Summary of Focus Group and Interview Findings

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Methodology Overview:

In April 2022, Tatiana Lin, Strategy Team Leader and Samiyah Para-Cremer, Analyst at the Kansas Health Institute (KHI) conducted focus group for the *Crisis Standards of Care* project (KDHE Project #: 2022-IRB-05). Focus groups were part of the efforts focused on developing guidance to provide to medical providers to inform their decision regarding who gets what medical resources and when during emergencies in the hospital setting. Medical resources may include but are not limited to beds, medical equipment, staff, and medicine. The results of these focus groups are meant to assist the Technical Advisory Panel (TAP) and Community Advisory Board (CAB) in the development of the 2022 Crisis Standards of Care Guidance Document by June 2022.

With the assistance of CAB, KHI recruited 45 participants for focus groups and interviews, including 16 consumers, 19 representatives from consumer advocate agencies, and 10 providers or administrators of safety net clinics or facilities *(Figure 1)*.

Figure 1. **Focus group target populations**

Stakeholder Type	Mode of Participation	Participants	Target Number of Participants
Safety net clinics or facilities	Virtual	Providers or administrators from Federally Qualified Health Centers (FQHC), free health clinics/charitable clinics, rural health clinics, safety net hospitals and local public health department	1 focus group – up to 10 individuals
Consumers	Virtual (with phone interview alternative)	Vulnerable populations and/or historically marginalized groups including those who are uninsured, low-income, persons with disabilities, LGBTQ+, Black, Hispanic, Latino, or Tribal origin, rural populations, older adults, parents or caregivers of children with ongoing illness or disabilities, and veterans.	2 focus groups – up to 10 individuals
Consumer advocacy groups	Virtual	Representatives from consumer advocacy groups	1 focus group – up to 10 individuals

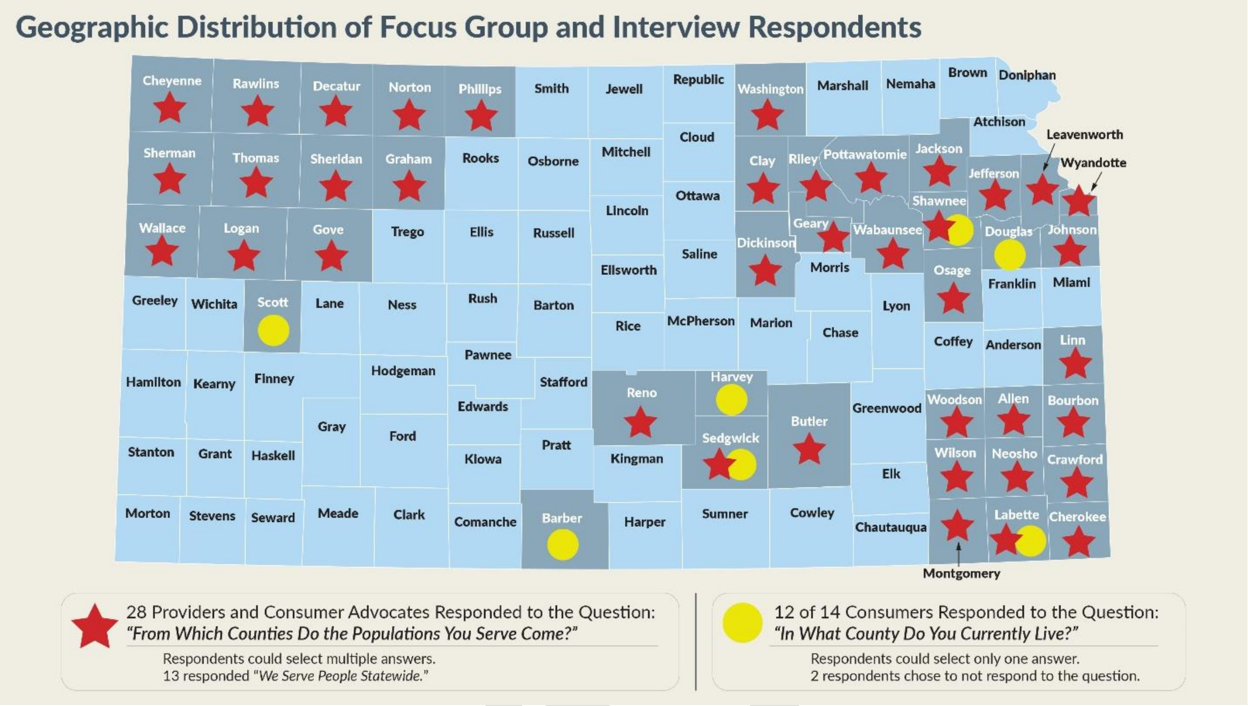
In advance of focus groups, individuals signed an informed consent document and were asked to complete an anonymous online survey (completed by 42 participants) that collected demographic information of participants (*Figure 2,* page 2*)*. Geographic distribution of these participants is described in *Figure 3,* page 3.

