Crisis Standards of Care
Meeting of Community Advisory Board
March 3, 2022
2:00-4pm

Meeting Notes

Meeting Materials
- Agenda Joint Meeting_CAB_0.3.03.2022.pdf [EMAIL]
- Joint Meeting Minutes_CSC_0.2.11.2022.pdf [EMAIL]
- Articles (Equity and CSC) [EMAIL]

Combined Agenda:
2:00pm – Introductions and Updates
2:10pm – Overview of the Project Scope and Q/A
2:30pm – Equity Considerations: CSC Guidelines
3:30pm – Equity Definition: CSC Guidelines
3:50pm – Next Steps
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; Tawny Stottlemire, Community Action, Inc; Alice Weingartner, Community Care Network of Kansas; Kathy Lobb, Self-Advocate Coalition of Kansas (SACK); LT Sebe Masquat, Haskell Indian Health Center; Sherrie Vaughn, National Alliance on Mental Illness, Kansas; Amy S. Hyten, Topeka Independent Living Resource Center, Inc.; Eric Arganbright, Kansas Statewide Homeless Coalition; Matthew Neumann, LGBTQ Foundation of Kansas; Andy Hubbard, community advocate.

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; John Carney, Center for Practical Bioethics

Staff: Tatiana Lin, KHI; Hina Shah, KHI; Samiyah Para-Cremer, KHI

Introductions and Updates
New Members
CAB introduced themselves. Since the last meeting, three new members joined CAB.

Roles of CAB
KHI reviewed the roles of CAB including:
- Meet once a month virtually from February-June 2022, in meetings lasting up to 2 hours each.
- Participate in a structured process to develop the CSC plan.

- Nominate an individual that will represent the Community Board on the panel of individuals responsible for developing the standards.
- Share considerations regarding different topics examined during the development of the plan.
- Inform the development and implementation of focus groups to gain community insights regarding considerations around the development of the Crisis Standards of Care (CSC) Plan.
- Contribute to and provide feedback on the plan.

Questions:

- **Can the roles be made available in plain language?**
    - Yes, KHI asked the group for recommendations of how to do this. A CAB member recommended the Hemingway App.
    - **Roles:**
        - Meet once a month virtually from February-June 2022, in meetings lasting up to 2 hours each.
        - Take part in a structured process to develop the CSC plan.
        - Select a Community Advisory Board (CAB) member to present your discussions to the Technical Advisory Panel (TAP).
        - Share considerations about different topics examined during the development of the plan.
        - Help develop focus group questions on CSC guidelines and recruit community participants.
        - Contribute to and provide feedback on the plan.
- **How diverse is the TAP, if at all? I'm concerned that the diverse perspectives seen on CAB aren't also at the table for TAP if TAP is the one leading this effort.**
    - TAP has regional and professionally diverse participants. However, it's important to recognize that this is not meant to be hierarchical. We see TAP and CAB as on a level playing field.

Update on Focus Groups

KHI reviewed the new focus group questions and explained how CAB feedback was incorporated:

- **Framing and Simplified Language:** Although the questions could not move away from "rationing" completely and maintain clarity in the wording, the framing of "who receives what medical resources and when" was adopted to replace "rationing" and "allocation of resources" language when possible. Language across questions was simplified when possible.
- **Clarified Definition of Rationing:** Because it was not possible to completely remove "rationing" from the focus group language due to clarity concerns, KHI offered the following definition of rationing that will be shared with focus group participants:
    - **Definition:** The goal of rationing is for everyone to receive some level of care, but they may not receive the same access to medical resources (such as beds, ventilators, nurses, etc.) that they would have received if there was not a crisis.
- **Collapsed Questions:** KHI said that they collapsed similar questions to better order and facilitate discussion.
- **Equity Question:** KHI added the following question: *How do you feel about dedicating greater medical resources to people who have historically been less able to access medical care and/or health-supporting resources? When, if at all, would this be appropriate?*
- **Local Hospital:** When asking participants to look at what hospitals should do, KHI modified the language to ask about their local hospital to prompt less theoretical perspectives.

- **Willingness to Seek Care:** The following question was added to ask about participants willingness to seek care and their perception of rationing of care: *If your local hospital had to ration medical care, what would worry you most? How might this impact your decision to seek medical care?*

Questions:

- **When I look at the numbers of safety net clinics stakeholders, you're looking at more than 300 people across the state. The focus groups proposed only allow you to interview 10 of them. Is there a possibility of doing regional focus groups to allow for more people to be interviewed?**
    - We appreciate that and it is a concern. However, for focus group feedback to be meaningfully incorporated into the new guidelines, we are trying to complete analysis by end of April. Because of this time constraint, adding more interviews is a challenge. We will look into it but can't promise that more will be possible.

