Crisis Standards of Care
Meeting of Community Advisory Board
April 7, 2022
2:00-4pm

Detailed Meeting Notes

Meeting Materials
Meeting materials available at khi.org/pages/csc

- Agenda CAB_0.4.07.2022
- CAB Member List 4.05.2022
- CAB Meeting Minutes_03.03.2022
- TAP Meeting Minutes_03.10.2022
- Environmental Scan

Combined Agenda:
2:00pm – Welcome and Agenda
2:10pm – Project progress and debrief from TAP meeting
2:40pm – TAP questions to CAB
3:40pm – Next Steps and Questions for TAP
4:00pm – Adjourn

Meeting Commitments:

- Come ready to discuss and compromise
- Keep remarks succinct and on topic
- Don't hesitate to ask clarifying questions
- Start and end on time

CAB members: Glenda DuBoise, AARP Kansas; Irene Caudillo, El Centro; Alice Weingartner, Community Care Network of Kansas; Kathy Lobb, Self-Advocate Coalition of Kansas (SACK); Sherrie Vaughn, National Alliance on Mental Illness, Kansas; Ami S. Hyten, Topeka Independent Living Resource Center, Inc.; Eric Arganbright, Kansas Statewide Homeless Coalition; Matthew Neumann, LGBTQ Foundation of Kansas; Carter Olsen, Nicol Home; Sheri Hall, Poetry for Personal Power

KDHE: Rebecca Adamson, Preparedness Program Section Director Bureau of Community Health Systems; Edward Bell, Preparedness Healthcare Coalition Program Manager Bureau of Community Health Systems

Supplemental Experts: Dennis Cooley, American Academy of Pediatrics, Kansas Chapter

Staff: Tatiana Lin, KHI; Kari Bruffett, KHI; Samiyah Para-Cremer, KHI

Welcome and Agenda

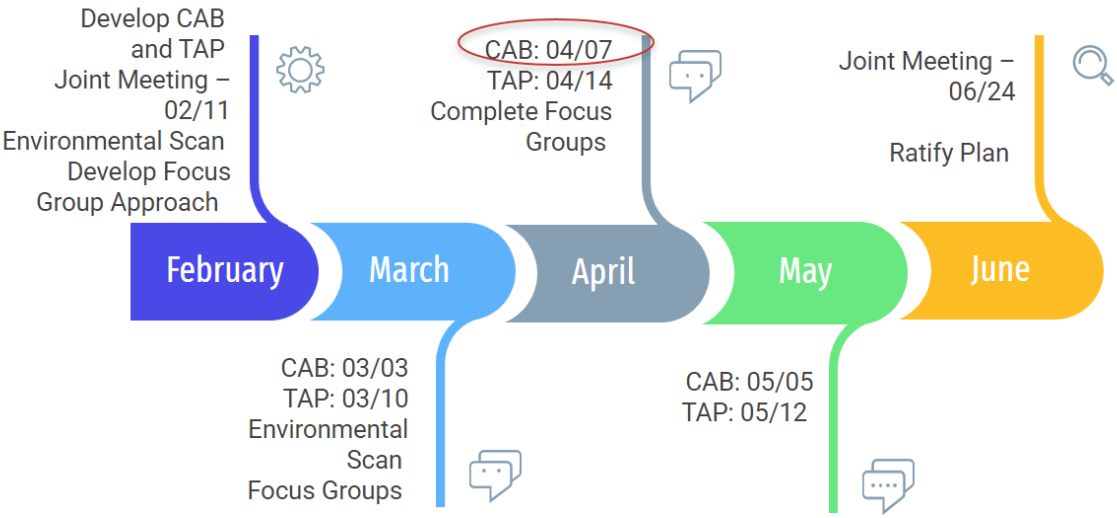
New Members
KHI welcomed CAB members and noted Rev. Tony Carter Jr., Pastor, Salem Missionary Baptist Church joined CAB.

Next, the attendees were offered to respond to the following question: What came to your mind since the last March 3rd meeting?

Discussion:
A few CAB members asked for updates as to the participation of individuals they recommended to CAB since the last meeting in order to ensure that different perspectives are represented on CAB. KHI explained that all recommended individuals had been contacted and requested additional recommendations for focus groups and interviews for particular perspectives CAB sees as missing from the discussions. CAB provided a few additional recommendations.

