

Crisis Standards of Care

A Systems Framework for
Catastrophic Disaster Response

Public Engagement

INSTITUTE OF MEDICINE
OF THE NATIONAL ACADEMIES

Crisis Standards of Care

A Systems Framework for Catastrophic Disaster Response

Volume 6: Public Engagement

Committee on Guidance for Establishing Standards of Care for Use in Disaster Situations

Board on Health Sciences Policy

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Willing is not enough; we must do.”*
—Goethe



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This report has been reviewed in draft form by individuals chosen for their diverse perspectives and technical expertise, in accordance with procedures approved by the National Research Council's Report Review Committee. The purpose of this independent review is to provide candid and critical comments that will assist the institution in making its published report as sound as possible and to ensure that the report meets institutional standards for objectivity, evidence, and responsiveness to the study charge. The review comments and draft manuscript remain confidential to protect the integrity of the deliberative process. We wish to thank the following individuals for their review of this report:

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its release. The review of this report was overseen by **Dr. Georges Benjamin**, American Public Health Association. Appointed by the Institute of Medicine, he was responsible for making certain that an independent examination of this report was carried out in accordance with institutional procedures and that all review comments were carefully considered. Responsibility for the final content of this report rests entirely with the authoring committee and the institution.



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Acronyms

ARS	audience response systems
CSC	crisis standards of care
HPP	Hospital Preparedness Program
PHEP	Public Health Emergency Preparedness
SOFA	Sequential Organ Failure Assessment

In its 2009 letter report, the committee emphasized the need for a robust community engagement process on the values associated with the allocation of scarce medications (e.g., medical countermeasures) and equipment (e.g., face masks) during a catastrophic disaster. This chapter provides a framework and offers a set of tools for conducting public engagement or “community conversations” about crisis standards of care (CSC).

GOALS AND BENEFITS OF PUBLIC ENGAGEMENT

Public engagement is necessary not only to ensure the legitimacy of the CSC planning process and guidelines, but also to achieve the best possible results in the event of a catastrophic disaster. A meaningful public engagement process will inform members of the community about the concept of CSC so that individuals and organizations responsible for CSC planning and implementation and members of the general public will understand why and when CSC guidelines may become necessary and how they will be applied. Recent examples (discussed below) also demonstrate that public engagement facilitates deliberation and provides policy makers with community perspectives on the fundamental ethical dilemmas involved in decisions about allocating scarce medical resources in crisis situations. As noted in the 2009 letter report, “ethically sound disaster policies require more than technical expertise. These policies should reflect specific values in choices about contested issues, such as priority setting for access to scarce resources (e.g., medical countermeasures, antivirals) and restrictions on individual choice (e.g., which provider to see, where care is received). A public engagement process is crucial for drafting ethical policies that reflect the community’s values and deserve its trust” (IOM, 2009, p. 31). The ultimate goal for public engagement is to ensure that CSC guidelines reflect community values and priorities and therefore will be more acceptable to the public if activated in a crisis. An additional benefit is that public engagement on CSC can raise individual and community awareness about the need to focus on the broader goals of disaster preparedness.

A MODEL FOR PUBLIC ENGAGEMENT: RESOURCES FOR STATE AND LOCAL AUTHORITIES

To encourage and support public engagement initiatives by state, regional, and local health authorities, the committee developed a model process and set of tools for community conversations on CSC. The development of these tools was guided by public and community engagement efforts already initiated in various parts of the country, including Seattle/King County (Washington), Harris County (Texas), and Minnesota (discussed in the ethics section of Chapter 4).¹ In addition, in fall 2011, the committee conducted two pilot community conversations in Boston and Lawrence, Massachusetts, to test and refine these methods and tools.

The final products can be found at the end of this chapter. The materials include (1) detailed agendas for half- and full-day sessions structured around facilitated large- and small-group discussions; (2) surveys, scenarios, slides, and other tools with which to educate participants from the general public about the need for CSC and to explore community views on the ethical underpinnings that should be reflected in CSC guidelines; and (3) separate guidebooks for sponsors, lead facilitators, and table facilitators/note takers to assist them in planning and leading a CSC public engagement process.

Although these materials are comprehensive, they were designed with the expectation that state and local jurisdictions will tailor the process and tools to their particular objectives and needs. The rest of this chapter addresses the fundamental principles and considerations that should govern public engagement and outlines some strategies for meeting the challenges of planning and executing successful CSC public engagement processes. It should be emphasized that while the committee is confident that communities utilizing and adapting these materials will be able to pursue public engagement productively, the strategies presented here are not the only ways of moving such engagement processes forward. The committee encourages planners to review this chapter, as well as other public engagement efforts carried out across the country, before deciding on the best way to move forward.

ESSENTIAL PRINCIPLES OF PUBLIC ENGAGEMENT

There is no single right way to conduct public engagement. Successful processes can take many forms depending on the nature of the issues, available resources, and the local culture and conditions. Nevertheless, certain basic principles are common to all public engagement processes (NIH, 2011).

¹ Beginning in 2008, Seattle/King County engaged 153 members of the community in four events on the topic of priorities in resource allocation and scarce resource allocation (Seattle and King County, 2012).

In 2011, Harris County Public Health and Environmental Services held eight day-long public engagement events, convening more than 600 members of the general public, and one day-long community engagement event, convening 30 organizational representatives. The goal was to receive input on the community's values and how these should be incorporated in a severe pandemic requiring the allocation of scarce resources (Shah, 2012).

The Minnesota Pandemic Ethics Project was undertaken to plan for the allocation of scarce resources. Public input on the plan was garnered through a series of small- and large-group public engagement sessions. This project was among the first of its kind to develop public engagement methods and analyze their success (Garrett et al., 2011).

Policy Makers Genuinely Want Advice and Are Committed to Considering Public Input

Public engagement is a useful approach for obtaining public input about pending policy decisions that require difficult choices among competing values. Although average citizens may lack the expertise to comment on technical issues (e.g., the use of Sequential Organ Failure Assessment [SOFA] scores to allocate ventilators), they are perfectly capable of deliberating on the values underlying such decisions as whether to withhold or withdraw life-preserving care in situations of scarce resources. As noted above, policy makers benefit from public engagement. But to reap these benefits, they should clearly define in advance the questions on which they want input. They also should be willing to commit time and effort to a process that is more complex than the typical rule-making processes with which they are familiar and to seriously consider the information gained through the process in their final decisions.

Participants Represent the Diversity of the Community

Both those responsible for planning for and implementing CSC and members of the general public should be at the table to promote the exchange of ideas across different sectors and interest groups. Those planning public engagement events should develop outreach and recruitment strategies to reach a broad cross section of the community and to involve difficult-to-reach and at-risk populations that are typically underrepresented in public discourse.

Participants Are Provided with Information and a Meaningful Opportunity to Engage in Discussion

The goal of public engagement is to inform and discuss. Any agenda should begin with presentations or activities designed to educate participants from the general public about the issues they will need to understand to engage fully in the session. Skilled, neutral facilitators should then lead participants through user-friendly exercises designed to prompt discussion and elicit information about predefined issues.

Deliberation Is a Goal in and of Itself

Sometimes participants will reach consensus, or the weight of opinion will be apparent. But consensus and absolute clarity are not essential to a successful outcome, nor are they likely to emerge on issues such as CSC. One of the values of public engagement is that it can help reveal misunderstandings, biases, and areas of deep disagreement. Policy makers then can work to address these matters during the development of CSC plans, as well as during the dissemination phase when interested community partners and the general public are informed of the policies that have been adopted.

Input from the Public Engagement Sessions Receives Consideration in the Decision Making Process

Planners should establish in advance how they will give consideration to the recommendations, conclusions, and other information that emerge from the public engagement sessions, and should disclose these plans to

participants at the start of each session. It should be clear that participants may not have a “vote” on final policy since policy makers ultimately may reach different conclusions. Regardless of the outcome, the best practice is for the sponsoring agency to communicate the final results or policy decision(s) to community participants. Such communications should explain the basis for the decision(s) and how the public engagement data were weighed. If policy conclusions differ from views expressed at the public engagement sessions, this, too, should be communicated to participants to provide for transparency and a sense of integrity in the input process to the extent possible.

Top-Down Support and Sufficient Resources Are Allocated to the Task

Public engagement on CSC planning is a significant undertaking. Health authorities should assess the sufficiency of internal and community resources for planning community conversations on CSC and leverage more support if necessary. They also should consider the political and other environments for public conversations about these important but challenging issues and establish a suitable communications strategy to address political and other considerations.

CHALLENGES AND STRATEGIES

To conform to the above principles, sponsors of public engagement should plan to address the following considerations at the outset.

When Is the Best Point in the Process to Conduct CSC?

Public engagement should take place somewhere midway in a jurisdiction’s development of CSC guidelines. The development process should be mature enough that a sponsoring agency can identify the key issues to be addressed through public engagement. That point might occur prior to the drafting of a CSC plan, for example, while the plan is in development, or after an initial draft has been completed. Planning should not, however, be so far along that it is unlikely that public input could have any significant impact on the final product or that the draft CSC guidelines might be perceived as not being subject to revision. Based on local planning considerations, entities can best decide then when public engagement should be conducted and how the results will be used in ongoing planning efforts.

How Should Community Partners Be Engaged?

Prior to the public engagement sessions, it is important for sponsors to seek advice and support from community partners, including health care providers and community advocates representing the interests of various constituencies that might have unique perspectives on issues related to CSC (e.g., elders, children, people with disabilities, immigrants and refugees, geographically isolated communities). One approach is for sponsors to convene a series of smaller meetings or roundtable discussions with representatives of each these groups. While sponsors should consider including health care providers in broader public engagements, this group may require special outreach given their unique responsibilities for implementing CSC, and sponsors

should consider holding a larger session to solicit their perspectives. Collaboration with community partners will inform the agenda for the public engagement sessions and assist in the recruitment of diverse community participants, and could provide crucial political or other support if needed.

How Can Sponsors Achieve Diverse Community Participation?

A truly inclusive public engagement process has broad participation that reflects the diversity of the community and includes at-risk, difficult-to-reach populations that are not well represented in the political process. Efforts should be made to incorporate ethnically and racially diverse populations as well (Drexel University Center for Health Equality and HHS Office of Minority Health, 2008; HHS, 2011). Involving community members in the development of CSC is important because the values of ordinary community members—including those who may need greater levels of assistance, have special medical needs, or can offer unique perspectives—should inform the actions of professionals and engender community trust in the CSC guidelines that are developed and the development process.

Outreach and recruitment are among the greatest challenges sponsors will face in the public engagement process. Whatever the methodology, community members are being asked to devote a significant amount of their limited free time to attending a meeting on a topic that is unfamiliar and perhaps unsettling. Specific recruitment strategies are covered in more detail in the sponsor guidebook that is part of the toolkit at the end of this chapter. The following are major considerations that sponsors will have to weigh and resolve.

Defining Community

The first step in achieving diverse representation is to determine the demographic mix of the target community, which in turn requires defining the boundaries of that community. Those boundaries are obvious for a statewide process, but may be less clear for local public health sponsors that may consider collaborating with neighboring agencies. Best practice is for each session of the public engagement process to include a mix of participants drawn from various constituencies so that participants can hear and reflect upon different perspectives. This ideal can be difficult to achieve, however, if people are reluctant to travel or mix with others outside of their immediate community, geographic or otherwise. Another approach is to aim for process-wide diversity so that even if each session is not perfectly diverse, all of the key constituencies are represented in at least some of the sessions, and overall diversity is achieved.

Offering Incentives

Recruiting sufficient numbers of participants for a CSC public engagement session may prove difficult without the offer of a stipend (or some other type of incentive) that compensates for out-of-pocket expenses (e.g., missed work, dependent care, and transportation) or simply provides an incentive to give up significant free time. The offer of a stipend will likely yield higher levels of attendance, encourage participants to remain until the end of the session, and/or introduce more socioeconomic diversity by eliminating one barrier to attending a session. Although stipends now are a typical recruitment strategy for public engagement, however, agencies could be criticized for using public funds to pay people to attend such a meeting or even face questions about whether the results are somehow biased because of the incentives offered. An additional concern is whether federal Public Health Emergency Preparedness (PHEP) or Hospital Preparedness Pro-

gram (HPP) cooperative agreements may be used to cover the cost of stipends. These and other issues will need to be considered by the sponsor's planning group.

Including Non-English-Speaking and Difficult-to-Reach Groups

In areas with large numbers of non-English-speaking residents, sponsors should consider the most effective ways to recruit these groups. One option is to provide translation and interpreter services at sessions conducted in English. Another is to conduct one or more session in the predominant language(s) of non-English-speaking groups. Sponsors also should consider recruiting or even holding sessions for difficult-to-reach groups (e.g., some immigrant and refugee populations) where they live. Although these strategies impose additional costs, they are the best way to ensure that the voices of such populations are heard.

Including People with Disabilities or Other Functional Needs

Including people with disabilities in the discussion is especially important given that many of these individuals are likely to face greater-than-average barriers to accessing care during a catastrophic disaster. Planners should make accessibility a priority and plan to accommodate various needs to the extent possible. People with disabilities should be recruited not only as participants but also as facilitators and note takers.

What Is the Appropriate Length of a Public Engagement Session?

Depending on the goals for the session, the resources available, and other logistical considerations, the sponsor should decide on the appropriate length of a community conversation. Both the half-day and full-day versions of the Massachusetts test sessions yielded valuable information and were well received by participants; as expected, the longer session afforded greater opportunity for in-depth discussion of a wider range of issues and for participants' thoughts to evolve. CSC will be a complex and novel topic for most, so sufficient time should be allotted for participants to absorb and digest the background information and to develop and express their ideas on the issues as fully as possible. Adequate time also will minimize the risk that participants will be left with the impression that the sponsor did not give them the chance to be heard or to receive answers to their questions.

The materials in the toolkit at the end of this chapter include a 5-hour agenda with suggestions for lengthening or shortening the time consistent with the sponsoring agency's purposes and resources. It will not be possible to cover every issue related to CSC in a single session regardless of its duration. The main goal is to derive outputs that are actionable. Sponsors will have to decide what information is most needed and estimate how long the session must be to yield it. Sponsors also should anticipate and allow time to answer participants' questions about local public health and emergency preparedness issues.

Will Participants Understand the Program Materials?

One of the greatest challenges of public engagement is the presentation of information about issues as complex and easily misunderstood as CSC in a format that is accessible to a general public audience. The language should be clear and simple without sacrificing accuracy or key ideas. Many words that are central to CSC, such as "allocation," "scarce," and "resources," will not resonate with the full range of people who should be included in a public engagement process. One strategy for overcoming literacy barriers is for

facilitators to read survey questions and scenarios aloud even if participants have received written materials. Another strategy is to minimize the need for participants to write responses to questions.

The pre- and post-survey instrument in the toolkit at the end of this chapter (see the sponsor guidebook) was designed not only to collect data on participants' opinions but also to jump start participants' understanding of the issues for discussion. The introductory slides provide additional background and reinforcement. If simultaneous sessions are being held and/or there is a desire to provide consistent introductory information to participants regardless of which session they attend, videotaping of the introductory presentation may be considered. Participants will come with different levels of knowledge and understanding and will learn in different ways. Offering the information through varied vehicles and formats increases the chance that, one way or another, everyone will absorb the information needed to be an active participant. Sponsors are encouraged to review and consider various strategies for engaging participants before deciding which strategies they will use.

What Skills and Background Do Facilitators Need?

Sponsors should make it a high priority to identify and recruit lead facilitators and table (small-group) facilitators with the experience and facilitation skills necessary to ensure the success of the conversation. Lead facilitators should be knowledgeable about CSC and the jurisdiction's CSC planning efforts and have a deep understanding of the public engagement process and program materials. The most effective lead facilitators are excellent communicators who enjoy connecting with the general public and are able to explain complex issues in terms that are accessible to lay audiences of varying literacy and education levels. It is preferable, but certainly not necessary, for the lead facilitator to have a clinical background because he or she may then be more prepared to answer questions that might be raised about medical care in a disaster, and because the public tends to trust clinicians on matters related to health care. Regardless, the key requirement for the lead facilitator is the ability to put participants at ease and make them comfortable with discussing difficult and challenging topics.

The most effective table (small-group) facilitators will be drawn from the local community (with an eye toward the ethnic and other characteristics of the participants) and will be highly skilled at leading small-group discussions. They need not have prior subject matter expertise, but should commit to familiarizing themselves with the guidebook for table facilitators and note takers in the toolkit and attending a training session conducted by the sponsor or the lead facilitator prior to the public engagement session.

How Will Data Be Collected and Analyzed?

A highly effective and engaging option to collect survey responses during public engagement is to use one of the audience response systems (ARS) now on the market. With ARS, participants use "clicker" devices to respond to questions and statements presented on slides. Data are automatically recorded for later analysis, eliminating the need for manual data entry. Another benefit of ARS is that facilitators can immediately display aggregated responses that reveal such information as how the group "voted" on a particular ques-

tion and whether changes of opinion occurred between the beginning and end of the session.² Participants and facilitators thereby gain additional knowledge about the views in the room, which in turn enriches the subsequent discussion. In the Massachusetts test sessions, one of which used ARS and the other of which relied on paper surveys, it was evident that the participants who used ARS liked using the clicker technology. Facilitators and observers also noted that the ARS session appeared to be more interactive and that the instant display of the range of opinions in the room had a significant impact on the depth of the discussion. Sponsors will need to consider cost and other factors before deciding whether to use such technologies in their engagement efforts.

Qualitative data are at least as important as quantitative data. Yet they can be more difficult to capture because skilled listeners should extract and synthesize key ideas from free-flowing conversations. The listening, analytical, and writing skills of note takers are critical because they will determine the usefulness of the information recorded during scenario discussions and report-outs. Note taking is thus an important role, and sponsors should recruit an appropriate number of note takers who are up to the task. Alternative strategies include digitally recording large- and small-group discussions. Although recording technology is now inexpensive, however, the cost of transcription or the time spent by staff listening to recordings after the sessions may be prohibitive.

How Can Sponsors Manage the Message?

