Respecting Choices® presents

Advance Care Planning (ACP) Redesign:
Transforming Person-Centered Care

September 7-10, 2016
Milwaukee, WI

SUMMIT REPORT 2016
MISSION

We guide organizations and communities worldwide to effectively implement and sustain evidence-based systems that provide person-centered care.

VISION

To transform healthcare culture by integrating and disseminating best practices to achieve person-centered care.

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I. Executive Summary

More than 200 people from 30 states and three countries attended the inaugural Respecting Choices® National Share the Experience Summit. The purpose of the Summit was to provide a national forum for Respecting Choices® (RC) stakeholders to share their RC advance care planning (ACP) implementation experiences, and to gain a deeper understanding of the critical need for healthcare transformation to ensure person-centered care: Care that honors an individual’s goals and values for future healthcare.

The older population is growing exponentially. Over the next two decades, the number of Americans over the age of 65 will double to more than 72 million, or one in five.¹ With life expectancy increasing, a better approach to care planning and decision making must be embedded into the culture of healthcare.

¹ U.S. Department of Commerce Economics and Statistics Administration U.S. CENSUS BUREAU
According to the 2014 Institute of Medicine Report, *Dying in America*, “Educational institutions, credentialing bodies, accrediting boards, state regulatory agencies, and healthcare delivery organizations should establish the appropriate training, certification, and/or licensure requirements to strengthen the palliative care knowledge and skills of all clinicians who care for individuals with advanced serious illness who are nearing the end of life.”

The Summit brought together advance care planning leaders and experts from state and community initiatives, ACP coalitions, and healthcare organizations to collaborate and exchange ideas and strategies focused on bridging the BIG gap between what people want based on their state of health versus what they receive in terms of advanced illness and end-of-life care.

Topics designed to stimulate new conversation and ways of thinking included:

- ACP Redesign
- First Steps®/Next Steps/Last Steps® ACP program innovations/outcomes
- Special population groups
- RC Instructors and Organization Faculty
- ACP program implementation
- Ethical dilemmas/challenging cases
- Legal/regulatory/financial

“We're good at addressing specific, individual problems . . . . Give us a disease and we can do something about it . . . . But give us . . . an elderly woman at risk of losing the life she enjoys — and we hardly know what to do and often only make matters worse.”

Atul Gawande, M.D.
Author of the book, *Being Mortal*
II. Introduction

Respecting Choices® (RC) is an internationally recognized, evidence-based advance care planning (ACP) program that is dramatically different from other programs. As innovators and leaders in ACP and systems development since 1991, Respecting Choices® continues to provide training, consultation, and materials to organizations and communities around the world. The staged, systematic RC approach to ACP has been successfully replicated in and integrated into major healthcare organizations and diverse communities and cultures worldwide.

Nearly 10,000 individuals have been certified as RC Facilitators, 800 have been certified as RC Instructors, and 30 have been trained as Organizational Faculty.

Respecting Choices® has always and continues to drive person-centered care through healthcare delivery system and policy change. On September 7–10, 2016, RC hosted its inaugural National Share the Experience Summit engaging more than 200 stakeholders globally.
A diverse assemblage of physicians, nurses, social workers, chaplains, researchers, professors, policy change advocates, and other ACP leaders gathered to discuss barriers and solutions for transforming the way healthcare is delivered in the United States. Discussion focused on:

- ACP system redesign that promotes improved person-centered care
- Strategies to overcome ACP challenges in creating ACP systems that transform person-centered care
- Research findings to assist with redesign of ACP systems to improve person-centered care

Bud Hammes, PhD, Respecting Choices® Executive Director, and Linda Briggs, MSN, MA, RN, Respecting Choices® Director of Program Development and Research, opened the summit by thanking all participants for their stellar work and for coming together to share their stories and renew their commitment to Respecting Choices®. Ms. Briggs recalled the first Respecting Choices® program implementation in the year 2000, and the dozens of implementations that have occurred since, with RC now having a presence in all but seven states in the United States and working with over 130 organizations.

Implementations in large healthcare systems include Kaiser Permanente, Dartmouth-Hitchcock, and Spectrum Health. Other initiatives include implementations in state medical societies, academic organizations, and communities. Ms. Briggs also talked about RC’s international relationships in Australia, Germany, Spain, as well as the six European country research study that is using the RC model.
III. The Current and Future of Federal Policy Supporting Advance Care Planning

Virginia Senator Mark Warner’s presentation (via video) addressed the critical need for healthcare system redesign to improve ACP. He reflected on a personal story of his mother’s 11-year struggle with Alzheimer’s disease and the importance of knowing a loved one’s wishes if they become unable to communicate those wishes. He acknowledged flaws in the current system that often leave patients and their families with a maze of fear and uncertainty and without the tools to prepare for the death of a loved one.

Senator Warner noted progress has been made with the Centers for Medicare & Medicaid Services (CMS) 2016 rule allowing for reimbursement for providers to discuss ACP with their patients, but recognized the need for further improvement. He discussed the Care Planning Act bill he has proposed to help the public gain a better understanding of what care planning means, and to advocate for aligning the care people want with the level of care they receive.

The Care Planning Act of 2015
US Senator Mark R. Warner, Commonwealth of Virginia
IV. Respecting Choices® – C-TAC partnership announcement

Dr. Hammes and Linda Briggs announced RC will move its operations from Gundersen Health System to the newly launched Coalition to Transform Advanced Care (C-TAC) Service Affiliate, C-TAC Innovations. Dr. Hammes discussed the reasons for the move, why C-TAC was chosen as a partner, and emphasized the move will only strengthen RC and the national ACP movement. The finalization of the agreement between Gundersen and C-TAC is anticipated to occur in October. The transfer of staff and operations should be complete by the end of the year. The main office will remain in La Crosse, WI.

