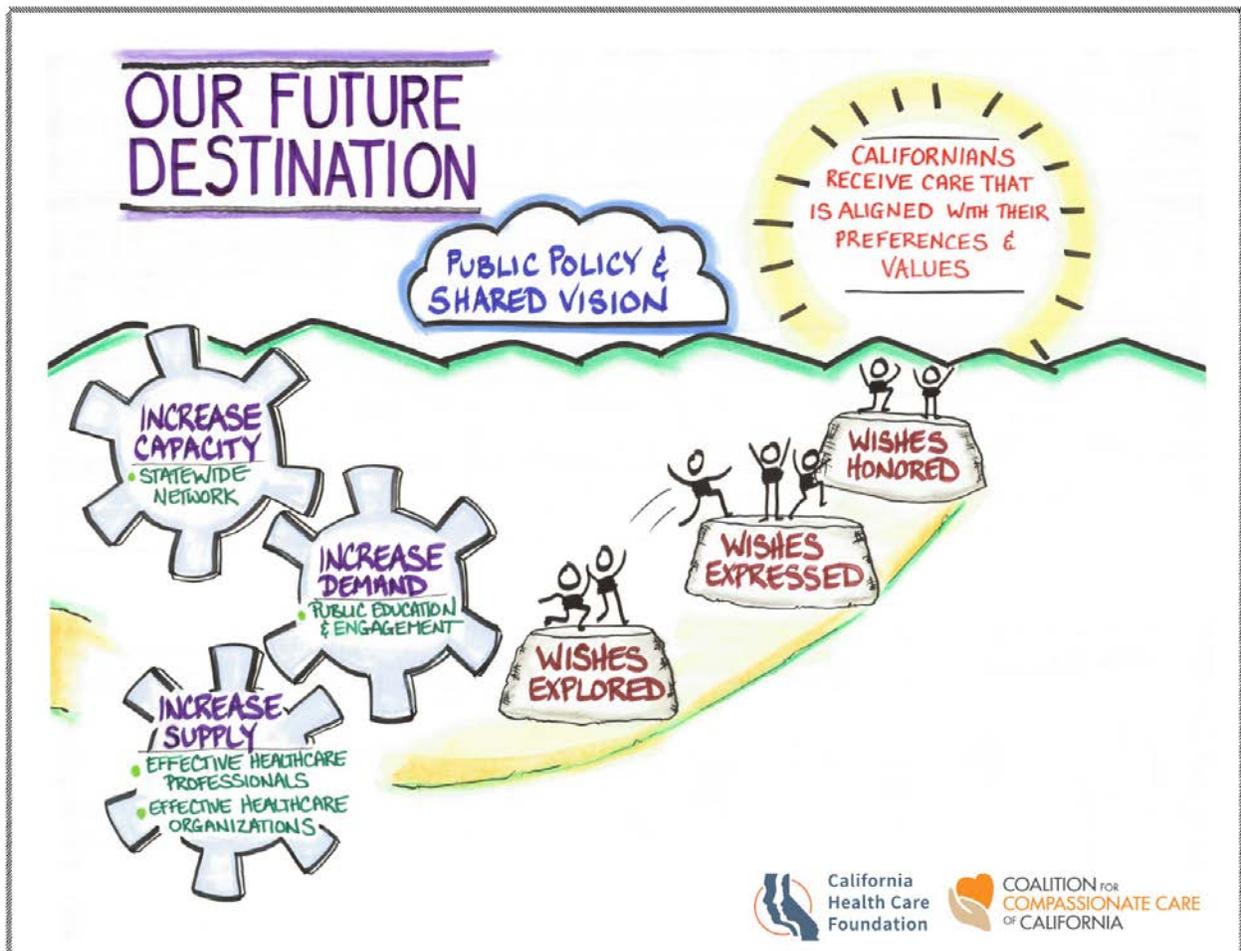


The Road Ahead for Serious Illness Care in California (and locally)

A Toolkit for Engaging Your Community, Strategizing and Action Planning



March 2017

**THE ROAD AHEAD FOR SERIOUS ILLNESS CARE:
CCCC's 10-Year Vision for California**

To transform health care in California so that medical care is aligned with individual patients' preferences: People get the care they need and no less; the care they want and no more

In 10 Years....