Sponsors should establish an effective communications strategy to manage the message in a challenging environment before they initiate recruitment activities. Such a strategy should include talking points aimed at explaining CSC to various target audiences, including the general public. It also should include development of a list of spokespersons comprising opinion leaders and community partners who have been trained to speak about the purposes of CSC and who are willing to be called upon to discuss the issues with community organizations, the press, or others should the need arise. As above, it is also helpful to have agency leadership or staff members attend some or all of the sessions to engender trust among participants, as well as to be able ultimately to speak for the utility of holding such community conversations.

Is It “Research” or “Deliberative Democracy”?

The sessions conducted in Massachusetts were simulations intended to test the process and tools for community conversations on CSC, and consequently required Institutional Review Board approval as human subjects research. Actual community conversations conducted by health authorities may be considered part of deliberative democracy, analogous to soliciting public comment on proposed regulations, guidelines, or other policies, not research. However, health authorities should seek confirmation concerning this aspect of their public engagement process.

² However, it should be noted that data collected are only representative of individuals in the room, and similar to the limitations of any public engagement exercise, may not necessarily reflect the majority or consensus view for the entire community.

TOOLKIT DESCRIPTION

The following materials form the committee’s public engagement toolkit: a sponsor guidebook, a lead facilitator guidebook, a guidebook for table facilitators and note takers, and a set of introductory slides. The toolkit is meant to provide a framework that can assist local and state agencies, especially public health agencies, in engaging the general public in their community on the values that underlie the allocation of scarce resources in response to a catastrophic disaster. Individual groups are encouraged to modify the materials to incorporate pertinent local details. Each guidebook is meant to identify issues relevant to a specific group responsible for funding, planning, and executing a public engagement event. The introductory slides are meant to be a part of the planning materials, but are provided separately for ease of editing as local groups may deem necessary.

Sponsor Guidebook

This guidebook is designed for use by state, regional, and local sponsoring public health agencies (“sponsors”) in organizing and convening community conversations on CSC. It identifies principles and strategies to assist with the planning process, while the two facilitator guidebooks (described below) provide detailed agendas, tools, and scripts for use during the sessions.

Lead Facilitator Guidebook

The lead facilitator of an event is responsible for introducing participants to the subject matter, moving the larger group discussions through and between activities, and highlighting themes elicited in small-group discussion. The lead facilitator guidebook provides the information and tools needed to lead productive discussion about the allocation of scarce medical resources during a disaster. It includes

- background information on CSC,
- the purpose and goals of the community conversation,
- an annotated agenda of the day’s activities,
- talking points and specific guidance on how to use the various program materials,
- copies of surveys, scenarios, and discussion questions, and
- general advice on facilitation.

The guidebook also familiarizes the lead facilitator with the context of CSC, the ethical questions to be addressed, and the design and goals of the public engagement program.

Guidebook for Table Facilitators and Note Takers

A table facilitator leads small-group discussions and engages participants in scenario activities. Therefore, this guide has many of the same elements as the lead facilitator guidebook, but provides scripts and rhetorical devices for leading small-group discussion. It also offers guidance for those taking notes on the proceedings.

Included as well is context for the ethical questions associated with CSC and the design and goals of the program.

Introductory Slides

The public engagement sessions provide an opportunity to communicate the concept of CSC and background on previous preparedness work to participants. The PowerPoint slides included in the toolkit are an example framework for imparting this information, but sponsors should adapt them to relevant examples based on the diversity of and ability to connect with the expected participants.

CONCLUSION

The Massachusetts test sites, as well as various other public engagement initiatives across the country for CSC/critical resource allocation, confirm that diverse community participants are willing and able to engage in productive deliberations about CSC, and that the provision of information and a forum for discussion can help shape and elicit public opinion in ways that can be useful to policy makers in developing CSC guidelines. The methods and tools for community conversations offered in this report are a starting point for use by state, local, and regional health authorities in planning their own successful public engagement processes. When they are used together with information and practices gleaned from other communities across the nation that have conducted public engagement sessions to date, it is anticipated that the challenging task of incorporating community values into CSC planning will more easily be accomplished.

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*“CRISIS STANDARDS OF CARE”
IN DISASTERS AND PANDEMICS
A Community Conversation*

SPONSOR GUIDEBOOK

Developed by the Institute of Medicine of the National Academies

What Are Community Conversations on Crisis Standards of Care?

Crisis standards of care should reflect the ethical values and priorities of the community about the use of scarce medical resources during a catastrophic disaster or pandemic. Meaningful community engagement—before a disaster strikes—is therefore essential to the successful development, dissemination, and implementation of crisis standards of care guidelines.

Community conversations on crisis standards of care offer opportunities for members of the public to talk with planning agencies and each other about how to deliver health care under circumstances when resources are insufficient to provide care as usual to all who need it. Community conversations on crisis standards of care are designed to

- inform members of the public about crisis standards of care and why they are necessary;
- ensure broad participation and ensure that vulnerable, hard-to-reach populations are represented;
- increase awareness and understanding about the development of a crisis standards of care plan or an existing draft plan; and
- gather input on the ethical considerations and priorities that should be the basis of a crisis standards of care plan or that are included in a draft crisis standards of care plan under review.

CRISIS STANDARDS OF CARE

Guidelines developed before disaster strikes to help health care providers decide how to provide...

THE BEST POSSIBLE MEDICAL CARE

...when there are not enough resources to give all patients the level of care they would receive under normal circumstances

The Purpose of This Guide

This guide, and the accompanying lead facilitator and table facilitator/note taker guides, are designed to be used by state, regional, and local sponsoring public health agencies (“sponsors”) to organize and convene community conversations on crisis standards of care. The sponsor guide identifies principles and strategies to assist with the planning process, while the two facilitator guides include detailed agendas, tools, and scripts for use during the sessions.

Principles of Public Engagement on Crisis Standards of Care

There is no single “right” way to conduct a community conversation on crisis standards of care. Successful processes can take many shapes and forms depending on the nature of the issues, available resources, and local customs. Nevertheless, certain basic principles should be observed.

Sponsors genuinely want advice and are committed to considering public input

Public engagement is a useful approach for obtaining public input about policy decisions that require hard choices between competing values. Although average citizens may lack expertise to weigh in on technical issues, they are perfectly capable of deliberating on the underlying values related to decisions such as whether to withhold or withdraw life-preserving care in situations of scarcity. To reap the benefits of a community conversation, sponsors must clearly define in advance the questions on which input is needed. Sponsors also must be willing to commit time and effort to a process that is more com-

plex than typical rule-making processes and to seriously consider the information that comes out of the process when making final decisions.

Participants represent the diversity of the community

Both community stakeholders and members of the general public should be at the table to promote an exchange of ideas across different sectors and interest groups. Sponsors should develop outreach and recruitment strategies to reach a broad cross-section of the community and to target hard-to-reach and at-risk populations that are typically underrepresented in public discourse.

Participants are provided with information and a meaningful opportunity to engage in discussion

The main goals of community conversations are to inform and discuss. Any agenda should lead off with presentations or activities designed to educate general public participants about the issues they will need to understand in order to fully engage in the session. Skilled, neutral facilitators should then lead participants through user-friendly exercises designed to prompt discussion and elicit information about predefined issues.

Deliberation is a goal in and of itself

Sometimes participants will reach consensus or the weight of opinion will be apparent. But consensus and absolute clarity are not essential to a successful outcome. Nor are they likely to emerge on issues such as crisis standards of care. One of the values of public engagement is that it can help reveal misunderstandings, biases, and areas of deep disagreement so that sponsors can work to address these during the dissemination phase, when community stakeholders and the general public are informed of the policies that have been adopted.

Input from the public engagement sessions receives consideration in the decision-making process

Sponsors should establish in advance how they will give consideration to the recommendations, conclusions, and other information that come out of the community conversation, and should disclose these plans to participants at the start of each session. It should be clear that citizen participants will not have a “vote” on final policy and that sponsors ultimately may reach different conclusions. Regardless of the outcome, best practice is for the sponsor to communicate the final results or policy decision to community participants. Such communications should explain the basis for the decision and how the data were weighed.

Top-down support and sufficient resources are allocated to the task

Community conversations on crisis standards of care are a significant undertaking. Sponsors should assess the sufficiency of internal and community resources for planning a community conversation, and leverage more support if necessary. Sponsors also should consider the political environment for public conversations about these important but challenging issues and put into place a suitable communications strategy.

The major costs associated with a community conversation are

- venue rental and audiovisual equipment;
- catering;
- web pages and registration modules;
- Audience Response System rentals or data entry and analysis;
- printing of materials and signs;
- host fees;
- lead facilitator and subject matter expert fees;
- table facilitator and note taker fees;
- participant stipends;
- accommodations for people with disabilities; and
- media coordinator fees.

Community Conversations: Challenges and Strategies

As sponsor, you should address the following considerations early in your planning.

When is the best point in the process to conduct crisis standards of care?

Public engagement should take place somewhere in the middle of a jurisdiction’s development of crisis standards of care guidelines. The development process must be far enough along for your agency to be able to identify the key issues to be addressed through public engagement. That point might occur prior to the drafting of a crisis standards of care plan, while the plan is in development, or after an initial draft has been completed. Planning should not, however, be so far along that it is unlikely that public input could have any significant impact on the final result—or that the perception might be created that draft crisis standards of care guidelines are a “done deal.”

How and when should community stakeholders be engaged?

Prior to the community conversations, it is important to seek advice and support from community stakeholders, including health care providers and community advocates who represent the interests of various constituencies that might have unique perspectives on issues related to crisis standards of care (e.g., elders, children, people with disabilities, immigrants and refugees, geographically isolated communities). One approach is to convene a series of smaller meetings or roundtable discussions with representatives of each of these groups. Health care providers will require special outreach given their unique responsibilities for carrying out crisis standards of care, and you should consider holding a larger session to solicit their particular perspectives. Collaboration with community stakeholders will inform the agenda, assist recruitment of diverse community participants, and provide crucial political support if needed.

How can diverse community participation be achieved?

A truly inclusive public engagement process has broad participation that reflects the diversity of the community and ensures that at-risk, hard-to-reach populations who are not well represented in the political process are included. Involving community members in the development of crisis standards of care is important because the values of ordinary citizens—including those who may need greater levels of assistance, have special medical needs, or offer unique perspectives—should inform the actions of

professionals and engender community trust in the process and the standards. As noted above, stakeholders are part of the community and their place at the table ensures that all perspectives are heard.

Outreach and recruitment are among the biggest challenges. Whatever the methodology, community members are being asked to devote a significant amount of their limited free time to attend a meeting about a topic that is foreign and perhaps unsettling. Specific recruitment strategies are covered in more detail below. Major considerations are as follows.

Defining community

The first step to achieving diverse representation is to determine the demographic mix of the target community, which, in turn, requires defining the boundaries of that community. Those boundaries are obvious for a statewide process, but might be less so for local public health agencies that are collaborating with neighboring agencies. Best practice is for each session of the public engagement process to include a mix of participants drawn from various constituencies so that participants can hear and reflect on different perspectives. That ideal can be hard to achieve, however, if people are reluctant to travel or mix outside of their immediate communities, geographic or otherwise. The second-best approach is to aim for process-wide diversity so that even if each session is not perfectly diverse, all of the key constituencies are represented in at least some of the sessions.

Stipends

Recruiting sufficient numbers of participants to attend a crisis standards of care public engagement session may prove difficult without the offer of a stipend that provides compensation for out-of-pocket expenses (e.g., missed work, dependent care, and transportation) or simply provides an incentive to give up significant free time. Offering stipends will likely yield higher levels of attendance, encourage participants to remain until the end of the session, and introduce more socioeconomic diversity by eliminating one barrier to attending a session. Keep in mind that although stipends are now a typical recruitment strategy in public engagement, sponsors could face criticism for using public funds to pay people to attend meetings. An additional concern is whether your source of funding (e.g., federal cooperative agreements, the Public Health and Emergency Preparedness and the Hospital Preparedness Program) may be used to cover the cost of stipends.

Non-English-speaking populations and hard-to-reach groups

If your area includes large numbers of non-English-speaking residents, you should consider the most effective ways to recruit these communities. One option is to provide translation and interpreter services at sessions conducted in English. Another is to conduct one or more sessions in the predominant language(s).

You also should consider going out to meet certain hard-to-reach groups (e.g., some immigrant and refugee populations) “where they live.” Although these strategies impose additional costs, they are sometimes the only way to ensure that the voices of such populations are heard.

People with disabilities

Including people with disabilities in the discussion is an especially important goal given that many of these individuals are likely to face higher-than-average barriers to accessing care in a disaster. You should prioritize accessibility and plan to accommodate various needs to the extent possible. People with disabilities should be recruited not only as participants, but as facilitators and note takers.

Certain groups will not be able to participate in community conversations directly (e.g., people with severe developmental disabilities, children). Invite advocates or service providers for these constituencies to represent their interests at the table.

What is the appropriate length of a crisis standards of care public engagement session?

Depending on your goals for the conversation, available resources, and other logistical considerations, you must decide on the appropriate length of the community conversation. A longer session will afford greater opportunity for in-depth discussion of a wider range of issues and for participants' thoughts to evolve. Crisis standards of care will be a complex and novel topic for most, so sufficient time should be allotted for participants to absorb and digest the background information and to develop and express their ideas on the issues as fully as possible. Adequate time also will minimize the risk that participants will be left with the impression that the sponsor did not give them the chance to be heard or to receive answers to their questions.

The accompanying facilitator guides include a 5-hour agenda with suggestions for lengthening or shortening the time consistent with local purposes and resources. It will not be possible to cover every issue raised by crisis standards of care in a single session, no matter how long the duration. The main goal is to end up with outputs that are actionable. You will have to decide what information is most needed in your jurisdiction and estimate how long a deliberation is necessary to obtain it. You also should anticipate and build in time to answer participant questions about local public health and emergency preparedness issues.

Will participants understand the program materials?

One of the greatest challenges of public engagement is the presentation of information about issues as complex and easily misunderstood as crisis standards of care in a format that is accessible to general public audiences. The language must be clear and simple without sacrificing accuracy or key ideas. Words that are central to crisis standards of care, such as "allocation," "scarce," and "resources," will not resonate with the full range of people who should be included in a public engagement process. One strategy for overcoming literacy barriers is for facilitators to read survey questions and scenarios aloud even if participants have been provided written materials. Another strategy is to minimize the need for participants to write responses to questions.

The pre- and postsurvey instrument included with this guide was designed not only to collect opinion data, but to jump-start participants' understanding of the issues for discussion. The introductory slides provide additional background and reinforcement. Participants will come with different levels of knowledge and understanding and will learn in different ways. Offering the information through varied vehicles and formats increases the chance that, one way or another, everyone will absorb the information they need to be active participants.

What skills and background do facilitators and note takers need?

You should identify and recruit lead facilitators and table (small-group) facilitators who have the experience and facilitation skills necessary to ensure the success of the conversation. Lead facilitators should be knowledgeable about crisis standards of care and the jurisdiction's crisis standards of care planning efforts, and must develop a deep understanding of the public engagement process and program materials. The most effective lead facilitators are excellent communicators who enjoy connecting with the general public and are able to explain complex issues in terms that are accessible to lay audiences of varying literacy and education levels. It is preferable, but certainly not necessary, for the lead facilitator to have a clinical background, because he or she might be more prepared to answer questions participants might raise about medical care in disasters, and because the public tends to trust clinicians on matters related to health care.

The most effective table (small-group) facilitators will be drawn from the local community and will be highly skilled at leading small-group discussions and able to remain neutral on the issues. They need

not have prior subject matter expertise, but must commit to familiarizing themselves with the accompanying table facilitator guide and attending a training session prior to the public engagement session.

How will data be collected and analyzed?

A highly effective and engaging way to collect survey response data during public engagement is to use one of the Audience Response Systems (ARSs) now on the market. With an ARS, participants use “clicker” devices to respond to questions and statements presented on slides. Data are automatically recorded for later analysis, eliminating the time and cost of manual data entry. Another benefit of an ARS is that facilitators can immediately display aggregated responses that reveal information such as how the group “voted” on a particular question and if changes of opinion occurred between the beginning and end of the session. Participants and facilitators gain additional knowledge about the views in the room, which in turn enriches the subsequent discussion.

Qualitative data are at least as important as quantitative data in public engagement. They can be more difficult to capture, however, because skilled listeners must extract and synthesize key ideas from free-flowing conversations. The listening, analytical, and writing skills of the note takers are critical because they will determine the usefulness of the information recorded during scenario discussions and report-outs. Note taking is thus an important role, and you should recruit note takers who are up to the task. Alternative strategies include digitally recording large- and small-group discussions. Although recording technology is now inexpensive, the cost of transcription or the time spent by staff listening to recordings after the sessions might be prohibitive.

How can sponsors manage the message?

You should put in place an effective communications strategy to manage the message in a challenging environment before initiating recruitment activities. Such a strategy should include a plan for earned and paid media to generate awareness and interest in crisis standards of care and the community conversations. It also should include talking points aimed at explaining crisis standards of care to various target audiences, including the general public. Finally, it should include development of a list of spokespersons made up of opinion leaders and community partners who have been trained to speak about the purposes of crisis standards of care and who are willing to be called on to discuss the issues with stakeholders, the press, or others, should the need arise.

Consider in advance how to manage media representatives who attend the community conversation by invitation or on their own initiative. Press should observe but not participate in the discussions, and should agree not to quote individual participants. Make sure that participants know they will not be identified in any media coverage to avoid a chilling effect on the discussion.

Is it “research” or “deliberative democracy”?

You should consider whether the particular community conversation that you have planned requires institutional review board (IRB) approval as human subject research. Community conversations on crisis standards of care might be considered research, or they might be viewed as a process analogous to public comment on proposed regulations. In any case, you should seek confirmation concerning the status of your particular process.

Planning a Community Conversation

As noted above, sponsors should consider collaborating with other area organizations that are involved in emergency preparedness or that can support the development or implementation of crisis

standards of care guidelines. To help manage logistics and participant recruitment, most sponsors will benefit from identifying partners with event planning experience and strong ties to diverse parts of the community. Although sponsors should, as needed, seek general advice and support with event management and community outreach, the following guidance is specific to planning a community conversation on crisis standards of care.

Definitions of key roles

Host: An organization or individual chosen by the sponsor to manage logistics and recruitment of facilitators, note takers, and participants. Hosts should have strong community networks and experience with event planning and recruitment of diverse participants. The role of a host varies according to the needs of the sponsor. A sponsor with sufficient staff resources might be able to act as its own host.