Figure 2. **Demographics of focus group and interview participants**

Demographic Survey Results for Focus Group and Interviews	
Characteristic	**Percent of Respondents**
Age	33.3% of respondents were aged 55 or older. 56.4% were aged 35 – 54 10.3% were aged 25 – 34.
Gender Identity	74.4% Female and 20.5% Male
Race	73.8% White, 7.1% Black or African American, 2.4% Asian and 9.5% Multiple races (including White/Black/African American and White/American Indian or Alaskan Native)
Hispanic, Latinx, or Spanish origin	2.6% were or Hispanic, Latinx, or Spanish origin
Education Level	44.7% with Graduate degree or higher. 36.8% with Bachelor's degree. 13.2% Some college or Associate's degree. 5.3% High school diploma/GED or less
Household Income (pre-tax)	32.4% earned less than $50,000 35.1% earned $50,000 - $99,999 32.4% earned more than $100,000
Health Insurance	2.6% did not have health insurance at the time of the focus group
Veteran of Armed Forces, Military Reserves or National Guard	5.3% were veterans
They or a family member are diagnosed with ongoing illness or disability	70.3% had they themselves or a family member been diagnosed with ongoing illness or a disability including 100% of consumers who participated.

Note: 42 participants took the survey. Of these, 14 respondents were consumers and 28 respondents were providers/administrators of safety net clinics or facilities or were consumer advocates. Numbers may not sum to 100 due to rounding or participants selecting “prefer not to respond.”

Figure 3. **Geographic distribution of participants collected via anonymous survey**



Of the 45 participants recruited, 40 people participated in focus groups or interviews including 14 consumers, 17 consumer advocates, and 9 providers. Participants who later chose to not participate mentioned changes to their schedules. Consumer participants with scheduling challenges were offered alternative interview or focus group times as their schedules allowed. Consumer focus groups were 60 minutes, and consumer advocate and provider/safety net focus groups were 90 minutes. Consumer interviews were approximately 20 minutes. All focus groups and interviews were conducted via Zoom and recorded. Audio recordings were then transcribed and analyzed by Lin and Para-Cremer using an open-coding approach in NVivo.

The results below are summarized thematically and presented by focus group question. Some participant statements inform themes across multiple questions. For more information and quotes providing additional context behind the themes listed below, please refer to *Crisis Standards of Care Focus Group Full Report*.

What is the first thing that comes to mind when you hear the words “rationing of care”?

> “Because the very first thing that crosses my mind as a person with a disability, when I hear rationing of care, is what are the standards that have been established to determine who is the first line of service and what type of group determined that?” -Consumer

Concerns and negative emotions

Consumer advocates and consumers

When asked what is the first thing that comes to mind when you hear the words “rationing of care,” consumer advocate responses indicated several concerns, including substandard care, unmet needs especially of some populations, inequitable access and judgements about individual worth. For consumers, the words “rationing of care” were associated with negative emotions, including substandard care, unmet needs especially of some populations, inequitable access and judgements about individual worth.

Concerns about discrimination by decisionmaker

Consumers

Consumers who participated in focus grouse or interviews described rationing of care as someone else making the decision for them, removing their agency. Participants also highlighted concerns of discrimination by the decisionmaker based on their disability, age, perceived ability to pay, perceived quality of life or perceived value. Some participants were concerned that a third party would decide they were not deserving of the care and would put them at the end of the line, referencing their own experiences and history of medical care access.

Considers rationing of care to be a prioritization process

Consumers

Some participants thought of rationing as a prioritization process during situations of limited medical resource supply. Some participants then described this prioritization as serving the most critical patients or deciding who the “correct people” are to receive the resources. A few participants expressed concern about the system and decisionmakers involved in that process

Triage process

Providers

For providers, the words “rationing of care” were associated with triaging resources to those most in need.

If hospitals had to ration medical care for consumers, what would worry you the most?

- **Consumer follow-up: How might this impact your decision to seek medical care?**

> “So that would concern me when I think about rationing of care, that sometimes those who are considered as more valuable in society may be more likely to get it, and those of us who are, kind of, maybe sometimes perceived as not valuable may be less likely to receive care.” - Consumer

Concerns about discrimination by decisionmaker

Consumer advocates and consumers

Consumer advocates and consumers expressed concerns regarding who will be making decisions regarding who gets what medical resources and the criteria used for making these decisions. They noted that these decisions would be influenced by personal assumptions and prejudgments held by decisionmakers as well as the inherently inequitable system. Many consumer participants said they were worried about themselves or their loved ones being discriminated against by being denied medical care because of their race, disability, chronic health conditions, health insurance, ability to pay, perceived quality of life, mental health diagnosis, medical history, age, or their status of living in a group home. Consumers referenced their past experiences advocating for their care and finding it difficult to be taken seriously by medical providers.

