The Advisory Board Company

Advisory Board
Community Impact

Implementing Decision Making Resources for Serious Illness

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

The Advisory Board Company in Numbers

3,800+
Hospitals and health care organizations in our membership

2,500+
Health care professionals employed

1,700+
Hospitals using our performance technologies

RESEARCH AND INSIGHTS

Memberships Offering Strategic Guidance and Actionable Insights

- Dedicated to the most pressing issues and concerns in health care
- 300+ industry experts on call
- 200+ customizable forecasting and decision-support tools

PERFORMANCE TECHNOLOGIES

National Peer Collaboratives Powered by Web-Based Analytic Platforms

- Leading provider: Over 60% of inpatient admissions in the United States flow through our technology platforms
- Over 1.6 million user sessions annually
- Key challenges addressed: population health, physician performance, growth, revenue cycle, supply/service cost, and surgical profitability

CONSULTING AND MANAGEMENT

Seasoned, Hands-On Support and Practice Management Services

- 2,600+ years of "operator" experience in hospital and physician practices
- Principal terrains: hospital-physician alignment/practice management, transition to value-based care, revenue cycle optimization, hospital margin improvement
- Range of engagements from strategy to best practice installation to interim management to fully managed services

TALENT DEVELOPMENT

Partnering to Drive Workforce Impact and Engagement

- Impacted the achievement of 84,000+ executives, physicians, clinical leaders, and managers
- 18,500+ outcomes-driven workshops tailored to partners' specific needs

Survey Solutions

- Customized strategies for improving employee and physician engagement
- National health care-specific benchmarking database of 740,000 respondents

180,000+
health care leaders served globally

$700+
million in realized value per year

1,700+
engagements completed

7,700+
employee-led improvement projects

COALITION TO TRANFORM ADVANCED CARE

" All Americans with advanced illness -- especially the sickest and most vulnerable -- will receive comprehensive, high-quality, person- and family-centered care that is consistent with their goals and values and honors their dignity."

- **C-TAC creates, supports and promotes the use of proven solutions to drive positive change in advanced illness care.**
- **Diverse Partnerships: 115+ Members.**
- **Partnership with Advisory Board to drive our shared vision.**

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

Landscape Analysis Findings

Wide Range of Decision Aids Available for Distinct Purposes

Five Categories of End-of-Life Decision Making Resources

#1: Conversation Starters and Guides

#2: Informational Resources

#3: Values Clarifiers

#4: Life-Sustaining Treatment Decision Aids

#5: Documentation Aids

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) Landscape Analysis Findings

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

Road Map

1 A Two-Stage Engagement Strategy

2 Fostering System-Wide Resource Access

3 Repurposing Decision Aids to Supplement Facilitation

Informed End-of-Life Choices a National Challenge

Wishes Infrequently Documented or Known to Providers

1 in 3

Adults have an advance directive expressing their wishes for end-of-life care

65-76%

Physicians do not know the advance directive exists when the patient has one

Patient Understanding of Illness Misinformed, Poorly Communicated

69%

Patients with metastatic (stage IV) lung cancer not reporting understanding that chemotherapy was not at all likely to cure their cancer

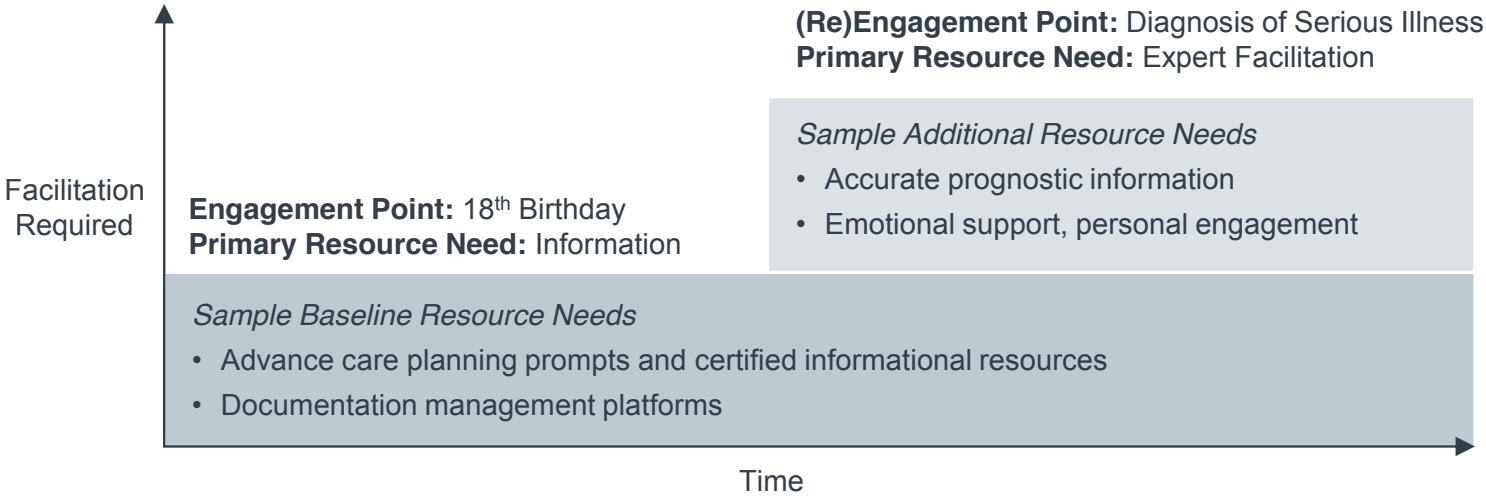
81%

Patients with metastatic (stage IV) colorectal cancer not reporting understanding that chemotherapy was not at all likely to cure their cancer

Source: Centers for Disease Control and Prevention, "Advance Care Planning: Ensuring Your Wishes Are Known and Honored if You Are Unable to Speak for Yourself," available at: www.cdc.gov/aging/pdf/advanced-care-planning-critical-issue-brief.pdf; Weeks et al., "Patients' Expectations about Effects of Chemotherapy for Advanced Cancer," *New England Journal of Medicine,* 2012, available at: www.ncbi.nlm.nih.gov/pmc/articles/PMC3613151/.

ACP Infrastructure Must Address Two Stages

Evolution of Ongoing Resource Needs by Patient Category



"People really fell into two camps. First, those who want to think about it ahead, those wanted a lot of information, explanation, and a lot of walking them through how to do it. Second, those who are never going to get that organized, you'll be really lucky to get to them right before something bad happened.

Jude Gallagher
Director, Complex Care Clinical Strategy, Humana

Source: Advisory Board interviews and analysis.

