

EXECUTIVE SUMMARY

September 2018

Respecting Choices Reinvention and Future Direction

Respecting Choices is an independent, not-for-profit, national organization committed to our mission to guide organizations and communities as they integrate and disseminate best practices to ensure that individual preferences and decisions for all individuals are *known and honored*.

Respecting Choices (RC) is engaged in a variety of exciting new changes and collaborative initiatives since its transition from Gundersen Health System to a division of C-TAC Innovations, an organization devoted to implementing delivery systems for those individuals with serious illness. C-TAC Innovations is a not-for-profit affiliate of the Coalition to Transform Advanced Care (C-TAC). This transition has afforded RC the opportunity to reinvent itself; to mentor organizations in leveraging value-based payment systems through provision of person-centered decision-making programs, materials, and systems that are affordable, scalable, and sustainable.

CONCEPTUAL EVOLUTION

RC has 25 years' experience implementing advance care planning programs. From its beginning, the goal of RC programs has been to know and honor individuals' preferences and decisions—a concept that is broader than ACP. Conceptually, the goal of RC programs aligns more closely with the holistic definition of person-centered care as used by the Institute of Medicine: "Care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions."¹

Transforming the culture to person-centered and family-oriented care requires behavior change. "Culture is the definition of what is acceptable behavior in an organization."² Simply increasing the volume of statutory advance directive documents is both ineffective^{3,4,5} and doesn't result in behavior change. Moving from a culture of treating diseases and injuries to person-centered and family-oriented care is challenging but is required to *know and honor* individuals' preferences and decisions.⁶ Past successes and failures show that only multi-modal interventions that transform the culture of healthcare can achieve this goal.³

To better illustrate how the RC programs work to transform the healthcare culture toward achieving person-centered care, the conceptual description of the RC programs has evolved. It is hoped that this new description should excite and inspire you and help you envision the broad impact in achieving person-centered and family-oriented care.

¹ Institute of Medicine Report. (2001). *Crossing the Quality Chasm: A New Health System for the 21st Century*. Washington, DC: The National Academies Press. <https://doi.org/10.17226/10027>.

² Kilo, Charles. (2015). <http://www.abimfoundation.org/wp-content/uploads/2016/01/2015-ABIM-Foundation-Forum-Summary.pdf>.

³ Wilkinson, A., Wenger, N., Shugarman, L. R.; Office of Disability, Aging and Long-Term Care Policy, Office of the Assistant Secretary for Planning and Evaluation, U.S. Department of Health and Human Services; & RAND Corporation. (2007, June). *Literature Review on Advance Directives*. Retrieved from <http://aspe.hhs.gov/daltcp/reports/2007/advdirlr.pdf>.

⁴ Kass-Bartelmes, B. L., Hughes, R., & Rutherford, M. K. (2003). *Advance care planning: Preferences for care at the end of life* (AHRQ Publication No. 03-0018). Rockville, MD: Agency for Healthcare Research and Quality.

⁵ IOM (Institute of Medicine). (2014). *Dying in America: Improving quality and honoring individual preferences near the end of life*. Washington, DC: The National Academies Press.

⁶ Connors AF, Dawson NV, Desbiens NA, et al. (1995). A Controlled Trial to Improve Care for Seriously Ill Hospitalized Patients: The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT). *JAMA*. 274(20):1591–1598. doi:10.1001/jama.1995.03530200027032.

1. Person-Centered Decision Making: Advance Care Planning and Shared Decision Making in Serious Illness

A core attribute of person-centered is person-centered decision making (PCDM), which is the active engagement and support of individuals on their journey through the decision-making process. RC has two programs that work together to embed PCDM as a standard of care in healthcare culture: Advance Care Planning (ACP) and Shared Decision Making in Serious Illness (SDMSI).

ACP helps individuals and their loved ones *prepare for future healthcare decisions*. ACP conversations guide individuals through a process of reflection on personal goals, values, and beliefs in the context of their current health status and possible future situations. As a result, individuals and their families become better prepared to fully participate and engage with clinicians when future key healthcare decisions need to be made. The recent addition of SDMSI focuses on the process of communication in which physicians and patients work together to *make current healthcare decisions* that align with what matters most to patients.⁷ Together, ACP and SDMSI create an interprofessional approach to PCDM.

