SHARED DECISION MAKING IN SERIOUS ILLNESS (SDMSI)

Honoring Preferences During Clinical Decision Making

Introductions

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Respecting Choices
Director, Program Development and Research

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Respecting Choices
Director, Physician Development and Program Improvement

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Audience Response

What's the most important feature of a shared decision-making conversation?

1. Detailed explanation of possible alternatives
2. Statistics regarding possible clinical outcomes
3. Integration of patient values, goals, and preferences

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Audience Response

Rank your current skills at having shared decision-making conversations with your patients.

1. No level of skill; no experience
2. Low level of skill; little experience
3. Moderate level of skill; significant experience
4. High level of skill; extensive experience

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Workshop Learning Outcomes

1. List at least three characteristics of shared decision making for patients with serious illness
2. Examine four fundamental components in implementing a shared decision-making program using an interdisciplinary approach
3. Examine the use of certified decision aids that enhance the goals of shared decision-making conversations
4. Apply shared decision-making skills for patients with serious illness in small group activities

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Meet Mr. Williams

HIPAA PERMITS DISCLOSURE TO HEALTH CARE PROFESSIONALS AS NECESSARY FOR TREATMENT

Physician Orders for Life-Sustaining Treatment (POLST)-Florida

Follow these orders until orders are reviewed. These medical orders are based on the patient's **current** medical condition and preferences. Any section not completed does not invalidate the form and implies full treatment for that section. With significant change of condition new orders may need to be written.

Patient Last Name: WILLIAMS | Patient First Name: JOHN | Middle Int.

Date of Birth: mm/dd/yyyy: 10 02 1953 | Gender: [X] M [ ] F | Last 4 SSN: 1 2 3 4

If the patient has decision-making capacity, the patient's presently expressed wishes should guide his or her treatment

A CARDIOPULMONARY RESUSCITATION (CPR): Patient is unresponsive, pulseless, and not breathing.

Check One
- [ ] Attempt Resuscitation/CPR
- [X] Do Not Attempt Resuscitation/DNR

When not in cardiopulmonary arrest, follow orders in B and C.

B MEDICAL INTERVENTIONS: If patient has pulse and is breathing

Check One
- [X] Full Treatment – goal is to prolong life by all medically effective means. In addition to care described in Comfort Measures Only and Limited Additional Interventions, use intubation, advanced airway interventions, and mechanical ventilation as indicated. Transfer to hospital and for intensive care unit if indicated. Care Plan: Full treatment including life support measures in the intensive care unit.
- [ ] Limited Medical Interventions – goal is to treat medical conditions but avoid burdensome measures In addition to care described in Comfort Measures Only, use medical treatment, antibiotics, IV fluids and cardiac monitor as indicated. No intubation, advanced airway interventions, or mechanical ventilation. May consider less invasive airway support (e.g. CPAP, BiPAP). Transfer to hospital if indicated. Generally avoid the intensive care unit. Care Plan: Provide basic medical treatments.
- [ ] Comfort Measures Only (Allow Natural Death) – goal is to maximize comfort and avoid suffering Relieve pain and suffering through the use of any medication by any route, positioning, wound care and other measures. Use oxygen, suction and manual treatment of airway obstruction as needed for comfort. Patient prefers no transfer to hospital for life-sustaining treatments. Transfer if comfort needs cannot be met in current location. Consider hospice or palliative care referral if appropriate. Care Plan: Maximize comfort through symptom management.

Additional Orders:

C ARTIFICIALLY ADMINISTERED NUTRITION: Offer food by mouth if feasible.

Check One
- [ ] Long-term artificial nutrition by tube.
- [ ] Defined trial period of artificial nutrition by tube.
- [ ] No artificial nutrition by tube.

Additional Instructions: _____

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Person-Centered Decision Making

An Attribute of Person-Centered Care

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Shared Decision Making in Serious Illness

"The Carol Goodman Story"

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Knowing and Honoring Preferences and Decisions

Care that is respectful of and responsive to individual patient preferences, needs, and values, ensuring that patient values guide all clinical decisions

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Person-Centered and Family-Oriented Care

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Desired Outcome of Person-Centered Decision Making

To know and honor individuals' well-informed preferences and decisions by…

- Creating an effective process to plan for future decisions
- Making plans available to treating health professionals
- Assuring plans are incorporated into current medical decisions

Fagerlin, A., & Schneider, C.E. (2004). Enough: The failure of the living will. *The Hastings Center Report*. *34*(2), 30-42.