Road Map

1 A Two-Stage Engagement Strategy

2 Fostering System-Wide Resource Access

3 Repurposing Decision Aids to Supplement Facilitation

Six Essentials for System-Wide Resource Access

Scaling Advance Care Planning Initiatives for the General Population

1

Resource Certification Processes

2

Institutional Buy-In and Leadership

3

Resource Management Capabilities

4

Training

5

Performance Tracking

6

Mechanisms to Identify Facilitation Needs

Source: Advisory Board interviews and analysis.

Establishing Standards for Educational Resources

Resource Validation and Management an Ongoing Process

Key Considerations if Creating Decision Making Resources In-House

Identify standards for resource quality and require internal certification against those standards prior to distribution

Establish teams responsible for consistently reviewing materials for changes in evidence or information accuracy

Test resource effectiveness where possible before rolling out information to the entire health system

Resource in Brief: International Patient Decision Aid Standards (IPDAS)

- International consortium of experts collaborating to identify standards by which to evaluate decision aids
- Consistently reviews and analyzes literature base on decision aid effectiveness
- Developed and updates official standards for evaluating the quality of patient decision aids
- Emphasizes scrutiny of the resource's content, development process, usability, and proven effectiveness

Source: Advisory Board interviews and analysis.

Role of Leadership Essential to Changing Culture

Critical Factors for Promoting Decision Aid Utilization

1 Upper Management Endorsement

Promote as priority at executive and managerial levels, develop culture change initiatives

2 Formal Clinician Champions

Contribute clinical perspective to program development, add legitimacy to selected resources

3 Locally Available Experts

Facilitate individual clinician skill development, support challenging scenarios

Not Just a "Nice to Have"

"Just relying on clinicians to recognize that this is the ethically right thing to do doesn't work. Clinicians have a lot of competing priorities, and unless you can make clear that this is an expected part of their routine, you're not going to get that far. Upper management has to say, **this is a priority, this is how we're going to do business**; it's not just a 'nice to have.' "

Dr. Dominick Frosch, Patient Care Fellow, Gordon and Betty Moore Foundation

Source: Advisory Board interviews and analysis.

Setting Organizational Goals and Tracking Progress

Baylor Scott and White's Dashboard For System-Wide Advance Care Planning

Tasks	Status (Summer 2014)
Create ACP patient resources for consumer portal and offices	Done
Create ACP tools and documentation in outpatient EMR (Centricity)	Done
Train physicians on ACP and how to use the tools in the EMR (HTPN)	In process
Promote ACP/AD as preventive care & monitor progress in Centricity	In process
Promote MOST[1] in state law (as in 17 other states)	Incomplete
Encourage movement to digital-age creation and storage of advance directives with MyDirectives and ADVault	In process
Work with major physician groups across DFW to facilitate integration of ACP into their practices	In process

Standardizing messaging a prerequisite to system rollout

Target audience: every patient 18 and older

1) Medical Orders for Scope of Treatment.

Source: Baylor Scott and White, North Division; Advisory Board Interviews and analysis.

Setting Organizational Goals and Tracking Progress (cont.)

Case in Brief: Baylor Scott and White Health, North Division

- Not-for-profit, 3,800-bed health system located in North Texas
- System Operations Board endorsed direction that "Advance Care Planning will be a routine part of patient and family centered care, including preventive care, across all care settings"
- Board endorsement includes direction that all outpatients and inpatients be asked about and provided opportunities to create and update advance care plans/advance directive on a regular basis
- Board endorsement also includes direction that Baylor and affiliated practices prioritize building advanced care planning triggers within electronic medical records (EMRs), specifying that until EMRs improve information sharing inpatient and outpatient physicians must transmit advance care plans or directives to each other
- System strategy promotes future goal of digital advance care plan creation, documentation, and update, starting with a partnership with MyDirectives

Source: Baylor Scott and White, North Division; Advisory Board Interviews and analysis.

Small Steps Ease Resource Accessibility

Sample Inconveniences Hindering Use	Solutions to Smooth Use
Difficult to access Centralized storage locations require busy clinicians to leave office, reducing time with patient or hampering productivity	***Lower Tech:*** **Store in convenient location within clinician's office**
	Higher Tech: **Store within EMR, promote access at ACP prompt**
Library unmanageable Maintaining large library of resources for different patient types is confusing, cumbersome	**Narrow decision aids to small, broadly applicable selection**

Source:: Advisory Board interviews and analysis.

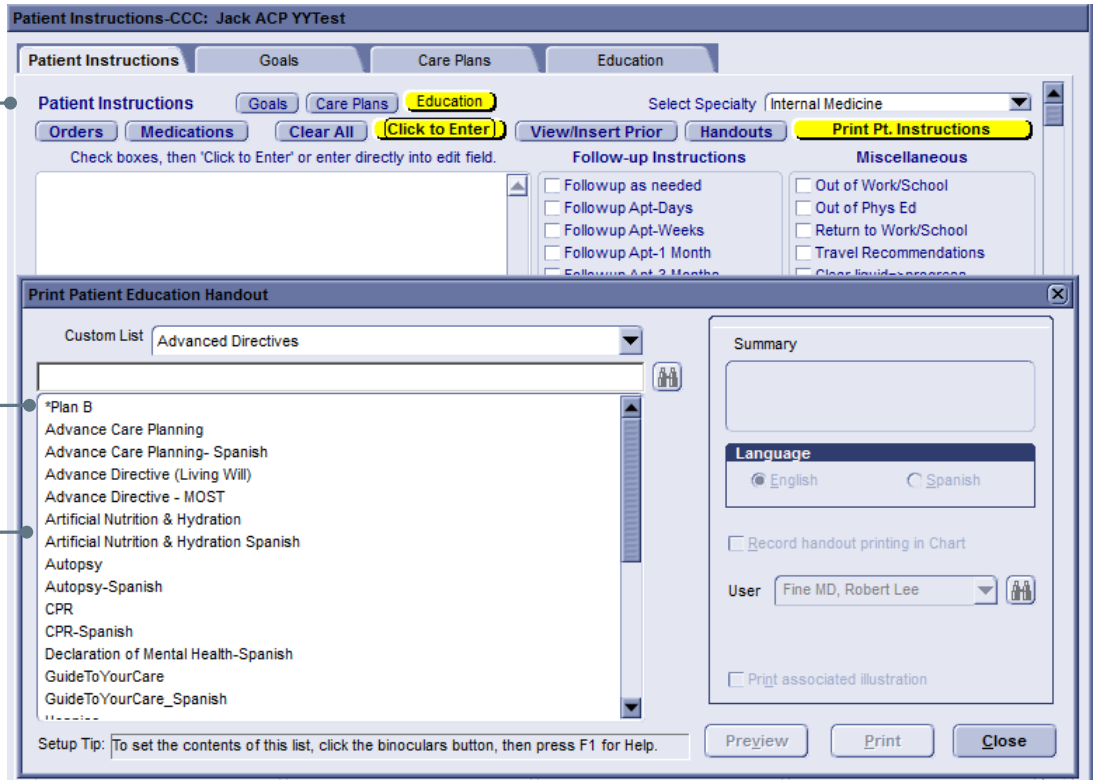
IT Integration Spreads Resource Access

Baylor Scott and White's EMR Advance Care Planning Resource Catalog

Advance care planning resources accessible and printable from EMR

"Plan B" materials direct patients to Baylor consumer portal and MyDirectives for support, storage