Project Progress and Debrief from TAP meeting

Update on Project Timeline
KHI provided a general update on the timeline of the CSC guidance document development process. KHI noted that focus groups will begin on Friday, April 8 with a goal to have the results available by later in April.



Debrief from TAP March 10 Meeting
Dr. Dennis Cooley provided an update on TAP's current progress and discussion including:

- **Scope of CSC Guidance Document**
  - Medical care settings (hospitals, EMS)
  - Initial document will be the foundation – a living document that will expand to other settings
- **Use Colorado and Minnesota CSC Plans to inform development of CSC Guidance Document**
- **Goals for the CSC Guidance Document:**
  - CSC document to provide clear, concise and easy to understand guidance
  - Implementation guidance to address equity and not increase inequities
  - Monitor shortages and scarce resources during crisis situations
  - Elevate voices of populations of focus
- **Purpose Statement**
    - TAP Reviewed 2013 KS and current CO purpose statements (see Figure 1 below)
    - TAP liked emphasis on equitable access to care
    - TAP was uncertain about Colorado's use of "intention to maximize patient survival" and the term "patients"
    - TAP suggested to focus on demand vs. volume of patients and include additional Kansas language about small hospitals
- **Core SC Principles**

    - Use a combination of principles discussed in CO and MN CSC plans as the foundation for the KS CSC Guidance document. Make changes to meet the needs of KS CSC Guidance document.
- **Additional Topics:** Other items discussed by Dr. Cooley included the declaration of an emergency, response, and triggers for crisis standards of care.

Figure 1. Purpose Statements from 2013 KS CSC and CO CSC Plan

PURPOSE STATEMENTS (Chart #1)	
2013 KS CSC	**CO's CSC Plan**
KDHE recommends that this protocol be used by hospitals throughout Kansas in their emergency planning to ensure that patients have equitable access to life-saving resources when the demand for these resources is greater than the supply, and when use of resources must be optimized.	Provide a framework and tools for altering normal patient care, staffing, medical equipment, supplies, and treatment decisions in any type of healthcare setting. Assist healthcare providers in their decision making with the intention of maximizing patient survival and minimizing the adverse outcomes that might occur due to changes to normal operations when the volume of patients surpasses the available capabilities and capacity of healthcare providers/facilities and normal standards of care can no longer be maintained.

Discussion:

- **'Fairness' as a 'Business as Usual' Approach:** CAB members recognized that hospitals have limits for how they can address systemic inequities but expressed concern that an approach of distributing resources in a "fair and equal" manner could perpetuate business as usual. Several CAB members mentioned that lessons learned from COVID-19 show that communities of color and others have been disproportionately impacted and that an approach of 'fairness' would not achieve equity. The emphasis should be on giving resources to those most in need, not the 'fairest' way. This involves both being more equitable in distribution of resources and action to address the systems that perpetuate the inequities. CAB members said it was not enough to just not make inequities worse; CSC guidelines should work to address the systemic issues that create these inequities. CAB members suggested that CSC guidance should include action that can help prevent diverse communities from being left behind during the next crisis including:
    - **Increasing diversity of hospital workers:** Adjusting hiring practices so that practitioners better resemble the patients in their communities.
    - **Engaging communities that have less access to health care:** Building relationships with these communities before an emergency occurs and continuing to reach out during times of crisis.
    - **Identify where the structural inequities exist and provide guidance for local level:** Using data to identify where communities experience greater inequities in accessing health care and provide guidance for how local hospitals should address these inequities.

    - **Incorporate correction-factors into scoring systems:** Using scoring system to recognize that people do not enter hospital on even-playing field because of systemic inequities.
- **Limited Resources is Not the Same as Limited Opportunities:** A CAB member said that just because resources may be limited in a situation does not mean that opportunities to engage communities most in need are also limited. An equitable approach involves finding ways to communicate with and distribute limited resources to these communities.
- **People-First- and Plain-Language:** CAB members said that it was important that CSC guidance be written in people-first- and plain-language so that patients can read and understand how the guidance applies to them. CAB members said it was particularly important that individuals with disabilities be able to understand how they might be affected by the guidelines so they can make informed decisions about seeking care.