Worries about a quality of life factor being used in decision making

Consumer advocates and consumers

Concerns regarding using a qualify of life factor among the criteria to decide who gets what medical resources were referenced by several respondents. The respondents said that if this factor was to be used, individuals with disabilities would likely be placed at the end of the line.

Worry about a worthiness factor being used to allocate medical resources

Consumer advocates and consumers

Concerns regarding using a worthiness factor among the criteria to decide who gets what medical resources was referenced by both consumers and consumer advocates. The respondents said that if this factor was to be used, individuals with disabilities, especially those with mental illness, would likely be placed at the end of the line and worried about someone deciding who is deserving or “worthy” of receiving medical care over others.

Left behind populations

Consumer advocates

The consumer advocate focus group respondents expressed concerns that certain populations would not be prioritized for care, including individuals with disabilities, including those who are deaf and hard of hearing, individuals with mental illness, individuals who have comorbidities, and individuals who do not have ability to cover medical expenses (uninsured, underinsured and those on Medicaid given that reimbursement rate is low). They noted that hospitals are businesses and might not decide to prioritize populations that require more resources such as access to interpreters or do not have insurance. Furthermore, respondents said that given that current systems are inherently inequitable, decisions about who gets what medical resources could further impact existing disparities. One individual noted that these decisions might result in unnecessary deaths.

Impact of patients' worry about rationing of care on decision to seek care

Consumers

For some consumers, worries about potential discrimination at, being denied care by, or not receiving the quality of care they need from a local hospital that was rationing care would make them reluctant to seek care. Some participants said they would delay seeking care even if it meant risking complications or more critical illness. One participant said they would go to a different hospital. Others mentioned leveraging their relationships with their primary providers or ER doctors for advice on how to care for themselves at home or how to time their arrival to the hospital. Another participant said that they would not delay their care but would instead need to advocate for themselves once they reached the hospital.

Patients' worry about understanding CSC process and how to access resources that are available

Consumers

One worry that consumers mentioned was that people, including themselves, would be confused by the information around rationing of care and would not know how to access resources available to them because of this. One participant expressed further concern that this communication difficulty would be even worse for non-English speakers. Participants were concerned that lack of communication would have the greatest negative effect on those with the least resources. Speaking from their own experience, one participant also explained that the lack of understanding of the reasons for rationing or a feeling like the providers aren't listening to your concerns can lead to individuals trying to exaggerate to find ways to receive care.

Misunderstanding of healthcare resource scarcity by public

Providers

Providers noted that public usually thinks about scarcity of medical resources in terms of equipment (e.g., ventilators, beds) versus staff such as nurses. During the pandemic, the staffing shortages topped the list of issues.

When medical resources are limited, what is the best way to decide who gets what medical resources and when?

- **Provider follow-up question: What factors should be considered in this decision?**

> “It's never going to be black and white. So, you just kind of have to be as proactive as possible and ready to make that decision. And, you know, for some people, it's never going to be the right answer, and others, it'll always be the right answer. And it's just the way it's going to be.” - Provider

Prioritize those with greatest need and who are most vulnerable

Consumer advocates and consumer

Consumer advocates and consumers described several populations that should be prioritized for care, such as individuals who are in most critical condition and individuals who are vulnerable due to their social and economic circumstances. Some consumers discussed triaging in a way that prioritized those who were deemed to have the most critical, life-threatening medical need. Some consumers with this perspective felt this decision should ignore all other factors including quality of life and potential for survival. Several consumer advocates expressed concerns that decisions about survivability could be subjective and put a certain group of individuals (e.g., people with disabilities, health conditions) at disadvantage. One consumer advocate and several consumers noted that the best chance of survival should also be considered during triage. One consumer discussed prioritizing those with the greatest medical need only until the patient’s condition is stabilized. Several consumers also said patients who are more vulnerable due to their age or medical condition and can’t advocate for themselves because of their IDD or because they live in an institutionalized setting like a nursing home or group home should be prioritized for medical care. One participant referred to this as a societal obligation to prioritize these individuals.

Need for objective triage process

Consumer advocates

The focus group respondents noted that there is a need to implement a systematic, transparent and non-discriminatory triage process that includes an opportunity to reevaluate decisions and make adjustments. Communication between members of a triage team was also identified as a key factor to making timely adjustments. Several respondents also said that having a tool in place could help address subjectivity. The tool could include a vulnerability scale to understand larger social and economic circumstances of an individual. At the same time, the tool should not consider social status or a “worthiness” factor.

Challenges with COVID-19 resource allocation processes

Consumer advocates

The respondents indicated several challenges that they have heard about during the COVID-19 triage process. They indicated that some people were put at the end of the line when hospitals could not accommodate their specific needs. Poor communication between healthcare staff and patients or their families in waiting rooms was cited as another issue that resulted in negative emotions regarding the process. A concern was expressed that urban centers had access to more resources that rural areas. One participant referenced the hubs and spokes model, saying “spokes always had to sacrifice what they had for resources for the hub."