Lead facilitator: A person skilled in large-group facilitation who has a solid foundation—if not expertise—in crisis standards of care or public health. The lead facilitator introduces the program agenda and tasks, facilitates large-group report-outs, and closes the event. Behind the scenes, the lead facilitator might work with the sponsor to develop the agenda. The lead facilitator also participates in or leads the training of table facilitators and note takers prior to the community conversation.

Subject matter expert: An individual who can present an overview of crisis standards of care to participants and be available to answer substantive questions that arise during the community conversation. The lead facilitator and subject matter expert roles can be combined, assuming that the individual possesses both sets of skills and content knowledge.

Table facilitators: Individuals who are skilled at small-group facilitation and who, through training, have acquired a good understanding of crisis standards of care. Table facilitators lead small-group activities during the community conversation.

Note takers: Individuals who are paired with table facilitators to document and synthesize participant comments at the small table discussions and during the report-back sessions. Note takers receive the same pre-session training as table facilitators to gain an understanding of crisis standards of care.

Participant recruitment and demographic targets

Consider who needs to be in the room, and in what proportion, to make the results of the community conversation credible:

- Review the demographics in the location where the community conversation will be held. An excellent source of data is the U.S. Census Bureau’s *State & County QuickFacts* website at <http://quickfacts.census.gov>.
- Set registration targets for each demographic category that you want represented. Demographic categories include age, sex, education, household income, race/ethnicity, minority language groups, and people with disabilities.
- Design participant preregistration materials to track recruitment goals.
- Conduct targeted outreach to particular groups through local civic, service, and advocacy organizations that serve those constituencies.
- Once you reach your preregistration target for a particular demographic group, waitlist (and notify) additional registrants in that category and focus further recruitment efforts on the underrepresented groups.

- Preregister 25-33 percent more people than you want to attend, the typical no-show rate for free public events such as these.

Reducing barriers to participation

To participate, some people will need additional services above and beyond wheelchair accessibility. Because the goal is to engage every sector in the community conversation, consider offering the following accommodations:

- Large print or Braille
- ASL (American Sign Language) or CART (Communication Access Realtime Translation) services
- Language translation/interpretation if there are significant non-English-speaking populations in the region
- Child care

Alert potential participants as to which of these services will be available by listing them on the preregistration form and other recruitment materials.

Stipends

Stipends often take the form of cash or gift cards. The size of the stipend depends on the length of the session and local practice. A typical stipend in 2012 is around \$50 for a half-day session and \$100 for a full-day session, although amounts vary. In any case, the stipend should cover reasonable out-of-pocket expenses that participants might incur in order to attend the community conversation (e.g., transportation, dependent care) and provide them with some nominal compensation for their time. The terms of any stipend should be made clear to participants in the recruitment and preregistration materials and again at the onsite registration to avoid any confusion or disappointment. Stipends cover time and expenses, and should not be conditioned on the level or quality of a person's contributions at the session. In most jurisdictions, it is acceptable to condition receipt of a stipend on arriving at the community conversation on time and staying through the duration. Some jurisdictions (and IRBs, if applicable) have different rules related to stipends that should be confirmed prior to any offer of compensation.

Venue and set-up

The venue for the community conversation should be reachable by public transportation, have adequate parking, and be fully accessible to people with disabilities. Meeting rooms at a local library or community center are good choices. Other options include hotel and academic conference facilities, although these venues might feel less inviting to some community members.

The accompanying community conversations agenda and tools were designed for multiple groups of 8 participants, with a table facilitator and note taker seated at small tables (up to 100 participants in the room). All of the activities take place in the same large room; breakout space is not necessary.

If possible, preassign participants to tables to separate family members and friends and to promote diversity within the small groups. Alternatively, randomly assign participants to tables during onsite registration.

Trainings for table facilitators and note takers

Table facilitators and note takers should receive and review the accompanying guidebook at least 1 week prior to the session. A group training of approximately 2 hours in length should be conducted by the host, lead facilitator, and/or subject matter expert. Ideally, this training should take place in the days immediately prior to the session so that table facilitators and note takers have sufficient time to digest and rehearse the materials on their own. If it is too impractical to convene everyone on an earlier date, the training can be conducted on the same day as the event.

Participant handbook

Consider creating and distributing a short handbook for participants to take home from the community conversation. The handout could include (1) a brief description of crisis standards of care; (2) information about the status of crisis standards of care planning efforts in your jurisdiction; (3) an explanation of how the information from the community conversations will be used in policy making; and (4) contact information for the sponsor.

Additional Crisis Standards of Care Public Engagement Resources

- ASTHO (Association of Territorial Health Officials). 2010. *Effective public engagement: A planning guide*. Arlington, VA: ASTHO.
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*“CRISIS STANDARDS OF CARE”
IN DISASTERS AND PANDEMICS
A Community Conversation*

LEAD FACILITATOR GUIDEBOOK

Including Annotated Agenda and Program Materials

Developed by the Institute of Medicine of the National Academies

This Guide

Thank you for serving as the lead facilitator for this community conversation on crisis standards of care. This guide will provide you with the information and tools you will need to lead a discussion about the allocation of scarce medical resources during extreme disasters and pandemics. It includes

- background information on crisis standards of care;
- the purpose and goals of this community conversation;
- an annotated agenda of the day's activities;
- talking points and specific guidance on how to use the various program materials;
- copies of the surveys, scenarios, and discussion questions; and
- general advice on facilitation.

Meaningful public engagement on this complex topic starts with community conversations like the one you are about to facilitate. This session is designed to engage citizens of diverse backgrounds in discussing the difficult decisions about who should receive health care in a disaster or pandemic when medical resources are insufficient to provide a normal level of care to everyone in need.

This guide will familiarize you with the context of crisis standards of care, the ethical questions to be addressed, and the design and goals of the program you will facilitate. Thank you again for your willingness to contribute in this important way.

What are “crisis standards of care” and why do we need them?

States, counties, tribes, and territories across the United States have been preparing for disaster situations, whether naturally occurring or manmade. If a disaster or pandemic were to strike, temporarily overwhelming our ability to provide health care as usual to everyone in need, how should scarce medical resources be allocated? How could the delivery of care be altered to maximize lives saved? How can this all be coordinated to ensure the most fair, ethical, and nondiscriminatory use of resources? Recent events at home and abroad—from Hurricane Katrina to the H1N1 pandemic to the Haiti earthquake—show the importance of addressing these concerns in advance. One part of this disaster planning is the development of **crisis standards of care**—ethical and clinical protocols and frameworks for delivering health care when medical resources are insufficient to provide care as usual.

One of the main goals of crisis standards of care is to save more lives than would be saved by business as usual. Crisis standards of care help conserve and stretch medical resources so they can help as many patients as possible in order to

- give critical resources to those who need them and/or will benefit the most;
- prevent hoarding and overuse of scarce resources;
- protect at-risk groups against discrimination in access to care; and
- ensure patients and their families trust that they will receive fair access to the best possible care under the circumstances.

CRISIS STANDARDS OF CARE

Guidelines developed before disaster strikes to help health care providers decide how to administer...

THE BEST POSSIBLE MEDICAL CARE

...when there are not enough resources to give all patients the level of care they would receive under normal circumstances.

How would crisis standards of care work?

Crisis standards of care guidelines

- promote best possible medical practice under the circumstances;
- allow reasonable health care provider discretion;
- adapt to the ever-changing circumstances of disasters; and
- emphasize early conservation, adaptation, and substitution of medical resources to avoid having to resort to more extreme measures.

Crisis standards of care guidelines stay in effect only until it is possible to return to normal care. The measures taken are only those needed to cope with the degree of lack of resources (so that the restrictions are proportional, or balanced to the demand).

Without a plan and good communication, different providers and hospitals may be functioning with different levels of resources and make very different decisions. This could lead to inconsistent levels of care in the community from hospital to hospital, which would be not only confusing, but unfair. Crisis standards of care require that medical providers, facilities, public health agencies, and public safety agencies have a plan to work together to do the most they can with the resources available.

When might crisis standards of care be needed? Examples

Two recent disasters offer examples of when crisis standards of care might be needed, as described in the following boxes.

Example 1: Hurricane Katrina—Hospital Overload

The week after Hurricane Katrina, 1,749 patients and 7,600 others sought shelter at 11 area hospitals. Hospitals required employees to work longer and longer shifts under increasingly desperate conditions. There was little or no power, backup generators were failing, and temperatures above 100 degrees destroyed drugs and equipment. Eyewitness accounts included

- doctors making rounds by flashlight;
- hospital staff unable to electronically control even basic equipment; and
- no food, clean water, or plumbing.

These conditions lasted for days. Individual doctors and nurses were left to decide how to use their limited resources. In the following months, ethical and legal inquiries were made about their decisions and actions because many decisions were made as individuals, and not as part of a crisis response plan.

Example 2: Flu Pandemic (H1N1)—Vaccine Shortage

In the early months of the H1N1 flu pandemic in 2009, officials at the Centers for Disease Control and Prevention (CDC) realized that not enough vaccine could be made fast enough to cover the whole population right away. The CDC identified the following groups to get vaccine first:

- pregnant women;
- household contacts and caregivers for children under age 6;
- health care and emergency medical services personnel;
- all people ages 6 months through 24 years; and
- people ages 25 through 64 years who had health conditions that put them at higher risk of medical complications from the flu.

These groups were considered highest priority because they were most likely to get the flu and/or suffer the most severe complications.

Why are community conversations on crisis standards of care necessary?

Involving community members in the development of crisis standards of care is important because the values of ordinary citizens should inform the actions of professionals, especially when there are no reliable ways to predict survival that help providers make decisions. Meaningful community engagement is critical for successful development, dissemination, and implementation of crisis standards of care. Community conversations take place before a disaster strikes for the purpose of enabling participants to understand each other's perspectives while tackling complex issues associated with allocating scarce medical resources.

What are the goals of a community conversation?

Community conversations on crisis standards of care are designed to

- inform members of the public about the concept of crisis standards of care and why they are necessary;
- ensure broad participation and ensure that vulnerable, hard-to-reach populations are represented;
- increase awareness and understanding about the development of a crisis standards of care plan or an existing draft plan; and
- gather input on the ethical considerations and priorities that should be the basis of a crisis standards of care plan or that are included in a draft crisis standards of care plan under review.

What is the public's role in developing crisis standards of care?

The voices of community members are important to the development of crisis standards of care. This is because crisis standards of care must reflect the community's ethical values and priorities about the use of scarce medical resources during disasters.

At this community conversation, participants will have a chance to share their opinions and concerns—not just hear from the “experts.” All participants will be encouraged to consider what principles should guide crisis standards of care, and to hear what others think.

How is the information from community conversations used?

Crisis standards of care raise challenging issues over which reasonable people will disagree. Community conversations help public health officials understand what values are important to individuals and to the entire group, and on what issues people differ.

The goal is *not* to reach consensus or agreement, or to take a vote. Instead, the opinions and concerns raised in this discussion will ensure that any final crisis standards of care guidelines accurately reflect, as much as possible, the views of the community about what is as fair and ethical as possible.

Lead Facilitator Guiding Principles

Facilitation is a way of providing leadership without taking over control. A facilitator’s job is to get others to assume responsibility and to take the lead.

1. Preparation is key!

- Prior to the session it is crucial that you thoroughly familiarize yourself with the agenda and program materials.
- Do a mental “dress rehearsal” to become more comfortable with the content and the flow and to identify any parts for which you need to seek clarification from the sponsor.

2. Facilitator responsibilities:

- You are in charge of managing the entire agenda.
- Enforce the ground rules:
 - *Participate actively*
 - *Listen with respect—only one person talks at a time*
 - *Keep an open mind*
 - *What is shared in the room stays in the room*
 - *Silence cell phones*
- Facilitators set the tone and make it an engaging, inclusive event for everyone:
 - Explain or repeat questions if necessary
 - Keep the discussion on topic
 - Explore disagreements, but defuse unproductive arguments
 - Encourage the “quieter” members to participate at a level that is comfortable
 - Manage individuals who are dominating the discussion
 - Thank participants for their contributions

3. You are neutral for purposes of the discussions and should not offer opinions regarding the substance of the issues.

4. Do not expect or push for consensus. It is more important to elicit and understand the wide range of opinions on these issues.

5. **Keep track of time** or ask someone else to serve as your timekeeper. Remind people when the current conversation will end and intermittently let the group know how much time remains.
6. **Move around the room** during discussion periods and monitor the table conversations. Support the table facilitators as needed and answer any questions.

All good facilitation relies on judgment in the moment as to how best to move the conversation, but here are various techniques and prompts that might be helpful.

Facilitation Skill	Examples of Verbal Prompts
Set up the discussion clearly and simply	“Our task in the next 20 minutes is to explore this question....”
Manage the allotted time	Announce the time allowed for each activity. Give periodic time warnings. “You have about 5 minutes left, so see if there are any other key ideas that have not been discussed so far.”
Stay neutral	Focus on the process and avoid offering your opinions about the topic under discussion. Give examples that are in the materials rather than from your experience.
Listen actively and paraphrase	Look people in the eye, use attentive body language, and paraphrase what they say. “Let me see if I can repeat your point in slightly different words. I want to make sure I understand what you are saying.” Or “Are you saying....?”
Synthesize	Help people to comment and build on each other’s thoughts to ensure that the ideas recorded represent collective thinking. This builds consensus and commitment. “Can anyone add to Aaron’s comments?”
Identify possible disagreements	Ask: “Bill, how does this fit with X that you said earlier?”
Summarize periodically	Listen attentively and then offer concise and timely summaries. Summarize when the group is stuck or when you want to wrap up a discussion. “What I have heard you all say is first....second....and finally....”
Ask questions	Questions should serve to further understand what has been said, to elicit comments from others, and to explore issues that might be overlooked.
Play ping pong	If someone asks a question or makes a comment, redirect it by sending it back to someone else to answer or build on. “Can anyone answer that question that Bill has posed to me?”
Allow participants to reflect	“Before we start, let’s take a minute to think to ourselves about the discussion question and our responses.”
Draw out participants	Use eye contact to let people know they can speak next and to prompt the quiet ones in the crowd to participate. “I want to make sure that we get a chance to hear from everyone.”

Gently limit dominant voices to equalize participation	"I want to see if we could include some other folks in this conversation...."
Curb anecdotes	Lengthy personal anecdotes can quickly sidetrack table discussions. When this occurs, try to gently coax the participant to conclude a lengthy anecdote. You may say, "So, that example leads you to say...."
Explore different points of view	"So, Joe has talked about the importance of X, and Mary has raised some concerns with X. I'm wondering how others see X."
Test for support among ideas	"Apparently, several people share the view that...."
Check perceptions	Describe what you perceive is the other person's inner state. "You appear upset by the last comment that was made. Are you?"
Test for clarity/ shared agreement	"Does this statement convey what you've been saying about...."

Community conversation goals

Keep in mind that, following this session, **participants** should be able to

- explain the concept of crisis standards of care and why they are necessary;
- understand the difficulty of making medical decisions in this context and clarify the values and principles that inform their decisions through the use of scenarios;
- in their small groups, identify areas of general agreement and disagreement regarding values and principles; and
- understand how the results of this meeting will inform and contribute to local or state crisis standards of care during a crisis.

The **sponsor's objective** for the community conversation is to facilitate a meaningful discussion that achieves all of the participant goals listed above, and in which participants believe they can voice their opinions and be heard. The sponsor's objectives also include collecting public opinion data that will be useful in developing policies on crisis standards of care.

Definitions of key roles

You are part of a team that interacts with the participants and supports them. To help you understand the context, below is a description of the other players with whom you will interact. Collaboration, inclusion, transparency, and respect are the values all of us are striving toward as we work on this project together.

Sponsor: A government agency or other organization that is developing a policy for crisis standards of care. This agency will recruit partners as needed to support community conversations; provide support as needed to hosts, facilitators, and subject matter experts; and ensure that the results and data from community engagement activities are properly collected.

Host: An organization or individual responsible for logistics, recruiting participants, and supporting the lead facilitator, table facilitators, and note takers in holding the community conversation. In some cases, the sponsor might also serve as the host for the community conversation.

Table facilitators: Individuals experienced with small-group facilitation. Their role is to lead a small group of participants at the table through the exercises and discussions. Table facilitators follow, and sometimes supplement, the instructions given by the lead facilitator. Table facilitators are given background materials and attend an orientation session to introduce them to the program design and agenda. They are expected to have prior experience facilitating small-group discussions and should have a good understanding of the concept of crisis standards of care.

Note takers: Individuals assigned to document what is said at the small-table discussions and during the report-back sessions.

ANNOTATED AGENDA¹

TIME	ELEMENT	PURPOSE	METHOD/TOOLS
-1:00	Participant Registration	<ul style="list-style-type: none"> Attendance Table assignments Consent (if required) 	<ul style="list-style-type: none"> Registration form Name tags/tent cards with first names only Participants (Ps) read and sign consent form (if required)
0:00	Opening Remarks	<ul style="list-style-type: none"> Welcome participants Introduce leaders/facilitators Briefly describe topic Explain charge of the day 	<ul style="list-style-type: none"> By lead facilitator (LF) Script
0:10	Table Introductions and Exercise	<ul style="list-style-type: none"> Break ice Take temperature—why did they attend, what is on their minds 	<ul style="list-style-type: none"> Tool: Worksheet Table facilitators (TFs) lead introductions, note takers (NTs) record on template Group selects one hope/one fear to report out
0:25	Brief Report-Out	<ul style="list-style-type: none"> Introduce Ps to report-out method Segue into crisis standards of care (CSC) 	<ul style="list-style-type: none"> Moderated by LF Volunteer from each table reports one hope and one fear
0:35	Presurvey	<ul style="list-style-type: none"> Quick immersion into CSC: context, scope, and complexity of the issues Help maintain focus on CSC vs. other preparedness or health care issues Establish baseline opinions 	<ul style="list-style-type: none"> Tools: <ul style="list-style-type: none"> PPT slides of survey statements Audience Response System² (ARS) or paper answer sheets LF reads statements aloud; Ps use “clicker” devices to respond or circle responses on answer sheets No review of responses or discussion; LF explains that survey will be repeated and responses discussed later in the session
0:50	Presentation on CSC and Q&A	<ul style="list-style-type: none"> Educate Ps about CSC: what, when, why, how 	<ul style="list-style-type: none"> Tools: Slides LF or content expert presents slides, responds to questions LF introduces scenario discussion, turns it over to TFs

¹ For a 5-hour session of ≤100 Ps seated at tables of 6-8 with TFs and NTs. If necessary, the session could be shortened by eliminating one of the two scenario discussions and reducing the numbers of participants so that the report-outs can be accomplished in less time. It can be lengthened by increasing the scenario discussion times, and by adding more content around community and individual preparedness awareness.