These are synergistic programs that work to engage and support individuals through their decision-making process by using consistent language, strategies, and processes across sites of care and over time. Each program addresses key design elements beyond education, focusing on systems to support the process, such as documentation systems, metrics, leadership engagement, and sustainability plans.

Systematic implementation has demonstrated improved health outcomes, improved experiences of care, and lowered the cost of healthcare.⁸ Despite evidence of its effectiveness, ACP and SDMSI programs remain relatively uncommon in healthcare settings.

2. The Five Promises

To assist in maintaining the focus of the work, Respecting Choices has elevated the *Five Promises* to keep the PCDM program aligned with the purpose—to focus on the individual.



FUTURE DIRECTION

Through market analysis, customer feedback, and program consultation, Respecting Choices has embraced a future that calls for diffusion of innovation through fidelity, reinvention, and adaptation⁹. This approach aligns with two key themes identified in the market analysis and heard from external feedback—a need for adaptability and attention to expense. These themes are integrated into RC’s strategic initiatives, a few of which are listed below (see *Exhibit* document for further description).

1. Curriculum development and maintenance
2. New program development
3. Customization of RC program implementation (Freedom within a Framework)
4. Collaboration and partnerships
5. Research and practice-based evidence

Thank you for your collaboration in helping to transform the culture to person-centered care!

⁷ National Quality Partners™ Action Brief. (2017, October). Shared Decision Making: A Standard of Care for All Patients. https://www.qualityforum.org/NQP/Shared_Decision_Making_Action_Brief.aspx.

⁸ Return on Investment: Implementation of Respecting Choices® Person-Centered Care Planning, https://respectingchoices.org/wp-content/uploads/2017/07/1.5_RC_0028_ROIforIMPLRC.pdf.

⁹ Dearing, J. & Cox, J. (2018). Diffusion of Innovations Theory, Principles, and Practice. *Health Affairs*, 37(2), 183-190. doi: 10.1377/hlthaff.2017.1104.

EXHIBIT: Respecting Choices' Strategic Initiatives September 2018

CURRICULUM DEVELOPMENT AND MAINTENANCE

Respecting Choices has a 25-year history of experience with, and commitment to, the development, testing, and improvement of competency-based programs in person-centered decision making. Respecting Choices' skills-based educational programs have become the gold standard through dedication of significant resources in updating these curricula every three years, integrating the latest in research and clinical experience.

Instructors complete a recertification process every three years, thus offering a national certification process that assures consistency in teaching strategies, content, and expertise (similar to the American Heart Association's Advanced Cardiovascular Life Support certification process). Instructors are typically cross-certified in more than one RC curriculum, allowing efficiency in expertise and in content delivery across a wide range of learners (e.g., non-healthcare volunteer to physician and advanced practitioners).

The First Steps (FS), Next Steps (NS), Advanced Steps (AS), and Shared Decision Making in Serious Illness (SDMSI) courses are strategically aligned to complement each other, and are designed using consistent strategies for learner engagement, including common terminology, conversation guides, standardized role-play exercises, and video demonstrations.

Online education, consisting of six ACP modules, is used as a prerequisite to the ACP Facilitator Certification courses. This curriculum is updated every three to four years. This online strategy has proven highly satisfying, prepares learners to immediately engage in the classroom experience, and has decreased classroom time.

In 2017, data from participants attending FS, NS, and AS courses offered throughout the U.S. was collated and is represented in the following tables. This data demonstrates stellar satisfaction with learning outcomes, achievement of personal goals, commitment to changing practice based on the course, and ability to apply content to the practice setting.