Fears about the triage process

Consumer advocates

According to focus group participants, during the COVID-19 pandemic some people expressed concerns about losing access to their private medical equipment and having their medical resources being reallocated to another patient. Changing perception that the system is discriminatory was identified as an important next step.

Difficulty making decision about who receives what medical resources

Consumers

Participants said that this was a difficult decision, and they were not sure how to best determine who gets what resource and when. One participant compared making these decisions to “playing God” and another participant said they couldn’t imagine their family member in the medical profession making such a decision. One suggestion was to decide based on first come, first served or based upon patients’ potential for survival. Another participant suggested that patients need to be involved in the decision in some way.

Participant rejected question itself (favoring a focus on prevention)

Consumers

Some participants explained that the premise of the question about the best way to decide who gets what medical resources and when during emergencies was flawed. Some of these participants said that the focus should instead be about finding a way to avoid resource shortages and save everyone. Methods for this varied including focusing on hospital coordination to share resources or redirect patients, expanding Medicaid, adopting a holistic healthcare model, reforming the current medical system, and increasing health education in communities to encourage people to take preventative health measures.

Impact of patients’ use of preventative care on medical resource prioritization

Consumers

Some participants focused on patients’ use of preventative care resources as a factor in resource allocation. Most participants who held this view were referring to patients’ decisions to take or not take preventative action for their own care, particularly in relation to vaccination against COVID-19. Although some participants felt strongly that vaccination status should or should not be considered, most said they were conflicted. These individuals thought using vaccination status or preventative care as a criterion could be discriminatory against those who have received misinformation or who were told not to take the vaccine by their provider. Two participants expressed concern that this would serve to blame patients and worried about the potential application beyond COVID-19.

Allowing patients to self-deny medical resources

Consumers

Some participants talked about patients' decision-making in terms of expressing agency and felt that patients should be offered the opportunity to self-deny life-prolonging medical treatment as a form of self-sacrifice to help others. Participants suggested that society could frame this as a heroic action patients could choose during a crisis.

Whether or not to allocate medical resources based on patient characteristics (age, disability, race), quality of life, or survival

Consumers

Some participants discussed decisions based on characteristics such as age, disability and race as well as based on quality of life or survival. Participants were divided on whether these factors should be considered during rationing situations. Some participants saw these factors as discriminatory and worried about patients with disabilities or elderly individuals being denied care. Others thought that these factors should be used, including prioritizing younger, childbearing age individuals for care over older individuals. There was also disagreement based on determinations that use quality of life judgements or survival assessments. Some participants felt these measures were subjective and potentially discriminatory depending upon who was making the decision. Comparatively, some participants said an individuals' long-term survival and quality of life should be considered in order to prioritize individuals that might benefit most from treatment.

Establish a triage process pre-emergency

Providers

Providers suggested establishing a clear triage process before an emergency. It was also noted that healthcare workers face tough decisions and even having an established process in place would not completely address all the issues given unique nature of some cases. Providers suggested being decisive and making the best possible decision.

Consideration of certain factors could lead to inequities

Providers

It was noted that considering factors such as life expectancy and underlying health conditions might create inequities. Access to certain healthcare services (e.g., COVID-19 tests) might also depend on having a primary care provider.

Implement blinded decision-making process and use factors based on type of emergency

Providers

Other suggestions included a blinded decision-making process to reduce bias and identifying and using factors based on the type of emergency.

To what extent should an individual's potential to survive be considered when deciding who gets what resources and when?

"I think there are a couple of precedents maybe to follow for this. You know, one is basically like emergency room triage for mass casualty. You know, one of the things that they look for is who's likely to get the most good out of the resources. You know, so if you're likely to die imminently, they're not going to try to resuscitate you. They're going to go to the next person who could be benefited the most from that." – Provider

Use trauma-informed care approaches

Consumer advocates

Some participants said it was important to understand a patient's situation and implement decisions with transparency, including providing clear and easy-to-understand options to families and the decision timeline as well as not pressuring families to make decisions about life-preserving care.

Various opinions about using survival as a factor

Consumer advocates

When asked to what extent should an individual's potential for survival be considered when allocating limited resources, participants expressed various opinions, including not to use survival as a factor when there is a doubt, not to factor in quality of life, to make sure that family understands the situation before making any decisions (informed consent), and to use a blinded decision-making process to avoid bias.

Use survival as a factor in decision making

Consumers

Some participants said survival should be considered; however, some participants expressed discomfort with these considerations, calling it "horrible" or hard. In general, participants who discussed using survival talked both about immediate survival through crisis period and long-term survival of multiple years or more. Individuals who discussed long-term survival also talked about a patient's willingness to continue care or maintain their health after receiving treatment as a consideration when looking at long-term survival, with several participants talking about a patient's dependency on drugs as a factor that could limit long-term survivability.