11

Definition: Advance Care Planning

ACP is a *process* of communication for planning for future medical decisions. To be effective, this process includes:

- **Reflection** on goals, values, and beliefs (including cultural and/or spiritual beliefs)
- **Understanding** of possible future situations and decisions
- **Discussion** of these reflections and decisions with others, including those who might need to carry out the plan

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Informed vs. Shared Decision Making

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National Quality Forum: SDM Call to Action

National Quality Partners SDM Action Team

- National call to action
- All individuals and organizations in healthcare
- Embrace and integrate shared decision making into clinical practice as a standard of person-centered care

(National Quality Partners™ Action Brief, October 2017)

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Definition: Shared Decision Making

SDM is a process in which clinicians and patients work together to make decisions that align with what matters most to patients. To be effective, this process requires

- **Unbiased** evidence about alternatives – including no intervention – and risks/benefits of each;
- Expertise in **communication**, tailoring evidence for individuals; and
- **Patient values**, goals, informed preferences, and concerns which may include treatment burdens.

(National Quality Partners™ Action Brief, October 2017)

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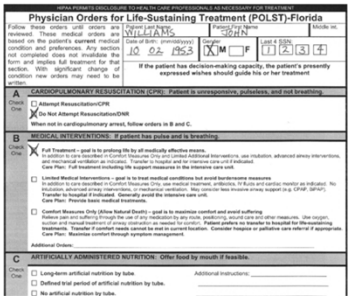
POLST: ACP or SDM?



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Gillick, M. (2015). Re-engineering shared decision-making. *J Med Ethics*. *41*(9), 785-788.

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Person-Centered Decision Making Within Systems of Care

- Not a standalone program
- Relies on other team members
- Focused on a specific target population
- Use of a shared set of communication skills
- Requires systems documentation and coordination

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Fragmented Care for Patients with Serious Illness

- Receive care in ambulatory settings with physicians unfamiliar with patient's history
- Receive episodic care for acute care exacerbations
- Visit multiple specialty clinics
- Primary care often serves as the interpreter for the specialty consult visit
- Ambiguity about who is responsible for having SDMSI conversations

American Hospital Association. (2012). Two reports on Advanced Illness Management Strategies. Retrieved from http://www.aha.org/about/org/aim-strategies.shtml

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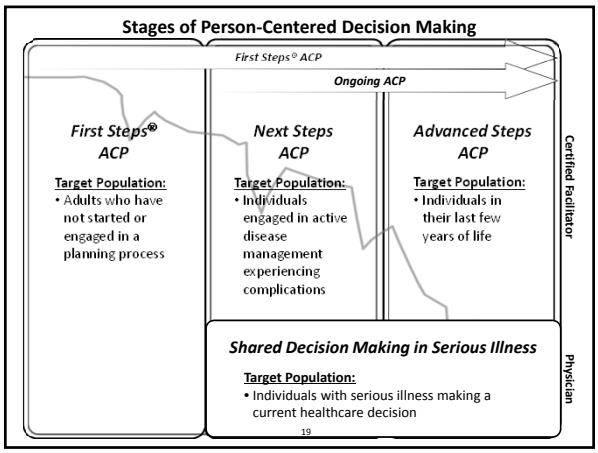

Shared Decision Making in Serious Illness

How *Should* SDM Be Different In Serious Illness?

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(National Quality Partners™ Action Brief, October 2017)

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The RC Difference: SDM In Serious Illness

Common Approach to SDM

- First, identify all options.
- Present options for intervention to patient.
  - FAQs
  - Risk: Benefit statistics
- Work with patient to make a treatment decision.

RC SDMSI Approach

- First, identify and understand patient's priorities and goals for care.
- Present options consistent with patient's goals.
- Frame "benefits and burdens" in context of patient's views of unacceptable outcomes.
- Explore non-intervention as a viable option.