- The demand for high-quality care for serious illness will be widespread
- *Individuals and communities* will engage in conversations about care for serious illness as a normal activity where people live, learn, work, play and pray.

In 10 Years....

- *Healthcare professionals* will be competent and comfortable talking with patients about goals of care and treatment preferences, and will skillfully guide them to receive the care they need and want.

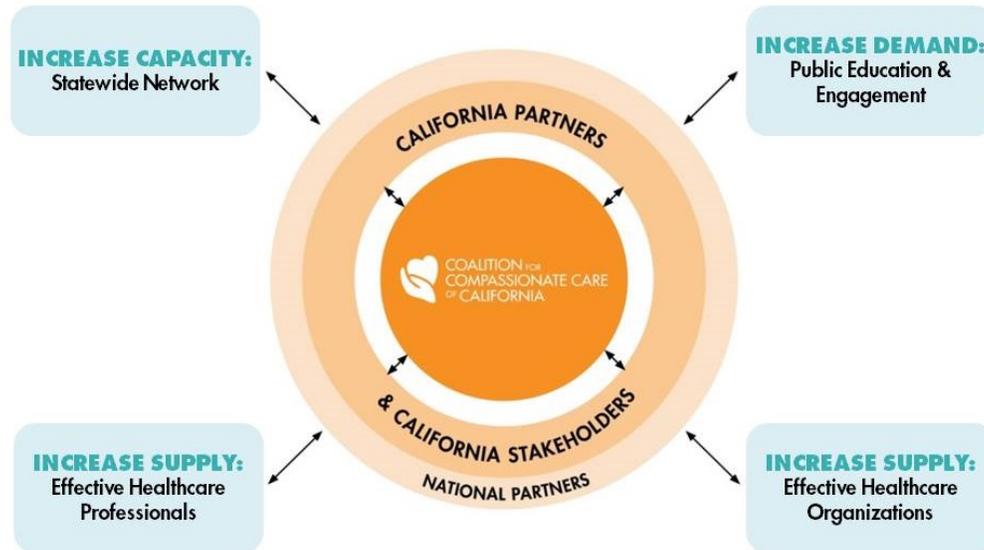
In 10 Years....

- *Healthcare organizations* will increase access to palliative care, make advance care planning conversations a consistent part of care, and ensure that patient wishes are honored at the end of life.

In 10 Years....

- *Public policy and provider reimbursement* will support these conversations
- Documentation of preferences will be shared across the care continuum

**THE ROAD AHEAD FOR SERIOUS ILLNESS CARE:
CCCC's 10-Year Vision for California**



THE ROAD AHEAD FOR SERIOUS ILLNESS CARE: Convener's Guide

Introduction

On October 31, 2016, more than seventy leaders from around California convened in Sacramento for "*The Road Ahead for Serious Illness Care in California*" – a daylong conversation hosted by the Coalition for Compassionate Care of California (CCCC) and the California Health Care Foundation (CHCF) on the topic of serious illness care in California. Attendees represented a wide range of stakeholders, including healthcare professionals, organizations, policymakers, academics, patients and more. The day provided an opportunity for participants discuss progress, gaps and opportunities related to serious illness care in our state. It was an ambitious day to help pave the way for the road ahead, working collaboratively to achieve a shared vision and agenda for living well with serious illness in California.

Bringing the work of *The Road Ahead* to your local community will allow you to build on the accomplishments of the statewide convening and move into local-level strategy that is specific and action-focused. You will address both the "what" and the "how" of improving serious illness care in your area while strengthening relationships and building collaboration. *The Road Ahead* also provides an excellent way to reinvigorate an existing coalition or to jump-start a new one.