Do not use survival as a factor in decision making

Consumers

Some participants said that survival for any length of time should not be considered when deciding how to best allocate resources during a crisis. Several of the participants who held this perspective spoke from personal experience about how they worry their chronic conditions would be used to justify a determination that they were less likely to survive. One participant offered a potential of using survival past a person's individual baseline but still expressed concern that this could result in disability discrimination.

Survivability should be considered during triage

Providers

During triage, decisions are often based on who most likely would benefit from the medical resources. Survival is one of the key factors. Any subsequent decisions may depend on other factors such as health history and demographic characteristics.

Should essential workers be prioritized when making decisions who gets what medical resources?

> "I think at some point though, it has to be somehow dependent on the scarcity of that type of worker, right?" – Consumer Advocate

The definition of essential workers should align with emergency

Consumer advocates

The focus group participants noted that there is need to develop a definition of an *essential worker* and this definition should align with the emergency at hand. Specifically, it should factor in a potential scarcity of certain type of workers. Roles/employees deemed essential should be weighted differently during allocation of medical resources. However, this process should only be activated on a limited basis and if it's critical to crisis management. Having a very broad definition was also expressed as a concern.

Prioritizing essential workers to keep community open

Consumer advocates

The focus group participants were divided about prioritizing essential workers for medical resources during emergencies. The focus group participants indicated that prioritization of essential workers could help keep a community open. Essential workers were also described as community advocates and individuals who often put themselves at risk on order to help others.

Tradeoffs associated with prioritizing essential workers

Consumer advocates

Several focus group participants noted that prioritizing essential workers might lead to discrimination and less services available for individuals with disabilities and older adults. The likelihood that essential workers will need time to recover and might not be able to get back to work quickly to address emergency was also seen as a reason for not prioritizing essential workers.

Who should be the one to make the decision [about who gets what medical resources and when]?

> "You know, it's a multidisciplinary team that would have to be developed that, you know, so that you get expertise from all these different areas, but if people have equal power in that decision making process, that's the key." - Consumer

Decision making should involve a team of people

Consumer advocates, Providers and Consumers

Consumer advocates, providers and consumers identified decisions should be made by a team. Consumer advocates noted that it should be an interdisciplinary team in which everybody has an equal voice. Providers and consumers noted that that having several groups of individuals involved in making decisions could help reduce bias. Some providers mentioned groups including a committee that created guidelines, providers directly involved with patient care, nurses, CEO, medical professionals and individuals who know the cost of equipment. Some consumers viewed the team as two or more doctors or medical professions. However, other consumers offered various suggestions for the makeup of this team including a combination of medical professionals, medical ethicists, epidemiologists, people with lived experiences (particularly those who live with a disability), and the patients themselves either through a living will or a discussion with the physician about limited resources. Other consumer advocate suggestions included a primary care physician, a context expert (individual with lived experience), parents/guardians, and patients if they are age 17 years and older. Several consumer participants also spoke about the importance of the decision-making team resembling the demographics of the individuals they serve in order to achieve more equitable decisions.

Patients' roles in the decision-making process

Consumers

Of those who felt the patient should be involved in the triage process, some participants said that patients who are awake and able to make decisions for themselves should be informed of the resource shortage and information about who else is in need for the resources. A participant also talked about physicians informing the patient about what their potential quality of life may be post-treatment. Participants with this perspective said it was important that patients or their families be given a way to provide input and advocate for themselves. Another common theme among the participants who felt patients should be involved was the perspective that patients should be given the final decision of whether to receive resources. Some participants discussed this as giving patients agency to deny themselves life-extending care if they knew others might benefit from it.

Who should not be making the decision about who gets what medical resources and when

Consumers

Participants expressed strong feelings against hospital boards and insurance companies deciding who receives what medical resources based on their ability to pay or their insurance coverage. Several participants recognized that hospitals are a business and therefore will need to discuss billing at some point, but should first focus on the people seeking care, explaining that the system of prioritizing individuals who have insurance or are able to pay should not continue to be used because it could create bias against people with lower incomes. One participant specifically said they worry that a family member on Medicaid would receive a lower quality of care because a decision was made based on money. Several participants also said that they did not want politicians making the decisions about who receives what medical resources or telling hospitals to begin rationing resources.

What information should be available to those making the decision [about who gets what medical resources and when]?

> "Because we all have our own biases, I think. Sometimes maybe we don't always acknowledge or identify them, but just making sure that we're not thinking because somebody is really poor or someone is homeless, versus somebody who's very wealthy or very famous, that those kind of biases are never really added into the equation when making those decisions. Somehow we're making sure that we've done some checks and balances there, that we're not making judgments so that there's no possibility for that to seep into the decision making."- Consumer

Only pertinent information should be provided to decisionmakers to avoid bias

Consumer advocates and consumers

Consumer advocates and consumers suggested including only pertinent information about health needs in order to avoid bias. Some consumers expressed concern that decisionmakers knowing some patient characteristics such as a patient's income, housing status, insurance, or perceived quality of life would result in biases. One consumer advocate focused on excluding information about psychiatric diagnoses and disabilities. Some consumers said it was important that there are of consistent recommendations that accounted for these biases.