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Why SDM in Serious Illness Needs To Be Different

- Patients unaware of their options
- Patients weigh various risk factors differently
- Physician bias, decision-making style
- Emotion and knowledge overload
- Living well is different for each patient

Halpern, S., et al. (2013). Default options in advance directives influence how patients set goals for end-of-life care. *Health Affairs, 32(2)*. 408-417.

Donovan, S., et al. (2000). *How People Learn: Brain, Mind, Experience, and School*. Washington, DC: The National Academies Press.

Gillick, Muriel. (2015). *Re-engineering shared decision-making.* J Med Ethics. 41(9), 785-788.

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Outcomes of Shared Decision-Making

- Patient's knowledge is increased.
- Patient's confidence in decision is increased.
- Patient is more actively involved and engaged
- Improved experience of care
- In many circumstances, individuals lean toward more conservative treatment options.
- More likely to receive care consistent with their values, goals and preferences

Stacey, D., et al. (2011). Decision aids for people facing health treatment or screening decisions. *Cochrane Database of Systematic Reviews*. doi: 10.1002/14651858.CD001431.pub3

(National Quality Partners™ Action Brief, October 2017)

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Fundamental Components in Implementing a SDMSI Program

More Than Education:
Designing a System

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Advanced Cardiovascular Life Support (ACLS)

What happens when a patient who desires CPR is found pulseless in a hospital?

- CPR is started and phone call is made to dispatcher.
- Dispatcher pages code team with location.
- Code team responds and has the skills and teamwork to be effective.
- Necessary equipment and drugs are available at scene.
- Every aspect of the system is constantly managed and reviewed for quality.

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NQF Call to Action: Six Fundamentals

1. Promote leadership and culture
2. Enhance patient education and engagement
3. Provide healthcare team knowledge and training
4. Take concrete actions
5. Track, monitor and report
6. Establish accountability

(National Quality Partners™ Action Brief, October 2017)

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Development of a SDMSI Program

The Respecting Choices Experience

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SDMSI Development: A Collaborative Process

- Original development was a partnership with a Respecting Choices customer and an Advisory Committee (Physicians and ACP experts from five organizations)
- Went through testing and evaluation at three organizations (Spectrum, Dartmouth-Hitchcock, Gundersen Heath System)
- Forum for SDMSI Instructors to continuously learn from each other
- Ongoing faculty development and improvement

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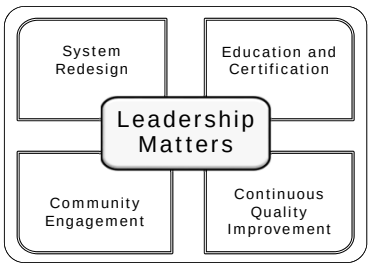
Design Elements of a System



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What is Culture?

"Culture is the definition of what is acceptable behavior in an organization.

…[Culture] is not elusive or intangible….it is a specific component of a delivery system that has to be managed as much as any other part of the system."

— Charles Kilo, MD

http://www.abimfoundation.org/Events/2015-Forum.aspx

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Cultural Change is Challenging

"Although talk about person-centered care is ubiquitous in modern healthcare, one of the greatest challenges of turning the rhetoric into reality continues to be routinely engaging patients in decision making."

Barry, M. & Edgman-Levitan, S. (2012). Shared Decision Making – The Pinnacle of Patient-Centered Care. *NEJM. 366,* 780-781.

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Drivers of Culture in Healthcare

How do we move from culture driven primarily by a goal of treating and managing diseases and injuries…

to a culture driven by…

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Person-Centered, Family-Oriented Care

…a goal to provide care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions.

IOM (Institute of Medicine). 2001. *Crossing the Quality Chasm: A New Health System for the 21st Century*. Washington, DC: The National Academies Press.