Advance directive forms and intervention-specific educational materials also available



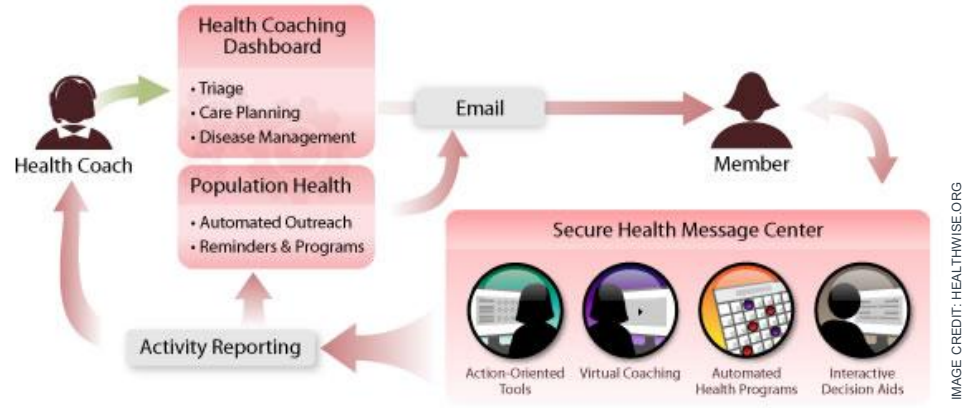
Source: Baylor Scott and White, North Division; Advisory Board Interviews and analysis.

Hardwiring Informed Decision Making

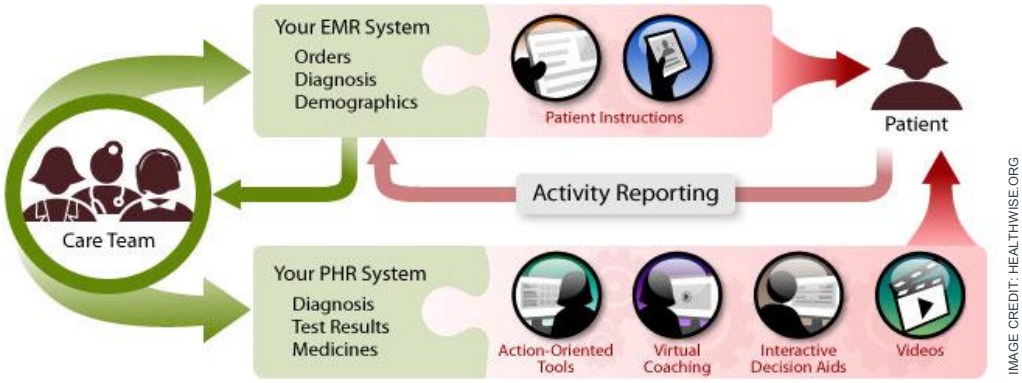
Activity Reporting Supports Provider, Patient Accountability Goals

Healthwise's Sample Information Exchange Between Facilitating Organization and Patient

Health Plan



Health System



Source: Healthwise; Advisory Board interviews and analysis.

Hardwiring Informed Decision Making (cont.)

Case in Brief: Healthwise

- Not-for-profit, patient education organization; develops shared decision-making resources, including advance care planning resources and decision aids for patients with serious illness
- Equips provider organizations and health plans with the IT capabilities to distribute shared decision making resources to patients, manage and track the patient's progress using recommended resources, and report activity to care managers to prompt further action and/or document decisions
- Maps recommended patient education resources to patient characteristics noted within the health system electronic medical record (EMR), prompting providers to prescribe patient education resources as part of the care plan
- Licenses Healthwise patient education resources to health systems; can co-brand and embed Healthwise patient education resources into public-facing websites and patient portals.

Source: Healthwise; Advisory Board Interviews and analysis.

Addressing Knowledge Gaps through Training

Experts Use Decision Making Resources as a Training Framework

Sample Features to Ensure Effective Training

Practice Run-Through

Example: The Conversation Project

Ask clinicians to walk through tool during session to demonstrate understanding, increase comfort

Overcomes barriers of discomfort, lack of experience with conversation

Interactive "Tests"

Example: ACP Decisions

Show sample encounter; build in questions, ask for critical feedback to test clinician understanding

Sample Questions:

- What did the clinician do well, and what did they do poorly?
- What questions would you ask the patient now?

Setting Option: Grand Rounds

Interactive sessions train clinicians on key concepts and provide practical guidance

"Most doctors have never had a palliative care lesson, have never been taught communication."

Angelo Volandes, M.D.
Co-Founder, ACP Decisions

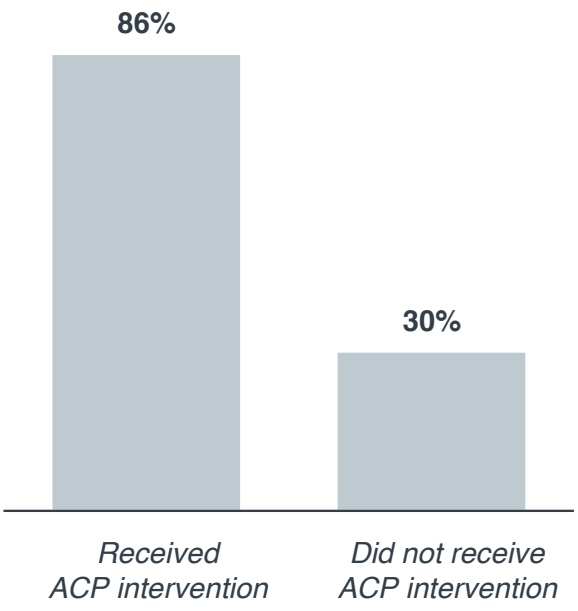
Source: The Conversation Project; Advance Care Planning Decisions; Advisory Board interviews and analysis.

Use Data to Frame Advance Care Planning Value

Sample Data: Impact of ACP Conversations

Medical Inpatients Over Age 80 Whose End-of-Life Wishes Were Known and Followed

n = 309



Data Critical for Health System Integration

"We really need to show physicians that there's actually a clinical advantage [to ACP] with hard data."