The Road Ahead convening will support your local efforts by:

- Engaging community leaders from across stakeholder organizations
- Leveraging the rich findings from the statewide meeting to assess local needs and jump-start local action
- Providing a framework for people to organize into work groups or activate a coalition
- Gathering ideas for how the Coalition for Compassionate Care of California can support your local work

The Road Ahead Toolkit includes:

- This Convener's Guide with event organizing tips
- The graphic illustration files from the original event for printing as handouts or posters
- A Facilitator's Agenda

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- A customizable PowerPoint slide show
- A local assessment tool built on key findings from the state meeting
- An action plan template
- An event evaluation form

Using CCCC's *The Road Ahead* Materials

The materials from the statewide gathering have been adapted to make them easy to use in local settings. They can be further revised to suit your local community's needs and interests. The goal is to hold an event with content, activities, and outcomes that are as relevant as possible for your community while also building connection to the larger statewide network. You may rebrand the materials with local coalition or other event host or sponsor names, but please also credit CCCC and CHCF in your materials.

The Road Ahead presents and builds on findings from the 2015 *Dying in California* report, which was based on the 2014 publication *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life*, from the Institute of Medicine. To review these reports, please visit the webpage for the Road Ahead Toolkit on the CCCC website coalitionccc.org/road-ahead-toolkit.

Attracting influential people to your event

The purpose of *The Road Ahead for Serious Illness Care* is to bring together people who have the ability to advance progress within their work setting or network, either as "doers" or "influencers." Including representatives from a diversity of organizations ensures a variety of perspectives and expands opportunities for collaboration. In addition to those directly involved with serious illness care, consider inviting leaders from organizations whose mission overlaps with serious illness, including foundations, academics, faith leaders, community clinic providers, seniors' services providers, health communications experts, and patients. Involving key leaders from the beginning, either with a phone call to solicit their input or an invitation to a planning meeting, helps them invest in the success of the event. Key organizations can act as event co-sponsors, providing the meeting venue, meals, or other material support, as well as help with hosting and facilitating the meeting.

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Planning your event

Plan and organize the event in the way that best engages the stakeholders in your area and suits your resources. Below are general suggestions for creating an effective event.

1. **Consider convening an event planning team**

A planning meeting with key leaders will build buy-in, increase participation, and ensure that content and logistics reflect the interests of these agencies. The goals of the planning process are to:

- Agree on goals and outcomes for the convening
- Identify stakeholders and create a list of invitees. A group of at least 25-30 will ensure a good exchange of ideas; larger groups work well too.
- Assign key event roles, including a coordinator, event hosts and sponsors, and facilitators for the meeting.
- Decide on the budget, venue, date, and time
- Determine how and when invitations will go out

2. **Create a plan for following up on resulting goals and next steps**

At the local level, *The Road Ahead* ideally will result in clear goals, priorities, and action steps. Subsequent follow-through will require on-going participant engagement and accountability. If you have an existing local coalition, event follow-up can be integrated into the coalition's agenda. If you want to start a coalition, forming work groups around the meeting action plan is a good way to get things rolling. If you are operating outside of a coalition model, the planning team or an ad hoc leadership group can be tasked with coordinating follow-up. Whatever mechanism you decide on, make sure that the follow-up process is clearly reflected in the implementation and wrap-up sections of the meeting so that everyone leaves with a clear understanding what to expect. (See the Facilitator's Agenda.)

Hosting your event

Schedule

The original *The Road Ahead* was a 6-hour event held from 8:30 am to 2:45 pm with 30 minutes of networking at the beginning, a 45-minute lunch, and a 15-minute afternoon break. The Facilitator's Agenda included in this kit is adapted from the state meeting and

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totals 5 hours and 5 minutes. It does not include lunch, which can be added. If needed, trimming off some agenda items or reducing the amount of time allocated to each activity can shorten the event.

Setting

The Road Ahead is designed around participant interaction and input. Since much of this activity takes place in small groups, a setting with multiple tables that seat 4-8 people each is ideal. If that is not possible, choose a venue with enough space for separating breakout discussion groups.

