



C-TAC At-A-Glance

The Challenge of Advanced Illness Care Today

Most Americans today are living longer and healthier lives than ever before. Yet, at some point, the vast majority will face advanced illness, which occurs *when one or more conditions become serious enough that general health and functioning decline, treatment begins to lose its effect, and quality of life increasingly becomes the focus of care—a process that continues to the end of life*. These people need and want seamless, person-centered, coordinated care that helps them live as comfortably and productively as possible. But few people are lucky enough to receive such care. Our health care system, despite its strengths, is ill-equipped to provide this kind of care when people are seriously ill. This is not a problem that can be ignored. Over the next two decades, the number of people over 65 will nearly double to more than 72 million, or one in five Americans. Most people with advanced illness will be in this age group. Without change, they will be at higher risk for unnecessary hospitalizations and unwanted treatment, adverse drug reactions and conflicting medical advice, with resulting higher cost-of-care to families and the nation. It doesn't have to be this way.

Our Guiding Principle

The Coalition to Transform Advanced Care (C-TAC) is dedicated to the ideal that *all Americans with advanced illness, especially the sickest and most vulnerable, receive comprehensive, high-quality, person- and family-centered care that is consistent with their goals and values and honors their dignity*. We will achieve this by empowering consumers, changing the health delivery system, improving public and private policies, and enhancing provider capacity.

How C-TAC Drives Change

As a large and growing alliance of over 100 national organizations and leaders, C-TAC creates, supports and promotes the use of proven solutions to drive positive change in advanced illness care. We see our role as a catalyst for the expanding movement across America to make things better.

C-TAC is a non-profit, non-partisan organization based in Washington, D.C. Members include: patient and consumer groups; health care professionals and providers; private sector stakeholders; faith-based organizations; and health care payers.

Our Priorities

Using our strategic plan as our guide, C-TAC works with our members and others across four integrated focus areas: policy and advocacy; public engagement; clinical models; and professional engagement. Among our priority programs are:



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Delivery System Innovation

➤ **Advanced Care Project (ACP)**

ACP is a partnership between the AHIP Foundation's Institute for Health Systems Solutions (IHSS) and C-TAC to identify, analyze, and compare best practice clinical models for advanced illness care management and to promote the results of this work to health care systems and others across the United States. We are complementing this work by outlining the key components of payment models that align financial incentives and encourage best practices. The goal is to make "the *right* way the *easy* way" for hospitals, health systems, physician groups, and health plans, as well as nursing homes, hospices, and community-based organizations in order to provide high-quality care for patients and families living with advanced illness.

Transforming Patient-Provider Interaction

➤ **Shared Decision Making**

Working with The Advisory Board Company, C-TAC has undertaken research to establish a baseline understanding of how care and treatment decisions among clinicians, patients and families are made, and how informed and shared decision-making among these participants can be improved. The next step is to convene experts to review the research and determine how to better integrate shared decision-making into care. Once this is established, we intend to promulgate this model to health professionals and public audiences.

➤ **CareJourney**

Patients and their families and caregivers crave information about serious illness, whenever it occurs. Today, the health system is often difficult to navigate, and people must search many diverse sources to get the information they need. To fill that void, C-TAC developed CareJourney—a consumer-based website aimed at helping patients and their caregivers understand their diagnoses, what they mean for the future, and how to plan for their the medical, financial and spiritual components of their care and caregiving. Visit www.carejourney.org for additional information.

➤ **Community Action Model**

C-TAC's alliance of faith leaders and others are piloting a replicable, community-based model to improve the quality of life for patients with advanced illness and for family caregivers. The goal is to extend and strengthen the health care delivery system, improve outcomes for people with advanced illness, reduce caregiver burden and reinforce community support for advanced illness care. This project is being piloted in Alameda County, California. Future sites may include Detroit, Washington, D.C., and others. As part of this initiative, a toolkit for community outreach is being developed. Ultimately, this work will be integrated with our best practice clinical models and will be extended throughout the United States.



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Policy Development and Implementation

➤ **Policy Agenda**

C-TAC developed a Policy Framework (http://www.thectac.org/wp-content/uploads/2015/02/C_TAC-Policy-Agenda.pdf) that describes the barriers in current law to higher-quality advanced illness care delivery and the issues that must be addressed in order to overcome those barriers, including: advance care planning; health information technology; consumer education and caregiver support; professional education; quality measurement; payment reform; research; and, other areas. C-TAC is working closely on a bipartisan, bicameral basis with congressional leaders in order to raise awareness and to support federal and state policy efforts. In addition, we developed an Advanced Illness Policy Review, providing an in-depth look at the specific federal policy measures introduced and considered in the past decade. Now, we have taken the next step: a comprehensive Policy Agenda that will help guide and direct federal and state advocacy initiatives across the country.