Discussion:

- **Definition of Rationing:** Supplemental experts explained that the distinction that everyone could still receive care but may not receive the same quality of care as they would have in non-crisis situations is crucial and the entire goal behind having CSC guidelines. It's important to make this clear so trust in medical professionals can be rebuilt to levels before COVID-19.
- **Role of Community Members in Decision of Who gets What Resources and When:** CAB members explained that when asked about what their role might be, they would rather not be involved but know that the person making the decision had all the information needed to make the right decision.
    - **Reasoning of Question:** The current wording of *What do you think the role of community members like yourself should be in [deciding who gets what resources and when]?* may not result in diverse answers but was suggested during the first CAB meeting to give people an opportunity to decide. Participants can answer either from the perspective of a patient or as a community member whose community is preparing to implement CSC.
        - **Potential Alternative Wording:** CAB members proposed the possible alternative wording: *What role should the patient and the patient's support network be in that situation?*

Overview of the Project Scope and Q/A

Presentation: Dr. Dennis Cooley

Summary

- **Scope of Work:** Crisis Standards of Care is a situation where there is some amount of resource shortages that will result in a substantial change in usual healthcare operations and the level of care it is possible to deliver. Everyone will receive care and it may not even be bad care. CSC just means that when resources are limited, care may not be optimal and decisions about prioritization of resources must be made.
    - Resources can be defined as anything in the medical field needed for the operation of health systems- in our case hospitals-, including people, emergency services, medical equipment and supplies, and medications
- **Focus on Hospitals:** CSC guidelines for June 2022 will focus on hospitals. Other concepts like vaccination and housing can be discussed but should still focus on hospitals. One way to focus on systematic inequities would be when thinking about hospital discharge.
- **Living Document:** This is not the final CSC draft. Over time, edits will be made.

- **Goals of CSC:** Goals include:
    - Make sure that critical resources go to those who will benefit the most.
    - Prevent hoarding and overuse of limited resources.
    - Conserve limited resources so that more people can get the care they need.
    - Minimize discrimination against vulnerable groups.
    - Ensure that all people can trust they will have fair access to the best possible care under the circumstances.
- **Scoring Tools:** To determine prioritization of care, some CSC guidelines recommend a scoring tool that uses a patient's clinical data. Patients are given a number to show the benefit of receiving the resource and survivability. They cannot look at age, ethnicity, or race. No scoring system is perfect, and each tool has limitations that need to be recognized prior to use.
- **Mandatory vs. Voluntary:** Kansas will not have mandatory CSC guidelines. The CSC guidelines created by June 2022 will only provide guidance and suggestions for local facilities to develop their own plans. The statewide CSC guidelines provide a foundation.

Questions

- **Does each clinic already use their own scoring tool? Is there a main tool that is recommended?**
    - It depends, scoring tools used to be common but we've learned more limitations. Some states still propose scoring tools be used but clinics have the option to choose their own tool.
- **Can facilities develop their own scoring tool?**
    - No, local facilities can develop their own CSC plan, but they won't develop their own scoring tool. It should be an evaluated tool and should not be the only way to decide how to distribute resources.
- **Can scoring tools be modified?**
    - Not really. Because the data on a tool is based on that tool, it is not recommended to change the tool. However, you can use it in combination with other tools and policies. For example, some states are already making considerations about race and ethnicity. The idea is that there is uniformity, so it doesn't rely on one person making an individual decision.

Equity Considerations: CSC Guidelines

What should be considered in score for purposes of allocation of medical resources during crisis:

CAB members identified the following items to include in a scoring tool:

- **Patient's desire to survive** – CAB discussed that patients who have expressed desire that they do not want to receive live-saving medical treatments should have wishes respected. For example, if a patient is eligible for one of the few ventilators but does not want to be placed on a ventilator, they should not be forced to receive one.
- **First impacted** – CAB discussed that although a first come, first serve model is not ideal, the people impacted first by a disease or lack of resource (the people who get sick first and in greatest numbers due to social inequities and systemic barriers) should be prioritized.
- **Severity of Disease** – CAB shared that people who are most likely to die without intervention should be prioritized in tie-breaker situation with other patients who have better chance of survival even without treatment.

- **Social Determinants of Health** – CAB identified that any scoring system to assist providers with the allocation of medical resources should involve an acknowledgement of social determinants of health.
    - **Geographic Indicator** – CAB expressed interest in learning more about a model like the Social Vulnerability Index that could help identify individuals likely to have higher negative health impact due to systemic disadvantages based on the neighborhood they live in. Some potential characteristics to select geographic locations discussed by CAB could include but are not limited to rural areas with limited health access, high poverty rates, and racially diverse areas. However, CAB members said these indicators should be used with caution as there could be differences in need within a geographic indicator, particularly if used at a larger zip-code level.

What should NOT be considered in a score for purposes of allocation of medical resources during crisis:

CAB identified all items currently recommended by MN to **not** consider in CSC situations should also be excluded as a basis for decision in KS, including:

- **Ability to pay;**
- **First-come, first-served;**
- **Judgments that some people have greater quality of life than others;**
- **Predictions about baseline life expectancy unless the patient is imminently and irreversibly dying, because rationing based on such baseline predictions would exacerbate health disparities;**
- **Race, gender, religion or citizenship;**
- **Age as a criterion in and of itself (this does not limit consideration of a patient's age in clinical prognostication);**
- **Judgments that some people have greater "social value" than others**

CAB also recommended the exclusion of the following characteristics as a basis for deciding on allocation of medical resources during a crisis:

- **Gender identity** – In addition to excluding gender, gender identity should be excluded as a basis for allocating resources during the pandemic. CAB members gave the example that Trans individuals should not be asked to identify their birth gender in most situations of resource allocation unless considered medically necessary.