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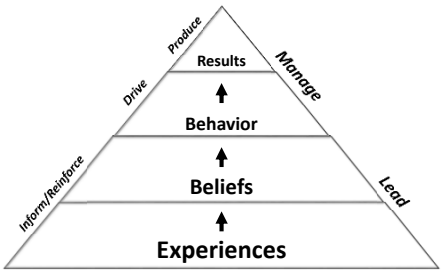
Pyramid of Culture Change



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Inspire a Shared Vision

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SPECTRUM HEALTH

One Organization's Implementation

Spectrum Health Leadership Vision

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The Role of Leadership: Creating Change

1. Understand and lead cultural change
2. Inspire shared vision within community
3. Set clear expectations…for accountability
4. Remove barriers
5. Lead by example

(National Academy of Sciences, Institute of Medicine, 2004)

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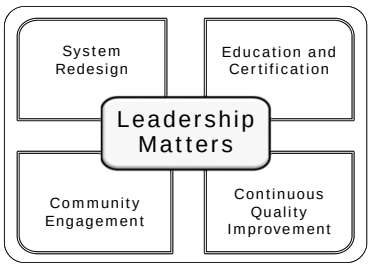
Design Elements of a System



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System Redesign

Hardwire behavior change

- Create triggers for SDM conversations
- Change workflow to accommodate
- Identify tools to enhance SDM
- Create documentation expectations and templates
- Ensure a mechanism to update, review, and share the care plan

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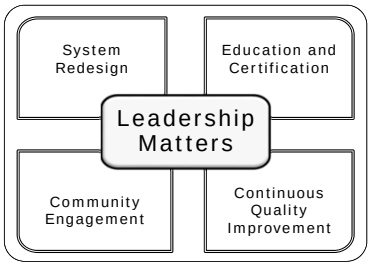
Design Elements of a System



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Education and Certification

Improve team competencies

- Defining 'the team' to be educated
- Developing the educators
- Delivering the course
- Supporting change in behavior

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SDMSI Instructor Certification

Teaching strategies

- Role model communication skills
- Stimulate critical thinking
- Effective storytelling
- Values clarification – self and others
- Conflict resolution
- Giving feedback
- Mentoring peers

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SDMSI Curriculum

Agenda content

- SDM as part of a continuum; role of provider
- Why SDM is important: the evidence
- Why SDM is different in serious illness
- Create self-awareness of skills, values, and biases
- Build person-centered communication skills
- The SDMSI conversation:
  - Discerning What Matters Most
  - Aligning Care Decisions with What Matters Most

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SDMSI Curriculum

Tools to support new behavior

- Video demonstration
- Specialty-specific role-play scenarios
- Conversation guides
- Decision aids
- Documentation exercises

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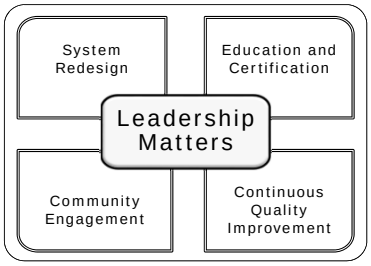
Design Elements of a System



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"Community" Engagement

Patients and Families

- Messaging that is aligned and motivating
- Resources to support process of understanding, reflection and discussion (ACP)
- Material that accommodate limited literacy and numeracy

Clinicians

- Enlisting champions for dissemination
- Sharing success stories
- Educational materials describing how SDM benefits patients and outcomes

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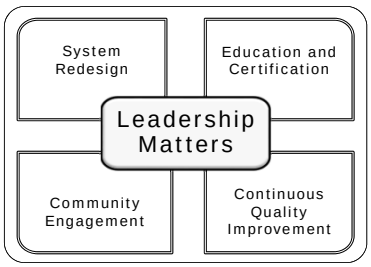
Design Elements of a System



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Continuous Quality Improvement

Measure what matters most

- Track, monitor, and report
- Healthcare team engagement in SDM
- Standardized data collection
- Regular sharing of performance
- Understand patient barriers to engaging in SDM

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SDMSI Program Metrics

- Pre- and post-course provider attitudes and competence
- Patient experience post-SDM conversation
- Documentation of goals of care from SDM conversation

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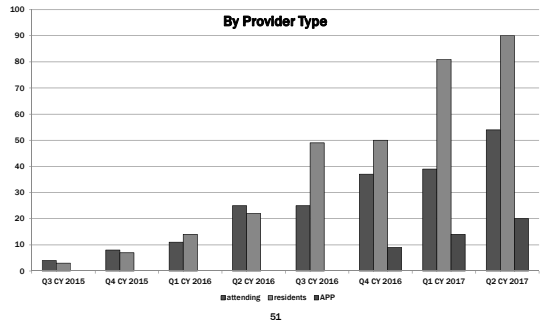
Cumulative Participants



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Practicing Physicians and APPs

RELEVANCY TO PRACTICE	
A. I will change my practice based on today's presentation	**4.75**
B. Information could be appliced to achieving person/professional goals	**4.89**
C. Course was appropriate to my education, experience, and licensure level	**4.93**
	4.86

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Signs of Cultural Transformation: What Does It Look Like?