Ami Hyten, CAB liaison to TAP provided her key takeaways from the March 10thTAP meeting including:

- **TAP seems to be Receptive of CAB's Feedback:** TAP is considering and engaging with CAB's questions and concerns.
- **Different Perspectives between TAP and CAB:** TAP and CAB are approaching the CSC guidance document development process from a different perspective, that of doctors and people who were on the front line of medical decisions during COVID-19. Ami encouraged CAB members to continue to engage in the back-and-forth process with TAP.

Equity Considerations from the Environmental Scan:

KHI shared the findings from the environmental scan and asked for CAB member feedback. The environmental scan is available at khi.org/pages/csc

Environmental Scan Finding: CSC protocols that will be used for making urgent allocation decisions in a disaster cannot be expected to remedy historic and structural inequity. However, they should not exacerbate underlying disparities.

CAB members provided the following feedback:

- **Language Feels Like We Are Giving Up:** CAB members said although they recognize that hospitals may be limited in what they can do, this language feels like we would be saying we know structural inequities exist, but we won't be doing anything to address them in advance of the next emergency situation.
- **Suggested Revision:** CAB members proposed the following revision:
    - CSC protocols should not exacerbate underlying disparities.

Environmental Scan Finding: No patient should be categorically excluded. All patients should be treated as eligible to receive critical resources and receive a priority assignment based on illness severity. Introduce a correction factor into patients' triage scores to reduce the impact of baseline structural inequities. Do not use perceived quality of life.

CAB members provided the following feedback:

- **Importance of Active Language:** CAB members said that it was important that CSC guidance be written using firmer, active language like "No patient will be…" rather than passive language like "No patient should be…" to communicate or imply an obligation instead of a preference and to help patients better understand the language.
    - **Guidelines vs. Mandates:** A CAB member agreed that active language is important but noted a potential challenge using the verb "will" given that the crisis

standards of care will be guidance rather than mandates. Thus, hospitals might not be able to adopt this language.

- **Use of Correction Factors in a Scoring Tool:** CAB members were in support of using correction factors in a scoring tool to recognize inequities that may exist. Some ideas for correction factors that were mentioned by CAB members included:
    - **Race and Ethnicity:** CAB members mentioned accounting for patients who belong to racial and ethnic groups who have historically had less access to medical care or faced greater inequities.
    - **Houselessness Status:** CAB members mentioned accounting for patients who do not have stable housing.
    - **Long-term Severe Illness or Disability:** CAB member mentioned accounting for patients on oxygen.
    - **Neighborhood:** CAB members mentioned using geographic data to help account for individuals living in neighborhoods that face more inequities.
    - **Preventative Behavior:** Some CAB members suggested exploring the feasibility of considering preventative action (i.e., in case of COVID-19, getting vaccinated or wearing masks) as a correction factor. During the discussion, several CAB members clarified that this should not penalize patients who were medically unable to utilize offered preventative resources.
        - **Alternative Perspective:** Some CAB members expressed disagreement about incorporating behaviors as a correction factor, expressing concern that the same principle has not been applied in non-COVID situations to other behaviors, such as smokers who do not take advantage of cessation resources. Another reason provided was that there is mistrust and misinformation around and differing levels of access to resources like vaccination, particularly in rural, low-income areas and patients and facilities should not be penalized because of the inclusion of a correction factor.
- **Suggested Revision:** CAB members proposed the revision of this purpose statement to say:
    - No patient will be categorically excluded. All patients will be treated as eligible to receive critical resources and receive a priority assignment based on illness severity. Introduce a correction factor into patients' triage scores to reduce the impact of baseline structural inequities. Do not use perceived quality of life.

Resource:
A CAB member shared the following resource in relation to the conversation about preventative behavior.

- KFF (2022). *KFF COVID-19 vaccine monitor: Views on the pandemic at two years.*

Question for TAP:
CAB members posed the following question to TAP:

- Should correction factors work in both ways (positive and negative) or should factors only work to benefit patients?