² Software and handheld devices for automated data collection and display.

1:10	Earthquake Scenario Discussion	<ul style="list-style-type: none"> Designed to elicit views specifically on age and likelihood of survival as criteria for resource allocation. Also, withdrawals of treatment, and whether all of the regions' health care providers should follow the same rules. Other features: sudden onset, geographically contained event. Methodology: Ps asked to do forced ranking of patients and share their perceptions of the associated challenges. Ps asked to share views on what underlying values and goals should drive decisions. 	<ul style="list-style-type: none"> Scenario and discussion questions
1:50	Earthquake Scenario Report-Out	<ul style="list-style-type: none"> Give table groups chance to share key thoughts and identify points of difference and intersection with the larger group Spark larger group discussion, input Further inform, influence thinking of Ps 	<ul style="list-style-type: none"> Facilitated by LF, with one NT recording key points on flip charts Volunteer from each table presents short summary of scenario findings—emphasis on points of agreement/disagreement, most notable impressions
2:20	Break		
2:50	Deadly Virus Scenario Discussion	<ul style="list-style-type: none"> Designed to elicit views on key worker status as criterion for resource allocation. Also addresses the issues of the role of government agencies in promoting consistent application of CSC rules within the affected area, and withdrawal of treatment. Ps asked to share views on what underlying values and goals should drive decisions 	<ul style="list-style-type: none"> Scenario and discussion questions
3:30	Deadly Virus Scenario Report Out	<ul style="list-style-type: none"> Give table groups chance to share key thoughts and identify points of difference and intersection within the larger group Spark larger group discussion, input Further inform, influence thinking of Ps 	<ul style="list-style-type: none"> Facilitated by LF, with one NT recording key points on flip charts Volunteer from each table presents short summary of scenario findings—emphasis on points of agreement/disagreement, most notable impressions
4:00	Postsurvey and Discussion	<ul style="list-style-type: none"> Identify changes in P views pre- and postsession Give Ps chance to consider range of opinions in the room Satisfy P interest in survey results Final opportunity to elicit more information on P views around CSC issues 	<ul style="list-style-type: none"> Tools: Survey slides and clickers LF reads statements aloud; Ps use clicker devices to respond or circle responses on answer sheets LF shows slides with pre- and postsurvey responses (if using ARS) LF leads large group through discussion of statements where there was the most change or disagreement

4:30	Final Question and Wrap-Up	<ul style="list-style-type: none"> • Big-picture question to wrap up discussion • Words from sponsor about local disaster preparedness planning initiatives and resources, and the importance of individual and community preparedness • Thank Ps 	<ul style="list-style-type: none"> • LF leads brief large-group discussion of final question • Sponsor gives brief presentation on local preparedness landscape and resources
4:50	Evaluation		<ul style="list-style-type: none"> • Tool: Evaluation form (ARS or paper) • TF and NT offer help to participants who need it
5:00	Participants Depart		<ul style="list-style-type: none"> • Ps turn in ARS devices and receive stipends, if applicable
5:15	Facilitator/Note Taker Debrief	<ul style="list-style-type: none"> • To gather data and elicit other relevant information or impressions not contained in the notes and templates 	<ul style="list-style-type: none"> • Led by Sponsor and LF
6:00	Adjourn		

*Lead Facilitator Script and Guidance*¹

¹ For a 5-hour session using an Audience Response System (ARS).

Lead Facilitator Script

NOTE: Italicized text is designed to be stated as written, though you should feel free to paraphrase or convey the ideas in your own voice. The tools referenced in the script are included in the program materials section.

0:00 *Opening (10 min.)*

- *Hello, my name is _____. Thank you for coming to today’s community conversation on crisis standards of care. I will be guiding the conversation with the help of your table facilitators.*
- *Your voice is critical in developing policies for crisis standards of care.*
 - *[BRIEFLY]: Crisis standards of care are guidelines to use in extreme public health emergencies to help decide how to provide medical care when there are not enough resources to give all patients the care they would receive under normal conditions.*
- *I will tell you more about crisis standards of care shortly.*
- *Agenda for community conversation*
 - *Today’s agenda includes a series of presentations, surveys, and discussion exercises to introduce you to the concept of crisis standards of care and give you the chance to share your views with others in the room.*
 - *Your input will help us develop of crisis standards of care guidelines that reflect the values and perspectives of the community.*
- *This is a “community conversation.” It is different from other public meetings that you might have attended in the past. Some of the differences are [use all or some of these ideas if you find them helpful]:*

Typical Debate	Community Conversation
Assumes there is a right answer and you have it	Assumes that many people have pieces of the answer that together can craft a new solution
Combative: Participants attempt to prove the other side wrong	Collaborative: Participants work together toward common understanding
Critiquing the other side’s position	Reexamining all positions
Defending one’s own views against those of others	Admitting that others’ thinking can improve on one’s own
Seeking a conclusion or vote that ratifies your position	Discovering new options, not seeking closure

- *Any information we collect from you (e.g., survey responses, discussion notes) is anonymous—and will remain so. Please help us by NOT writing your name on any of the worksheets you will be using.*
- *We also ask each of you to preserve the confidentiality of today’s conversations. Although we encourage you to discuss today’s session with friends and family, please do not identify your fellow participants by name when relating the opinions and other comments expressed in this room.*

- *This session will run for around [5] hours with a refreshment break.*
 - [Any other relevant logistics]
- Introduce key participants:
 - *Table facilitators will help lead the activities for your small group.*
 - *Note takers will ensure that the key discussion points at your table are recorded and reported back.*
 - *Facilitators and note takers, please stand up.*
 - Introduce anyone else in the room whom participants should know about (staff, etc.).
- [If media are present, explain their role and how they will operate during the meeting.]

0:10 *Table introductions (15 min.)*

- Set-up
 - *We want you to get to know the people at your tables, so I am now going to give you time for introductions.*
 - *When you are done, I will ask one person from each table to report back to the large group.*
- Turn over to table facilitators, who will lead participants through an introductory exercise.

0:25 *Brief report-out (10 min.)*

- Set-up
 - *I want to hear one hope and one fear from each table. Table 1—someone share one hope that you heard in your group. Table 2.... Table 3...., etc.*
- [Write the hopes and fears on two flip charts or have a note taker record this for you so you can remain facing the audience and focused on the feedback.]

0:35 *Presurvey (15 min.)*

- Set-up
 - *Before we get started, I am going to have you take a short survey.*
 - *This survey is designed to introduce and spark discussion about the ethical dilemmas that health care providers and communities could face during a major disaster when critical medical resources are in short supply.*
 - Explain how to use Audience Response System (ARS) clicker devices. If using paper answer-sheets, ask table facilitators to distribute them to participants and modify instructions accordingly.
 - *To answer, simply push the button that matches your response on your clicker.*
 - *If you make a mistake, you can change your answer by pushing another button as long as I have not moved on to the next slide.*
 - *Ask for a show of hands by anyone who needs help.*
 - *The first several slides ask you to answer some basic questions about you.*
 - *The rest of the slides contain a series of statements about medical care in disasters and pandemics. You will indicate how strongly you agree or disagree with each of these statements by using your clicker device.*
 - *THERE ARE NO RIGHT OR WRONG ANSWERS. Even though you probably won't be sure of your opinion about many of the statements, please respond to them all, even if it is just your gut reaction.*
 - *Your responses will be anonymous—we do not know whose clicker belongs to whom.*

- Later in the day, I will show you the results of the survey.
- Show statements on PowerPoint slides, and read them out loud at a reasonable pace.
- PLEASE KEEP TRACK OF YOUR CLICKERS. We will use them again later. And we need you to return them at the end of the day—they are very expensive, but of no use to you outside of this room!

0:50 Crisis standards of care slide show and Q&A (20 min.)²

- Set-up
 - You no doubt are beginning to have many questions about crisis standards of care. I will now present some background and answer some of your questions.
- Present crisis standards of care slides (screen shots of slides are attached).
- Notes for Slide 4:

KATRINA:

The week after Hurricane Katrina, 1,749 patients and 7,600 others sought shelter at 11 area hospitals. Hospitals required employees to work longer and longer shifts under increasingly desperate conditions. There was little or no power, backup generators were failing, and temperatures above 100 degrees destroyed drugs and equipment. Eyewitness accounts included

- *doctors making rounds by flashlight;*
- *hospital staff unable to electronically control even basic equipment; and*
- *no food, clean water, or plumbing.*

These conditions lasted for days. Individual doctors and nurses were left to decide how to use their limited resources. In the following months, ethical and legal inquiries were made about their decisions and actions because many decisions were made as individuals, and not as part of a crisis response plan.

H1N1:

In the early months of the H1N1 flu pandemic in 2009, officials from the Centers for Disease Control and Prevention, or CDC, realized that not enough vaccine could be made fast enough to cover the whole population right away. The CDC identified the following groups to get vaccine first:

- *pregnant women;*
- *household contacts and caregivers for children under age 6;*
- *health care and emergency medical services personnel;*
- *all people ages 6 months through 24 years;*
- *people ages 25 through 64 years who had health conditions that put them at higher risk of medical complications from the flu.*

These groups were considered highest priority because they were most likely to get the flu and/or suffer the most severe complications.

² Can be presented by lead facilitator or another subject matter expert.

- Notes for Slide 10:

When a disaster leads to shortages of critical medical resources, it will not be possible to treat all patients the way they would be treated under normal conditions. In the presurvey, we asked you to tell us if you agreed or disagreed with certain ways of deciding who should get what care when it is impossible to give all patients everything they need.

*In an actual disaster, many of these choices will require **trade-offs**. For example, some of you probably agreed that we should both (1) save as many lives as possible and (2) give special treatment to health care workers. But what if prioritizing health care workers leads to fewer people being saved overall? How should we balance these competing goals?*

There are no easy answers—just pros and cons to every possible strategy:

Distributing resources “first-come, first-served”

Pro: Easy to administer; feels “fair” to many

Con: Some may question whether they’ll have the same notice and ability to “get in the line” as others

Treating all patients equally (lottery, drawing straws, etc.)

Pro: A lottery feels fair, is hard to manipulate

Con: A lottery ignores the fact that some people will need treatment more than others in order to survive

Saving the most lives possible

Pro: It makes sense to save as many people as possible—so it makes sense to use resources for those with the best chance to benefit from treatment

Con: Certain groups of people (people with health conditions related to age, disability, or chronic disease) who might be less likely to live or who take more resources to treat may end up lower on the priority list

Taking care of health care workers and emergency responders who risk their own health to help others

Pro: It is important to protect people who take risks to say “thank you”; if they aren’t protected, maybe they’ll decide not to go to work

Con: These workers have jobs—that’s already a privilege over people who can’t get work; many of them took an oath—they will and should go to work regardless

Protecting people whose jobs keep society functioning (utility, health care, and transportation workers, etc.)

Pro: Disasters pose two kinds of threats to life and health: the disaster itself (like flooded waters or disease) and the threats caused by collapse of life-saving functions (like power and heat going out or clinics being closed). Prioritizing preventive care and treatment to key workers can help keep them healthy or allow them to recover so they can continue to help others.

Con: If you give too many resources to workers, there won’t be enough left for the general public. Badly injured or very sick workers won’t recover in time to help during the crisis.

- Offer to take questions about what was covered in the slides for whatever time is left. Ask for a show of hands.

1:10 Earthquake scenario discussion (40 min.)

- Set-up
 - We will now discuss a scenario about a shortage of medical resources following a major earthquake. You will be asked to make and explain some hard choices about which patients should receive care.
 - Ask table facilitators to hand out the scenario and worksheets.
 - Read the scenario out loud to the large group (just the scenario, not the associated questions).
 - Ask if anyone needs clarification about the facts of the scenario.
 - Your table facilitator will review the scenario with you and explain your task in more detail.
 - Your note taker will record the key points from your discussion on a master worksheet. The note taker will not record the names of who said what.
 - Later on, I will ask one person from each group to report back your table's key decisions and discussion points to the larger group.

- Turn over to table facilitator

1:50 Earthquake scenario report-out (30 min.)

- Set-up
 - You will guide a representative from each table through the report-out of key decisions and takeaways from the earthquake scenario.
 - A note taker will record key points on flipcharts at the front of the room, if practical.

- Report-out
 - Ask for volunteers from each of the tables.
 1. How did your table come out on the ranking activity?
 - Which patients did you select to receive treatment?
 - Which patients did you select NOT to receive treatment?
 - Was there a high level of agreement or disagreement among people at your table?
 - What were the main reasons behind your table's decisions?
 - Then, pose the following questions to the large group:
 1. Did you consider:
 - **Likelihood of survival**
 - How important was likelihood of survival in deciding who should receive treatment?
 - Did the patient's expected quality of life affect your decision?
 - **Age**
 - How important was age in deciding who should receive treatment?
 - What were your reasons for favoring or not favoring younger people? Older people?
 - **Other considerations?**
 2. Is there anything else people wanted to know about **the patients** or **the circumstances** before deciding who to treat?
 3. Did most of your group feel that their choices seemed fair? Why or why not?
 - Ask all tables to report on the values and goals that they believe are most important to decisions like these.
 - One last question to large group: *What did your group find most challenging about this exercise?*

2:20 Break (30 min.)

- We will now take a break. Please be back in 30 minutes.

2:50 Deadly virus scenario discussion (40 min.)

- Set-up
 - We will now conduct a discussion about a scenario about a deadly virus for which there is not enough of a lifesaving drug to go around. You will be asked to make and explain some hard choices about which patients should receive the limited supply of the drug.
 - Your table facilitator will hand out the scenario and discussion. He or she will read through the scenario with you and explain the task in more detail.
 - As before, your note taker will record the key points from your discussion on a master worksheet. The note taker will not record the names of who said what.
 - Later on, one person from each group will report back your table's key decisions and discussion points to the larger group.
- Turn over to table facilitator

3:30 Deadly virus scenario report-out (30 min.)

- Set-up
 - Ask for table volunteers to report out. Try to start with tables that spoke last during the earthquake scenario report out.
- Report-out
 - Ask half of the tables to report on the first question. After the first table reports out, ask subsequent tables to focus on points that are different from or build off the previous tables' comments:
 1. Should the agency's guidelines give health care workers priority for treatment? How about other workers on whom society relies for saving lives (e.g., electrical power and water supply workers, police, firefighters, and other key workers)?
 - What did your group find were the best reasons for and against such a policy?
 - Did a health care worker's specific role or contact with patients matter to people at your table? (e.g., patient care providers such as doctors and nurses; custodians or food service workers; managers or administrative staff)?
 - Did people in your group think it mattered whether the worker would recover in time to return to work during the crisis?
 - How did your group respond to the question: Should key workers' family members who catch the virus be given priority for treatment?
 - Ask the other half of the tables to report on the second question, again building off the comments of previous tables:
 2. In order to save the most lives, the agency is planning to direct all hospitals and clinics to restrict use of the antiviral drug to sick patients in the two high-risk groups (pregnant women and previously healthy young adults) until more of the drug becomes available.
 - What did your group think about this policy? What were your reasons for agreeing or disagreeing?
 - Is it important for all hospitals and clinics in the city to follow the same rules when deciding which patients to treat?

- *What did your group think? Why or why not?*
- *Did those who thought everyone should follow the same rules believe there are some circumstances when individual hospitals or doctors should be allowed to make decisions that go against the rules?*
- Ask all tables to report on the following question:
 - “It is now day 3 of treatment for patients in the first group to receive the drug. Two of those patients have not responded to treatment, and their doctors now believe they will almost certainly die. If treatment is stopped now, there will still be enough of the drug left over to treat one more patient who might be saved. The families of the two dying patients will not agree to end the treatment.”
 - *What did your group think about the question: Should the hospital go against the patients’ and families’ wishes and use the remaining doses to try to save another patient?*
- Ask all tables to report on the values and goals that they believe are most important to decisions like these.

4:00 *Postsurvey and large-group discussion (30 min.)*

- **Set-up**
 - *You are now going to retake the same survey you completed at the beginning of the session. Use your clickers to respond.*
 - *After you are done, I will show you the results of both surveys and how they compare. Then we can discuss.*
- **Conduct survey**—read slides out loud as in presurvey
- **Display comparison slides**
 - As you run through slides, identify those where there is either wide variation in opinions OR a significant change between the pre- and postsurveys.
 - Ask participants what they conclude from these variations or changes.
 - Ask participants to volunteer WHY they took the position they did on these questions.

4:30 *Final large-group question and wrap-up (20 min.)*

- **Final Question** to the full group
 - *In an actual disaster, what do you think would make people more likely to understand and accept decisions to give scarce medical treatments to some groups or individuals over others? What do you think would make them less likely to accept such decisions?*
- Have participants raise their hands to offer a comment.
- Ask a note taker to record key points on a piece of paper.
- **Words from Sponsor**
 - Brief presentation on local disaster preparedness planning initiatives and resources, and the importance of individual and community preparedness
- **Wrap-up**
 - *This almost concludes our community conversation.*

- *We have covered a lot of ground. If you have questions or comments that were not addressed during the session, please feel free to write them on one of the index cards on your table. If it is a question to which you would like a response, please include your name and a way you can be reached and someone will get back to you.*

4:50 Evaluation (10 min.)

- *Finally, I am going to ask you to use your clickers to answer some questions about what you thought of today's session [show slides and read questions aloud].*
- *Your table facilitator will now hand you a comment form for you to complete and turn in.*
- *Please write your table number in the space at the top of the form, but DO NOT write your name.*
- *Your evaluation of this community conversation is very important to us. I know you have been working hard all day, but please take some time to share your thoughts.*
- *Your table facilitator will collect from each of you:*
 - *Your evaluation/comment form.*
 - *Any index cards on which you wrote questions or comments.*

5:00 Participants adjourn

- *Thank you for your attention and hard work throughout this session.*
- *Your participation in this session has made a valuable contribution to this important work on crisis standards of care.*
- **Remind facilitators and note takers to gather all materials and clickers, place them in the large envelope, and convene for debriefing.**
- *Say goodbye and thank participants for coming.*

Program Materials

GROUND RULES

1. Participate actively
2. Listen with respect—only one person talks at a time
3. Keep an open mind
4. What is shared in the room stays in the room
5. Silence cell phones

Why did you decide to attend today’s community conversation?