- People start using different language and terminology.
- Professionals talk about how the work has changed them personally; reenergizing their purpose and commitment to providing quality healthcare.
- Individuals' preferences and decisions are integrated into care.
- When conflict or uncertainty emerges, people start asking different questions.
- There are organizational signs of transformation.

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Use of Decision Aids in Clinical Encounters

Tools to Support Patient-Centered Decision Making

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Evidence supporting use of DAs during SDM

- Better decisions and more satisfied patients
- Improved communication between patient and provider
- Less decisional conflict
- Reduced overuse of certain procedures
- Potential to lower costs
- Reduced medical liability risk

Stacey, Dawn, et al. (2017) *Decision Aids for People Facing Health Treatment or Screening Decisions.* Cochrane Database of Systematic Reviews.

Arterbur, David, et al. (2012) *Introducing Decision Aids at Group Health was Linked to Sharply Lower Hip and Knee Surgery Rates and Costs.* 3 Health Affairs 2094-104.

Barry, Michael, et al. (2008) *Reactions of Potential Jurors to a Hypothetical Malpractice Suit: Alleging Failure to Perform a Prostate-Specific Antigen Test.* 36 J. Law Med. Ethics 396-402 (2008).

55

Definition of Patient Decision Aid

"Tools designed to help people participate in decision making about healthcare options, with the goal of promoting deliberation between patients, healthcare providers, and others about those options."

Stacey D, Légaré F, Col NF, Bennett CL, Barry MJ, Eden KB, et al. *Decision aids for people facing health treatment or screening decisions.* Cochrane database Syst Rev [Internet]. 2014 Jan [cited 2014 Jul 28];1:CD001431. Available from: http://www.ncbi.nlm.nih.gov/pubmed/24470076.

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Audience Response

How many of you use decision aids in SDM conversations?

1. Routinely
2. Rarely
3. Never
4. Not sure

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Decision Aids

What They DO

- Define a process
- Share accurate/ unbiased facts
- Support deliberation about values
- Promote discussion with providers

What They DON'T Do

- Advise people to choose one option over another
- Replace conversations with providers

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Patient Education and Fact Sheets

What They DO

- Help inform decision-making process
- Allow patients to review information on their own
- Provide information for general audiences

What They DON'T Do

- Help make decisions
- Function as a tool during SDM conversation
- Provide information for specific population (e.g., with serious illness)

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Standard Setting for PDA Certification

International Patient Decision Aids Standards (IPDAS) Collaboration

The Washington State Healthcare Authority

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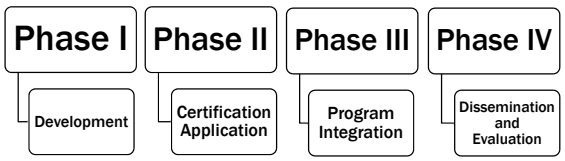
Decision Aid Development



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Decision Aid Development

Standard Operating Procedure (SOP)

- Guiding principles
- Common definitions and terms
- General policy standards
- Standard DA development procedure
- Standard templates and forms
- Research and references

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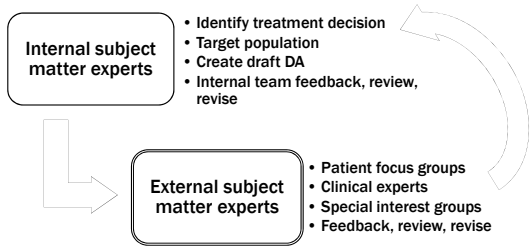
Phase I Development



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Cardiopulmonary Resuscitation (CPR) Decision Aid

Respecting Choices® PERSON-CENTERED CARE

For people with serious illness (like heart or lung disease or cancer) facing a decision about attempting CPR.