Environmental Scan Finding: When patients who use ventilators in their daily lives (e.g., home ventilation) present to acute care hospitals, their personal ventilators should not be reallocated to other patients. Designate triage officers as the decision makers and train them to respect disability rights. Include disability rights advocates in policy development and dissemination. Give heightened priority to individuals in essential, high-risk occupations.
CAB members provided the following feedback:

- **Reallocation of Personal Ventilators:** CAB members all agreed that patients who use personal ventilators ***should not*** have their ventilators taken away and reallocated to other patients. They noted that this statement should be explicitly described in the CSC Guidance document.
- **Required Triage Training Around Disability Rights:** CAB members said all triage team members should be required to receive training around disability rights. A CAB member referenced the COVID-19 experience and the Department of Justice reissuing guidance to ensure Americans with Disabilities Act protections and other laws were not violated by crisis standards of care protocols, saying that people making triage decisions need to be trained and informed about how to maintain these protections.
- **Local Consumer Engagement in CSC Process**: CAB members said hospitals should engage consumers at local levels so they can provide input on the hospital's decision to implement CSC protocols.
- **Do not use term "Triage Officers":** CAB members said the designation of "triage officer" grants authority that shuts down further discussion with patients and their families and should not be used. CAB members proposed the designation of "triage team" instead.
- **Triage Team Composition:** Multiple CAB members emphasized the importance of patient's/patient's family voices in triage decisions. The triage team should be made up of clinician, patient, the patient's family/power of attorney, and people with lived experiences, particularly those with a disability. CAB members said that it is essential that someone with a disability or who is differently abled is part of the triage team to provide a check to prevent quality of life decisions from being made that discriminate against people with disabilities. CAB members also said the patient and the patient's family should be included in the triage decision Note: Given that the CAB members suggested a "blinded decision-making process" during the March 3 meeting, KHI team asked a follow-up question in a survey administered after the meeting to clarify the recommendation about the triage team composition.
- **Individuals with High-Risk Occupations:** CAB members were divided about whether high-risk occupations (such as frontline workers and those identified as working in essential, high-risk occupations) should be used as a correction factor. Some CAB members said they may support this if and only if the definition of essential was well-defined, clear, and inclusive of those who are often excluded like home-care workers and grocery clerks. However, other CAB members said a person's occupation should not be considered at all because they felt it places a value on a person's life based solely on the perceived value they present to the community.

TAP Questions to CAB

During the next section of the agenda, CAB members were asked to discuss some of the questions posed by TAP members to CAB.

To what extent should an individual's potential to survive be considered when allocating medical resources?

KHI shared Environmental Scan context for this question that found the following:

- Use hospital survival and near-term prognosis (e.g., death expected within a few years despite treatment) but not long-term life expectancy.

- Perform a thorough individualized review of each patient without assuming a specific diagnosis is determinative of prognosis or near-term survival.

Discussion:
CAB members were divided on the question about whether to consider a patient's potential to survive when allocating medical resources. Viewpoints shared during the meeting included:

- **Concern someone is making wrong decision:** Some CAB members said it *"made them sick to their stomach"* that someone is deciding an individual's hospital survival or near-term prognosis, expressing concern that these prognoses could be wrong.
- **Individualized review not representative of reality:** Some CAB members were concerned that during times of crisis, practitioners do not perform thorough individualized review of each patient due to staff shortages, resulting in errors. They agreed that individualized review is a good target but should not be used as a justification for using survival to make CSC decisions because they do not believe the reviews would be properly implemented.
- **Patient should ultimately make the decision:** Some CAB members said that the decision of survival and resource allocation should be left solely up to the patient and the patient's family/power of attorney. A CAB member said that people may not understand the medical prognosis, but they know when they are going to die and should be allowed to communicate this.
- **Survival could be discriminatory:** Some CAB members said that using survival could be discriminatory against elderly patients who still have a good quality of life that would not be communicated by their prognosis.
- **Short-term survival should not be compared with long-term survival:** Some CAB members said that a potential to survive two weeks should not be compared with a potential to survive two years because the value of these time periods should not be compared between two people.
- **Survival as a consideration is a reality:** Some CAB members said that the reality is that these decisions and prognoses are made, and it does not make sense to provide limited medical resources to the individual with a lower potential to survive in the case of a tie-breaker situation.

Next Steps and Questions for TAP

CAB members were asked to:

- Complete post-meeting survey to answer remaining TAP questions
- Submit additional consumer recommendations for focus groups.

Additionally, CAB members were advised of the following meetings:

- Thursday April 14, from 2-5pm, *Technical Assistance Panel (TAP) Meeting*
- Thursday May 5th, from 2-4pm, *Community Advisory Board (CAB) Meeting*

CAB asked the following question to TAP:

- *Should correction factors work in both ways (positive and negative) or should factors only work to benefit patients?*