Decisionmakers should receive all information possible when allocating medical resources

Consumers

Some participants said they believed the best decision for the patient could only be made with all the information possible, including nearest other available resources, a patient's own perspective on receiving care given others who need the resources and the patient's potential quality of life post-treatment, and a patient's life expectancy.

Medical-based guidelines should be used to prioritize care

Providers

Medical-based guidelines should be used to inform decisions about the type of care individuals need to receive. The cost associated with needed resources should not guide the decisions, even if financial considerations are brought up by hospital leadership. To build transparency and understanding of the process, consideration should be given how to best provide information to community members.

What barriers do you see to implementing these decisions [about who gets what medical resources and when]?

“I think a barrier would be that social status would creep in. It would be very hard to keep out pulling strings for important people or who society thinks is important.” - Consumer advocate

Various barriers to implementing decisions about who gets what medical resources and when

Consumer advocates

The focus group participants noted several barriers to implementing decisions, including consideration of social status when prioritizing resources, personal biases, decisions made my frontline workers instead of designated decisionmakers and availability of resources within the community, especially in rural areas.

What do you think the role of community members should be in that decision [about who gets what medical resource and when?

> "I think embedded in maybe some of our organizations is a community board. You know, our board is community members. So, hospital boards, you know, sometimes are community members. So, the first thing you would look at is board members that represent the community." - Provider

Need for unbiased decision

Consumer advocates

The participants expressed the need for making the process as objective as possible, especially given a risk of considering worthiness of an individual as a factor when making decisions.

Role of the family

Consumer advocates

Including family members in the process was described as a barrier to creating an objective process given that family members would have a strong desire to save loved ones. However, it might be harder to avoid in rural communities. The participants suggested to ensure that there is a good communication between a triage team and family members to help them understand what decisions are being made and inquire about a living will. Furthermore, they noted that community consultation should be in advance of a crisis and ongoing throughout it rather than focused on community consultation at bedside.

Community member roles should involve supporting patients

Consumers

Some participants saw community members' roles in the crisis standards of care process as a way to support and empower patients to advocate for themselves during times of rationing or to help educate themselves and prepare a living will in advance with their wishes. However, one participant said they would not want to be involved with other patients' medical care because they didn't know their medical history.

Community member roles should involve ensuring hospital accountability and transparency

Consumers

Some participants said community members should have a role in holding hospitals accountable and increasing transparency about resource availability. This could involve having some community representatives either from city government or disability advocates on the triage team to help assist with the decision making and holding the facility accountable to non-discrimination, particularly if the community feels that mistakes are being made. Another idea from participants included an educational campaign about resource availability and hospital procedures; however, one participant expressed concern that this could cause panic in crisis situations, suggesting instead these educational campaigns only be done on a long-term basis. Some participants discussed how it was important to begin this dialogue with the community and hospitals prior to an emergency to build the relationship and trust.

Community member roles could include serving on boards

Providers

In general, providers noted that having a community representation in decision making is important so providers will have a better sense of public understanding of the emergency. Serving on a board of a hospital or a health department was suggested as a potential role for a consumer. It was also suggested that the group should also include someone familiar with the cost of the resources being allocated if there is a consideration of the financial implications on the hospital.

How should people find out their local hospitals are facing shortages and may need to ration care?

- **Provider follow-up: What other type of information should be communicated to the public?**

> “[The information] should be really easily understood too, not in hospital speak.” - Consumer

The public should receive information about resource shortages, allocation protocols, and guidance for patients

Consumer advocates and Consumers

Consumer advocates and consumers indicated that the information about hospital capacity, available medical resources and what to expect should be publicly available. Consumer advocates said the hospital should be very transparent because lack of information could create a lot of concerns among community members. Consumers further requested that how long rationing protocols will be in place, how decisions on resource allocation will be made, and what alternative options or resources exist for patients to seek care be made public for the whole community to see and understand prior to a patient arriving at the hospital. Consumers said this information should be provided in a way that patients understand how it affects them and their ability to seek care for different conditions. Consumers also said it was important to provide guidance to patients about when to seek care or delay elective procedures, where to seek care, as well as alternate resources or care options near a patient denied resources. Several consumers also said that hospitals or providers should notify people initially denied care at which point care would become available, with this being explained as a more equitable approach. A few consumers also suggested that hospitals consider the messaging around these resource shortages and avoid terms like “rationing” because it could create misunderstandings about the process and panic.