“In a disaster, my greatest hope for my community is that...”

“In a disaster, my greatest fear is that...”

*This worksheet will help you collect your thoughts. Writing is always optional. The note takers will record key points—but not anyone’s name.

	<input type="checkbox"/> 18-30	<input type="checkbox"/> 31-50	<input type="checkbox"/> 51-65	<input type="checkbox"/> 66-80	<input type="checkbox"/> 81+
b. Adults					
researcher, or educator)?	<input type="checkbox"/> Yes <input type="checkbox"/> No				
emergency response?					



2.	More medical care should go to save younger patients because they have the most years to live.	1	2	3	4
		Strongly Agree	Agree	Disagree	Strongly Disagree
4.	The sick and injured should be treated “first-come, first-served”—whether or not they are likely to survive.	1	2	3	4
		Strongly Agree	Agree	Disagree	Strongly Disagree

¹ Sponsors should choose from (or add to) the following opinion statements so that they reflect the actual scope of the issues on which they are seeking public input.

² Sponsors should ask these demographic questions only if they intend to analyze the results according to these subgroups.

6. Family members of health care workers should be at the front of the line for vaccines and treatment if they face an increased risk of illness.	1 Strongly Agree	2 Agree	3 Disagree	4 Strongly Disagree
7. People should not get limited medical resources if they will survive, but end up severely disabled.	1 Strongly Agree	2 Agree	3 Disagree	4 Strongly Disagree
8. Health care providers should be at the front of the line for care if they will be able to help save others when they recover.	1 Strongly Agree	2 Agree	3 Disagree	4 Strongly Disagree
9. Most medical care should go to patients who probably will die unless they receive treatment.	1 Strongly Agree	2 Agree	3 Disagree	4 Strongly Disagree
10. Elderly patients should get less medical care so that more children and young adults can be saved.	1 Strongly Agree	2 Agree	3 Disagree	4 Strongly Disagree
11. Health care providers should be at the front of the line for treatment if they are risking their health and safety to care for others.	1 Strongly Agree	2 Agree	3 Disagree	4 Strongly Disagree
12. A person's ability to pay should not matter when deciding who should receive limited medical resources in a crisis.	1 Strongly Agree	2 Agree	3 Disagree	4 Strongly Disagree
13. Every hospital in the disaster area should follow the same rules when deciding how to use limited medical resources.	1 Strongly Agree	2 Agree	3 Disagree	4 Strongly Disagree
14. People who do jobs that keep society running (transportation workers, utility workers, etc.) should be at the front of the line for treatment.	1 Strongly Agree	2 Agree	3 Disagree	4 Strongly Disagree
15. Elderly patients should get more medical care than younger people because they have important wisdom and experience.	1 Strongly Agree	2 Agree	3 Disagree	4 Strongly Disagree
16. Doctors and nurses should be free to make their own decisions about which patients will get treatment and which ones will not.	1 Strongly Agree	2 Agree	3 Disagree	4 Strongly Disagree
17. More medical care should go to save young and middle-aged adults because they care for children and elders and make up society's workforce.	1 Strongly Agree	2 Agree	3 Disagree	4 Strongly Disagree
18. The best way to decide who should be treated is to do a lottery or draw straws.	1 Strongly Agree	2 Agree	3 Disagree	4 Strongly Disagree

1

"Crisis Standards of Care"

A Community Conversation

[Location]
[Date]

[Sponsor]

"Disaster" Defined

What do disasters have in common?

- People's needs exceed available resources
- Help cannot arrive fast enough



How do disasters differ?

- Some are long-lasting and widespread (*flu pandemic*)
- Others are sudden and geographically limited (*earthquake, terrorist attack*)



Preparing for Disasters: *The Challenge*

- Disasters can lead to **shortages of critical medical resources**
- Shortages require **hard decisions**, *for example*—
 - Who should be at the front of the line for vaccines or antiviral drugs?
 - Which patients should receive lifesaving ventilators or blood?
- In extreme cases, **some people will not receive all of the treatment they need**

How do we give the best care possible under the worst possible circumstances?

Recent Examples

Hurricane Katrina

- **Hospital overload**



H1N1 Pandemic

- **Vaccine shortage**



The Response: “Crisis Standards of Care”

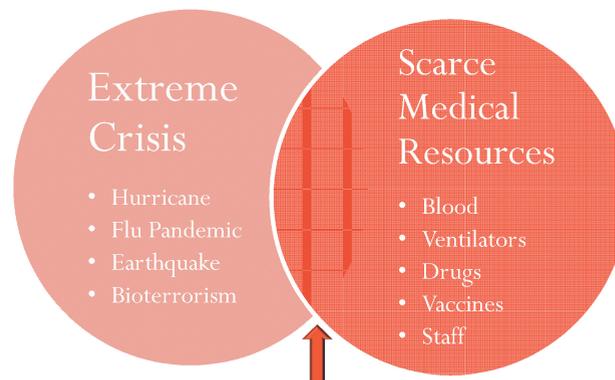
Guidelines developed **before disaster strikes**—

To help healthcare providers decide how to administer...

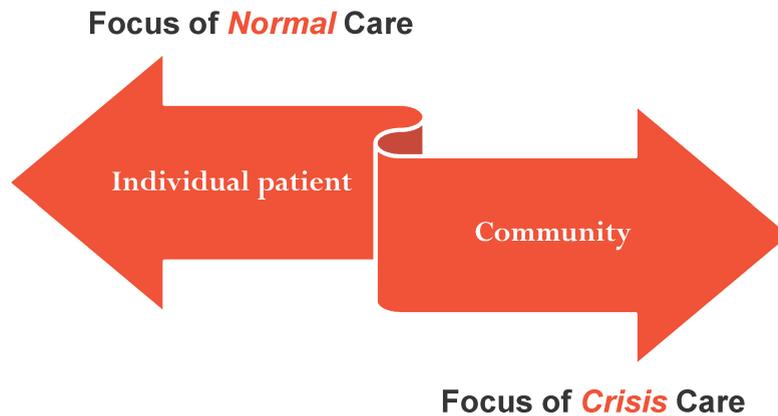
THE BEST POSSIBLE MEDICAL CARE

...when there are not enough resources to give all patients the level of care they would receive under normal circumstances.

When Might We Need Crisis Standards of Care?



How Are Crisis Standards of Care **Different?**

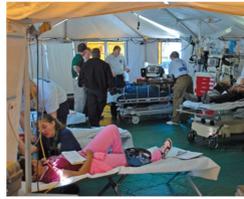


Possible Reasons for Crisis Standards of Care

- To make sure that critical resources go to those who will **benefit the most**
- To **prevent hoarding** and **overuse** of limited resources
- To **conserve limited resources** so more people can get the care they need
- To **minimize discrimination** against vulnerable groups
- So all people can **trust** that they will have fair access to the best possible care under the circumstances

Possible Strategies to Maximize Care

- **Space**
 - Put patient beds in hallways, conference rooms, tents
 - Use operating rooms only for urgent cases
- **Supplies**
 - Sterilize and reuse disposable equipment
 - Limit drugs/vaccines/ventilators to patients most likely to benefit
 - Prioritize comfort care for patients who will die
- **Staff**
 - Have nurses provide some care that doctors usually would provide
 - Have family members help with feeding and other basic patient tasks



When there isn't enough to save everyone... how should we decide who gets what?

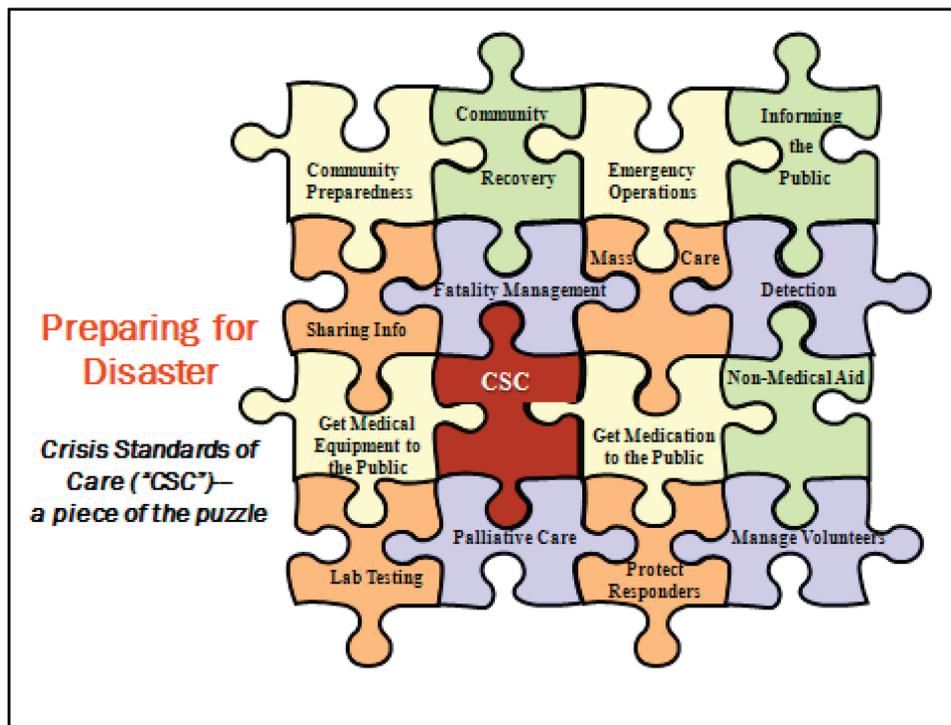
Some options—

1. First-come, first-served?
2. Lottery?
3. Save the most lives possible by giving more care to people who need it the most?
4. Favor certain groups?
 - The old OR the young?
 - Healthcare workers and other emergency responders?
 - Workers who keep society running (utility workers, transportation workers, etc.)?

Where Do *You* Come In?

Community Conversations help policy makers:

- **Understand community concerns about** the use of limited medical resources during disasters
- **Develop crisis standards of care guidelines** that reflect *community values and priorities*



Scenario 1: Major Earthquake

Early one morning, without warning, a violent earthquake strikes your community. Buildings sway and many crumble to the ground. Water shoots out from broken water-main lines, and electric power seems to be out everywhere.

Highways and main streets are blocked by debris, bridges have collapsed into the river, and railroad tracks and airport runways are badly damaged. Phone service, television, radio, and other means of communications are severely disrupted, adding to the anxiety and concern of people in the community. The number of injured and dead is quickly rising.

It is now 12 hours after the earthquake. Your community's only hospital is caring not only for earthquake victims, but for patients with other serious health problems unrelated to the earthquake. Critical medical supplies are starting to run out. The health care workers and emergency personnel who were able to report to work are stretched to the limit. Patients are being placed in hallways and cafeterias as space begins to run out. The community is cut off from outside federal and state help and will not be reconnected for some time. The hospital has nowhere to turn.

The hospital has nine critically injured or sick patients, but only enough medical supplies and staff to treat five of them. The four patients who do not receive treatment probably will die before more help arrives—these patients will continue to receive comfort care to minimize their suffering.

1. Which of the following patients should receive treatment?

Patients Who Need Immediate Treatment			Rank 1 = Treat First 9 = Treat Last
Patient ID	Age	Chance of Survival with Treatment	
A	2	Low (10-30%)	
B	35	Low (10-30%)	
C	80	Low (10-30%)	
D	11	Medium (40-60%)	
E	55	Medium (40-60%)	
F	75	Medium (40-60%)	
G	8	High (70-90%)	
H	25	High (70-90%)	
I	85	High (70-90%)	

2. Discussion Questions

1. **Patient ranking**
 - a. Which patients did you select to receive treatment?
 - b. Which patients did you select NOT to receive treatment?

2. What were the **main reasons** behind your decisions? Did you consider:
 - a. **Chance of survival**
 - i. How important is chance or likelihood of survival in deciding who should receive treatment?
 - ii. Would the patient's long-term quality of life affect your decision?
 - b. **Age**
 - i. How important is age in deciding who should receive treatment?
 - ii. What would be your reason(s) for favoring or not favoring younger people? Older people?
 - c. **Any other factors?**

3. Is there anything else you wanted to know about **the patients** or **the circumstances** before deciding who to treat?

4. When you can't save everyone, what matters most? What values or goals are most important?
 - a. Providing care on a "first-come, first-served" basis?
 - b. Lottery or drawing straws?
 - c. Saving the most lives—by giving limited resources to people who need them the most?
 - d. Other?

5. Did your decisions about whom to treat seem **fair** to you?
 - a. Why or why not?

For your information, see the next page for the guidance provided to table facilitators and note takers on how to conduct this scenario

FOR TABLE FACILITATORS AND NOTE TAKERS

Scenario Discussion 1—Earthquake

Purpose: This scenario is designed to elicit views specifically on *age* and *chance of survival* as criteria for scarce resource allocation. It also seeks opinion on what *values and goals* should drive these hard decisions.

Method:

1. Distribute Scenario Worksheet
2. Read scenario aloud
3. Ask participants to rank patients on the chart
4. Lead a discussion of the follow-up questions
5. Give participants a chance to revise their patient rankings based on the discussion
6. Record key points on template for use in report-out session
7. Have the group select one person to report out your table's key points (if no one is willing, one of you can perform this role)

Remember: Participants do not have to write their answers to the scenario questions. You are responsible for reading the scenario, leading the discussion, and recording key points.

Discussion:

1. Affirm that today's questions are unusual and challenging (intellectually and emotionally), and this is why broad public input is important. If the answers were obvious, there would be no need for input.
2. Stress the importance of hearing from everyone and respectfully listening to one another.
3. Explain in advance that you might have to interrupt from time to time, not because someone's comment is unimportant, but because it's important that all have a chance to be heard.
4. Ask for (but do not force) responses from everyone at the table. Work at a friendly and crisp pace. Try to manage the conversation so that one or two voices do not dominate the discussion. Use your own judgment about intervening a little (if the group is conversing easily and well) or a lot (if the group is struggling or going off track).
5. Groups are free to come to agreement (and you may assist them to get there). However, consensus is *not* required, and opposing views do not have to be reconciled. It is more important that various perspectives and ideas are shared and heard within the group.
6. **Ask WHY!** This is one of the main objectives of the day: to understand the *WHYs*. Emphasize the importance of sharing the reasons behind opinions. This will help everyone understand each other better. Ask what values and criteria people use to guide their answers. Probe for the underlying values, goals, interests, fears, hopes.
7. State and seek confirmation of the key themes you hear, including views held in common and issues seen differently around the table.

Scenario 2: New Deadly Virus

A new deadly virus has killed many thousands of people around the world. It is highly contagious and is now spreading quickly in the United States.

There is only one known treatment for people who fall ill with this virus—an antiviral drug that is in short supply worldwide. It will take several months to make enough of this drug to treat most of the people in this country who need it. A vaccine to protect against this virus will not be ready for even longer, so the numbers of people sickened by the virus will continue to rise.

The virus reached your community last week. People of all walks of life have started to fall ill, including health care and other emergency workers. Of those people who catch the virus, 20 percent will die if they are not treated with the drug. Although everyone is at risk of dying, experts have determined that among those who catch the virus, healthy young adults and pregnant women face the highest risk of death by far.

Your community's public health agency will receive its first supply of the antiviral drug in a few days, but only enough to treat fewer than half of the seriously ill patients who currently need this treatment. The agency will divide the drugs between the local hospitals and temporary clinics that have been set up to handle the overflow of patients. The hospitals and clinic will have to make do with whatever supply of the antiviral drug they receive—there is no other source from which they can get more at the present time. Patients who are chosen for treatment will need to take the drug for 7 days.

The agency is now preparing guidelines to help the hospitals and clinics decide which patients to treat with this limited supply of the antiviral drug.

Discussion Questions

1. Should the agency's guidelines give health care workers priority for treatment? How about other workers on whom society relies for saving lives (e.g., electrical power and water supply workers, police, firefighters, and other key workers)?
 - a. What are the best reasons for and against such a policy?
 - b. Does a health care worker's specific role or contact with patients matter (e.g., patient care providers such as doctors and nurses; custodians or food service workers; managers or administrative staff)?
 - c. Does it matter whether the worker would recover in time to return to work during the crisis?
 - d. Should key workers' family members who catch the virus be given priority for treatment?

2. To save the most lives, the agency is planning to direct all hospitals and clinics to restrict use of the antiviral drug to sick patients in the two high-risk groups (pregnant women and previously healthy young adults) until more of the drug becomes available.
 - a. Do you agree with this policy? Why or why not?
 - b. Is it important for all hospitals and clinics in the city to follow the same rules when deciding which patients to treat?
 - i. If not, why?
 - ii. If so, are there some circumstances in which individual hospitals or doctors should be allowed to make decisions that go against the rules?
3. It is now day 3 of treatment for patients in the first group to receive the drug. Two of those patients have not responded to treatment, and their doctors now believe that they will almost certainly die. If treatment is stopped now, there will still be enough of the drug left over to treat one more patient who might be saved. The families of the two dying patients will not agree to end the treatment. Should the hospital go against their wishes and use the remaining doses to try to save another patient?

For your information, see the next page for the guidance provided to table facilitators and note takers on how to conduct this scenario

FOR TABLE FACILITATORS AND NOTE TAKERS

Scenario Discussion 2: Deadly Virus

Purpose: To elicit views on **key worker status** as a criterion for scarce resource allocation. Also addresses role of government in promoting **consistent application of rules** and **withdrawal of treatment**.

Method:

1. Distribute scenario worksheet
2. Read scenario aloud
3. Lead a discussion of the questions
4. Record key points on template for use in report out session
5. Have the group select one person to report out your table's key points (if no one is willing, one of you can perform this role)

Strategies to encourage participants to take a position:

- Some people will find creative ways to avoid making decisions like these altogether. The idea of withholding or denying critical medical care is uncomfortable, and some participants may offer suggestions to avoid such an outcome, such as “develop domestic manufacturing capacity,” “increase stockpiles,” or “use isolation and quarantine to prevent the spread of the disease.”
- To move the conversation along, consider the following PROMPTS:
 - Withholding critical medical resources is always a last resort. Federal and state governments have stockpiled drugs and other critical medical supplies, and have plans for isolation and quarantine. Everyone agrees on the desire to avoid denying anyone life-saving care, so let's not spend time on that.
 - When confronting a new, deadly virus, no matter how much we plan in advance and work to control the disease's spread, shortages are inevitable. We're here to discuss what should happen when, despite the best planning, there are not enough resources to go around.
 - Invite participants to write their other suggestions on a 3x5 card.