Why this new partnership?

Respecting Choices® required a larger, national platform for purposes of growth, improvement, and sustainability. This new partnership will set the stage for two programs with common interests to make a real difference in the aging of America.

Why C-TAC?

• Clear alignment of mission
• Complimentary work
• National reach
• Represents a large, diverse set of organizational members

What can you anticipate?

• Ongoing mission and vision
• Ongoing commitment to quality programs and materials
• Ongoing commitment to research
• National Faculty recruitment
• Expert advisory groups
• Improved evaluation of our services
• New program development

Sigurd Gundersen, III, MD, Chairman of the Board, Gundersen Medical Foundation, and C-TAC co-founders and co-chairs, Bill Novelli and Tom Koutsoumpas, reiterated the positive opportunity the RC/C-TAC partnership presents. Mr. Novelli and Mr. Koutsoumpas provided background information on C-TAC and described C-TAC’s strategies as follows:

1. Identify, disseminate and implement community and clinical care delivery models.
2. Advocate for legislative and regulatory policy change.
3. Engage the public to help people make informed decisions and to support delivery system and policy changes.
4. Support effective organizations and programs and seek partners to create sustainable, positive change.
Leadership team under the new partnership

Bud Hammes, PhD  
Executive Director

Linda Briggs,  
MSN, MA, RN  
Director, Program Development and Research

Stephanie Anderson,  
MSN, RN, CHPN  
Director, Consultation and Education Services

Faculty and staff

Pat Tadel, MSN, RN  
Senior Faculty Consultant

Kathleen Ziemba,  
MSW, LCSW  
Senior Faculty Consultant

Britt Welnetz  
Business Development Consultant

Elizabeth Kim  
eLearning Consultant

Kate McMahon  
Business Coordinator

Mary Thurin  
Business Coordinator

Michelle Byom  
Business Coordinator

Evonna Burr  
Education Materials Specialist
V. Respecting Choices®: More than Advance Care Planning

Dr. Hammes announced Respecting Choices® is repositioning the program’s key messages.

From: *Respecting Choices® Advance Care Planning*
      
To: *Respecting Choices® Person-Centered Care*
      
and

From: *An Advance Care Planning System That Works*
      
To: *A System for Person-Centered Decision Making That Transforms Healthcare*

He explained the intent of RC’s work from the beginning has been a focus on a person-centered, family-oriented process of shared decision making as part of routine care, not just advance care planning. Dr. Hammes stressed when this process is done effectively and sustained over time, it creates a culture that becomes the norm of how decisions are made.

**Person-centered care and transformation examples presented during the summit**

**Impacting the Lives of Individuals and Their Families**

- ACP in Multicultural Settings
- Implementing ACP in Patients with Dementia, Special Needs, Memory Impairment, Vulnerable Populations, Pediatrics
- ACP and Faith Communities
- ACP and Serious Illness

**Impacting Healthcare Culture**

- Large scale implementation (across organizations, communities, regions, and healthcare systems)
- Rural implementation
- Integration of ACP and palliative care
- Leadership strategies for sustainability
- Building improved systems for storage and retrieval, reimbursement, and metrics

**Impacting the Lives of Professionals and Others**

- Shared Decision Making in Serious Illness: Aligning Care with What Matters Most to Patients
- First Steps® ACP and the Novice Nurse
- ACP and the Role of the MD and Medical Resident
- Volunteer Facilitators
- The Novice Social Worker’s Experience
VI. Plenary sessions and speakers

Executive Leadership’s Role in ACP
Program Development
Carole Montgomery, MD, FHM, MHSA,
Clinical Vice President, Health
Management, Spectrum Health Medical Group

Statewide ACP Initiatives: The Honoring Choices Model
Donn Dexter, MD, FAAN, Chief Medical Officer, Wisconsin Medical Society
Karen Peterson, BSN, Executive Director, Honoring Choices Minnesota, Twin Cities Medical Society

Transforming an Advance Care Planning Culture: Learning from a Large Integrated System
Daniel Johnson, MD, FAAHPM, Physician Lead for Palliative Care, Care Management Institute, Kaiser Permanente
Melissa B. Stern, MBA, Managing Director, Life Care Planning, Kaiser Permanente – Northern California

An Interim Analysis of an ACP Intervention in Nursing Homes
Susan E. Hickman, PhD, Professor, Indiana University School of Nursing, Executive Director, Indiana Patient Preferences Coalition

Sharing the Journey of Successful Implementation of a Next Steps ACP Program
Jill A. Jarvie, RN, MSN, CNS, Next Steps ACP Faculty, Life Care Planning, Kaiser Permanente – Northern California

Building Quality in Clinical Trials: The ACTION Study
Ida J. Korfage, PhD, Assistant Professor, Quality of Life, Erasmus MC, University Medical Center Rotterdam
VII. Research Study Presentations

The following research studies, which integrate one of the Respecting Choices® Stages of Planning programs, were presented at the summit:

**First Steps®**

*Building Quality in Clinical Trials: The ACTION Study*

Ida Korfage, PhD, Assistant Professor of Quality of Life at Erasmus MC –University Medical Center Rotterdam

A clinical trial in six European countries with over 1,300 patients with advanced cancer that integrates Respecting Choices® First Steps® and Last Steps® facilitated ACP conversation.

**Next Steps**

*Randomized Clinical Trials of Family Centered (FACE) ACP: Integrating Respecting Choices® Next Steps for Teens with Cancer and HIV*

Maureen Lyon, PhD, Clinical Health Psychologist, Children’s National, Washington, D.C.

A clinical trial using the Family-Centered Advance Care Planning for Teens with Cancer and HIV (FACE-TC, FACE-HIV) intervention for teens that integrates the Respecting Choices® Next Steps ACP facilitated interview.