Table 1: Learner Satisfaction with Achievement of Learning Objectives

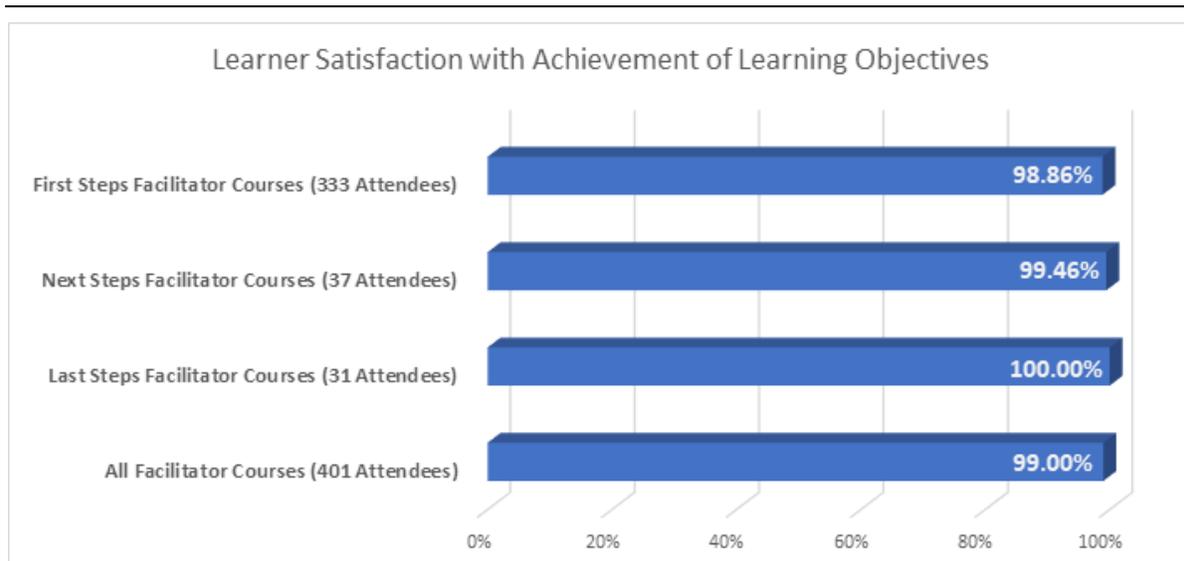
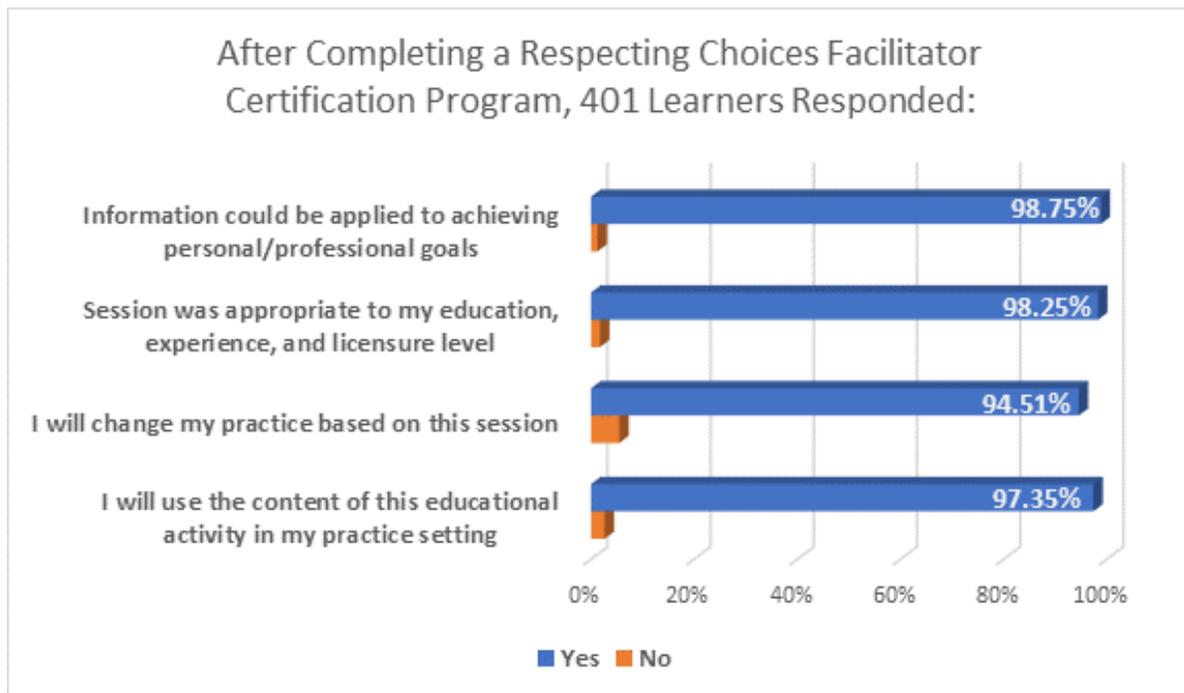
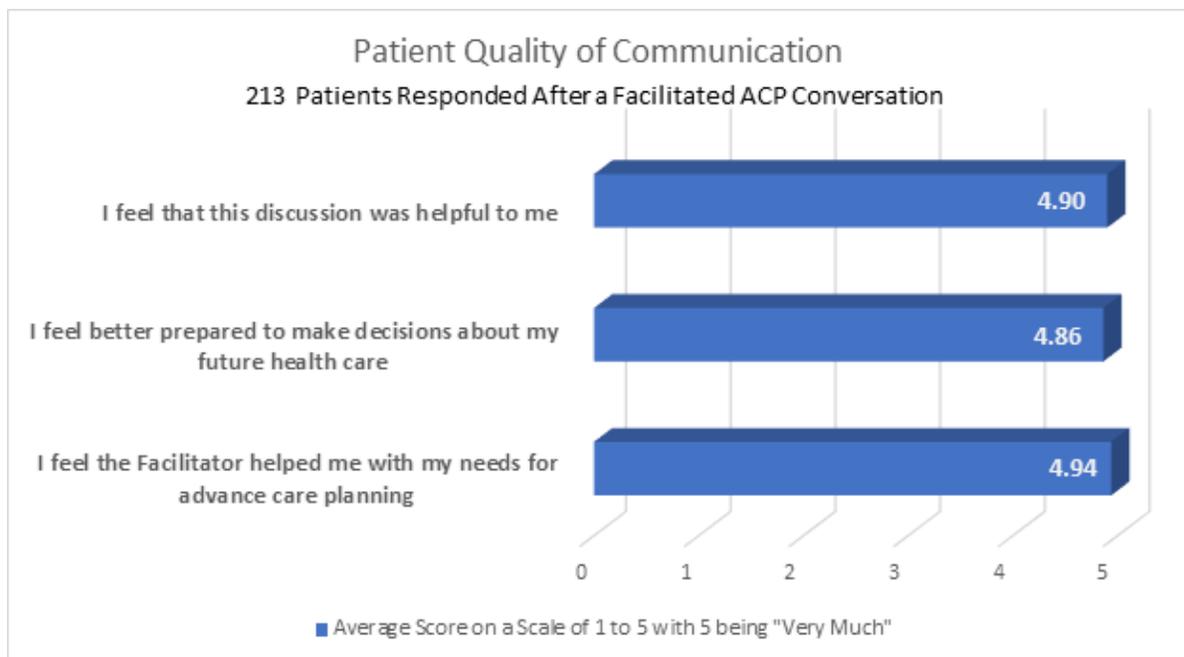