Raising National Awareness

➤ **Measuring Progress**

Two sets of metrics are being developed to assess progress. The first is a consumer baseline to determine current public perceptions and reported behaviors regarding advanced illness/end of life issues. This baseline will be used to assess progress and effectiveness in public engagement and information efforts. The second, called metrics of success, is a full array of measures of the overall progress being made in improving advanced illness care, including care utilization and quality, patient and family satisfaction, cost of care, and other components. Both these projects are underway, and funding and partnerships are being sought to implement them.

➤ **Institute of Medicine Report**

In September 2014, the Institute of Medicine (IOM) released its first report and recommendations in 17 years on advanced illness/end of life issues in America. *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life* marked a critical milestone in the evolution of how we care for the sickest and most vulnerable people in this country. C-TAC promoted the IOM report's findings, including a panel discussion at our annual meeting last November, and is advocating for the adoption of the report's recommendations. Victor Dzau, MD, President of the IOM, will also discuss the report at the National Summit on Advanced Illness Care. We will continue to work with IOM to identify new ways to distribute the report and supporting materials.

➤ **Member Meeting**

C-TAC's annual Member Meeting was held November 18, 2014 in Washington, D.C. at AARP. Serving in our role as a convener and catalyst for the advanced care movement, our members reviewed the state of advanced illness care, progress achieved, and areas where more action is



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needed. A number of the initiatives listed above were presented and discussed among members at this event.

➤ ***“A Roadmap for Success: Transforming Advanced Illness Care in America” – A Blueprint for Transforming Advanced Illness Care in America***

This new book provides an understanding of the key issues, challenges, and solutions needed for reform; builds on the shared mission in the national movement for change; identifies action steps for achieving high-quality, advanced illness care; and, provides a call to action. It is directed to the professional community: clinicians, public health executives, health care companies, policy analysts, policy makers, faith leaders, academics and other thought leaders. It is available in print now and will be available online in March 2015. Authors of “*The Roadmap for Success*” are experts from C-TAC’s member organizations. For further information or your own copy, contact Meagan Johnston at mjohnston@thectac.org.

➤ **2015 National Summit**

C-TAC’s second National Summit on Advanced Illness Care: *Driving change through Leadership, Evidence, and Action* will take place March 2-3, 2015, at the National Academy of Sciences building in Washington, D.C. The 2015 Summit focused on evidence-based solutions and metrics for person-centered advanced illness care; policy reform, public engagement and shared and informed decision-making; research priorities, the value of comparative effectiveness research, and strategies to close critical gaps in the evidence base. For further information, contact jbuate@thectac.org.

Follow Up with C-TAC

For further information, visit www.thectac.org. To discuss any of the issues and topics above, please contact Meagan Johnston at mjohnston@thectac.org.

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Priority Initiative – The Policy Agenda

The development and implementation of federal and state policies is critical to improving and sustaining innovative, high-quality, and well-coordinated advanced care delivery.

To achieve comprehensive reform, C-TAC has identified barriers in current law to improving advanced care delivery, examined those barriers vis-à-vis successful sector care innovations, and developed a consensus-based Policy Agenda to advocate for high-quality, person-centered advanced care for all Americans. The following initiatives were undertaken as the foundation of the Policy Agenda.

- ✓ **C-TAC Guiding Principles (Spring 2012).** The C-TAC Policy & Advocacy Workgroup initially developed a set of principles to align and guide the efforts of not just the Workgroup, but the entire Coalition.
- ✓ **Policy Framework (Spring 2013).** The Workgroup developed a comprehensive policy framework that identifies the key barriers to improving advanced care delivery and examined options to remove those barriers.
- ✓ **Policy “Compendium” (Fall 2013).** While identifying policy options to address these barriers, we compiled a desk reference guide of current policies that have been introduced in the past five sessions of Congress, entitled *Advanced Illness Policy Review: The Landscape for Improving Advanced Illness Care in America*.
- ✓ **Policy Survey (November 2013).** Following the release of the Policy “Compendium,” Workgroup members ranked each policy option by level of priority and support before initiating the Policy Agenda.
- ✓ **Policy Outline (Spring 2014).** To create the Policy Agenda, the Workgroup prepared a consensus-based guide to advanced illness public policy using the results from the Policy Survey.
- ✓ **POLICY AGENDA (January 2015).** The comprehensive federal Policy Agenda was released to the entire membership. This document will guide and inform C-TAC’s advocacy efforts moving forward.

Policy Agenda

The Policy Agenda reflects the expertise of dozens of key experts and individuals from the Policy & Advocacy Workgroup, the Advanced Care Project (ACP), and the Community Action Project. As findings from these priority projects are released, the Policy Agenda will be further enhanced and refined.

Our Coalition and its members have consistently served as a substantive resource for leaders on the Hill and in the Administration. C-TAC will focus on disseminating the Policy Agenda and supporting policy reforms that align with our mission to transform advanced care across the United States. We invite your comments and participation in advocating for the Policy Agenda going forward.