**Last Steps®**

*Systematic Advance Care Planning in the Nursing Home: Preliminary Outcomes from the OPTIMISTIC Demonstration Project*

Susan Hickman, PhD, Professor, Indiana University School of Nursing, Co-Director of RESPECT

A clinical trial to determine processes and preliminary outcomes from a systematic advance care planning intervention using Respecting Choices® Last Steps® ACP facilitated interview in the nursing home setting.

There are several research studies that, if funded, RC has agreed to work with.
VIII. Awards

Respecting Choices® presented five Recognition for Excellence Awards at the Summit:

**Excellence in Leadership – Spectrum Health, Grand Rapids, MI**

This award recognizes outstanding leadership in moving ACP program implementation efforts forward, not turning back, and demonstrating sustainability while supporting spread. The Spectrum Health, Grand Rapids, MI. The Spectrum Health team has implemented all three stages of planning and created a strong path to sustainability with two Organization Faculty and an administrative champion. This team has been integral to the development of the new Shared Decision-Making in Serious Illness curriculum that was introduced at the Summit.

**Excellence in ACP Facilitator Certification and Staff Education – Dartmouth-Hitchcock, Lebanon, NH**

This award recognizes the development of effective strategies to provide ACP education and Facilitator Certification and maintenance. The Dartmouth-Hitchcock team created strategies for building Facilitator competence and skills, designing a mentorship program for Facilitators and Instructions, embedding the role of Facilitator into job descriptions, and designing applications for system-wide education.
Excellence in System Redesign – Kaiser Permanente - Northern California

This award recognizes innovative leadership and strong system-wide champions in the implementation of all three stages of planning. The Kaiser Permanente - Northern California team has demonstrated the ability to disseminate effective and sustainable implementation across a large multicultural healthcare system. Kaiser represents the most successful Next Steps implementation to date. This team has continued to move this work forward, creating playbooks for new teams and consistently looking at quality indicators to strategize and embed a transformative culture shift in their organization.

Excellence in Community Engagement – Honoring Choices Wisconsin (HCW)

This award recognizes the successful ongoing dissemination of the RC First Steps® ACP program throughout Wisconsin under the leadership and sponsorship of the Wisconsin Medical Association. The systematic penetration of HCW has been supported by the first statewide model to integrate the role of RC Organization Faculty. This team has initiated a faith ambassador program and assisted with health literacy review of RC materials. As part of dissemination and sustainability, they have embedded support for ACP through physician educational offerings, including creation of an ACP provider performance improvement program to support implementations.

Excellence in Providing Leadership in Promoting Person-Centered Healthcare – Linda Briggs, MSN, MA, RN

This award recognizes an individual who is committed to and successful at transforming healthcare to a person-centered model. Linda Briggs is devoted to the training of health professionals and the redesigning of health delivery so the person with an illness is always the center of care. Her dedication spans more than 17 years by creating curriculum for advance care planning facilitators and instructors as well as providing expert advice on health system redesign. Linda is the lead innovator for the Next Steps process of decision making that assists in planning for future healthcare decisions and focuses on immediate goals and values of persons with serious illness so they get care that is aligned with these values and goals. Linda has also helped test and refine these shared decision-making processes through numerous research projects in adults and adolescents in the United States and Europe.
IX. Vision and Challenges for the Future of ACP

The vision for ACP is to transform healthcare culture by integrating and disseminating best practices in advance care planning throughout healthcare and community settings.

The Respecting Choices® program improves population health. To be successful, this approach to planning needs to be supported by an organized ACP system and skilled facilitators who assist individuals and their surrogate and family to understand, reflect upon, and discuss goals for making future healthcare decisions in the context of their values and beliefs.

The three most important elements to maintaining high-quality ACP programs are leadership, resources, and program design.

Leadership Challenges

- Senior leadership
  - Overcoming the organizational silos to achieve a high functioning ACP system across a healthcare system and in a community
  - Setting ACP as a top priority
- Operational leadership
  - Providing time for ACP facilitators
  - Overseeing metrics and QI functions
- Clinical leadership
  - Maintaining the quality of ACP facilitators
  - Building and maintaining the ACP team

Resource Challenges

- ACP facilitators
  - Training – initial and ongoing
  - Providing the ACP services
- ACP health system improvement/maintenance
  - Work of ACP coordinator
  - Work of oversight committee
  - Quality Improvement/Information Technology work
• Community engagement
  - Working with partner organizations to provide ACP
  - Direct marketing to public about value of ACP

Program Design Challenges

• Maintaining the quality of ACP facilitation through training of an adequate workforce and maintaining their ACP skills
• Continuous Quality Improvement: Making sure that ACP systems are managed, maintained, and improved over time.
• Ongoing orientation and training of all health professionals so they understand their ACP roles and can carry out these roles competently

Conclusion

Quality ACP can only be maintained when:

1) A well designed system is initially put into place;
2) Senior leadership is dedicated to maintaining and improving the ACP system; and
3) The needed resources are provided to do this ACP work (at both the system and facilitation levels).
Appendix A: Summit Agenda

Respecting Choices® National Share the Experience
Advance Care Planning (ACP) Redesign: Transforming Person-Centered Care

September 7–10, 2016
Hyatt Regency
Milwaukee, Wisconsin, USA

Wednesday, September 7

4:00 PM  Registration opens

7:00  Welcome
Linda Briggs, MSN, MA, RN, Associate Director, Respecting Choices®;
Bernard Hammes, PhD, Director, Respecting Choices®

Video Presentation
The Current and Future of Federal Policy Supporting Advance Care Planning
The Honorable Senator Mark Warner of Virginia

Leading the Way: Developing a Better Care Model for Advanced Illness
Bill Novelli, Co-Chair, Coalition to Transform Advanced Care, and Professor,
McDonough School of Business, Georgetown University;
Tom Koutsoumpas, Co-Chair, Coalition to Transform Advanced Care,
President and CEO, National Partnership for Hospice Innovation