Director of Advanced Care Planning, Vaus Health System[1]

1) Pseudonym.

Source; Detering Karen M., et al., "The impact of advance care planning on end of life care in elderly patients," *BMJ*, 340 (2010): c1345; Advisory Board interviews and analysis.

Sending the Right Signals

Dartmouth's CollaboRATE Program Measures, Reports Quality

Current State: Metrics Developed

Patients Asked Questions Following Appointment to Measure Quality

- How much effort was made to help you understand your health issues?
- How much effort was made to listen to the things that matter most to you about your health issues?
- How much effort was made to include what matters most to you in choosing what to do next?

Questions designed to evaluate shared decision-making, but could be adapted to evaluate decision aid utilization

Ideal Use: Clinicians Evaluated

Score Reported to Clinicians

- **Signals importance** of decision aid utilization to organization
- **Alerts clinician to shortcomings** that may otherwise go unnoticed

> "We don't measure these issues, and often in health care what gets measured is what gets done. So by not measuring these issues, **we're not signaling that these are important things that we care about**."
>
> *Dr. Dominick Frosch, Gordon and Betty Moore Foundation*

Source: Elwyn G., et al., "Developing CollaboRATE," *Patient Educ. Couns.*, 93, no. 1 (2013): 102-7; Gordon and Betty Moore Foundation; Advisory Board interviews and analysis.

Sending the Right Signals (cont.)

Case in Brief: CollaboRATE

- Team of researchers funded by Dartmouth Center for Health Care Delivery Science of Dartmouth College created brief measure evaluating efficacy of shared decision making conversation, called CollaboRATE
- Identified key questions based around core principles of shared decision making: explanation of relevant health issues and treatment options, and elicitation of patient's preferences
- Tool could be adapted to focus questions on decision aid utilization as well as conversation more broadly
- Score could be reported to clinicians to encourage utilization of decision aids, identify shortcomings

Source: Elwyn G., et al., "Developing CollaboRATE," *Patient Educ. Couns.,* 93, no. 1 (2013): 102-7; Gordon and Betty Moore Foundation; Advisory Board interviews and analysis.

Care Team Built Around Patient's Specific Needs

FICA Tool Guides Referral to Chaplain, Specialized ACP Services

1 FICA Spiritual History Tool Assesses Patients' Religious, Spiritual Needs

- Equips clinicians and other professionals with tool to assess patients' spiritual issues
- Spiritual histories taken by clinicians as part of regular history during annual exam, new patient visit, or follow-up visit
- Assesses faith and belief, importance of spirituality, community, and how to address these matters in care

2 Chaplains, Spiritual Advisors Referred Based on Assessment

- Assessment determines if chaplain should be referred to patient for specialized care
- Chaplain provides religious, spiritual guidance and information to help patient put care decisions in the context of faith
- Chaplain, spiritual advisor helps patient integrate their spiritual needs with their values

"A lot of nurses and clinicians want to ask about [end of life care] but they're scared…Tell them to ask whether religion and spirituality are important to the patient, and ask them to talk about it."

Reverend George Handzo,
HealthCare Chaplaincy Network

Source: Advisory Board interviews and analysis; FICA tool available at: http://smhs.gwu.edu/gwish/clinical/fica/spiritual-history-tool.

Combating Low Utilization with Automated Prompts

Automated Advanced Care Planning Consultation Referral at Vaus Health[1]

Developed ACP Facilitator Program →

- Physicians refer patients to trained facilitators
- Facilitators offer to meet in person for conversation, or inform of upcoming group educational sessions

Lack of ACP Conversations Limited Referrals →

- Referrals to facilitators limited due to clinicians' reluctance to hold initial ACP conversations

Created Automated Referral Prompts

- Built and set order in Epic EMR for ACP consultation referral
- Order prompted automatically for certain types of inpatients upon discharge

Key Information to Include in Prompt

- ✓ Staff member to have conversation
- ✓ Setting for conversation
- ✓ Necessary documentation for conversation

1) Pseudonym.

Source; Advisory Board interviews and analysis.

Combating Low Utilization with Automated Prompts (cont.)

Case in Brief: Vaus[1] Health

- Health system located in the South including acute care hospitals, outpatient clinics, and home health
- Developed team of ACP facilitators, including five RNs and one LSW[2]
- Physicians refer patients to facilitators, who either call patient to offer consultation, or send mailing informing of upcoming ACP education sessions for less complicated situations
- Clinicians often reluctant, unprepared for ACP conversations, limiting potential clinician referrals to ACP facilitators
- Set ACP consultation referral order in Epic EMR to promote referrals; specified referral as automatic for certain types of patients upon discharge

1) Pseudonym.
2) Licensed social worker.

Source: Advisory Board interviews and analysis.