Roles for the day of the event

You will need at least one primary host/meeting facilitator, a meeting scribe, and at least four facilitators to elicit, record, and report on group discussions from breakout discussions.

After your event

Feedback from your event helps CCCC support your local efforts to improve serious illness care and strengthens our statewide network.

We encourage you to complete our event convener's feedback form. Please send us: (a) the feedback form; and (b) the results from your discussion group surveys on how CCCC can best support local work. You may also contact us with any questions about the Toolkit. Mail or email to:

Suzanne Richards

Coalition for Compassionate Care of California
1331 Garden Highway, Suite 100 Sacramento, California 95833
(916) 993-7737
srichards@CoalitionCCC.org



THE ROAD AHEAD FOR SERIOUS ILLNESS CARE: Facilitator's Agenda

[Insert date, time]

(Additional presenter talking points are included in the PowerPoint presentation)

Goals for the day

1. Assess progress, gaps, and opportunities in serious illness care in our community
2. Strengthen relationships and collaboration
3. Create a shared vision for the future
4. Define and prioritize next steps for local action

TIME

SUBJECT

00:00-00:00 Welcome, Introductions & Setting the Stage
(10 min)

- Purpose and objectives for the gathering
- Introductions: Name, organization, role, and one thing you'd like to leave with

00:00-00:00 The Road We've Been On— California *(Presentation)*
(20 min)

- Background: Fall 2016 Convening in Sacramento - Gathered leaders to look at "The Road Ahead for Serious Illness Care in California"
- Anniversary of 2015 *Dying in California* report, based on the seminal IOM *Dying in America* report
- Review overall findings from *Dying in California* report
- Review four central focus areas:
 - **Topic 1: Delivery of Care**
 - **Topic 2: Clinician-Patient Communication & ACP**
 - **Topic 3: Professional Education & Development**
 - **Topic 4: Public Education & Engagement**

Note that policy and payment systems were an additional focus area in the IOM report, but are interspersed throughout these four focus areas

THE ROAD AHEAD FOR SERIOUS ILLNESS CARE: Facilitator's Agenda

00:00-00:00 The Road We've Been On— Our Local Accomplishments (*Small group activity*) (35 min)

- Introduce the activity: The goal is to take time to capture and acknowledge local progress. There will be 20 minutes for small group discussion.
- Make sure there is a designated scribe (or have a facilitator at each table)
- Direct participants to go around their table and each take a few minutes to share what they think are some of the most important local strengths and accomplishments in any of the above four topic areas.
- Have each group choose a person to report back to the full group. Have a meeting scribe capture accomplishments on a central flip chart visible to the full group. (15 minutes)
- **Note:** *have handouts with copies of the graphic illustration posters on each table*

00:00-00:00 Visioning: The Road Ahead (*Presentation followed by discussion*) (35 min)

- Presentation: Review of CCCC's 10-Year Vision for California
- Small group discussion (at tables or in breakout groups of 4-5).
 - Have participants discuss the question: *What is our local version of this vision? What would you change or add to make these points as relevant as possible to our local needs and goals?*
 - Make sure there is a designated scribe (or have a facilitator at each table)
 - **Note:** *Each table will have handouts of the CCCC 10-year vision.*
- Have each group report back to full group after 15 minutes of discussion.
- Take another 10 minutes to have a note-taker capture comments from all groups on a central flip chart visible to the full group.
- **Note:** *Flip chart pages can be prepared in advance to mirror the topics covered in the CCCC vision handout.*
- Full group discussion: Take another 10 minutes to see if the full group can arrive at consensus on a shared vision. (Consensus is not essential.)