Closing Remarks
Respecting Choices®: More than Advance Care Planning. A Program to Provide Person-Centered Care Through Shared Decision Making
Linda Briggs, MSN, MA, RN, Associate Director, Respecting Choices®;
Bernard Hammes, PhD, Director, Respecting Choices®

8:30  Reception and social
(complimentary hors d’oeuvres and refreshments)

I honestly felt that this was one of the best conferences I’ve attended in a long time. I learned so much about best practices that are going on nationally and can bring these things back to our hospital and community. Excellent conference!
Thursday, September 8

7:00 AM  Registration and continental breakfast

7:50  Welcome
Linda Briggs, MSN, MA, RN, Associate Director, Respecting Choices®
Respecting Choices® Recognition Award: Leadership

8:00  Plenary Session
Executive Leadership’s Role in ACP Program Development
Carole Montgomery, MD, FHM, MHSA,
Clinical Vice President, Health Management,
Spectrum Health Medical Group

9:15  Break and refreshments

9:30  Concurrent Sessions

1. Leadership
   Physician Champion: Key to ACP Implementation
   Jonathan Sande, MD, Director of ACP,
   Essentia Health

   The Challenges of Ensuring Physician Leadership Support
   Sanders Burstein, MD, Medical Director, Honoring Care Decisions,
   Dartmouth-Hitchcock

   Engaging Primary Care Physicians Across a System
   Kara Sankey, Manager of Case Management Services, Mercy Health System

2. Systems and ACP Redesign
   Advocating for Improved Access to Advance Care Plans
   Robin Cummings, MSHA, Director, Honoring Choices Virginia; J. Brian Cassel,
   PhD, Assistant Professor, Hematology/Oncology and Palliative Care, Virginia
   Commonwealth University, Richmond, VA.

   Advance Directive Availability Redesign: Partnership between Health Information Exchange and Healthcare Organization
   Rose Seavolt, BSN, RN, CCP, Organization Faculty, Spectrum Health; Steve Spieker, Manager of Solution Support, Great Lakes Health Connect

   Advance Care Planning Across a Health Care System Using Epic
   Maureen Tyra, MSW, LICSW, ACP Coordinator, North Memorial Health Care

I am re-energized and able to bring a new focus and vocabulary about this work. This will revolutionize the way we talk about ACP in my organization.
3. **Community Engagement**

   *Building Community Engagement Capacity: A Case Study of National Healthcare Decisions Day in Wisconsin*

   Maria Tielens, BS, MS, LPC in training, Chaplain Counselor, Bellin Health

   *Creating Your Own Advance Care Planning Department: Lessons Learned*

   Melissa Hale, MSW, LCSW, ACP Coordinator, ProHealth Care

10:30 **Break and refreshments**

11:00 **Workshops**

1. **Shared Decision Making in Serious Illness: A New Respecting Choices® Curriculum Designed to Assist Providers in Aligning Care with What Matters Most to Patients**

   Linda Briggs, MSN, MA, RN, Associate Director, Respecting Choices®; Carole Montgomery, MD, FHM, MHSA, Clinical Vice President, Health Management, Spectrum Health Medical Group; Sanders Burstein, MD, Medical Director, Dartmouth-Hitchcock/Honoring Care Decisions

2. **“But We are Already Doing That”: Exploring the Intersection of ACP and Palliative Care**

   Dan Johnson, MD, FAAHPM, Physician Lead for Palliative Care, Care Management Institute, Kaiser Permanente; Patrice Tadel, MSN, RN, Sr. Faculty Consultant, Respecting Choices®; Anna Scott, RN, Manager, Inpatient and Clinic Palliative Care, Kaiser Permanente

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*I am so glad that I got to attend this conference just weeks before our First Steps pretraining. I feel like I received the "insiders scoop" on what works well, what could work better and what might not work. I appreciate the leadership from Bud and Linda and the rest of the RC staff in setting a tone for shared learning and transparency. Was unlike any other conference I have attended related to everyone’s willingness to share and to want to learn from others.*
3. ACP Facilitator Attainment and Maintenance of Certification: Strategies from the Field

Strategies for Supporting Instructors and Facilitators
Joyce Smerick, BS, Program Coordinator and Organization Faculty, Honoring Choices Wisconsin

Supporting the Troops: Engaging and Mentoring Next Steps Facilitators
Jill Jarvie, RN, MSN, CNS, Clinical Practice Consultant, Kaiser Permanente, Northern California

How Recertification Can Improve the Integrity of an ACP Program
Susan Fitzgibbons, Program Manager, Dartmouth-Hitchcock / Honoring Care Decisions

4. Advance Care Planning in Multicultural Settings
Karen Peterson, BSN, Executive Director, Honoring Choices Minnesota

5. ACP Communication and the Electronic Medical Record: Creating a Build That Works for the Clinician
Danielle Rathke, DNP, RN, ACP Coordinator, Gundersen Health System; Kari Shaw, Clinical Informationist, Gundersen Health System; Kat Thomas, BSN, RN, Implementation Services, Epic

12:15 PM Lunch provided

12:55 Respecting Choices® Recognition Award: ACP Facilitator Certification and Staff Education

1:00 Plenary Session
Statewide ACP Initiatives: The Honoring Choices Model
Karen Peterson, BSN, Executive Director, Honoring Choices Minnesota
Donn Dexter, MD, FAAN, Chief Medical Officer, Wisconsin Medical Society

