- Report summarizing findings of categorization exercise and literature review

### Phase #2: Interview Series

**Methodology:**
Interview series with 20+ stakeholders and experts in end-of-life decision making identified by C-TAC

**Goal:**
Determine best practices for incorporating end-of-life decision aids into health care provider settings

**Final Product:**
One-hour presentation of findings, including supporting case studies (forthcoming July 31st)
**Landscape Analysis Findings**

**Wide Range of Decision Aids Available for Distinct Purposes**

**Five Categories of End-of-Life Decision Making Resources**

<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>#1: Conversation Starters and Guides</td>
<td></td>
</tr>
<tr>
<td>#2: Informational Resources</td>
<td></td>
</tr>
<tr>
<td>#3: Values Clarifiers</td>
<td></td>
</tr>
<tr>
<td>#4: Life-Sustaining Treatment Decision Aids</td>
<td></td>
</tr>
<tr>
<td>#5: Documentation Aids</td>
<td></td>
</tr>
</tbody>
</table>

**Major Findings from Evidence Review**

- **No comparative effectiveness** research regarding various decision aids
- **Inconsistent standards** for evaluating success of decision aids
- **Select characteristics influence effectiveness** of decision aids broadly\(^1\)
  - Design for low health literacy
  - Inclusion of values clarification
  - Use of default options within decision aid design
  - Inclusion of personal stories
  - Availability of training and clinician champions for decision aid use

---

\(^1\) Extrapolated from broader literature base regarding the effectiveness of decision aids and not exclusive to end-of-life decision making resources.

Source: Advisory Board interviews and analysis.
Forthcoming Interview Findings

Preliminary Framework: Interview Series Findings
Three Opportunities to Improve Efficacy of End-of-Life Decision Aids

I

Identifying Ideal Decision Aid Functions

II

Clarifying Care Team Responsibilities

III

Incorporating Decision Aids into Provider Workflow

Source: Advisory Board interviews and analysis.
Opportunity 1: Identifying Ideal Decision Aid Functions

Experts Recommend Focus on Values Clarification

Alternative Uses Overcome Impediments to Goals of Care Conversations

Sample Limitations of Decision Aids

Static resources fail to account for dynamic, repetitive nature of conversations, changes in values

Decision aids impede relationship between care team and patient, create physical barriers during conversation

Resources lack up-to-date prognostic information, limiting quality of information to inform decisions

Tactics to Improve Resource Viability

Repurpose resources to facilitate conversation training

Prioritize resources to engage non-communicative patients/families

Narrow decision aid focus to values clarification

Source: Advisory Board interviews and analysis.
Clear Roles Necessary for Resource Alignment

Key Physician Roles Include Prognosis and Treatment Risk Explanation

Lesson #1: Define a clear, realistic physician role

Lesson #2: Support clinicians with end-of-life communication experts

Lesson #3: Use decision tools to customize care team composition (i.e. involving spiritual advisors)

Source: Advisory Board interviews and analysis.
### Evidence of Need, Ease of Use Support Clinician Buy-In

**Provide Training and Evidence to Justify Changes**
- Provide training in medical school, grand rounds
- Frame decision aids as resources to provide structure to end-of-life care conversations
- Present data supporting the clinical benefits of advance care planning & shared decision making

**Ease Use of Decision Aids**
- Keep resources readily accessible (i.e. in exam rooms or central location)
- Narrow resource set to 1-2 widely applicable resources
- Select decision aids with purposes least duplicative to existing goals of care conversations

**Embed Decision Aids within Management Processes**
- Signal initiative importance at C-suite level, tap clinician champions
- Create electronic medical record (EMR) alerts to prompt conversations
- Store decision aids within EMRs and care team workflow tracking tools
- Track clinician documentation of conversation occurrence and content

Source: Advisory Board interviews and analysis.