THE ROAD AHEAD FOR SERIOUS ILLNESS CARE: Facilitator's Agenda

00:00-00:00 Break (15 Minutes) [Can be longer to accommodate a lunch break]
(15 min)

00:00-00:00 Assessing Gaps and Opportunities (*Breakout exercise*)
(60 min)

- Introduce the activity: *The Road Ahead* gathering in Sacramento resulted in a compilation of ideas and recommendations for furthering progress in each of the four topic areas. We are going to use these ideas as a jumping-off point for assessing local needs and opportunities and moving into action steps.
- There will be two, 30-minute facilitated "discussion circles."
- Participants are to choose the two topics of highest interest/relevance to their work. They will spend 30 minutes at one topic table and then rotate at the 30-minute mark to the second area of their choice.
- (**Note:** *Assign prepared facilitators for each of the four topic areas in advance. Facilitators will stay at the topic table; participants will rotate. The topic area posters or a sign designating the topic should be posted at each table for easy identification. Facilitators will have copies of the "Assessing Needs and Opportunities" tool for their designated topic areas at their table. Each table will also have copies of "Ideas for Support from CCCC."*)
- 1ST Rotation = 00:00-00:00; 2nd Rotation = 00:00-00:00

Topic 1: Delivery of Care- Name of facilitator

Topic 2: Clinician-Patient Communication & ACP- Name of facilitator

Topic 3: Professional Education & Development - Name of facilitator

Topic 4: Public Education & Engagement- Name of facilitator

Note: *remind participants that policy and payment systems can fall within these topic areas as well*

- Using the "Assessing Needs and Opportunities" tool, facilitators will guide participants to 1) Discuss where the greatest needs and opportunities are in their local serious illness care network (adding items if they are not

THE ROAD AHEAD FOR SERIOUS ILLNESS CARE: Facilitator's Agenda

already listed) and 2) Choose the top four and brainstorm action steps to address each one.

- **Note:** *Facilitators will remind participants that action and implementation depend on people's willingness to do the work involved. Encourage people to be thinking in terms of actions they are willing to lead or help with.*
- Each group will also spend a few minutes prioritizing from the list of "Ideas for Support from CCCC"

00:00-00:00 Report-Out on Needs and Opportunities (40 min)

- The event host will call on each of the facilitators to present a summary of the "Top 4 Needs & Opportunities and Actions" from each of the four topic areas and the "Ideas for Support from CCCC"
- A note-taker will record the findings on a central flip chart visible to the full group.
- **Note:** *Pages with the four topic titles should be prepared in advance. There will likely be more than four top items when input from both groups is combined. Eliminate duplicates. Some of the results may be similar enough to combine across topics. (Four is not a magic number; it is fine for groups to choose more than four priority items. It comes down to whatever the group decides is realistic for implementation.)*
- **Note:** *Please set aside the input for CCCC and assign someone to send it to back to CCCC along with evaluation form(s)*

00:00-00:00 Break (10 Minutes) (10 min)

00:00-00:00 Implementation of Next Steps (Full group discussion) (40 min)

- Using the lists of action steps in each of the four areas, determine if there are participants who want to take the lead in coordinating an implementation process for specific areas of action. Depending on the item, implementation actions can include:

THE ROAD AHEAD FOR SERIOUS ILLNESS CARE: Facilitator's Agenda

- Convening a work group with other participants who want to be involved
- Initiating a work process within their organization
- Sending out a survey to gather additional needed information on the action
- Volunteering to add the item to the agenda of another related meeting
- **Note:** Use the "Action Plan" template for recording this information so that it can be shared with all participants after the meeting.
- If there is a shortage of people offering to help with follow-up, have the group go through another polling process to prioritize a total of three or four actions from all of the topic areas. (Have each person choose his or her top three or four. Then have a show of hands for each and go with the top vote-getters.) These items can then be used to focus the efforts of the coalition or others who will be doing follow-up. **The goal is to come away with at least a few concrete next steps with accountable parties and timeframes.**

00:00-00:00 Wrap-up (40")

- Thank you for your participation!
- We will be in touch
- Please complete an evaluation