Strategies for addressing suggestions by participants that some groups should be “excluded”:

- PROMPT: The emphasis of this discussion is to determine who should come first, second, and so on, not whether some groups should be excluded completely. Focusing on the “tail end” of the problem isn't the most important aspect of the discussion.
- PROMPT: Ask for clarification: “Are you saying that X group should get no resources at all under any circumstances, or are you saying that X group should be ‘deprioritized’ and receive resources later than other groups?”
- Note takers should capture “exclusion” concerns/recommendations.
- Remind participants of the option to put such concerns/recommendations on 3x5 cards.

Evaluation

Your Table Number: _____				
A. The <i>table introductions</i> and community <i>hopes and fears exercise</i> helped me feel comfortable and got my table's conversation started.				
Strongly Agree <input type="checkbox"/>	Somewhat Agree <input type="checkbox"/>	Undecided <input type="checkbox"/>	Somewhat Disagree <input type="checkbox"/>	Strongly Disagree <input type="checkbox"/>
B. The <i>first survey</i> gave me a good idea of what today's program would be about.				
Strongly Agree <input type="checkbox"/>	Somewhat Agree <input type="checkbox"/>	Undecided <input type="checkbox"/>	Somewhat Disagree <input type="checkbox"/>	Strongly Disagree <input type="checkbox"/>
C. The <i>introductory slide presentation</i> helped me understand what crisis standards of care are about.				
Strongly Agree <input type="checkbox"/>	Somewhat Agree <input type="checkbox"/>	Undecided <input type="checkbox"/>	Somewhat Disagree <input type="checkbox"/>	Strongly Disagree <input type="checkbox"/>
D. The <i>earthquake and deadly virus scenarios</i> were a good way to discuss how decisions about limited medical resources should be made.				
Strongly Agree <input type="checkbox"/>	Somewhat Agree <input type="checkbox"/>	Undecided <input type="checkbox"/>	Somewhat Disagree <input type="checkbox"/>	Strongly Disagree <input type="checkbox"/>
E. When I took the <i>second survey</i> , I had a better understanding of the statements.				
Strongly Agree <input type="checkbox"/>	Somewhat Agree <input type="checkbox"/>	Undecided <input type="checkbox"/>	Somewhat Disagree <input type="checkbox"/>	Strongly Disagree <input type="checkbox"/>
F. The session helped me understand the difficult decisions that health care providers might have to make in a disaster.				
Strongly Agree <input type="checkbox"/>	Somewhat Agree <input type="checkbox"/>	Undecided <input type="checkbox"/>	Somewhat Disagree <input type="checkbox"/>	Strongly Disagree <input type="checkbox"/>
G. Overall, the program gave me a chance to express my ideas.				
Strongly Agree <input type="checkbox"/>	Somewhat Agree <input type="checkbox"/>	Undecided <input type="checkbox"/>	Somewhat Disagree <input type="checkbox"/>	Strongly Disagree <input type="checkbox"/>
H. Overall, the program gave me a chance to hear other people's views.				
Strongly Agree <input type="checkbox"/>	Somewhat Agree <input type="checkbox"/>	Undecided <input type="checkbox"/>	Somewhat Disagree <input type="checkbox"/>	Strongly Disagree <input type="checkbox"/>
I. I would recommend that my friends and family attend an actual community conversation on crisis standards of care if they have the chance.				
Strongly Agree <input type="checkbox"/>	Somewhat Agree <input type="checkbox"/>	Undecided <input type="checkbox"/>	Somewhat Disagree <input type="checkbox"/>	Strongly Disagree <input type="checkbox"/>

Which parts of this session did you find most valuable?

Was there anything missing (e.g., certain information you wish we had provided, other topics you thought the survey or scenarios should have covered)?

Please share any additional thoughts.

*“CRISIS STANDARDS OF CARE”
IN DISASTERS AND PANDEMICS
A Community Conversation*

GUIDEBOOK FOR TABLE FACILITATORS AND NOTE TAKERS

Including Annotated Agenda and Program Materials

Developed by the Institute of Medicine of the National Academies

This Guide

Thank you for serving as a table facilitator or note taker for a community conversation on crisis standards of care. This guide will provide you with the information and tools you will need to help lead a meaningful discussion about the allocation of scarce medical resources during extreme disasters and pandemics. It includes

- background information on crisis standards of care;
- the purpose and goals of community conversations like the one in which you are about to participate;
- an annotated agenda of the day’s activities;
- copies of the surveys, scenarios, and discussion questions;
- general advice on facilitation and note taking; and
- talking points and specific guidance on how to use the various program materials.

Please read this guide in its entirety before arriving at the session. Although you will complete a pre-session training, you will get more out of that training and be more comfortable leading your groups if you are already familiar with the activities and discussion questions, the types of questions we anticipate, and strategies for responding and moving your table discussions forward.

What are “crisis standards of care” and why do we need them?

States, counties, tribes, and territories across the United States have been preparing for disaster situations, whether naturally occurring or manmade. If a disaster or pandemic were to strike, temporarily overwhelming our ability to provide health care as usual to everyone in need, how should scarce medical resources be allocated? How could the delivery of care be altered to maximize lives saved? How can this all be coordinated to ensure the most fair, ethical, and nondiscriminatory use of resources? Recent events at home and abroad—from Hurricane Katrina to the H1N1 pandemic to the Haiti earthquake—show the importance of addressing these concerns in advance. One part of this disaster planning is the development of **crisis standards of care**—ethical and clinical protocols and frameworks for delivering health care when medical resources are insufficient to provide care as usual.

One of the main goals of crisis standards of care is to save more lives than would be saved by business as usual. Crisis standards of care help conserve and stretch medical resources so they can help as many patients as possible in order to

- give critical resources to those who need them and/or will benefit the most;
- prevent hoarding and overuse of scarce resources;
- protect at-risk groups against discrimination in access to care; and
- ensure patients and their families trust that they will receive fair access to the best possible care under the circumstances.

CRISIS STANDARDS OF CARE

Guidelines developed before disaster strikes to help health care providers decide how to administer...

THE BEST POSSIBLE MEDICAL CARE

...when there are not enough resources to give all patients the level of care they would receive under normal circumstances.

How would crisis standards of care work?

Crisis standards of care guidelines

- promote best possible medical practice under the circumstances;
- allow reasonable health care provider discretion;
- adapt to the ever-changing circumstances of disasters; and
- emphasize early conservation, adaptation, and substitution of medical resources to avoid having to resort to more extreme measures.

Crisis standards of care guidelines stay in effect only until it is possible to return to normal care. The measures taken are only those needed to cope with the degree of lack of resources (so that the restrictions are proportional, or balanced to the demand).

Without a plan and good communication, different providers and hospitals may be functioning with different levels of resources and make very different decisions. This could lead to inconsistent levels of care in the community from hospital to hospital, which would be not only confusing, but unfair. Crisis standards of care require that medical providers, facilities, public health agencies, and public safety agencies have a plan to work together to do the most they can with the resources available.

When might crisis standards of care be needed? Examples

Two recent disasters offer examples of when crisis standards of care might be needed, as described in the following boxes.

Example 1: Hurricane Katrina—Hospital Overload

The week after Hurricane Katrina, 1,749 patients and 7,600 others sought shelter at 11 area hospitals. Hospitals required employees to work longer and longer shifts under increasingly desperate conditions. There was little or no power, backup generators were failing, and temperatures above 100 degrees destroyed drugs and equipment. Eyewitness accounts included

- doctors making rounds by flashlight;
- hospital staff unable to electronically control even basic equipment; and
- no food, clean water, or plumbing.

These conditions lasted for days. Individual doctors and nurses were left to decide how to use their limited resources. In the following months, ethical and legal inquiries were made about their decisions and actions because many decisions were made as individuals, and not as part of a crisis response plan.

Example 2: Flu Pandemic (H1N1)—Vaccine Shortage

In the early months of the H1N1 flu pandemic in 2009, officials at the Centers for Disease Control and Prevention (CDC) realized that not enough vaccine could be made fast enough to cover the whole population right away. The CDC identified the following groups to get vaccine first:

- pregnant women;
- household contacts and caregivers for children under age 6;
- health care and emergency medical services personnel;
- all people ages 6 months through 24 years; and
- people ages 25 through 64 years who had health conditions that put them at higher risk of medical complications from the flu.

These groups were considered highest priority because they were most likely to get the flu and/or suffer the most severe complications.

Why are community conversations on crisis standards of care necessary?

Involving community members in the development of crisis standards of care is important because the values of ordinary citizens should inform the actions of professionals, especially when there are no reliable ways to predict survival that help providers make decisions. Meaningful community engagement is critical for successful development, dissemination, and implementation of crisis standards of care. Community conversations take place before a disaster strikes for the purpose of enabling participants to understand each other's perspectives while tackling complex issues associated with allocating scarce medical resources.

What are the goals of a community conversation?

Community conversations on crisis standards of care are designed to

- inform members of the public about the concept of crisis standards of care and why they are necessary;
- ensure broad participation and ensure that vulnerable, hard-to-reach populations are represented;
- increase awareness and understanding about the development of a crisis standards of care plan or an existing draft plan; and
- gather input on the ethical considerations and priorities that should be the basis of a crisis standards of care plan or that are included in a draft crisis standards of care plan under review.

What is the public's role in developing crisis standards of care?

The voices of community members are important to the development of crisis standards of care. This is because crisis standards of care must reflect the community's ethical values and priorities about the use of scarce medical resources during disasters.

At this community conversation, participants will have a chance to share their opinions and concerns—not just hear from the “experts.” All participants will be encouraged to consider what principles should guide crisis standards of care, and to hear what others think.

How is the information from community conversations used?

Crisis standards of care raise challenging issues over which reasonable people will disagree. Community conversations help public health officials understand what values are important to individuals and to the entire group, and on what issues people differ.

The goal is *not* to reach consensus or agreement, or to take a vote. Instead, the opinions and concerns raised in this discussion will ensure that any final crisis standards of care guidelines accurately reflect, as much as possible, the views of the community about what is as fair and ethical as possible.

Facilitator and Note Taker Guiding Principles

Facilitation is a way of providing leadership without taking over control. A facilitator’s job is to get others to assume responsibility and to take the lead.

1. Preparation is key!

- Familiarize yourself with the agenda, activities, and goals of this session by reading this guide. Make note of any questions so that you can ask them at the presession training.
- Pay close attention to the text boxes labeled “*For Facilitators and Note Takers*” in the program materials below. These contain step-by-step instructions and suggestions for running each of the small-group activities.

2. Facilitator Responsibilities:

- You are in charge of keeping the table discussions flowing and on topic.
- You can take notes if you wish. At the end of the session, please turn in any notes that help supplement your note taker’s notes.
- Facilitators set the tone and make it an engaging, inclusive event for everyone:
 - Explain or repeat questions if necessary
 - Keep the discussion on topic
 - Explore disagreements, but defuse unproductive arguments
 - Encourage the “quieter” members to participate at a level that is comfortable
 - Manage individuals who are dominating the discussion
 - Enforce the ground rules (see below)
 - Thank participants for their contributions

3. Note Taker Responsibilities:

- You are in charge of capturing the discussion—what people recommend, what concerns them, and always “why, why, why”—the reasons behind their opinions.
- Think of yourselves as “co-facilitators.” If you see that the group is stuck or has strayed off topic, offer a suggestion. If you don’t understand someone’s comment, ask for clarification.
- Note takers record major themes, comments, and ideas:
 - During table discussions, record your notes on the notepads provided
 - After the discussion, summarize your notes on the templates provided for each activity

- **To preserve confidentiality and privacy, do NOT record any names.** Who said what is not important
 - Be as detailed, accurate, and neat as possible
 - Make note of significant non-verbal behavior (e.g., facial expressions, group dynamics)
 - Do not include your own opinions in the notes
4. **Facilitators and note takers are neutral for purposes of the discussions and should not offer opinions regarding the substance of the issues.**
 5. **Do not expect or push for consensus.** It is more important to elicit and understand the wide range of opinions on these issues.
 6. **Keep track of time** in small-group discussions. Remind people when the current conversation will end and intermittently let the group know how much time remains.
 7. **Be aware of the resources and support available to you:**
 - This guide.
 - The “Quick Reference” sheet that contains an outline of the program and your main tasks and talking points for each activity.
 - 3x5 cards on tables for capturing questions/recommendations.
 - Flip chart—use it if it helps your group, but not if it doesn’t.
 - Roving experts to answer questions and help you facilitate if your group gets “stuck.”

All good facilitation relies on judgment in the moment as to how best to move the conversation, but here are various techniques and prompts that might be helpful.

Facilitation Skill	Examples of Verbal Prompts
Set up the discussion clearly and simply	“Our task in the next 20 minutes is to explore this question....”
Manage the allotted time	The time allowed for each table discussion and task will be announced by the lead facilitator, who also will give periodic time warnings. Additionally, you may find it useful to ask someone at your table to play timekeeper. “We have about 5 minutes left, and I want to see if there are any other key ideas that we’ve not heard so far.”
Stay neutral	Focus on the process and avoid offering your opinions about the topic under discussion. Give examples that are in the materials rather than from your experience.
Listen actively and paraphrase	Look people in the eye, use attentive body language, and paraphrase what they say. “Let me see if I can repeat your point in slightly different words. I want to make sure I understand what you are saying.” Or “Are you saying....?”
Synthesize	Help people to comment and build on each other’s thoughts to ensure that the ideas recorded represent collective thinking. This builds consensus and commitment. “Jackie, what can you add to Aaron’s comments?”

Identify possible disagreements	Ask: "Bill, how does this fit with X that you said earlier?"
Summarize periodically	Listen attentively and then offer concise and timely summaries. Summarize when the group is stuck or when you want to wrap up a discussion. "What I have heard you all say is first....second....and finally...."
Ask questions	Questions should serve to further understand what has been said, to elicit comments from others, and to explore issues that might be overlooked.
Use "round robin" or "popcorn"	Ask participants to go around the table so that each participant contributes. In other situations you may prefer "popcorn" style where anyone who has an idea speaks up.
Play ping pong	If someone asks a question or makes a comment, redirect it by sending it back to someone else to answer or build on. "Sally, how would you answer that question that Bill has posed to me?"
Allow participants to reflect	"Before we start, let's take a minute to think to ourselves about the discussion question and our responses. Feel free to jot some ideas on page X in your guide or on your worksheet."
Draw out participants	Use eye contact to let people know they can speak next and to prompt the quiet ones in the crowd to participate. "I want to make sure that we get a chance to hear from everyone."
Gently limit dominant voices to equalize participation	"I want to see if we could include some other folks in this conversation...."
Curb anecdotes	Lengthy personal anecdotes can quickly sidetrack table discussions. When this occurs, try to gently coax the participant to conclude a lengthy anecdote. You may say, "So, that example leads you to say...."
Explore different points of view	"So Joe has talked about the importance of X, and Mary has raised some concerns with X. I'm wondering how others see X."
Test for support among ideas	"Apparently several people share the view that...."
Check perceptions	Describe what you perceive is the other person's inner state. "You appear upset by the last comment that was made. Are you?"
Test for clarity/ shared agreement	"Does this statement convey what you've been saying about...."

Thank you

Thank you for taking the time to help lead this community conversation. We know that you have limited free time, and appreciate your willingness to spend some of it at this session. Please know that you are performing a valuable public service, and that your contributions will make a difference.

ANNOTATED AGENDA

TIME	ELEMENT	PURPOSE	METHOD/TOOLS
-1:00	Participant Registration	<ul style="list-style-type: none"> Attendance Table assignments Consent (if required) 	<ul style="list-style-type: none"> Registration form Name tags/tent cards with first names only Participants (Ps) read and sign consent form (if required)
0:00	Opening Remarks	<ul style="list-style-type: none"> Welcome participants Introduce leaders/facilitators Briefly describe topic Explain charge of the day 	<ul style="list-style-type: none"> By lead facilitator (LF) Script
0:10	Table Introductions and Exercise	<ul style="list-style-type: none"> Break ice Take temperature—why did they attend, what is on their minds 	<ul style="list-style-type: none"> Tool: Worksheet Table facilitators (TFs) lead introductions, note takers (NTs) record on template Group selects one hope/one fear to report out
0:25	Brief Report-Out	<ul style="list-style-type: none"> Introduce Ps to report-out method Segue into crisis standards of care (CSC) 	<ul style="list-style-type: none"> Moderated by LF Volunteer from each table reports one hope and one fear
0:35	Presurvey	<ul style="list-style-type: none"> Quick immersion into CSC: context, scope, and complexity of the issues Help maintain focus on CSC vs. other preparedness or health care issues Establish baseline opinions 	<ul style="list-style-type: none"> Tools: <ul style="list-style-type: none"> PPT slides of survey statements Audience Response System¹ (ARS) or paper answer sheets LF reads statements aloud; Ps use “clicker” devices to respond or circle responses on answer sheets No review of responses or discussion; LF explains that survey will be repeated and responses discussed later in the session
0:50	Presentation on CSC and Q&A	<ul style="list-style-type: none"> Educate Ps about CSC: what, when, why, how 	<ul style="list-style-type: none"> Tools: Slides LF or content expert presents slides, responds to questions LF introduces scenario discussion, turns it over to TFs

¹ Software and handheld devices for automated data collection and display.