Table 2: Learner Responses After Completing A Respecting Choices Facilitator Certification Program



Satisfaction with the RC educational programs goes beyond the classroom or learner experience. A sampling of 213 patient reports following a facilitated ACP conversation (and using a standardized survey) was collated from five different ACP implementation teams. Facilitated ACP conversations are consistently helpful in addressing individuals’ needs and preparing them to make future healthcare decisions.

Table 3: Patient Quality of Communication After A Facilitated ACP Conversation



NEW PROGRAM DEVELOPMENT

Respecting Choices has an array of educational programs that support an organization or community transformation to a person-centered healthcare culture and continues to review and expand its offerings for ultimate success.

1. **FS and NS Facilitator and Instructor Certification course updates** (released by end of 2018).
Highlights include:
 - a. Decreased classroom time; remains focused on skill achievement
 - b. NS Facilitator Certification course includes a one-day course for experienced clinicians that has demonstrated an ability to certify participants quickly and efficiently (Thus far, 17 individuals who have completed this course were certified as NS Facilitators within two weeks of the course.)
 - c. Updated conversation guides for person-centered decision making
2. **Shared Decision Making in Serious Illness.** The SDMSI program for physicians and advanced practitioners provides a mechanism to engage physicians in their roles in helping patients make current treatment decisions that align with their goals and values and understanding the value of ACP. This physician-focused curriculum also aligns with consistent strategies, terminology, and techniques used in the ACP program, therefore providing a unique opportunity for interprofessional collaboration and continuity for patients.
3. **Online ACP curriculum for physicians and advanced practitioners** (to be released in Fall 2018). *Building Physician Skills in Basic Advance Care Planning* is focused on basic, or FS planning conversations, including documentation and ACP billing reimbursement strategies.
4. **Decision aids and educational tools** created using a robust development process, including clinician and consumer input and attention to reading comprehension.
 - a. **Decision aids.** CPR, Help with Breathing, and Long-Term Tube Feeding are certified by the Washington State Health Care Authority and have been created specifically for adults with serious illness. These decision aids have been integrated into the NS, AS, and SDMSI course curricula.
 - b. **Educational fact sheets.** While decision aids are intended for those with serious illness and intended to assist in decision making, the RC Fact Sheets (e.g., CPR) are educational tools intended for a general audience to improve understanding of a treatment decision. The new CPR Fact Sheet is integrated into the FS educational program.