Information should be communicated using multiple communication channels

Consumer advocates, Providers and Consumers

Having access to information through various communication channels was identified as a priority by consumer advocates, providers, and consumers. Providers noted that local news and social media would be the most effective ways to communicate with the community the information needed to help people decide if they need to use emergency department services or seek an alternative approach. For areas with limited or no broadband, consumer advocates suggested having patient representatives making phone calls to follow up with patients. Information should be also available in languages other than English and consider patients’ literacy level. Furthermore, consumers said that individuals who have specific needs (e.g., deaf or hard of hearing) should receive information and not be left in a waiting room without assistance. Consumers further stressed the importance of sharing information in as many ways as possible in order to reach the greatest number of people. Consumers’ ideas for different methods of communication included:

- Patient portals or provider emails to patients
- Hospital signage and flyers

- Hospital webpage
- Email list
- Mailed letters
- Advertisements typically used for hospital funding
- Social media (including Facebook and others)
- Cable or TV news
- Newspaper
- Public Service Announcements
- Radio
- Text alerts

Provide information to patients upon entry to hospital

Consumer advocates

In addition to providing publicly available information, the focus group participants noted the importance of providing information to patients as they enter a hospital.

All information shared publicly should be in plain language

Consumers

In addition to highlighting the importance that the information is publicly available, participants said that the information should be provided in a way that is easy to understand by using plain language. One recommendation was to collaborate with self-advocates and nonprofits in the community to help translate the information into plain language. Participants also spoke about the importance of this information also being provided in languages other than English.

Hospitals, nonprofits, governments, and advocates roles in communication efforts

Consumers

Overall, participants said that it was the hospitals' and providers' responsibility to notify people of the resource shortages and rationing. However, some participants also suggested that other groups like statewide nonprofits, local self-advocates particularly in the disability rights community, and local government such as public health departments also assist in sharing information about resource shortages so that the information can reach the greatest number of people possible.

Provide easy-to-understand information

Providers

Broadcasting healthcare related information before an emergency (as part of weekly news from CEO) could help a hospital establish a regular communication channel with their community. This approach could also help the public learn about available specialists and how to access them. Other suggestions noted by providers focused on providing easy-to-understand information (spotlight report) and describe options if certain services are not available. Furthermore, if numbers are provided, they should be put into context to help the public understand the potential implications on access to services or other needs.

Is it possible to make fair decisions about who gets what medical resources and when? Why or why not?

> “I think certainly planning on it now like we're doing, talking about it and getting those ideas ahead of time is going to make it a lot easier to do that than it would be if you wait 'til the last minute, and then it's chaos and you're just really dealing with whoever shows up. And that's going to definitely be more biased than if we plan out some things ahead of time.” – Provider

Equitable approach should be a goal when making decisions about who gets what medical resources and when

Consumer advocates, Providers and Consumers

Consumer advocates, providers and consumers said equity in the decision-making process should be a goal. Consumer advocates said decisions about who gets what medical resources should try to be as equitable as possible. However, one concern of consumer advocates was about the current system being inequitable. Some providers also said that striving for an equitable approach and recognizing bias and existing social, racial and ethnic disparities should be the goal when making decisions regarding who gets what medical resources. However, some providers said limited resources could lead to inability to provide resources to all the people who need them, thus making this less equitable. Consumers suggested potential areas to achieve equity in this process, including determining who is making the decisions, using an equitable decision-making tool, using transparent communication that clearly defines the process and ‘leveling the playing field’ by allocating greater resources to those who historically have not had access.

Focus on doing our best

Consumer advocates

In general, participants agreed that it should be possible to make fair decisions. To make fair decisions, they suggested focusing on doing “our best” and spend less time deciding who should be included or excluded. On one hand, a standardized tool was seen as a vehicle for making fair decisions. On the other hand, participants recognized that the tool would not be able to account for all circumstances.

Fairness is possible when making decisions about who receives what medical resources and when

Consumers

Some participants said fairness was possible but discussed fairness in slightly different ways. For some participants, fairness was when the decision was made by qualified, trained individuals who were following a pre-set plan or guidance. For other participants, fairness was having a clear understanding of why and how decisions were made and who they were made by. Some participants also specified that fairness was possible but is not currently implemented, stating a need for system changes and guarantees that decisions are not based on discriminatory judgements like a patient’s ability to pay.

Fairness is not possible when deciding who gets what medical resources and when in crisis

Consumers

Some participants said fairness was not possible in a crisis situation and could only be achieved through long-term reform of the health system. Participants explained that the quick decisions required of providers during a crisis could result in mistakes being made or in biased judgements that lead to someone missing out.

Health system changes needed for fair decision-making about who gets what medical resources and when in the future

Consumers

Some participants did not think it was currently possible to make fair decisions but that this should be a goal. Some participants made recommendations for changes to the health system that would result in fairer decision-making, including better connecting patients and families to available resources similar to models from other countries and passing Medicaid expansion. There was also discussion about what terminology would result in the fairest decision-making and best patient perception of the process with some participants preferring the term "prioritizing." However, other participants thought rationing was the best terminology because it recognized the gravity of the decisions being made and would be better understood by most patients.