2:00 Break and refreshments

2:15 Concurrent Sessions

1. Large Scale First Steps® Implementation
Honoring Choices Pacific Northwest: The Power of Collaboration
Jessica Martinson, MS, Director, Clinical Education & Professional Development, Washington State Medical Association; Carol Wagner, RN, MBA, Sr. VP Patient Safety, Washington State Hospital Association
Collaboration over Competition
Robin Cummings, MSHA, Director, Honoring Choices Virginia; Rebecca Gruszkos, ACP Project Educator, Bon Secours Health System; Deborah Griffith, RN, Critical Care Special Projects Coordinator, Henrico Doctors’ Hospital; Ken Faulkner, MDiv, MA, ACP Coordinator, VCU Health

2. First Steps® ACP Implementation
Implementing Respecting Choices® within Midwestern Quaternary Healthcare Delivery System – Toward the End of the Beginning
Iris Boettcher, MD, CMD, Medical Director, MyLife Care Planning, Spectrum Health

We are Switzerland: Building Blocks for a Free-Standing, Nonprofit ACP Program
Carol F. Robinson, DNP, MS, BSN, RN, CHPN, Community Coordinator, Making Choices Michigan; Ben Emdin M.Ed., President, Making Choices Michigan; Steve Spieker, LPC, Manager of Solution Support at Great Lakes Health Connect

3. Community Engagement
Group Facilitation: How to Do It and When to Use It
Joyce Smerick, BS, Program Coordinator and Organization Faculty, Honoring Choices Wisconsin

Wheel of Conversation
Marjorie Hackbarth, MBA, Service Line Administrator, Aspirus; Jamie Myers, ACP Professional, Aspirus

4. Next Steps ACP Implementation
The Pedagogy of Phenomenological Aspects of Chronic Disease: Notes from Faculty on Teaching the Experience of Chronic Illness
Patrice Tadel, MSN, RN, Sr. Faculty Consultant, Respecting Choices®

The range of options and the caliber of presenters was outstanding! This is an important opportunity for those of us in this field to come together to support one another and strategize on how to have engagement across the country in a consistent and organized way to accomplish this important work.
Implementing Advance Care Planning with Patients with Dementia
Sara McCumber, DNP, APRN, CNP, NP in neurology

Disease Specific Advance Care Planning Conversations Impact on Patients, Advocates and the Healthcare Team
Rose Seavolt, BSN, RN, CCP, Organization Faculty, Spectrum Health

5. Implementation Strategies
The Coalition to Transform Advanced Care (C-TAC) Model: Redesigning Care Delivery to Support Personal Preference and Shared Decision Making
Khue Nguyen, PharmD, COO, C-TAC Services; Brad Stuart, MD, CMO, C-TAC Services

“I'll Get to It Later”: Understanding and Overcoming Procrastination in Advance Care Planning”
Dan Johnson, MD, FAAHPM, Physician Lead, Palliative Care, Care Management Institute, Kaiser Permanente

3:15 Break and refreshments
3:30 Concurrent Sessions

1. Organization and Regional Implementation
If You Can Make It There, You Can Make It Anywhere: The New York, NY Experience with Respecting Choices®
Tom Sedgwick, MSSW, LCSW, ACSW, CCM, Director of Social Work, NYU Langone Medical Center; Christine Wilkins, PhD, LCSW, ACP Manager at NYU Langone Medical Center

Ready to Respect Patient's Wishes for End of Life Care
Sabina Mustic, MSIS, Research Librarian, Sanford Standards; Kelly Hasvold, RN, Director, Quality and Patient Safety, Sanford Standards

Collaborating for Mission
James Kraft, MTh, Director, ACP and Collaborative Care, Henry Ford Health System

Thanks for the opportunity. I wish that I had been able to bring along my whole leadership team. There would be no question about the value in designing, implementing and sustaining a robust ACP program.
2. **Implementation Strategies**

*Development of a Comprehensive Fully-Integrated Inpatient / Outpatient Palliative Care and Advance Care Planning Program*

Charles Nolan, MD, Palliative Care Physician, Guadalupe Regional Medical Center; Tom Jones, Palliative Care Chaplain and Executive Director of LIFE Care Services, GRMC; Lilana De La Torre, Palliative Care Chaplain, Director of Advance Care Planning Services, GRMC; Carmen Andersen, LMSW, Palliative Care Social Worker, GRMC; Tavie Erwin, RN, Nursing Director of Hospice, GRMC

*Community Benefit Realized Partnership between Community-Based and Healthcare Organization ACP Programs*

Carol F. Robinson, DNP, MS, BSN, RN, CHPN, Community Coordinator, Making Choices Michigan; Nicky Lewis, LMSW, ACP Coordinator, Mercy Health Saint Mary's Health System; Rose Seavolt, BSN, RN, CCP, ACP Organization Faculty, Spectrum Health

*Community Education for End-of-Life Care Plans*

Judith Reifsteck, PsyD, LPC, Psychology at James Madison University and J. Sargeant Reynolds Community

3. **Special Populations**

*My Wishes Workshops*

Betsy Payne, MSN, Executive Director, Looking Ahead, Inc.; Veronica Coyne, MD, Medical Director, Looking Ahead

*Implementing Community-Based Advance Care Planning with Special Needs Populations*

Nancy Leipzig, BS, Regional Program Director, Community Care, Inc.