CUSTOMIZATION OF RC PROGRAM IMPLEMENTATION

Historically, RC has focused on helping organizations understand the core principles of designing an ACP program and applying these principles to the organizations' specific goals, culture, and resources. Organizations have made tremendous strides in creating systems and foundations for effectively implementing and spreading new work. They continue to need help applying the foundation to ACP. Therefore, moving forward, RC will be applying a new concept for adapting to meet the needs of organizations called "Freedom within a Framework" (adapted from General Electric). RC's experience and evidence provide the "framework" for implementation while the organization will experience the "freedom" to choose implementation strategies. This conceptual shift will combine RC's experience, best practices, and

lessons learned in a mentorship role with the organization's leaders to assist in designing a customized implementation experience.

A few examples include:

1. **Streamlining multi-program delivery.** Organizations who intend to implement more than one RC program require the adaptation of RC's delivery strategies to a) meet the organization's needs; b) decrease duplication of effort and complexity of implementation thus reducing cost; and c) reduce a "silo" effect between programs or stages of planning.
2. **Accelerating implementation and broad adoption.** RC is committed to redesigning implementation materials and processes to accelerate adoption of programs within an organization/community. As an example, RC will create innovative mentoring models to reach broader audiences (e.g., no longer focus only on mentoring one organization at a time) and reduce the burden of implementation while maintaining quality and patient/clinician satisfaction.
3. **Building program resilience and fortitude.** RC consultation will have an enhanced focus on sustaining the work through achieving cultural transformation. This focus includes new/ revised mentoring and consultation strategies, content, and focus on affordable pricing.

COLLABORATION AND PARTNERSHIPS

Respecting Choices understands the importance of collaboration to achieve the common goal of providing person-centered care. This is accomplished in several ways.

1. **Collaboration with those doing the work**
 - a. Advisory groups (AG) have been used to help RC improve and create new programs, including the NS and FS program revisions and recertification process, the physician online ACP curriculum, and SDMSI program revisions in 2017 and 2018.
 - b. In 2018, RC will create and convene national advisory groups with diverse representation and perspectives to inform our program improvement and development (new and revision).
 - c. Organization Faculty quarterly conference calls to share best practices and identify challenges and opportunities across the country.
 - d. The bi-annual National Share the Experience for Respecting Choices teams, partners, and others to have a forum to share best practices and disseminate collaborative learning.
 - e. With the addition of RC Prime, organizations will continue to receive ongoing support for program dissemination through a cost-effective and ongoing relationship with RC consultants, materials, and programs.
2. **Collaboration with external partners**
 - a. Technology solutions: Epic, Vynca, WiserCare
 - b. Experts in field: National POLST paradigm, CAPC, PREPARE for Your Care

RESEARCH AND PRACTICE-BASED EVIDENCE

RC remains committed to partnerships with research teams that will continue to provide evidence of the effectiveness of the RC strategies. Currently, RC is involved with several randomized-controlled or comparative-effectiveness studies.

While evidence-based practice through controlled research efforts is critical, practice-based evidence (the documentation and measurement of real-world practice) also exists.

For example, the ultimate outcome of an ACP program is the ability to know and honor an individual's goals, values, and preferences. Research has demonstrated the impact of the RC program on this outcome.

Practice-based evidence gathered from RC teams has demonstrated:

1. Increase in patient-surrogate congruence
2. Concordance with patient treatment preferences
3. Patients making different choices (i.e., they opt for less aggressive treatment under conditions of unacceptable outcomes)
4. NS ACP conversation results in decreased ICU stays, increased admission to hospice, and increased hospice lengths of stay
5. POLST form completion using the RC Advanced Steps ACP conversation consistently results in concordance with patient treatment preferences