Road Map

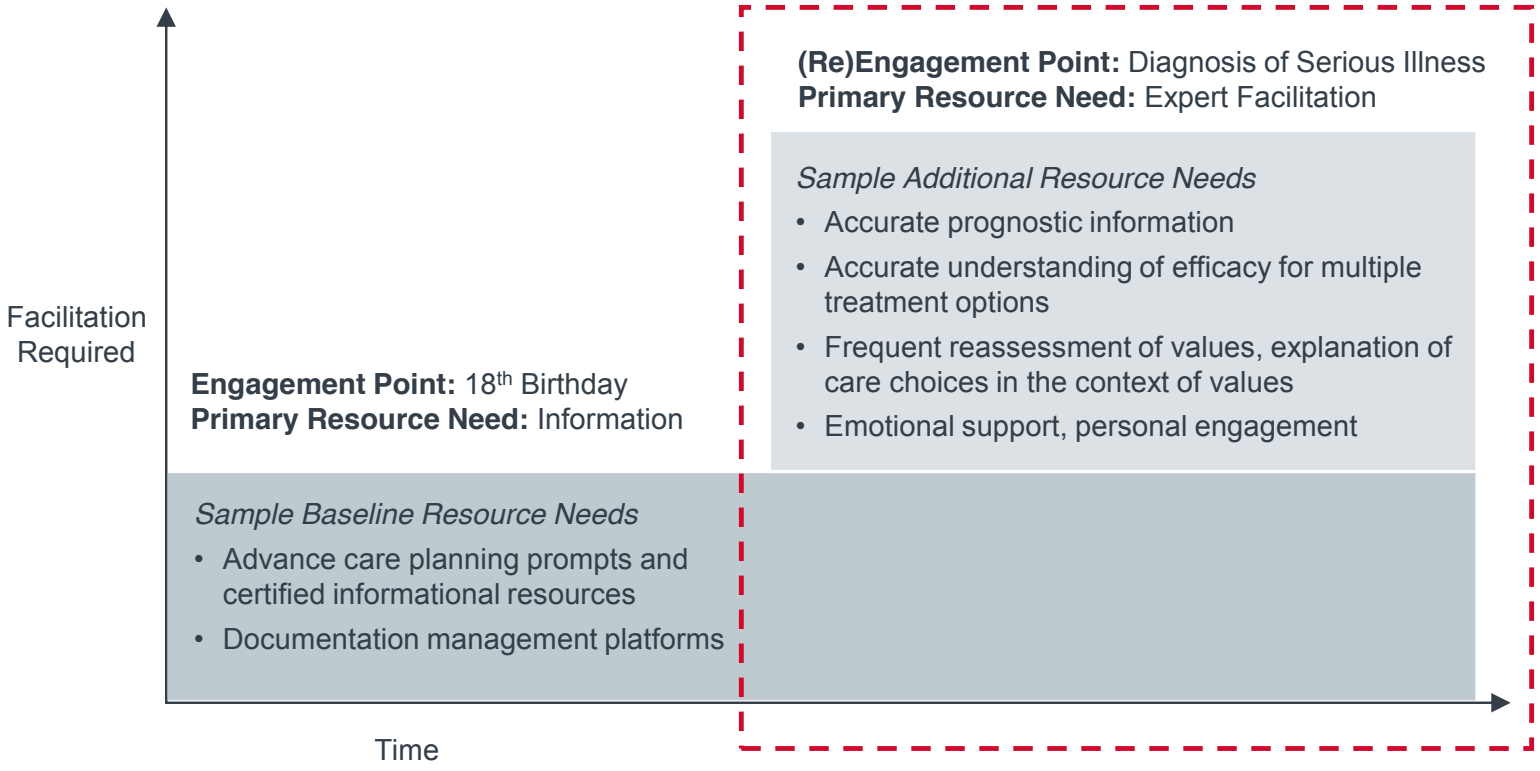
1 A Two-Stage Engagement Strategy

2 Fostering System-Wide Resource Access

3 Repurposing Decision Aids to Supplement Facilitation

Addressing Resource Needs for Complex Situations

Evolution of Ongoing Resource Needs by Patient Category



Source: Advisory Board interviews and analysis.

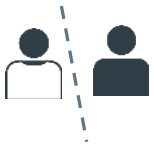
Major Limitations to Decision Aid Effectiveness

Four Decision Aid Deficiencies in Supporting End-of-Life Conversations

#1: Static Resource

Unlike decision aid, patient's values, disease change

#2: Limited Human Engagement



Tools cannot sense reactions, provide clarification, or comfort

#3: Encourages Abdicating Responsibility

Resource allows clinician to supply decision aid in lieu of conversation

#4: Lacks Prognostic Customization

Patient's individual symptoms, vitals, prognosis not reflected in tool

> "I can't tell you how many people think it's all about the decision tools. It's not about the paper with the little boxes, that is not sufficient."
>
> *Dr. Bruce Chernof*
> *CEO, SCAN Foundation*

Source: Advisory Board interviews and analysis.

Facilitation Challenges Necessitate Human Presence

Resources Fail to Address Patient Reactions, Keep Pace with Values

Sample Patient Issue	Decision Aid Response	Direct Engagement Response
Emotionally upset, unable to continue with decision process	None, unable to evaluate or react to user's emotional state	Offer comfort, try to identify and address source of disturbance
Answers to prompts are vague, incomplete	None, cannot press for additional detail	Encourage patient to specify, elucidate underlying values
Finds term confusing, unsure how to proceed	May provide glossary, link to other resources	Give detailed explanation, provide additional resources when appropriate

> "As an illness progresses we know that patients' priorities change. **What was a priority last week may not be a priority next week**."
>
> *Director of Shared Decision Making, Vaus Health*[1]

1) Pseudonym.

Source: Advisory Board interviews and analysis.

Risk of Misinformation without Clinician Input

Prescriptive Decision Aids Fail to Incorporate Full Disease Profile

Decision Aid-Delivered Information

To achieve applicability across patients, decision aids only describe intervention efficacy, risks for the general population

Lung cancer, stage four

Clinician-Delivered Information

Clinician understanding of prognosis and other patient risk factors associated with intervention support informed decisions

Lung cancer, stage four and…

- Dyspnea
- No response to initial treatment
- Elevated BP[1]
- Obese

Areas of ACP Affected by Individual Prognosis

Benefits, risks of individual interventions

Patient values, relevance of values to end-of-life medical interventions

Patient qualification for certain treatments, interventions

1) Blood Pressure.

Source: Advisory Board interviews and analysis.

Ideal Decision Aids a Supplement, Not a Centerpiece

Providers Must Define Levels of Facilitation to Build Ideal Decision Aids

The Problem:

Not all decision aids are flawed, but the existing portfolio and their current application hinders or **fail to match ideal level of human facilitation** for end-of-life decision making

Goals for Health Care Providers

1. Define provider roles, responsibilities for facilitating end-of-life decision making
2. Develop decision-making resources to support each defined responsibility
3. Train stakeholders to use decision making resources as supplements to facilitation rather than centerpieces

> "A decision aid is not a program. It's a piece of a program. And it's not clear how effective it can be on its own."
>
> *Dr. Bud Hammes*
> *Director, Respecting Choices©*

> "It's not about the decision aid, the paper, it's all about the process. Advance Care Planning is an ongoing process."
>
> *Amy Berman, BS, RN*
> *Senior Program Officer, The Hartford Foundation*

Source: Advisory Board interviews and analysis.

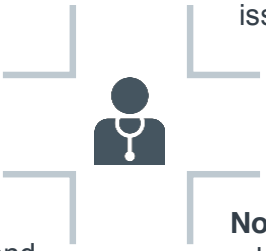
Expert-Level Facilitation Unlikely from All Physicians

Multi-Stakeholder Model Necessary to Scale Facilitation Access

Barriers to Physician Participation Necessitate Team Approach

"Too busy" for lengthy, recurring conversations

Uncomfortable discussing end-of-life issues



Not trained to handle specific end-of-life scenarios

Not reimbursed for advance care planning conversations

All potential experts in end-of-life decision making if given defined roles and training

> "It's very difficult for physicians to have these conversations. **They aren't necessarily trained for this, and it isn't always in their realm of comfort."**
>
> *Dr. Kate Lally, Medical Director of Palliative Care and Hospice, Kent Hospital*

> "Physicians avoid conversations about death, which is fine if we're not going to be good at it, but **somebody has to sit down and have this conversation**."
>
> *Dr. Thomas Smith, Director of Palliative Care, Johns Hopkins Medical Center*

Source: Advisory Board interviews and analysis.