**C-TAC and AHIP Foundation's Institute for Health Systems Solutions:
Advanced Care Project**

*The **Advanced Care Project** is a national collaboration among health plans, health systems, a range of clinicians and related organizations, community-based groups, and other stakeholders to identify, analyze and implement best practice clinical care models to improve care for patients and families living with advanced illness. Major goals of the project include encouraging the implementation of models based on evidence, continued assessment, and scale and replication.*

The Challenge

There are a number of advanced illness care models that improve the quality of life for patients and their families—and offer better, higher quality, and more cost-effective health care. Unfortunately, these innovative models and interventions are often isolated across current siloes, such as the care setting or stage of diagnosis, rather than integrated across the advanced illness continuum. Other barriers, including varied reimbursement methods and complex eligibility criteria, have also played a role in preventing broader application.

Toward a Solution

In order to help address the issues affecting our current health system, the AHIP Foundation's Institute for Health Systems Solutions (IHSS) and the Coalition to Transform Advanced Care (C-TAC) have formed a partnership—**The Advanced Care Project (ACP)**—to improve care for patients with advanced illness and their families.

The ACP brings together a select group of health plans, employers, health systems and clinicians to:

- Sustain the delivery of quality, evidence-based person-centered care for those with advanced illnesses.
- Build a bridge from the current fee-for-service reimbursement for advanced illness care to shared-risk, shared-savings, and accountable care with a focus on encouraging integration of care across acute, post-acute, and long-term care settings.

Becoming Involved

Participating organizations will have the opportunity to:

- Lead the development of a national advanced care model.
- Access latest thinking and best practices for advanced care.
- Network with other pioneering organizations.

The ACP was launched in 2014 with support from the Commonwealth Fund & project participants. The ACP continues today with participants convening throughout the year. For 2015, significant focus is being given to payment model and measurement development to help enable successful implementation of advanced care programs.

About the AHIP Foundation's Institute for Health Systems Solutions: The AHIP Foundation is a non-profit, non-partisan 501(c)(3) organization. Its Institute for Health Systems Solutions' mission is to advance solution-based, forward-looking, collaborative ideas and thought leadership focused on health systems change that improves the quality, affordability, and availability of care and puts the health care system on more sustainable financial footing. For more information, visit: <http://www.healthsystemssolutions.org>.

About the Coalition to Transform Advanced Care: C-TAC is a non-profit, non-partisan alliance of patient and consumer advocacy groups, health care professionals and providers, private sector stakeholders, faith-based organizations and health care payers. Its mission is to transform advanced illness care by empowering consumers, changing the health delivery system, improving public and private policies and enhancing provider capacity. <http://www.theCTAC.org>



Priority Initiative – Community Action Project

The Challenge:

The faith-based community presents an important opportunity for C-TAC to help further our mission of providing people with advanced illness with the right care at the right time and place. Specifically, we know that:

- Clergy want and need training and information to help their congregants deal with advanced illness and the particular and overwhelming challenges that come with such diagnoses.
- Community organizations (faith-based and others) are a critical resource for helping ill persons and their families get the care they need. Not only do they often help underserved populations, they also have a long history of developing effective solutions to addressing critical unmet needs.
- Many local health systems have advanced illness management programs, but no reliable ways to communicate with hard-to-reach populations.

The C-TAC Response:

C-TAC is developing the community action project to bring together health systems and community-based organizations to improve advanced illness care. The project's three main objectives are:

- ✓ Foster partnerships to improve communications and trust between health systems and community organizations to fill critical gaps in care delivery;
- ✓ Give each partner the proper tools and knowledge necessary to help ill persons ask for and receive the kind of care they want and need; and
- ✓ Help health systems deliver existing advanced illness management programs to an underserved population of ill persons and their families.

C-TAC's draft framework consists of four key elements: 1) a community-specific needs assessment; 2) a meeting involving ill persons and caregivers, community organizations, and health systems; 3) necessary technical assistance (e.g., action plan, communications, education on advanced illness, etc.); and, 4) a resource sharing tool designed to facilitate the exchange of best practices from our member organizations. As the community action project continues to evolve, this framework will change to reflect lessons learned.

Next Steps

C-TAC is working to operationalize the community action program so that it can be easily replicated in any community. We are developing evaluation tools, as well as outcomes and impact measures aligned against the program's goals. We will also assist with developing a plan for partnership sustainability. The Alameda County Care Alliance (ACCA) is a pilot of the program underway in Alameda County, California; for more information on the ACCA, contact Rev. Cynthia Carter Hill, Executive Director, ACCA at chillc123@gmail.com. Future collaborations are planned in other regions. For more information on C-TAC, contact Jackie Buente at JBuente@thectac.org.