*Team Collaboration to Enhance Advance Care Planning at an Ambulatory Cancer Center*

Jennifer Wagner, MSN, RN, NE-BC, ACP Coordinator, Lancaster General Hospital; Heather Nelson-Przywara, ACHP-SW, LCSW, Social Worker; Ann B Bashinger Cancer Institute; Patti I. Roda, MSN, BS, RN, Manager, Clinical Services

4. **Academic Implementation**

*A Good Start: First Steps® ACP Facilitation and the Novice Nurse*

Ruth Gliss, MSN, RN, CNE, Associate Professor of Nursing, Genesee Community College
Including ACP Facilitation into a Baccalaureate Nursing Curriculum
Barbara Carranti, MS, RN, CNS, Clinical Associate Professor, Le Moyne College

An Interdisciplinary Approach to an ACP Course in Academia
Patricia Bresser, PhD, RN, Associate Professor of Nursing, St. Cloud State University; Phyllis Greenberg, PhD, MA, Associate Professor of Gerontology, St. Cloud State University

5. Cultural Perspectives
Respecting Choices® as Cultural Change
Neil Rosen, JD, PhD, Program Director, Professionalism, Ethics and Humanities, Rowan University School of Osteopathic Medicine

Developing a Faith-Based Model for ACP in the African American Community
Mark Repenshek, PhD, Senior Director, Ethics Integration and Education, Ascension Health; Robert Ramerez, BS, Manager of Community Services; Julia Means, BSN, Columbia–St. Mary’s

4:30 Break and refreshments

4:45 Interest Groups

1. ACP Leaders (includes ACP Coordinators)
   Danielle Rathke, DNP, RN, ACP Coordinator, Gundersen Health System; Bernard Hammes, PhD, Director, Respecting Choices®

2. First Steps® Organization Faculty
   Kathleen Ziemba, MSW, LCSW Sr. Faculty Consultant, Respecting Choices®

3. Honoring Choices Wisconsin
   Joyce Smerick, BS, Program Coordinator and Organization Faculty, Honoring Choices Wisconsin

4. Academic
   Patrice Tadel, MSN, RN, Sr. Faculty Consultant, Respecting Choices®

Truly the best conference ever attended. The mutual sharing of experiences was invaluable. This process enables conceptualization of success stories and translation into various practice areas to promote, implement and sustain ACP.
Friday, September 9

7:00 AM  Registration and continental breakfast
7:50     Welcome
Respecting Choices® Recognition Award: Systems Redesign
8:00     Plenary Session
   Transforming an Advance Care Planning Culture: Learning from a Large Integrated System
   Dan Johnson, MD, FAAHPM, Physician Lead for Palliative Care, Care Management Institute, Kaiser Permanente; Melissa Stern, MBA, Managing Director, Supportive Care Services, Kaiser Permanente–Northern California
9:15     Break and refreshments
9:30     Concurrent Sessions
1.  ACP and the Role of the MD
   Development and Utilization of an Advance Care Planning Workshop for Physicians to Improve Their Confidence and Knowledge during Patient Encounters
   Thomas Harter, PhD, Director, Center for Bioethics, Humanities, and ACP, Gundersen Health System; Danielle Rathke, DNP, RN, ACP Coordinator, Gundersen Health System; Shola Akinshemoyin Vaughn, MD, resident, Gundersen Health System; Addison Demer, MD, resident, Gundersen Health System; Alison Gegios, MD, resident, Gundersen Health System
   Medical Students Assist in Advancing ACP Implementation and Evaluation
   Sanders Burstein, MD, Medical Director, Dartmouth-Hitchcock/Honoring Care Decisions
   Reflections on Five Years of Teaching Medical Students about Respecting Choices®
   Neil Rosen, JD, PhD, Program Director, Professionalism, Ethics and Humanities, Rowan University School of Osteopathic Medicine

The conference was an excellent opportunity to learn a wide variety of information relevant to my work. It was so energizing to meet with people from all over the country who share the same passion for Advance Care Planning.
2. **Rural Implementations**

*New Harmony Conversations: A Progressive Community-Based First Steps® Initiative that Marches to the Beat of Its Own Drum*

Kevin Valadares, PhD, Associate Professor and Chair, Health Administration, University of Southern Indiana; Karen Walker; Cindy Bernardin, Chaplain, St. Mary’s Health, Minister, St. Stephen’s Episcopal Church; Jennifer Palmer, RN, Deaconess Health System; Carol Scarafia, RN, Deaconess Health System; Vicki Campbell; David Campbell; Christine Crews; Historic New Harmony; Connie Weinzapfel; Amy Koch, Executive Director, Ford Home; Tracey Will, Director, Life Enrichment of the Ford Home; Erin Merris, Historic New Harmony

*Implementing Advance Care Planning in a Rural Community*

Sandra Carlson, MA, APRN, CNS, Program Coordinator, ACP, Director, Hospice, Essentia Health

3. **Faith-Based Implementation**

*Positive Impact Strategies for Faith-Based Communities*

Kellie Durgan, RN, BSN, Manager, ACP, Providence Health System

*The Impact of Faith & Culture on Advance Care Planning & Medical Decision Making*

James Kraft, MTh, Director, ACP and Collaborative Care, Henry Ford Health System

4. **First Steps® ACP: Special Populations**

*Just in Time First Steps® ACP with Memory Impairment and Dementia*

Kay Adams, LCSW, Clinician in Memory Clinic, Kaiser Permanente

*ACP and Vulnerable Populations: Case Study with Individual with Cerebral Palsy*

Vanessa Bablitch, MSW, APSW, Gundersen Health System; Danielle Rathke, DNP, RN, ACP Coordinator, Gundersen Health System

5. **Adolescent/Pediatric ACP Research and Implementation**

*Randomized Clinical Trials of Family Centered (FACE) ACP: Integrating Respecting Choices® Next Steps for Teens with Cancer and HIV*

Maureen Lyon, PhD, Clinical Health Psychologist, Children’s National

*ACP Implementation in the High-Risk Pediatric Population*

Jonathan Sande, MD, Director of ACP, Essentia Health

10:30 **Break and refreshments**
11:00 Workshops

1. *Respecting Choices® First Steps® Implementation in Faith Communities: New Approaches and Strategies*
   Patrice Tadel, MSN, RN, Sr. Faculty Consultant, Respecting Choices®