Adding a Support Layer for Tough Conversations

Conversation Nurse Devoted to Treatment Goals, EOL Discussions

Physician[1] Identifies Need, Type of Support Required

- Physician identifies need for conversation, can directly request support from the conversation nurse
- Chooses a nurse-led conversation or a supported conversation, depending on situation, physician preference

Conversation Nurse Provides Desired Level of Support

Nurse-Led Conversation

- Nurse meets directly with patient and/or family
- Relays information back to the medical team

Supported Conversation

- Nurse joins physician in conversation with patient and/or family
- Physician leads conversation, nurse provides support as needed

Role in Brief: Conversation Nurse

- Supports physicians by discussing goals of care, end-of-life decisions with patients
- Qualifications include strong leadership skills, previous experience with end-of-life care, and a personality that puts patients at ease
- Helps address the 70% of palliative care consults requesting goals of care discussion

1) Nurses and others can also request a palliative care consult.

Source: Kent Hospital, Warwick, RI; O'Reilly KB, "Hospitals Teach Being 'Conversation-Ready' for End-of-Life Care," *American Medical News*, April 15, 2013; Advisory Board interviews and analysis.

Supporting Physicians in Tough… (cont.)

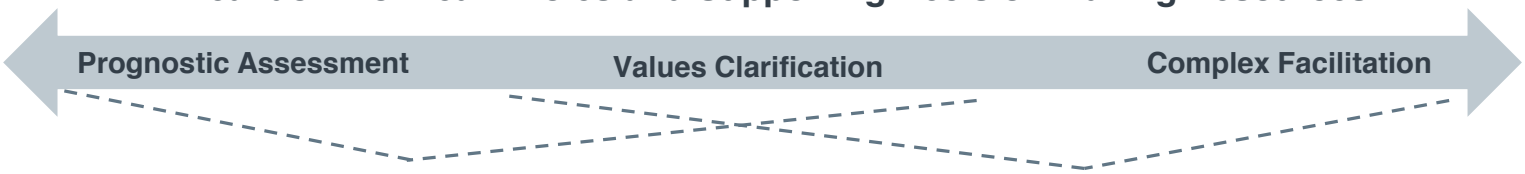
Case in Brief: Kent Hospital

- 275-bed teaching hospital in Warwick, Rhode Island
- "Conversation Nurse" is a member of the palliative care team who specializes in discussing goals of care and end-of-life decisions with patients and families
- Original conversation nurse was hired as a hospice liaison, but the palliative care director found that she was skilled in having conversations about goals of care, and there was a large need for such conversations among patients earlier on in their disease trajectory—before hospice was an appropriate option
- The conversation nurse receives about 30 direct consult requests each month and also supports additional conversations as determined necessary by the palliative care team
- The program has been so successful in its first year that the hospital has already hired a second conversation nurse for another hospital in the system

Source: Kent Hospital, Warwick, RI; O'Reilly KB, "Hospitals Teach Being 'Conversation-Ready' for End-of-Life Care," *American Medical News*, April 15, 2013; Advisory Board interviews and analysis.

Role Definition Yields Distinct Resource Needs

Breakdown of Team Roles and Supporting Decision Making Resources



Physician Role

- Providing prognostic information
- Explaining specific treatment and intervention options at end of life
- Pairing treatment-specific wishes with patients values and goals of care

Expert Care Team Role

- Surfacing, clarifying values and wishes
- Facilitating iterative and ongoing advance care planning processes
- Coordinating and communicating wishes among providers

Areas of Value for Future Decision Making Tools

- Evidence-based prognosis calculators
- Evidence-based treatment efficacy calculators
- Guides to help interpret/match treatment options to specific patient values
- Guides to support end-of-life care conversations, delivering bad news
- Alternate media to engage challenging patients (game, video, interactive online)
- Resources for non-urgent values clarification
- Reference information to introduce patient to new world of advanced illness
- Information not presentable through conversation

Source: Quill T, et al., "Generalist plus Specialist Palliative Care," *New England Journal of Medicine*, 368(2013):1173-1175; Advisory Board interviews and analysis.

Physicians Bring Unique Value to ACP

Best Positioned to Provide Prognostic, Treatment-Specific Information

Top-of-License Physician Use of Decision Aids

Critical Roles

Providing prognostic information to guide patients as they make care decisions

Explaining specific treatment and intervention options

Ideal Role

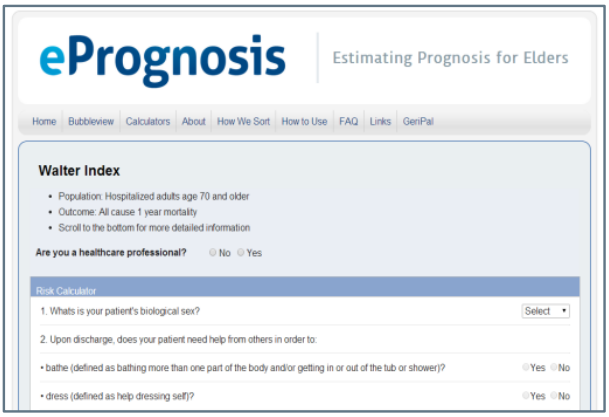
Pairing treatment-specific wishes with patients' values and goals of care

> "The specialist physician is in the best position to handle the medical side of the conversation- answering questions like 'what can actually be done for my pancreatic cancer?'"
>
> *Dr. Thomas Smith, Director of Palliative Care, Johns Hopkins Medical Center*

Source: Advisory Board interviews and analysis.

Supporting an Accurate, Up-to-Date Prognosis

Online Tool Provides Prognostic Guidelines, Evidence to Clinicians



Four Key Steps to ePrognosis

1. Select the Best Prognostic Index (or Indices) for your Patient.
2. Estimate Mortality Risk Using a Prognostic Index.
3. Interpret Mortality Risk from a Prognostic Index.
4. Integrate Prognosis into Clinical Care.

Tool in Brief: ePrognosis

- Helps clinicians obtain evidence-based information on patients' prognosis through four step process
- Repository of published geriatric prognostic indices
- Rough guide to inform clinicians about possible mortality outcomes
- Designed for the elderly population with multiple illnesses
- Allows clinicians to provide the most accurate ACP information possible given evidence base

Source: Advisory Board interviews and analysis. ePrognosis available at: http://eprognosis.ucsf.edu.