**THE ROAD AHEAD for SERIOUS ILLNESS CARE
ACTION PLAN**

What	How	Who	By When

**THE ROAD AHEAD for SERIOUS ILLNESS CARE
ACTION PLAN**

What	How	Who	By When

THE ROAD AHEAD FOR SERIOUS ILLNESS CARE: Identifying Needs and Opportunities

DELIVERY OF CARE

- Break down silos and improve communication among intersecting providers
- Address the disconnect between community-based and hospital-based programs
- Identify and disseminate local common practices/ best practices
- Create opportunities to learn from each other (cross-training and cross-learning)
- Standardize PC/ACP/EOL terminology and components for providers and patients (e.g. palliative care; DNR vs. comfort care; PC vs. AIM vs. hospice)
- Make it routine to prospectively identify patients needing PC and standardize care
- Implement quality control with POLST training and POLST conversations – some doctors don't trust that the conversations were done well and therefore disregard the forms
- Address service disparities by recognizing/including diverse populations and perspectives
- Be inclusive of all ages (include pediatrics)
- Partner with patient navigators
- Other local needs or opportunities:

**THE ROAD AHEAD FOR SERIOUS ILLNESS CARE:
Identifying Needs and Opportunities**

DELIVERY OF CARE - TOP FOUR NEEDS/ OPPORTUNITIES

1. Need/Opportunity:

Action:

2. Need/Opportunity:

Action:

3. Need/Opportunity:

Action:

4. Need/Opportunity:

Action:

THE ROAD AHEAD FOR SERIOUS ILLNESS CARE: Identifying Needs and Opportunities

CLINICIAN-PATIENT COMMUNICATION

- Bring care conversations further upstream; build ACP into workflow
- Involve the patient from the point of diagnosis onward
- Agree upon and use common, user-friendly terminology for both providers and patients
- Improve understanding of what to expect down different care paths, e.g. hospice
- Develop messages and communication tools appropriate for different patient populations
- “Broaden the bench” - educate a wider diversity of communicators to normalize the conversation
- Attend to cultural differences and nuances as well as limited English-language proficiency
- Other local needs or opportunities:

**THE ROAD AHEAD FOR SERIOUS ILLNESS CARE:
Identifying Needs and Opportunities**

CLINICIAN-PATIENT COMMUNICATION -TOP FOUR NEEDS/ OPPORTUNITIES

1. Need/Opportunity:

Action:

2. Need/Opportunity:

Action:

3. Need/Opportunity:

Action:

4. Need/Opportunity:

Action:

THE ROAD AHEAD FOR SERIOUS ILLNESS CARE: Identifying Needs and Opportunities

PROFESSIONAL EDUCATION AND DEVELOPMENT

- Improve providers' understanding of who would benefit from PC
- Partner with state and local medical associations to define and implement PC training standards and competencies
- Provide training across the continuum of care (nurses, social workers, chaplains, etc.)
- Agree on a training product (e.g. Vital Talk, CSU Institute for Palliative Care, ACP Decisions, Ariadne Labs) and adopt it as a local standard
- Clarify role of APNs and PAs (on POLST as well as more generally)
- Better define primary palliative care and disseminate those skills
- Create opportunities for PC specialists to model to other providers what PC is
- Enhance/promote current training and education opportunities; provide CEUs
- Educate administration and management – not just clinicians – to get their buy-in to the need for professional development and training
- Other local needs or opportunities:

**THE ROAD AHEAD FOR SERIOUS ILLNESS CARE:
Identifying Needs and Opportunities**

PROFESSIONAL EDUCATION AND DEVELOPMENT - TOP FOUR NEEDS/ OPPORTUNITIES

1. Need/Opportunity:

Action:

2. Need/Opportunity:

Action:

3. Need/Opportunity:

Action:

4. Need/Opportunity:

Action:

THE ROAD AHEAD FOR SERIOUS ILLNESS CARE: Identifying Needs and Opportunities

PUBLIC EDUCATION AND ENGAGEMENT

- Educate the community about palliative care - make it simple: “ask your doctor about palliative care.”
- Create a standardized and consistent message for use publicly and in all service settings
- Collaborate in coordination of messaging and dissemination of information to the public
- Start the conversation early, e.g. “death ed.” in high school
- Connect and engage with natural allies such as faith-based organizations, financial advisors, and elder law community
- Increase education and outreach to diverse populations
- Find ways to engage local funding for public education and outreach efforts
- Other local needs or opportunities:

**THE ROAD AHEAD FOR SERIOUS ILLNESS CARE:
Identifying Needs and Opportunities**

PUBLIC EDUCATION AND ENGAGEMENT- TOP FOUR NEEDS/ OPPORTUNITIES

1. Need/Opportunity:

Action:

2. Need/Opportunity:

Action:

3. Need/Opportunity:

Action:

4. Need/Opportunity:

Action:

THE ROAD AHEAD FOR SERIOUS ILLNESS CARE: Identifying Needs and Opportunities

- Assist with developing a common language; assist with defining palliative care
- Help establish quality metrics and standards for PC
- Support local efforts/coalitions and serve as resource center
- Create a comprehensive inventory and “warehouse” of training resources, including primary and specialty PC training slots, training programs, and resources
- Identify successful PC models
- Develop outreach resources targeted to specific community settings (like the existing CCCC resource for faith-based leaders)
- Help identify and improve PC revenue streams
- Engage with DPH and other senior level agencies to disseminate information and coordinate campaigns
- Invite payers and funders to the table
- Leverage existing policy efforts and progress
- Coordinate messaging around new/recent legislation leverage
- Promote integrated palliative care
- Other forms of support from CCCC

TOP FOUR IDEAS FOR SUPPORT FROM THE COALITION FOR COMPASSIONATE CARE OF CA

- 1.
- 2.
- 3.
- 4.



**THE ROAD AHEAD FOR SERIOUS ILLNESS CARE:
Participant Evaluation**

	Strongly Agree	Somewhat Agree	Somewhat Disagree	Strongly Disagree
Meeting Objectives				
1. The meeting increased my knowledge of progress, needs, and opportunities related to serious illness care in our community.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. The meeting helped create a shared vision for serious illness care in our community.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. The meeting helped identify and prioritize actions to improve serious illness care in our community.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. The meeting helped me to strengthen my connections to others working to improve serious illness care.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5. The meeting motivated me to participate in collaborative efforts to improve serious illness care in our community.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6. The meeting met my professional goals.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7. I would like to see more meetings like this in the future to increase collaboration around serious illness care in our community.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8. What part of the meeting did you find most useful?				
9. What part of the meeting did you find least useful?				
10. What suggestions do you have for improving this meeting?				



**THE ROAD AHEAD FOR SERIOUS ILLNESS CARE:
Post-Event Survey for Local Event Convener**

- 1. In your opinion, was this a successful event? Why or why not?**

- 2. Who were your partners or co-sponsors for The Road Ahead?**
 - a. What was their role in the event?

 - b. Had you collaborated with them before?

- 3. How successful were you at attracting to your event the people you hoped would attend? Do you have any advice for future hosts on attracting the desired stakeholders?**

- 4. How closely did the stated goals for the local convening of *The Road Ahead* align with your local goals?**

- 5. How well would you say this event helped you reach your goals?**

- 6. Did you have any additional outcomes you were hoping to achieve? If yes, please explain.**

- 7. What themes or topics, if any, seemed most important for your participants?**



**THE ROAD AHEAD FOR SERIOUS ILLNESS CARE:
Post-Event Survey for Local Event Convener**

8. How would you rate the following *The Road Ahead* toolkit resources in helping you host a successful event? (Please rate each on scale of 1-5, with 5 being the most helpful)
- a. ____ The convener's guide with event organizing tips
 - b. ____ The graphic illustrations for printing as handouts or posters
 - c. ____ The facilitator's agenda
 - d. ____ The PowerPoint slides show
 - e. ____ The local assessment tool built on key findings from the state meeting
 - f. ____ The action plan template
 - g. ____ The event evaluation form
9. Do you have ideas or suggestions for others who may be planning a local *The Road Ahead for Serious Illness Care* gathering?
10. Do you have any advice for CCCC on promoting and supporting these kinds of local events?