2. *The Unmet Need for Pediatric ACP: Opportunities and Challenges*
   Linda Briggs, MSN, MA, RN, Associate Director, Respecting Choices®; Maureen Lyons, PhD, Clinical Health Psychologist, Children’s National; Jonathan Sande, MD, Director of Advance Care Planning, Essentia Health

3. *POLST: National Update*
   Stephanie Anderson, MSN, RN, CHPN, Sr. Faculty Consultant, Respecting Choices®; Susan Hickman, PhD Professor, Indiana University School of Nursing, Co-Director of RESPECT

4. *ACP Reimbursement: How Did We Get Here and What Does It Mean?*
   Bernard Hammes, PhD, Director, Respecting Choices®; Phil Rodgers, MD, Associate Professor, Family Medicine and Internal Medicine, University of Michigan; Penny Osman Bahr, BA, CHC, CPC, CPC-I, Director of Health Solutions

5. *End-to-End Advance Care Planning for Persons Living with Chronic Disease*
   Jill Jarvie, RN, MSN, CNS, Clinical Practice Consultant, Kaiser Permanente, Northern California; Laurel March, MA, Clinical Department Director, Kaiser Permanente; Melissa Stern, MBA, Managing Director, Supportive Care Services, Kaiser Permanente—Northern California

12:15 PM Lunch provided

12:55 Respecting Choices® Recognition Award: Community Engagement

1:00 Plenary Session

*An Interim Analysis of an ACP Intervention in Nursing Homes*
Susan Hickman, PhD, Professor, Indiana University School of Nursing, Co-Director of RESPECT

2:00 Break and refreshments
2:15

Concurrent Sessions

1. **ACP Implementation: Leadership Strategies**
   *A Resource to Simplify ACP Program Design and Implementation*
   Susan Fitzgibbons, Program Manager, Honoring Care Decisions, Dartmouth-Hitchcock; Sanders Burstein, MD, Medical Director, Honoring Care Decisions, Dartmouth-Hitchcock; Jennifer McCalley, MSW, ACHP-SW, Program Coordinator, Honoring Care Decisions, Dartmouth-Hitchcock

   **ACP Coordinator: An Essential Component to an ACP Program**
   Danielle Rathke, DNP, RN, ACP Coordinator, Gundersen Health System

2. **ACP and Economics**

   *Development and Implementation of ACP Quality Indicators for an Alberta Dashboard*

   *The Importance and Application of Systematic Review Methodology Assessing the Economics of ACP*

   *Evaluating Change Management as a Strategy to Overcome Barriers*

   *Implementing ACP in a Regional Cancer Center*

   Konrad Fassbender, MD, Assistant Professor, Palliative Care Medicine, University of Alberta

3. **Last Steps® ACP Implementation**

   *Participation in a Cluster Randomized Controlled Trial on the Effects and Costs of Advance Care Planning in Elderly Care*

   Ida Korfage, PhD, Assistant Professor of Quality of Life at Erasmus MC – University Medical Center Rotterdam

   *Incorporating Advance Care Planning as Part of Routine Healthcare in a Home-Based Primary Care Model*

   Iris Boettcher, MD CMD, Medical Director, MyLife Care Planning, Spectrum Health

4. **Cultural and Faith-Based ACP**

   **ACP Communities and Faith Ambassadors**

   Chuck Orme-Rogers, MA, MDiv, ACPE Supervisor/Educator, UnityPoint Health–Meriter; Jennifer Gotto, LCSW, UnityPoint Health
Culturally Sensitive Advance Care Planning
Melissa Hale, MSW, LCSW, ACP Coordinator, ProHealth Care

3:15 Break and refreshments

3:30 Concurrent Sessions

1. ACP Implementation Strategies
   Building Community Centers of Service for ACP
   Carolyn Newsom, MBA, PhD, JD, BCHIP

   SCMA Physician Practice Innovations: An Initiative to Expand ACP
   Wilma Rice, MSN, RN, CEN, Professional Development Education Specialist, Roper St. Francis Healthcare; John C. Ropp, III, MD, MBA, FAAFP, Palmetto Family Medicine and Senior Care, Chair of the SC Coalition for the Care of the Seriously Ill

   Volunteer Facilitators: A Good Choice?
   Joyce Smerick, BS, Program Coordinator and Organization Faculty, Honoring Choices Wisconsin

2. Implementation Challenges
   Ida Korfage, PhD, Assistant Professor of Quality of Life at Erasmus MC – University Medical Center Rotterdam

   Honoring Patient’s Preferences for Care: A Systems Approach
   Scottie Gaskins, MA Ed, Sr. Administrator, Vidant Home Health and Hospice

3. The Social Worker’s Role in ACP
   Macro Level Social Work Practice and Advance Care Planning
   Mia Morrisette, MBA, CSW, ACP Coordinator, UW Health

   Learning to Facilitate Advance Care Planning: The Novice Social Worker’s Experience
   Kay Muggenberg, PhD, RN, CHPN, Associate Professor, Goldfarb School of Nursing at Barnes Jewish College on Washington University Medical Campus; Karla Washington, PhD, MSW, LCSW, Assistant Professor, Department of Family and Community Medicine, University of Missouri, Columbia; Sharon Bowland, PhD, MSW, LCSW, MSW, MPS, Assistant Professor, Eastern Washington University
Igniting the Conversation in the Community and in the Hospital
Jacqueline Dinterman, LBSW, MA, Manager, Care Management, Frederick Regional Health System

4. POLST Implementation and Catholic Concerns
Community-Based Medical Orders: Part of the Process in Catholic Health Care
Nickijo Hager, RN, MSN, VP Mission & Organizational Development, Mayo Clinic Health System

5. Next Steps Implementation
Widespread Integration and Use of Advance Directives in Acute Care Settings for Persons Engaged in Disease-Specific ACP
Rose Seavolt, BSN, RN, CCP, ACP Organization Faculty, Spectrum Health