1:10	Earthquake Scenario Discussion	<ul style="list-style-type: none"> Designed to elicit views specifically on age and likelihood of survival as criteria for resource allocation. Also, withdrawals of treatment, and whether all of the regions' health care providers should follow the same rules. Other features: sudden onset, geographically contained event. Methodology: Ps asked to do forced ranking of patients and share their perceptions of the associated challenges. Ps asked to share views on what underlying values and goals should drive decisions. 	<ul style="list-style-type: none"> Scenario and discussion questions
1:50	Earthquake Scenario Report-Out	<ul style="list-style-type: none"> Give table groups chance to share key thoughts and identify points of difference and intersection with the larger group Spark larger group discussion, input Further inform, influence thinking of Ps 	<ul style="list-style-type: none"> Facilitated by LF, with one NT recording key points on flip charts Volunteer from each table presents short summary of scenario findings—emphasis on points of agreement/disagreement, most notable impressions
2:20	Break		
2:50	Deadly Virus Scenario Discussion	<ul style="list-style-type: none"> Designed to elicit views on key worker status as criterion for resource allocation. Also addresses the issues of the role of government agencies in promoting consistent application of CSC rules within the affected area, and withdrawal of treatment. Ps asked to share views on what underlying values and goals should drive decisions 	<ul style="list-style-type: none"> Scenario and discussion questions
3:30	Deadly Virus Scenario Report Out	<ul style="list-style-type: none"> Give table groups chance to share key thoughts and identify points of difference and intersection within the larger group Spark larger group discussion, input Further inform, influence thinking of Ps 	<ul style="list-style-type: none"> Facilitated by LF, with one NT recording key points on flip charts Volunteer from each table presents short summary of scenario findings—emphasis on points of agreement/disagreement, most notable impressions
4:00	Postsurvey and Discussion	<ul style="list-style-type: none"> Identify changes in P views pre- and postsession Give Ps chance to consider range of opinions in the room Satisfy P interest in survey results Final opportunity to elicit more information on P views around CSC issues 	<ul style="list-style-type: none"> Tools: Survey slides and clickers LF reads statements aloud; Ps use clicker devices to respond or circle responses on answer sheets LF shows slides with pre- and postsurvey responses (if using ARS) LF leads large group through discussion of statements where there was the most change or disagreement

4:30	Final Question and Wrap-Up	<ul style="list-style-type: none"> • Big-picture question to wrap up discussion • Words from sponsor about local disaster preparedness planning initiatives and resources, and the importance of individual and community preparedness • Thank Ps 	<ul style="list-style-type: none"> • LF leads brief large-group discussion of final question • Sponsor gives brief presentation on local preparedness landscape and resources
4:50	Evaluation		<ul style="list-style-type: none"> • Tool: Evaluation form (ARS or paper) • TF and NT offer help to participants who need it
5:00	Participants Depart		<ul style="list-style-type: none"> • Ps turn in ARS devices and receive stipends, if applicable
5:15	Facilitator/Note Taker Debrief	<ul style="list-style-type: none"> • To gather data and elicit other relevant information or impressions not contained in the notes and templates 	<ul style="list-style-type: none"> • Led by Sponsor and LF
6:00	Adjourn		

*Program Materials
and Table Facilitator/Note Taker
Guidance*

“CRISIS STANDARDS OF CARE” IN DISASTERS AND PANDEMICS
A Community Conversation

6-74

Quick Reference for Table Facilitators and Note Takers

Time	Activity	Table Facilitator (TF)/Note Taker (NT) Actions
0:10	Table Introductions and Exercise	Distribute introductions worksheet to participants TF—Lead table through introductions and exercise on p. 18 of Guide NT—Record notes on template Select participant to give report-out
0:25	Brief Report-Out	
0:35	Presurvey	Distribute clickers to participants (if using ARS)
0:50	Presentation on CSC and Q&A	
1:10	Earthquake Scenario Discussion	<i>See program materials for detailed guidance on this scenario</i> <i>See program materials for facilitation hints and prompts</i> Distribute earthquake scenario to table participants TF—Lead table through scenario NT—Record notes on template Select participant to give report-out Collect ranking chart
1:50	Earthquake Scenario Report-Out	
2:20	Break	
2:50	Deadly Virus Scenario Discussion	<i>See program materials for detailed guidance on this scenario</i> <i>See program materials for facilitation hints and prompts</i> Distribute earthquake scenario to table participants TF—Lead table through scenario NT—Record notes on template Select participant to give report-out
3:30	Deadly Virus Scenario Report-Out	
4:00	Postsurvey and Discussion	
4:30	Final Question and Wrap-Up	
4:50	Evaluation	Distribute and collect evaluation forms
5:00	Participants Depart	Thank participants
5:15	TF/NT Debrief	
6:00	Adjourn	

FOR TABLE FACILITATORS AND NOTE TAKERS

Starting the small-group process

1. Make participants feel welcome. Thank them for coming.
2. Introduce yourself and the note taker and your respective roles.
3. **Note taker:** Explain that you are NOT writing down participants' names. You're taking notes about what gets said, not who says it.
4. **Facilitator:** Instruct participants not to write their names on any of the program materials so that everything stays anonymous.
5. Explain the ground rules:
 1. *Participate actively*
 2. *Listen with respect—only one person talks at a time*
 3. *Keep an open mind*
 4. *What is shared in the room stays in the room*
 5. *Silence cell phones*
6. Give participants a few minutes to think about the questions on the worksheet below. Tell them that they can jot notes if they would like, but that it is entirely optional.
7. Go around the table and ask people to state their first names and briefly share their answers to the table introduction questions with the group.
8. Ask the group to agree to the one “hope” and one “fear” that they want to report out. Pick two backups for each category in case another table expresses the same ideas before yours.
9. Also recruit a participant volunteer to make the report to the large group.

Table Introductions and Exercise*

GROUND RULES

Why did you decide to attend today's community conversation?

"In a disaster, my greatest hope for my community is that..."

"In a disaster, my greatest fear is that..."

*This worksheet will help you collect your thoughts. Writing is always optional. The Note Takers will record key points—but not anyone's name.

A few questions about you...

1. Sex	<input type="checkbox"/> Male	<input type="checkbox"/> Female			
2. Age	<input type="checkbox"/> 18-30	<input type="checkbox"/> 31-50	<input type="checkbox"/> 51-65	<input type="checkbox"/> 66-80	<input type="checkbox"/> 81+
3. Does your household include any dependents:					
a. Children	<input type="checkbox"/> Yes	<input type="checkbox"/> No			
b. Adults	<input type="checkbox"/> Yes	<input type="checkbox"/> No			
4. Do you work in health care (as a patient care provider, administrator, researcher, or educator)?	<input type="checkbox"/> Yes	<input type="checkbox"/> No			
5. Do you work in public safety or emergency response?	<input type="checkbox"/> Yes	<input type="checkbox"/> No			

IMAGINE that a major disaster or pandemic has struck. Suddenly, there is not enough medical care to give the normal level of treatment to everyone in need.

Do you agree or disagree with the following statements?

1. It is better to save the most lives—even if it means that some people won’t get all of the medical care they would get under normal conditions.	1 Strongly Agree	2 Agree	3 Disagree	4 Strongly Disagree
2. More medical care should go to save younger patients because they have the most years to live.	1 Strongly Agree	2 Agree	3 Disagree	4 Strongly Disagree
3. Health care providers should be allowed to perform services different from their usual duties if that might save more patients.	1 Strongly Agree	2 Agree	3 Disagree	4 Strongly Disagree
4. The sick and injured should be treated “first-come, first-served”—whether or not they are likely to survive.	1 Strongly Agree	2 Agree	3 Disagree	4 Strongly Disagree
5. Firefighters, police, and other first responders should be at the front of the line for medical care because they are important for public safety.	1 Strongly Agree	2 Agree	3 Disagree	4 Strongly Disagree
6. Family members of health care workers should be at the front of the line for vaccines and treatment if they face an increased risk of illness.	1 Strongly Agree	2 Agree	3 Disagree	4 Strongly Disagree
7. People should not get limited medical resources if they will survive, but end up severely disabled.	1 Strongly Agree	2 Agree	3 Disagree	4 Strongly Disagree

8. Health care providers should be at the front of the line for care if they will be able to help save others when they recover.	1 Strongly Agree	2 Agree	3 Disagree	4 Strongly Disagree
9. Most medical care should go to patients who probably will die unless they receive treatment.	1 Strongly Agree	2 Agree	3 Disagree	4 Strongly Disagree
10. Elderly patients should get less medical care so that more children and young adults can be saved.	1 Strongly Agree	2 Agree	3 Disagree	4 Strongly Disagree
11. Health care providers should be at the front of the line for treatment if they are risking their health and safety to care for others.	1 Strongly Agree	2 Agree	3 Disagree	4 Strongly Disagree
12. A person's ability to pay should not matter when deciding who should receive limited medical resources in a crisis.	1 Strongly Agree	2 Agree	3 Disagree	4 Strongly Disagree
13. Every hospital in the disaster area should follow the same rules when deciding how to use limited medical resources.	1 Strongly Agree	2 Agree	3 Disagree	4 Strongly Disagree
14. People who do jobs that keep society running (transportation workers, utility workers, etc.) should be at the front of the line for treatment.	1 Strongly Agree	2 Agree	3 Disagree	4 Strongly Disagree
15. Elderly patients should get more medical care than younger people because they have important wisdom and experience.	1 Strongly Agree	2 Agree	3 Disagree	4 Strongly Disagree
16. Doctors and nurses should be free to make their own decisions about which patients will get treatment and which ones will not.	1 Strongly Agree	2 Agree	3 Disagree	4 Strongly Disagree
17. More medical care should go to save young and middle-aged adults because they care for children and elders and make up society's workforce.	1 Strongly Agree	2 Agree	3 Disagree	4 Strongly Disagree
18. The best way to decide who should be treated is to do a lottery or draw straws.	1 Strongly Agree	2 Agree	3 Disagree	4 Strongly Disagree

Scenario 1: Major Earthquake

Early one morning, without warning, a violent earthquake strikes your community. Buildings sway and many crumble to the ground. Water shoots out from broken water-main lines, and electric power seems to be out everywhere.

Highways and main streets are blocked by debris, bridges have collapsed into the river, and railroad tracks and airport runways are badly damaged. Phone service, television, radio, and other means of communications are severely disrupted, adding to the anxiety and concern of people in the community. The number of injured and dead is quickly rising.

It is now 12 hours after the earthquake. Your community's only hospital is caring not only for earthquake victims, but for patients with other serious health problems unrelated to the earthquake. Critical medical supplies are starting to run out. The health care workers and emergency personnel who were able to report to work are stretched to the limit. Patients are being placed in hallways and cafeterias as space begins to run out. The community is cut off from outside federal and state help and will not be reconnected for some time. The hospital has nowhere to turn.

The hospital has nine critically injured or sick patients, but only enough medical supplies and staff to treat five of them. The four patients who do not receive treatment probably will die before more help arrives—these patients will continue to receive comfort care to minimize their suffering.

1. Which of the following patients should receive treatment?

Patients Who Need Immediate Treatment			Rank 1 = Treat First 9 = Treat Last
Patient ID	Age	Chance of Survival with Treatment	
A	2	Low (10-30%)	
B	35	Low (10-30%)	
C	80	Low (10-30%)	
D	11	Medium (40-60%)	
E	55	Medium (40-60%)	
F	75	Medium (40-60%)	
G	8	High (70-90%)	
H	25	High (70-90%)	
I	85	High (70-90%)	

2. Discussion Questions

1. Patient ranking

- a. Which patients did you select to receive treatment?
- b. Which patients did you select NOT to receive treatment?

2. What were the **main reasons** behind your decisions? Did you consider:

a. Chance of survival

- i. How important is chance or likelihood of survival in deciding who should receive treatment?
- ii. Would the patient's long-term quality of life affect your decision?

b. Age

- i. How important is age in deciding who should receive treatment?
- ii. What would be your reason(s) for favoring or not favoring younger people? Older people?

c. Any other factors?

3. Is there anything else you wanted to know about **the patients** or **the circumstances** before deciding who to treat?

4. When you can't save everyone, what matters most? What values or goals are most important?

- a. Providing care on a "first-come, first-served" basis?
- b. Lottery or drawing straws?
- c. Saving the most lives—by giving limited resources to people who need them the most?
- d. Other?

5. Did your decisions about whom to treat seem **fair** to you?

- a. Why or why not?

For your information, see the next page for the guidance provided to table facilitators and note takers on how to conduct this scenario

FOR TABLE FACILITATORS AND NOTE TAKERS

Scenario Discussion 1—Earthquake

Purpose: This scenario is designed to elicit views specifically on *age* and *chance of survival* as criteria for scarce resource allocation. It also seeks opinion on what *values and goals* should drive these hard decisions.

Method:

1. Distribute Scenario Worksheet
2. Read scenario aloud
3. Ask participants to rank patients on the chart
4. Lead a discussion of the follow-up questions
5. Give participants a chance to revise their patient rankings based on the discussion
6. Record key points on template for use in report-out session
7. Have the group select one person to report out your table's key points (if no one is willing, one of you can perform this role)

Remember: Participants do not have to write their answers to the scenario questions. You are responsible for reading the scenario, leading the discussion, and recording key points.

Discussion:

1. Affirm that today's questions are unusual and challenging (intellectually and emotionally), and this is why broad public input is important. If the answers were obvious, there would be no need for input.
2. Stress the importance of hearing from everyone and respectfully listening to one another.
3. Explain in advance that you might have to interrupt from time to time, not because someone's comment is unimportant, but because it's important that all have a chance to be heard.
4. Ask for (but do not force) responses from everyone at the table. Work at a friendly and crisp pace. Try to manage the conversation so that one or two voices do not dominate the discussion. Use your own judgment about intervening a little (if the group is conversing easily and well) or a lot (if the group is struggling or going off track).
5. Groups are free to come to agreement (and you may assist them to get there). However, consensus is *not* required, and opposing views do not have to be reconciled. It is more important that various perspectives and ideas are shared and heard within the group.
6. **Ask WHY!** This is one of the main objectives of the day: to understand the WHYS. Emphasize the importance of sharing the reasons behind opinions. This will help everyone understand each other better. Ask what values and criteria people use to guide their answers. Probe for the underlying values, goals, interests, fears, hopes.
7. State and seek confirmation of the key themes you hear, including views held in common and issues seen differently around the table.

Note Taker Template

Earthquake Scenario

1. Treatment priorities
[Collect patient ranking charts from participants and attach to this template]
2. What were the main reasons behind the patient ranking decisions? Did they consider:
 - a. **Likelihood of survival**
 - i. How important is likelihood of survival in deciding who should receive treatment?

 - ii. Would the patient's expected quality of life affect the decision?

 - b. **Age**
 - i. How important is age in deciding who should receive treatment?

 - ii. What would be the reason(s) for favoring or not favoring younger people? Older people?

 - c. **Other significant ideas?**
3. Is there anything else participants wanted to know about ***the patients*** before deciding who to treat?
Major themes:

Minor themes of note:

4. Is there anything else participants wanted to know about *the circumstances* before deciding who to treat?

Major themes:

Minor themes of note:

5. *When not everyone can be saved*, what *values or goals* were most important to participants?
 - a. Providing care on a first-come, first-served basis?
 - b. Lottery or drawing straws?
 - c. Saving the most lives—by giving limited resources to people who need them the most?
 - d. Other?
6. Did their choices seem *fair* to participants? Why or why not?

Major themes:

Minor themes of note:

Scenario 2: New Deadly Virus

A new deadly virus has killed many thousands of people around the world. It is highly contagious and is now spreading quickly in the United States.

There is only one known treatment for people who fall ill with this virus—an antiviral drug that is in short supply worldwide. It will take several months to make enough of this drug to treat most of the people in this country who need it. A vaccine to protect against this virus will not be ready for even longer, so the numbers of people sickened by the virus will continue to rise.

The virus reached your community last week. People of all walks of life have started to fall ill, including health care and other emergency workers. Of those people who catch the virus, 20 percent will die if they are not treated with the drug. Although everyone is at risk of dying, experts have determined that among those who catch the virus, healthy young adults and pregnant women face the highest risk of death by far.

Your community's public health agency will receive its first supply of the antiviral drug in a few days, but only enough to treat fewer than half of the seriously ill patients who currently need this treatment. The agency will divide the drugs between the local hospitals and temporary clinics that have been set up to handle the overflow of patients. The hospitals and clinic will have to make do with whatever supply of the antiviral drug they receive—there is no other source from which they can get more at the present time. Patients who are chosen for treatment will need to take the drug for 7 days.

The agency is now preparing guidelines to help the hospitals and clinics decide which patients to treat with this limited supply of the antiviral drug.

Discussion Questions

1. Should the agency's guidelines give health care workers priority for treatment? How about other workers on whom society relies for saving lives (e.g., electrical power and water supply workers, police, firefighters, and other key workers)?
 - a. What are the best reasons for and against such a policy?
 - b. Does a health care worker's specific role or contact with patients matter (e.g., patient care providers such as doctors and nurses; custodians or food service workers; managers or administrative staff)?
 - c. Does it matter whether the worker would recover in time to return to work during the crisis?
 - d. Should key workers' family members who catch the virus be given priority for treatment?

2. To save the most lives, the agency is planning to direct all hospitals and clinics to restrict use of the antiviral drug to sick patients in the two high-risk groups (pregnant women and previously healthy young adults) until more of the drug becomes available.
 - a. Do you agree with this policy? Why or why not?
 - b. Is it important for all hospitals and clinics in the city to follow the same rules when deciding which patients to treat?
 - i. If not, why?
 - ii. If so, are there some circumstances in which individual hospitals or doctors should be allowed to make decisions that go against the rules?
3. It is now day 3 of treatment for patients in the first group to receive the drug. Two of those patients have not responded to treatment, and their doctors now believe that they will almost certainly die. If treatment is stopped now, there will still be enough of the drug left over to treat one more patient who might be saved. The families of the two dying patients will not agree to end the treatment. Should the hospital go against their wishes and use the remaining doses to try to save another patient?

For your information, see the next page for the guidance provided to table facilitators and note takers on how to conduct this scenario

FOR TABLE FACILITATORS AND NOTE TAKERS

Scenario Discussion 2: Deadly Virus

Purpose: To elicit views on **key worker status** as a criterion for scarce resource allocation. Also addresses role of government in promoting **consistent application of rules** and **withdrawal of treatment**.