Best way to decide who receives medical care resources (e.g., ventilator, medicine, beds) at times when medical resources are limited:

CAB members proposed the following ideas for the best ways to allocate limited medical resources:

- **Coordinate with Power of Attorney and Patient –** Some CAB members said it was important for the person identified as power of attorney for the patient or the patient's family be consulted when making the decision
- **Blinded-Decision Making** – CAB said it was important that the person making the decisions was not at the patient's bedside and/or could not see the socio-demographic information about the patient when making triage decisions to help prevent the impact of implicit biases of decisionmaker
    - **Social Determinants of Health** – CAB said that even in blinded-decision making, it is important to still recognize patients are not necessarily on level playing field with their health. Blinded decisions should still have a way to account for these inequities that may change a person's clinical indicators.

Additional Discussion:

- **Equity Concern of Objective Indicators:** Some CAB members said they are concerned that using objective measures for everyone would be equal but not equitable because objective measures often fail to recognize the role of systemic inequities. A utilitarian perspective seems to be the way this discussion is focused and that may not be the best approach. A justice approach is important and scoring systems and CSC guidelines should recognize some people are starting behind the starting line because of systemic barriers.
- **First Come, First Serve vs. First Impacted:** CAB discussed the definition of first come, first serve compared to first impacted. Some CAB members expressed concern that first come, first serve would be unfair to older adults who have less access to transportation. Some CAB members thought of first come, first serve as being the first to arrive at the hospital and get in line. However, other CAB members thought of this being more about who were the first to get sick and be impacted by COVID-19 or another crisis. CAB was opposed to prioritizing resources based on who arrived at the hospital first but had interest in looking at who was impacted first. However, some CAB members said they were concerned that the groups first impacted may not have enough resources to say they had been impacted.
- **Age as a criterion in and of itself (this does not limit consideration of a patient's age in clinical prognostication):** CAB members asked the supplemental experts what this deciding factor meant in the context of MN's list of what not to include in a scoring tool. Supplemental experts clarified that age as a prognostic indicator could be about assessing fragility and concerns around further health complications. However, MN's plan is saying that two people with equal severity of illness, but one is 50 years old, and one is 80 years old, the ventilator should not be given to the 50-year-old simply because they are younger.
- **Power of Attorney:** Some CAB members said they believe that the person designated as the patient's power of attorney should be involved in the decision of who receives medical resources and when.
- **Inherent Biases:** CAB members said their worry about people making CSC decisions is that people are human and have inherent biases about a patient's race, sexual identity, ethnicity, prior drug convictions, lifestyle, and more that isn't explicitly included into a scoring tool but may impact a person's decision. CAB members discussed that a solution would be to have the decisionmakers not know who the person was and not be able to see them. Another solution proposed by a CAB member was to use an algorithm that could make the decision for them.
    - **Equity Concern of Objective Indicators:** CAB members said that it is important that in addressing these inherent biases, it's important to recognize that historic and systemic bias in the system may have impacts on the health records of patients due to their race and gender presentation even if these characteristics are not used on their own to determine resource allocation.
- **Scope of Conversation:** Some CAB members suggested that it is harder to conceptualize ways to create equitable access to care with something like ventilators or beds, but that medicine is an easier discussion. Although what medicine comes into a community may be outside of the community's control, the conversation about fair access and distribution is much easier, particularly when accounting for concerns in access due to disability, mobility, etc.
- **Considerations for Geographic Indicators:** CAB members said they were interested in the use of geographic indicators to be incorporated into a scoring system, particularly one that recognizes high poverty rates and racially diverse areas. However, members said that it was important to define poverty rate at a threshold that isn't too low that very few people meet it. Another consideration of CAB is that the data points used to determine these geographic indicators should be easily publicly accessible.

    - **Social Vulnerability Index:** Supplemental experts mentioned the Social Vulnerability Index to calculate geographic indicators. CAB members said they would like to receive information about this over email so they can explore it further.
- **Role of Patient's Mental Health:** CAB members said that the role of patient's mental health should be considered, particularly if using a patient's desire to survive to determine allocation of resources. Patients' answers may change based on unstated factors unknown by the clinician.
- **Social Determinants of Health:** CAB members said that social determinants need to be considered throughout the process. For example, one consideration could be, due to the environmental factors experienced by the patient, how likely are they to return for treatment if discharged.

Next Steps

CAB members were asked to:

- Email Tatiana Lin if they would like to nominate themselves as an alternative liaison to TAP during the March 10 meeting
- Complete the emailed survey to recommend potential focus group participants. *Reminder, we cannot contact people until IRB approval is received.*

Additionally, CAB members were advised of the following meetings:

- Thursday March 10, from 2-5pm, *Technical Assistance Panel (TAP) Meeting*
- Thursday April 7, from 2-4pm, *Community Advisory Board (CAB) Meeting*