Supporting a Framework for Conversation

Steps of the SPIKES Protocol at MD Anderson Cancer Center

S – Setting Up the Interview

P – Assessing the Patient's **Perception**

I – Obtaining the Patient's **Invitation**

K – Giving **Knowledge** and Information to the Patient

E – Addressing the Patient's **Emotions** with Empathetic Responses

S – Strategy and Summary

Tool in Brief: The SPIKES Protocol

- Provides a framework for clinicians to break bad news to patients in an accurate and empathetic manner
- Designed to address survey results indicating 55% of oncologists ranked "how to be honest with the patient and not destroy hope" as their highest of four stressors (of time, dealing with patient emotions, and involving friends and family)
- 99% of oncologists surveyed to assess the tool reported it practical and easy to understand

Source: Baile et al., "SPIKES-A Six-Step Protocol for Delivering Bad News: Application to the Patient with Cancer," *The Oncologist*, 2000, available at: http://theoncologist.alphamedpress.org/content/5/4/302.full; Advisory Board interviews and analysis.

Even Experts Can Use Additional Help

Roles for Decision Aids to Supplement Expert Facilitators

1 Frame the Decision Making Landscape

Provide an overview to frame the goals and process of advance care planning

2 Facilitate Values Clarification

Prompt continuous values reflection to support preparation for facilitated sessions

3 Engage Challenging Patients and Families

Engage patients/families through alternate media to overcome discussion barriers

4 Present Difficult-to-Describe Information

Present information that cannot be ideally described or remembered in verbal form

Source: Advisory Board interviews and analysis.

Decision Aids Outline ACP Process

Background Information Eases Patient Into Decision-Making

ACP Initiation Difficulties

- ACP process often begins with diagnosis of a serious illness; patient may be scared, upset, overwhelmed
- Most patients not familiar with the treatment, care setting, and legal decisions they will have to make
- Difficult to consider ACP options when overall process still unclear

Role of Decision Aid: ACP Roadmap

- Familiarize patients with decisions, terminology, and options common in end of life planning
- Allow patient to engage with advanced care planning at their own pace in a non-clinical environment
- Sample resources: Put It In Writing, Finding Your Way, The Wise Conversations Starter Kit

Patients Need Introduction to Advanced Care Planning

"The **landscape has to be framed**… most people aren't entrenched in health care so when you jump into advanced care conversations you might as well be telling patients 'go drive across Australia' when they don't even know Australia's on the map."

Gretchen Alkema, VP of Policy and Communications
SCAN Foundation

Source: Post-Acute Care Collaborative interviews and analysis.

Decision Aids Help Surface Patient Values

Defining Features of Values Clarification Aid

Sample Resources:

- Five Wishes
- Go Wish
- Thinking Ahead

- Can be used alone or with family and friends
- Structured approach helps prioritize value set
- Relevant regardless of individual prognosis

Values Clarification: First Step in ACP

"Only when people can truly understand what's important to them can they decide what medical treatments will help them. I sometimes joke that **we've taken the whole theory of informed consent in medicine and turned it upside down**."

Dr. Bud Hammes, Director, Respecting Choices™
Gunderson Lutheran Health System

Sample Prompts Included in Values Clarification Tools

"Do you think life should **always be prolonged** as long as possible?

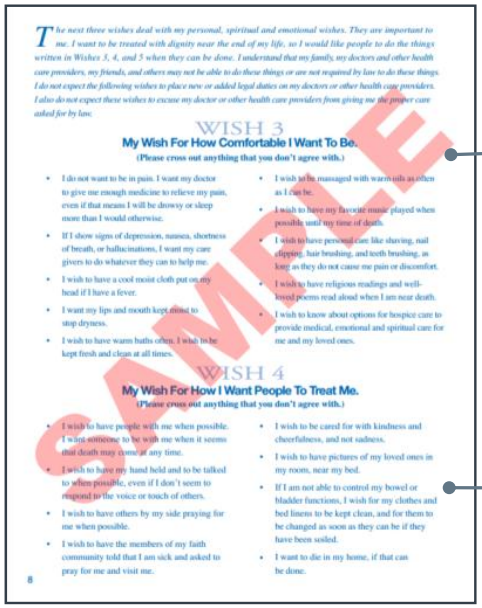
What do you **value most** about your life?

In terms of living through serious illness, how do you **define quality of life?**

How do you want to **be remembered?**"

Source: "End of Life Values-Choices Checklist," Caring Community, www.caringcommunity.org/advanced-care-planning/advance-directives/end-of-life-values-choices-checklist; "Patient Values Questionnaire," Vermont Ethics Network, www.vtethicsnetwork.org/patientvaluesquestionnaire.html; "Thinking Ahead," Society of Certified Senior Advisors, www.csa.us/wp-content/uploads/Docs/endoflifeworkbook.pdf; Post-Acute Care Collaborative interviews and analysis.

Sample Values Clarification Resource: Five Wishes



The next three wishes deal with my personal, spiritual and emotional wishes. They are important to me. I want to be treated with dignity near the end of my life, so I would like people to do the things written in Wishes 3, 4, and 5 when they can be done. I understand that my family, my doctors and other health care providers, my friends, and others may not be able to do these things or are not required by law to do these things. I do not expect the following wishes to place new or added legal duties on my doctors or other health care providers. I also do not expect these wishes to excuse my doctor or other health care providers from giving me the proper care asked for by law.

WISH 3

My Wish For How Comfortable I Want To Be.

(Please cross out anything that you don't agree with.)

- I do not want to be in pain. I want my doctor to give me enough medicine to relieve my pain, even if that means I will be drowsy or sleep more than I would otherwise.
- If I show signs of depression, nausea, shortness of breath, or hallucinations, I want my care givers to do whatever they can to help me.
- I wish to have a cool moist cloth put on my head if I have a fever.
- I want my lips and mouth kept moist to stop dryness.
- I wish to have warm baths often. I want to be kept fresh and clean at all times.
- I wish to be massaged with warm oils as often as I can be.
- I wish to have my favorite music played when possible until my time of death.
- I wish to have personal care like shaving, nail clipping, hair brushing, and teeth brushing, as long as they do not cause me pain or discomfort.
- I wish to have religious readings and well-loved poems read aloud when I am near death.
- I wish to know about options for hospice care to provide medical, emotional and spiritual care for me and my loved ones.

WISH 4

My Wish For How I Want People To Treat Me.

(Please cross out anything that you don't agree with.)

- I wish to have people with me when possible. I wish someone to be with me when it seems that death may come at any time.
- I wish to have my hand held and to be talked to when possible, even if I don't seem to respond to the voice or touch of others.
- I wish to have others by my side praying for me when possible.
- I wish to have the members of my faith community told that I am sick and asked to pray for me and visit me.
- I wish to be cared for with kindness and cheerfulness, and not sadness.
- I wish to have pictures of my loved ones in my room, near my bed.
- If I am not able to control my bowel or bladder functions, I wish for my clothes and bed linens to be kept clean, and for them to be changed as soon as they can be if they have been soiled.
- I want to die in my home, if that can be done.