Method:

1. Distribute scenario worksheet
2. Read scenario aloud
3. Lead a discussion of the questions
4. Record key points on template for use in report out session
5. Have the group select one person to report out your table's key points (if no one is willing, one of you can perform this role)

Strategies to encourage participants to take a position:

- Some people will find creative ways to avoid making decisions like these altogether. The idea of withholding or denying critical medical care is uncomfortable, and some participants may offer suggestions to avoid such an outcome, such as “develop domestic manufacturing capacity,” “increase stockpiles,” or “use isolation and quarantine to prevent the spread of the disease.”
- To move the conversation along, consider the following PROMPTS:
 - Withholding critical medical resources is always a last resort. Federal and state governments have stockpiled drugs and other critical medical supplies, and have plans for isolation and quarantine. Everyone agrees on the desire to avoid denying anyone life-saving care, so let's not spend time on that.
 - When confronting a new, deadly virus, no matter how much we plan in advance and work to control the disease's spread, shortages are inevitable. We're here to discuss what should happen when, despite the best planning, there are not enough resources to go around.
 - Invite participants to write their other suggestions on a 3x5 card.

Strategies for addressing suggestions by participants that some groups should be “excluded”:

- PROMPT: The emphasis of this discussion is to determine who should come first, second, and so on, not whether some groups should be excluded completely. Focusing on the “tail end” of the problem isn't the most important aspect of the discussion.
- PROMPT: Ask for clarification: “Are you saying that X group should get no resources at all under any circumstances, or are you saying that X group should be ‘deprioritized’ and receive resources later than other groups?”
- Note takers should capture “exclusion” concerns/recommendations.
- Remind participants of the option to put such concerns/recommendations on 3x5 cards.

Note Taker Template

New Deadly Virus Scenario

1. Should the agency's guidelines give healthcare workers priority for treatment? Yes or no (why?).

2. How about other workers on whom society relies for saving lives (e.g., electrical power and water supply workers, police, firefighters, and other key workers)? Yes or no (why?).
 - a) What are the best reasons for and against such a policy?

 - b) Does a health care worker's specific role or contact with patients matter (e.g., patient care providers such as doctors and nurses; custodians or food service workers; managers or administrative staff)?

 - c) Does it matter whether the worker would recover in time to return to work during the crisis?

 - d) Should key workers' family members who catch the virus be given priority for treatment?

3. To save the most lives, the agency is planning to direct all hospitals and clinics to restrict use of the antiviral drug to sick patients in the two high-risk groups (pregnant women and previously healthy young adults) until more of the drug becomes available.
 - a) Did participants agree with this policy? Why or why not?

b) Is it important for all hospitals and clinics in the city to follow the same rules when deciding which patients to treat?

i. Yes or no (why?).

ii. If so, are there some circumstances when individual hospitals or doctors should be allowed to make decisions that go against the rules?

A. Yes or no (why?).

3. It is now day 3 of treatment for patients in the first group to receive the drug. Two of those patients have not responded to treatment, and their doctors now believe they will almost certainly die. If treatment is stopped now, there will still be enough of the drug left over to treat one more patient who might be saved. The families of the two dying patients will not agree to end the treatment. **Should the hospital go against their wishes and use the remaining doses to try to save another patient?**
Yes (why?)

No (why?)

Evaluation

Your Table Number: _____				
A. The <i>table introductions</i> and community <i>hopes and fears exercise</i> helped me feel comfortable and got my table's conversation started.				
Strongly Agree <input type="checkbox"/>	Somewhat Agree <input type="checkbox"/>	Undecided <input type="checkbox"/>	Somewhat Disagree <input type="checkbox"/>	Strongly Disagree <input type="checkbox"/>
B. The <i>first survey</i> gave me a good idea of what today's program would be about.				
Strongly Agree <input type="checkbox"/>	Somewhat Agree <input type="checkbox"/>	Undecided <input type="checkbox"/>	Somewhat Disagree <input type="checkbox"/>	Strongly Disagree <input type="checkbox"/>
C. The <i>introductory slide presentation</i> helped me understand what crisis standards of care are about.				
Strongly Agree <input type="checkbox"/>	Somewhat Agree <input type="checkbox"/>	Undecided <input type="checkbox"/>	Somewhat Disagree <input type="checkbox"/>	Strongly Disagree <input type="checkbox"/>
D. The <i>earthquake and deadly virus scenarios</i> were a good way to discuss how decisions about limited medical resources should be made.				
Strongly Agree <input type="checkbox"/>	Somewhat Agree <input type="checkbox"/>	Undecided <input type="checkbox"/>	Somewhat Disagree <input type="checkbox"/>	Strongly Disagree <input type="checkbox"/>
E. When I took the <i>second survey</i> , I had a better understanding of the statements.				
Strongly Agree <input type="checkbox"/>	Somewhat Agree <input type="checkbox"/>	Undecided <input type="checkbox"/>	Somewhat Disagree <input type="checkbox"/>	Strongly Disagree <input type="checkbox"/>
F. The session helped me understand the difficult decisions that health care providers might have to make in a disaster.				
Strongly Agree <input type="checkbox"/>	Somewhat Agree <input type="checkbox"/>	Undecided <input type="checkbox"/>	Somewhat Disagree <input type="checkbox"/>	Strongly Disagree <input type="checkbox"/>
G. Overall, the program gave me a chance to express my ideas.				
Strongly Agree <input type="checkbox"/>	Somewhat Agree <input type="checkbox"/>	Undecided <input type="checkbox"/>	Somewhat Disagree <input type="checkbox"/>	Strongly Disagree <input type="checkbox"/>
H. Overall, the program gave me a chance to hear other people's views.				
Strongly Agree <input type="checkbox"/>	Somewhat Agree <input type="checkbox"/>	Undecided <input type="checkbox"/>	Somewhat Disagree <input type="checkbox"/>	Strongly Disagree <input type="checkbox"/>
I. I would recommend that my friends and family attend an actual community conversation on crisis standards of care if they have the chance.				
Strongly Agree <input type="checkbox"/>	Somewhat Agree <input type="checkbox"/>	Undecided <input type="checkbox"/>	Somewhat Disagree <input type="checkbox"/>	Strongly Disagree <input type="checkbox"/>

Which parts of this session did you find most valuable?

Was there anything missing (e.g., certain information you wish we had provided, other topics you thought the survey or scenarios should have covered)?

Please share any additional thoughts.

Wrap Up

Collect and place in the large manila envelope:

- All program materials (scenarios, worksheets, sorting cards)
- Any index cards with participant questions or comments
- Evaluation forms
- Note Taker templates and any other notes
- CLICKERS (if using ARS)**

Remember to **thank the participants** for their contributions to the session.

Thank you!

Introductory Slides

“Crisis Standards of Care”

A Community Conversation

[Location]

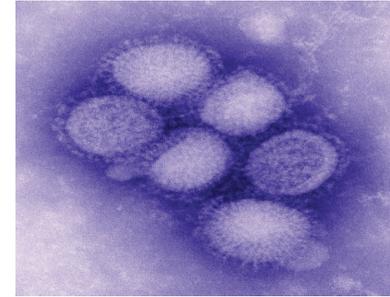
[Date]

[Sponsor]

“Disaster” Defined

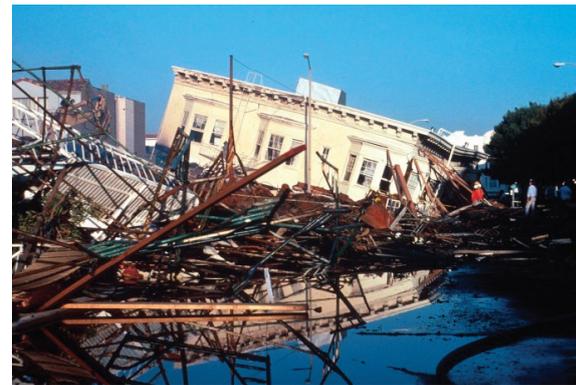
What do disasters have *in common?*

- People’s needs exceed available resources
- Help cannot arrive fast enough



How do disasters differ?

- Some are long-lasting and widespread (*flu pandemic*)
- Others are sudden and geographically limited (*earthquake, terrorist attack*)



Preparing for Disasters: *The Challenge*

- Disasters can lead to **shortages of critical medical resources**
- Shortages require **hard decisions**, *for example*—
 - Who should be at the front of the line for vaccines or antiviral drugs?
 - Which patients should receive lifesaving ventilators or blood?
- In extreme cases, **some people will not receive all of the treatment they need**

How do we give the best care possible under the worst possible circumstances?

Recent Examples

Hurricane Katrina

- Hospital overload



H1N1 Pandemic

- Vaccine shortage



The Response: “Crisis Standards of Care”

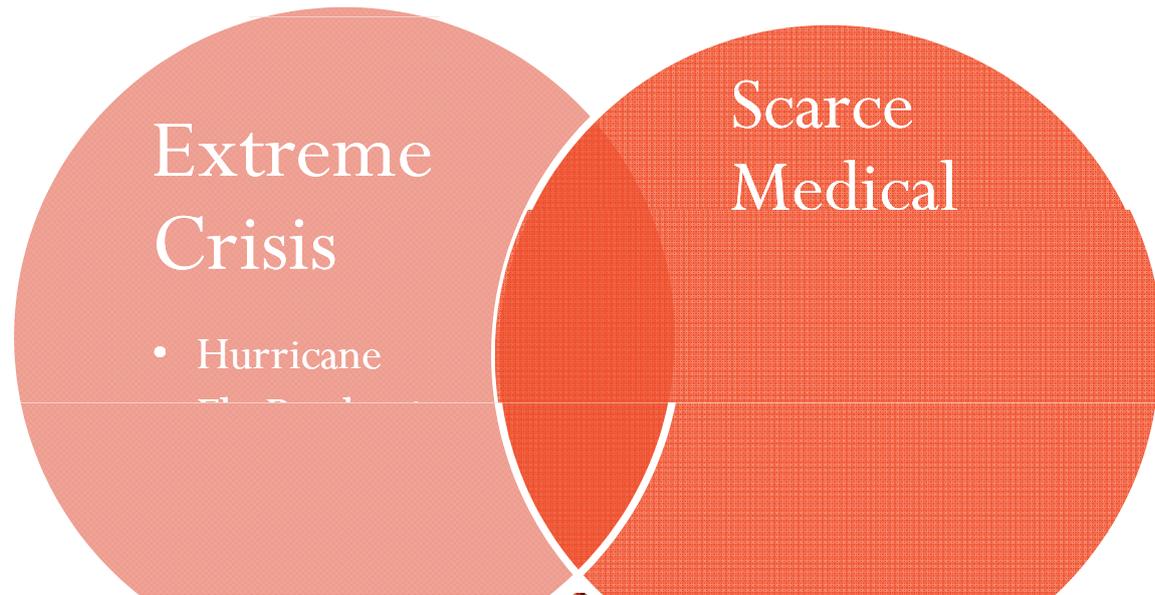
Guidelines developed **before disaster strikes**—

To help healthcare providers decide how to administer...

THE BEST POSSIBLE MEDICAL CARE

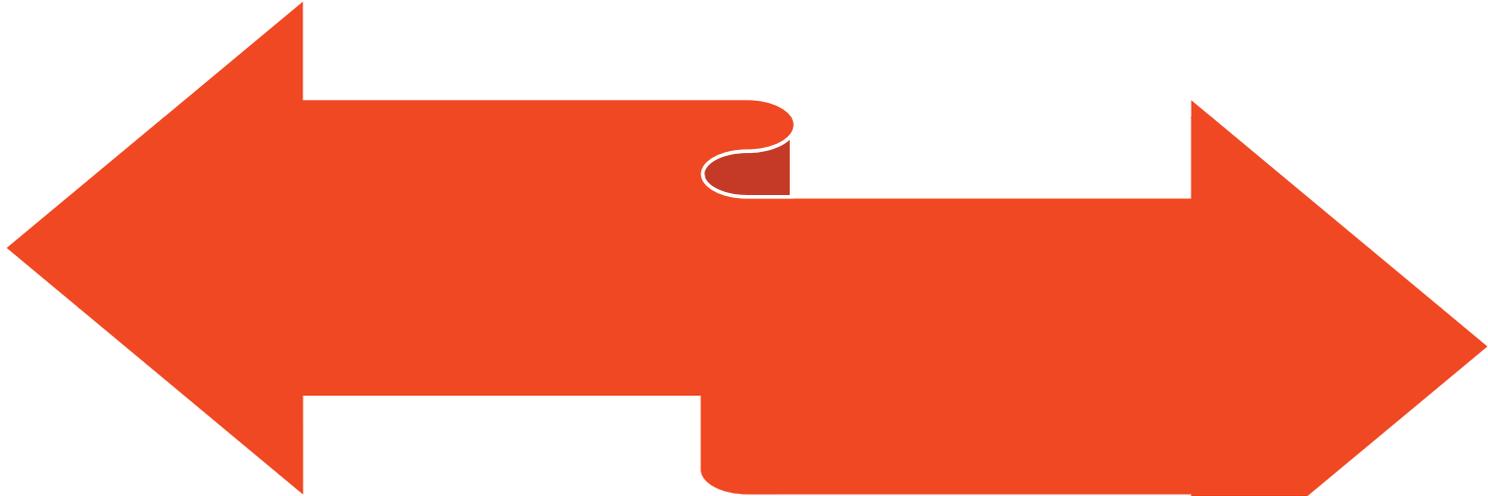
...when there are not enough resources to give all patients the level of care they would receive under normal circumstances.

When Might We Need Crisis Standards of Care?



How Are Crisis Standards of Care **Different?**

Focus of *Normal* Care



Possible Reasons for Crisis Standards of Care

- To make sure that critical resources go to those who will **benefit the most**
- To **prevent hoarding** and **overuse** of limited resources
- To **conserve limited resources** so more people can get the care they need
- To **minimize discrimination** against vulnerable groups
- So all people can **trust** that they will have fair access to the best possible care under the circumstances

Possible Strategies to Maximize Care

- **Space**
 - Put patient beds in hallways, conference rooms, tents
 - Use operating rooms only for urgent cases
- **Supplies**
 - Sterilize and reuse disposable equipment
 - Limit drugs/vaccines/ventilators to patients most likely to benefit
 - Prioritize comfort care for patients who will die
- **Staff**
 - Have nurses provide some care that doctors usually would provide
 - Have family members help with feeding and other basic patient tasks



When there isn't enough to save everyone... how should we decide who gets what?

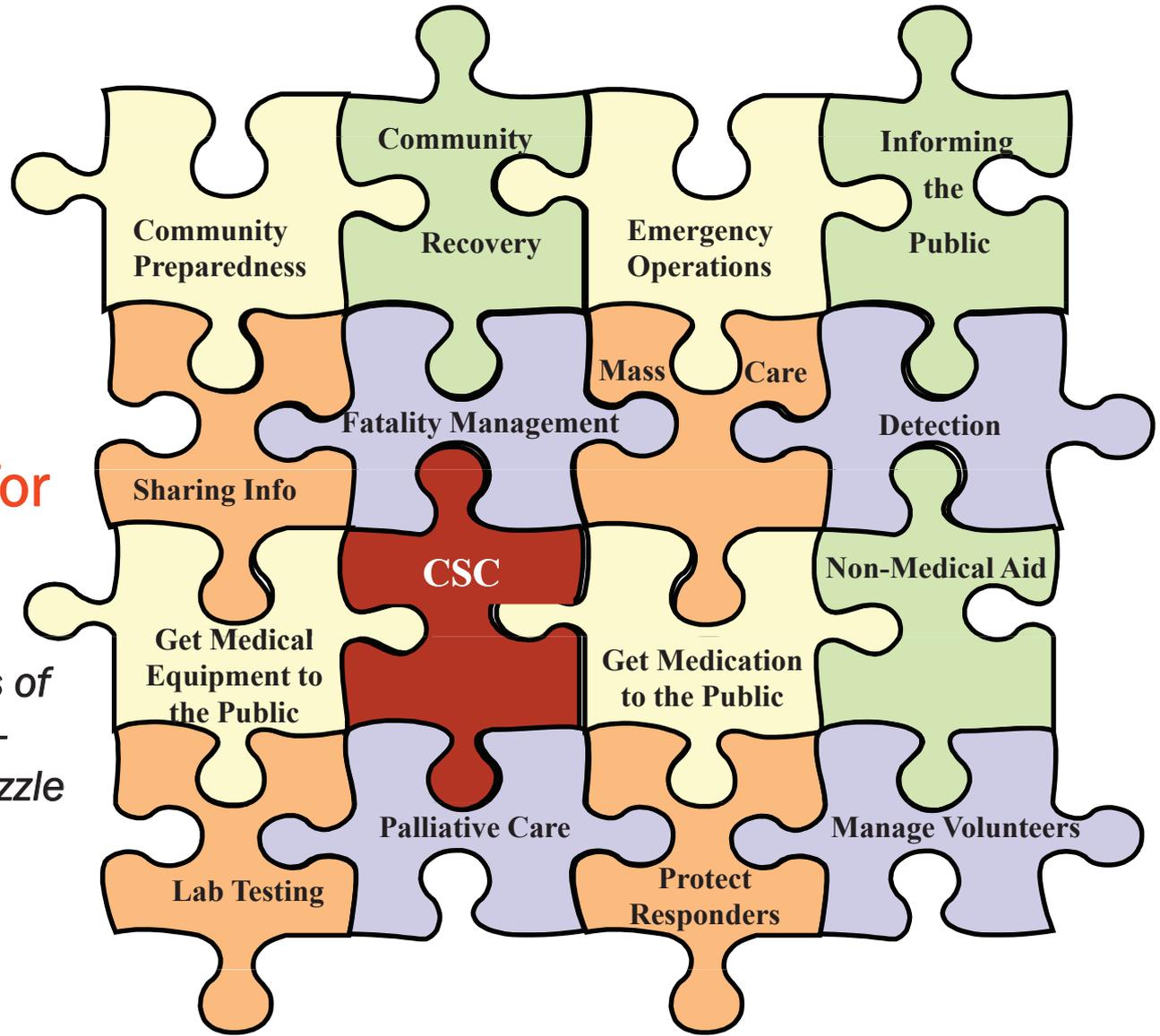
Some options--

1. First-come, first-served?
2. Lottery?
3. Save the most lives possible by giving more care to people who need it the most?
4. Favor certain groups?
 - The old OR the young?
 - Healthcare workers and other emergency responders?
 - Workers who keep society running (utility workers, transportation workers, etc.)?

Where Do *You* Come In?

Community Conversations help policy makers:

- **Understand community concerns about** the use of limited medical resources during disasters
- **Develop crisis standards of care guidelines** that reflect *community values and priorities*



Preparing for Disaster

*Crisis Standards of Care ("CSC")—
a piece of the puzzle*