What care do you want if your heart and breathing stop? This decision aid will help you consider your options for CPR and your personal values. You may change your choice at any time. Review the information on both sides of this decision aid. Talk with your doctor about what to expect.

What are your options?	Attempt CPR	Do Not Attempt CPR
What is it?	CPR is done for you by someone else and can include: • Pressing on your chest • A tube to help you breathe • Electrical shock and drugs	CPR is not provided. You will receive other care to treat your symptoms and keep you comfortable.
What does it do?	CPR attempts to restart your heart and breathing.	Not attempting CPR allows a natural death.
What are the benefits?	CPR may restart your heart and breathing. *Review the facts (on the back) about the chances of CPR restarting your heart and breathing.*	Not attempting CPR avoids machines. Not attempting CPR avoids the burdens of CPR.
What are the short-term burdens?	You will need to be on a breathing machine for a time. You will need to be in the intensive care unit (ICU). You may have damaged or broken ribs.	You will die.
What are the long-term burdens?	You may have mild to severe brain damage. You may no longer be able to live alone.	
Which option best matches your values?	**Your Values**	**Your Values**
	You want the chance to live. You are willing to accept the fact that CPR may not restart your heart and breathing. You are willing to accept the burdens of CPR.	You prefer a natural death. You are unwilling to accept the fact that CPR may not restart your heart and breathing. You are unwilling to accept the burdens of CPR.

Primary developers: Linda Briggs, MSN, MA, RN, and Sandra Schellinger, MSN, RN, NP-C

Funding and materials provided by Respecting Choices®, www.respectingchoices.org.

This product has been certified by the Washington State Health Care Authority pursuant to RCW 7.70.060. The date of certification is April 9, 2018, and will expire two years from this date, or sooner pursuant to Washington State policy. A full description of Washington's certification process, including required criteria is available at http://www.hca.wa.gov/about-hca/healthier-washington/shared-decision-making.

CPR_DA_RC 0301_v04.18

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CPR in the hospital	*CPR outside the hospital*	
Adults with serious illness who get CPR and live	**Adults living in the community who get CPR and live**	**Adults living in a residential setting who get CPR and live**
At most, 15 out of 100 leave the hospital and may live an average of 4 months[1]	**5 out of 100 leave the hospital and may live up to 1 year[2]**	**2 out of 100 leave the hospital and may live up to 1 year[2]**

1. Stapleton RD, Ehlenbach WJ, Deyo RA, Curtis JR. Long-term outcomes after in-hospital CPR in older adults with chronic illness. *Chest.* 2014;146(5):1214-1225.
2. Shah MN, Fairbanks RJ, Lerner EB. Cardiac arrests in skilled nursing facilities: continuing room for improvement? *J Am Med Dir Assoc.* 2007;8(3 Suppl 2):e27-31.

Questions I have for my doctor after reviewing this CPR information: _____

My values most align with: ☐ Attempting CPR ☐ Not attempting CPR

CPR_DA_RC 0301_v04.18

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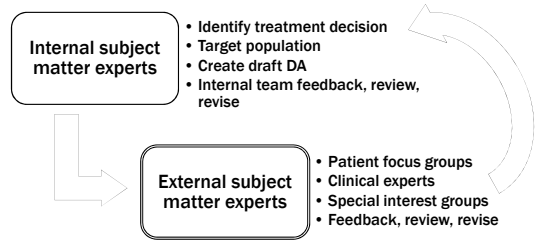
Phase I Development



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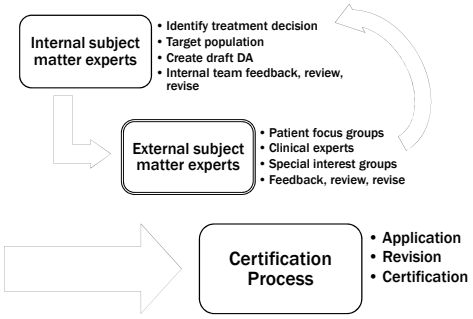
Phase II Certification Application



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Phase III Program Integration

- DA webinar and user guide
- Integrate into existing programs
- Additional decision aids

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Phase IV Dissemination and Evaluation

Dissemination

- Awareness
- Availability

Evaluation

- Feedback from users
- Revisions process and schedule

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Choosing the Decision Aid/Fact Sheet

- Review decision aid/fact sheet tools available within your organization.
- When selecting decision aids/fact sheets, consider the following:
  - Which decision aids/fact sheets should be used?
  - Have these materials been reviewed and endorsed by the care team?
  - How and when should they be used?
  - Does the decision aid/fact sheet complement the SDMSI conversation?
  - How are follow-up questions and concerns addressed?