8

SAMPLE

Wishes are non-clinical

Options expressed as positive statements

Tool in Brief: Five Wishes

- Developed by Aging with Dignity
- Recommended for use by all adults
- Helps user identify, document preferences in five major areas of advanced care planning
- Areas covered include: health care proxy, medical treatment, level of comfort, treatment by others, communication with loved ones

> "5 wishes really sets the stage for a successful advance care planning conversation"
>
> *Gail Hunt, CEO*
> *National Alliance for Caregiving*

> "We love 5 wishes, it's really comprehensive about values"
>
> *Robyn Golden, Director of Health and Aging*
> *Rush Medical Center*

Source:"5 Wishes," Aging with Dignity, www.agingwithdignity.org/five-wishes.php; Post-Acute Care Collaborative interviews and analysis.

"Go Wish" Provides Alternate Form of Engagement

Card Game Decision Aid Improves Conversations for Patients, Experts

IMAGE CREDIT: GOWISH.ORG.

"…having the patient consider his or her priorities beforehand may lead to a more effective dialogue about advance care planning while working within the time constraints of the medical provider."

Lankarani-Fard et al.,
Journal of Pain and Symptom Management

Tool in Brief: Go Wish

- An online and hard copy card game; players rank cards that represent advance care planning priorities
- Developed for elderly people with limited cognition, those with limited literacy, and those with limited English skills
- Tool educates about end-of-life care, helping individuals understand, prioritize their wishes
- Tool allows patients to consider values that may not seem important at first to the patient or the provider

Source: Lankarani-Fard A et al., "*Feasibility of Discussing End-of-Life Care Goals with Inpatients Using a Structured, Conversational Approach: The Go Wish Card Game,*" Journal of Pain and Symptom Management, 39, no. 4 (2010): 637-643; Advisory Board interviews and analysis.

Choosing Resources that Complement Facilitators

Go Wish Game Selected for Alternate Engagement Style, Applicability

Resource Selection at Sutter Health

Identified Library as Utilization Barrier

Encountered logistical challenge of offering large library of tools

Chose Single Preferred Tool

Narrowed to one preferred tool, **Go Wish**, based on input from staff social workers

Key Factors in Selection

- **Game-style structure** appeals to patients uncomfortable with or resistant to conversation
- **Universal applicability** of values clarification process

> "When we first started, we offered five to six different tools team members could use to facilitate conversations with patients and families. It was impractical, though, to carry around multiple tools that often took up space in their bags and were clumsy to bring to every visit.
>
> *Betsy Gornet,*
> *Chief Advanced Illness Management Executive, Sutter Health*

Source: Sutter Health; Advisory Board interviews and analysis.

Choosing Resources that Complement Facilitators (cont.)

Case in Brief: Sutter Health

- Health system located in the West including acute care hospitals, research institutes, urgent and express care, and post-acute care
- Developed Advanced Illness Management (AIM) program ; program provides ongoing counseling, facilitates transitions to help patients and families navigate health care system and make patient-centered end-of-life care decisions
- Team of social workers experienced difficulty managing, carrying around library of five to six decision aids
- Identified Go Wish as most universally applicable decision aid, due to values clarification nature and ability to make patients more comfortable communicating via game structure; designated it as the single decision aid to keep on hand and physically give to patients
- Refer patients to Five Wishes, additional decision aids as needed to look up independently for further support if desired

Source: Sutter Health; Advisory Board interviews and analysis.

Incorporation of Video Supports Conversation

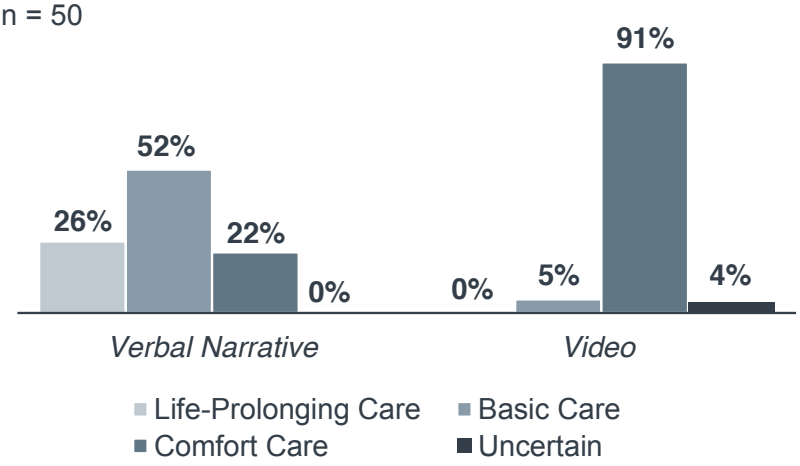
Resource in Brief: ACP Decisions

- Evidence-based, scientifically tested suite of videos to support informed decision-making
- Videos designed for low health literacy in multiple languages, allows patient to see their care choices being performed
- Videos not designed to encourage comfort care, rather language is values-neutral

Sample Comparative Impact of Video Format

Cancer Patient Decision Making

n = 50



> "The answer is not video. The answer is the doctor, the nurse, the clinician, taking the time to have the conversation. It just so happens that **video helps the conversation go along**."
>
> *Angelo Volandes, M.D.*
> *Co-Founder, ACP Decisions*

Source: El-Jawahri, A. et. al, "Use of video to facilitate end-of-life discussions with patients with cancer: a randomized controlled trial." *Journal of Clinical* Oncology, 2010, available at: http://www.ncbi.nlm.nih.gov/pubmed/?term=use+of+video+cancer+end+of+life+volandes; Advisory Board interviews and analysis.

Key Recommendations for Provider Organizations

Opportunity to Align Resources within Realities of Health Care Delivery

1. **Segment resource dissemination strategies**
   Experts note that two primary patient types must be addressed when supporting decision making for serious illness. First, select patients within the general population (age 18+) are willing to address end-of-life decision making if prompted. This population requires *access to accurate information*. Other patients will not independently address advance care planning. This population requires *human facilitation* most effectively applied at diagnosis of an advanced illness. Provider organizations should design resource and engagement strategies to support each of these populations.

2. **Define care team roles before developing decision making resources**
   To develop effective tools that will be used by health care providers, such roles in facilitating the decision making process must be properly defined. We accordingly provide sample expectations for the physician and for the teams of experts trained and experienced in facilitating informed decision making. Provider organizations must in turn define the specific roles for informed decision making stakeholders within their own organizations.

3. **Match resource development to fill gaps in defined stakeholder roles**
   Despite noted challenges in meaningfully deploying decision aids, opportunities exist to further develop resources that support the interactions between patients and various stakeholders in the health care system. Providers should structure decision making resources to support gaps in the relationship between the patient, physician, and facilitation team to avoid the conflict of duplicating or inhibiting this critical relationship.

Source: Advisory Board interviews and analysis.