A Comparison of Cost and Resource Utilization between First Steps® and Next Steps ACP
Thomas Harter, PhD, Director, Center for Bioethics, Humanities, and ACP, Gundersen Health System

Utilizing Technology to Promote Early Identification of Next Steps Appropriate Individuals
Melissa Revels, RN, BSN, DNP candidate, Gundersen Health System

4:30 Break and refreshments

4:45 Interest Groups

1. Last Steps® Organization Faculty
Stephanie Anderson, MSN, RN, CHPN, Sr. Faculty Consultant, Respecting Choices®

2. Respecting Choices® Instructors
Kathleen Ziemba, MSW, LCSW, Sr. Faculty Consultant, Respecting Choices®

3. Next Steps Organization Faculty
Patrice Tadel, MSN, RN, Sr. Faculty Consultant, Respecting Choices®; Linda Briggs, MSN, MA, RN, Associate Director, Respecting Choices®
Saturday, September 10

7:00 AM  Registration and continental breakfast

7:50  Welcome
Respecting Choices® Recognition Award: Excellence in Providing Leadership in Promoting Person-Centered Healthcare

8:00  Plenary Session
Building Quality in Clinical Trials: the ACTION Study
Ida Korfage, PhD, Assistant Professor of Quality of Life at Erasmus MC – University Medical Center Rotterdam

9:00  Plenary Session
Sharing the Journey of Successful Implementation of a Next Steps ACP Program
Jill Jarvie, RN, MSN, CNS, Clinical Practice Consultant, Kaiser Permanente–Northern California

10:00  Break and refreshments

10:30  Closing Session
Vision and Challenges for the Future of ACP

1. Recommendations for Optimal ACP: Results from the Delphi Study of the European Association for Palliative Care Taskforce
   Ida Korfage, PhD, Assistant Professor of Quality of Life at Erasmus MC – University Medical Center Rotterdam

2. Coalition to Transform Advanced Care and Respecting Choices®
   Brad Stuart, MD, Chief Medical Officer, Coalition to Transform Advanced Care

3. Sustainability
   Bernard Hammes, PhD, Director, Respecting Choices®

4. Strategies to Effectively Integrate ACP into Person- and Family-Centered Care
   Linda Briggs, MSN, MA, RN, Associate Director, Respecting Choices®
Appendix B: Participants and Comments

We were thrilled to have the participation of 218 individuals (both RC users and non-users) from 113 organizations. It was exciting and truly an honor to witness the passion and commitment so many have for this important work. We look forward to seeing you again!

★★★★

*It truly was one of the very best events I have ever attended, and knowing how hard it is to do a ONE-day event I am totally in AWE of you for doing this massive undertaking!!!*

★★★★

*One of the best conferences I have ever been [to]. So much great information to come home with.*

★★★★

*The conference was great and reflected the huge amount of work which was put into it!! You can all be very proud! I came away with so many notes and ideas to look at incorporating into our projects. I was only sorry that I had to leave Saturday morning and miss that day’s offerings.*

★★★★

*Thank you RC staff, the conference was wonderful.*

★★★★

*Thank you for all your team did to make this conference such a wonderful experience. Good to see you as well.*

★★★★

*What a pleasure to attend and participate in the 2016 NSTE in Milwaukee. It was nice to see you and your team as well. Putting “real” faces to names was enjoyable beyond words, one of my highlights. Relationships, right?*

★★★★

*I have come to value the quality and care all members of Gundersen Health/Respecting Choices embody.*

★★★★

*Thank you for a wonderful conference in Milwaukee.*
Thank you to everyone at Respecting Choices® for an outstanding conference!

You and your team did a phenomenal job putting on the Share the Experience Conference! You should feel super proud and I hope you can take a break and enjoy the fruits of your labor. It was actually hard for me to leave yesterday, I felt like a kid who did not want to leave the best summer camp ever! :)

A BIG thank you to you and the whole team for an excellent conference. I came away with inspiration and ideas that I can apply right away to our ACP system at Dartmouth. I hope you get some rest this week and some time to bask in the glory of your team’s big accomplishment!

What a conference!! Such an honor to participate.

Congratulations on a phenomenal conference! I can’t express how gratifying it was to see so many people from the movement in one place. Bravo.

Thank you so much for a truly inspiring conference! It really did feel like a community of colleagues, which encouraged my own enthusiasm for ACP and the RC Model. I was particularly moved by how safe it was for all presenters to talk openly about parts of our programs that didn’t go as expected or challenges we faced and what we learned from that. In medicine (or any profession), that is rare and pretty revolutionary. Can’t wait for the next STE!
Acknowledgments

We are grateful for the generous support of our sponsors who helped make this event possible.

Coalition to Transform Advanced Care
Dartmouth-Hitchcock Medical Center
Epic Systems Corporation
Gordon and Betty Moore Foundation
Honoring Choices Minnesota
The John A. Hartford Foundation
Kaiser Permanente Institute for Health Policy
New York University Langone Medical Center
Sentara Center for Healthcare Ethics

Thanks to the many people who helped make the Inaugural Summit a tremendous success. We appreciate the staff from Hyatt Regency Milwaukee, Visit Milwaukee, KSM Convention Management, and KVL Audio Visual Services for their exceptional care throughout the event. Finally, we thank our speakers for giving their time and sharing their expertise. For additional information on the Summit and to watch videos of some of the presentations, please visit www.gundersenhealth.org/respecting-choices/news-events-research/events/.

I am returning to my organization and community with many new tools and resource links to use in re-energizing our approach to ACP. I’m also encouraged by the new merger/partnership with C-TAC and the wave of the future for more awareness of the need for ACP and how to make progress in shifting focus in medical communities to a philosophy of shared decision making. Thank you!