Butler, M., Ratner, E., McCreedy, E., Shippee, N., & Kane, R. L. (2014). Decision Aids for Advance Care Planning. U. S. Department of Health and Human Services, Agency for Healthcare Research and Quality, Publication No. 14-EHC039-EF.

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CPR Discussion with Mr. Williams

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Patient Last Name: WILLIAMS | Patient First Name: JOHN | Middle Int.

Date of Birth: 10 02 1953 | Gender: [X] M [ ] F | Last 4 SSN: 1 2 3 4

If the patient has decision-making capacity, the patient's presently expressed wishes should guide his or her treatment

A Check One — **CARDIOPULMONARY RESUSCITATION (CPR): Patient is unresponsive, pulseless, and not breathing.**

- [ ] Attempt Resuscitation/CPR
- [X] Do Not Attempt Resuscitation/DNR

When not in cardiopulmonary arrest, follow orders in B and C.

B Check One — **MEDICAL INTERVENTIONS: If patient has pulse and is breathing.**

- [X] **Full Treatment – goal is to prolong life by all medically effective means.** In addition to care described in Comfort Measures Only and Limited Additional Interventions, use intubation, advanced airway interventions, and mechanical ventilation as indicated. Transfer to hospital and /or intensive care unit if indicated. Care Plan: Full treatment including life support measures in the intensive care unit.
- [ ] **Limited Medical Interventions – goal is to treat medical conditions but avoid burdensome measures** In addition to care described in Comfort Measures Only, use medical treatment, antibiotics, IV fluids and cardiac monitor as indicated. No intubation, advanced airway interventions, or mechanical ventilation. May consider less invasive airway support (e.g. CPAP, BiPAP). Transfer to hospital if indicated. Generally avoid the intensive care unit. Care Plan: Provide basic medical treatments.
- [ ] **Comfort Measures Only (Allow Natural Death) – goal is to maximize comfort and avoid suffering** Relieve pain and suffering through the use of any medication by any route, positioning, wound care and other measures. Use oxygen, suction and manual treatment of airway obstruction as needed for comfort. Patient prefers no transfer to hospital for life-sustaining treatments. Transfer if comfort needs cannot be met in current location. Consider hospice or palliative care referral if appropriate. Care Plan: Maximize comfort through symptom management.

Additional Orders:

C Check One — **ARTIFICIALLY ADMINISTERED NUTRITION: Offer food by mouth if feasible.**

- [ ] Long-term artificial nutrition by tube. Additional Instructions:
- [ ] Defined trial period of artificial nutrition by tube.
- [ ] No artificial nutrition by tube.

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Shared Decision Making in Serious Illness

CPR Video

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DAs Can Address Barriers to SDM

Patient Barriers

- Cognitive biases
- Innumeracy
- Cultural acceptance

Provider Barriers

- Bias toward intervention
- Lack of communication training

System Barriers

- Standardize information presented

Gillick, Muriel. (2015). *Re-engineering shared decision-making.* J Med Ethics. 41(9), 785-788.

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Small Group Activity

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Audience Response

Which concept presented today was most important in shifting your thinking about SDMSI conversations?

1. SDM is different for individuals who have serious illness.
2. Discerning what matters most to patients effectively guides SDM conversations.
3. Simply educating all clinicians is not enough to create change.
4. Decision aids can be useful tools for both patients and physicians.

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Audience Response

What one shared-decision making strategy that you learned today will you adopt in practice?

1. I will begin using decision aids with my patients.
2. I will begin SDM conversations with a question to explore patient's current understanding ("Ask-Teach-Ask").
3. I will use prior advance care planning documents to support current decision-making conversations.
4. I will refer to advance care planning services.

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