Planning in advance to reduce bias in decision making

Providers

Planning in advance could help reducing biases in decision making during emergencies. This planning could include creating a community committee or board that could provide information and education, especially about ethics.

Are there any approaches of how to design an equitable tool [to help decide who gets what resources and when]?

“Like income and ability to pay for services should not be part of this tool as well.” – Consumer advocate

Exclude information that may lead to bias

Consumer advocates

The focus group participants offered a few suggestions regarding how make the screening tool equitable. They noted that there is a need to eliminate a potential bias but also be transparent about the tool’s limitations. Suggestions included: not including information about individual’s ability to pay, race/ethnicity, disability status, income and comorbidities.

What groups of people could be at greater risk for not having all their medical needs met when care is being rationed?

> “I think also uninsured people and people with disabilities. Also people that aren't documented” – Consumer

Populations at greatest risk of not having medical needs met

Consumers and Consumer advocates

Both consumers and consumer advocates specified that people who are low-income, people of color, and people who are uninsured might be at greater risk of not having all their medical needs met. Consumer advocates further specified people who live in rural areas, people who lack transportation and people who have language barriers, including those who are deaf or hard of hearing, or for whom English is not the first language. Consumers further specified:

- People in institutional settings like state hospitals, nursing homes and group homes
- People with disabilities
- People with mental or behavioral health diagnoses
- People with chronic illness
- People who are overweight
- Recipients of Medicaid/KanCare
- Women
    - Women of color
- People who are older
- People who are undocumented

Should CSC be implemented at the local, state or federal level?

> "But then at the local level, it's nice if they knew about it, but at the same time, the bias is higher, right, at the local level, because those tend to shoo away outsiders that are not from the local area. And so, their information might be even more limited to the local, and they're not sharing that information, as opposed to the state would share it and be more visible." – Consumer advocate

Need for a balanced approach between state and local

Consumer advocates

The participants noted the need for a balanced approach, in which state and local communities are working together to implement the CSC guidance.

Tradeoffs: State vs. Local

Consumer advocates

The state was seen as a vehicle for proving medical resources across the state, while communities having a clearer understanding of local needs. On the other hand, there was concern that state might not be able to meet the needs of all the communities, especially rural communities. Equitable allocation of resources across communities was described as an afterthought. For local communities, participants said, the main concern was about prioritizing self-interest and not being able to see the big picture.

Voluntary guidance can result in inconsistent implementation

Consumer advocates

The participants expressed a concern that the voluntary nature of the guidance would result in inconsistent implementation, especially by hospitals that have less resources. According to participants, a risk of discrimination is another concern.

CSC should be implemented at local level

Providers

Providers noted that the crisis standards of care should be implemented at the local level given that each community is unique. As one provider noted: "the closer to home the better."

Keep politics out of decisions about crisis standards of care

Providers

Keeping politics out decisions regarding crisis standards of care was also noted by several providers during a focus group.

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?

> "The system should not just assume that everyone has the same health risks, the same... there are differences among some of the groups."– Consumer

Yes, prioritize historically marginalized populations

Consumer advocates, providers and consumers

Consumer advocates, some providers and some consumer participants agreed that it will be important to dedicate greater medical resources to people who have historically been less able to access medical care and/or health-supporting resources and trauma. Some providers suggested this would help prevent exacerbation of existing equities due to patients' social circumstances. Some consumers explained the importance of this action because of historic injustices and barriers that these groups of people face or as a way to right past wrongs they see perpetrated against these groups of people. Other consumers explained their stance as a question of privilege and resources, feeling that people with fewer resources are at greatest risk during a crisis and should therefore receive treatment soonest. Some consumers also said that certain groups experience greater health risks that would disadvantage them if compared to someone without these same experiences. Consumer advocates said that if not provided, the impact of the emergency might be long lasting on these populations. Some consumer advocates were concerned that consideration of this issue is often an afterthought. Populations for prioritization mentioned by consumer advocates included Native American individuals and people who are hard hearing or deaf. Some consumers suggested using data in a community to help decide how best to allocate resources to groups who most need it. Consumers also suggested the following groups be prioritized:

- Black individuals, particularly black women
- Indigenous individuals
- Hispanic individuals
- Rural populations
- Low-income individuals
- People with disabilities
- People without insurance
- People without primary care doctors
- Non-traditional families
- Non-gender conforming youth
- Unauthorized immigrants
- Those making personal medical decisions about their bodies
- Women seeking reproductive health

No, serve everyone equally rather than prioritizing historically marginalized populations

Consumers

Some participants were against the idea of dedicating greater resources to these populations because they preferred a need-based system where everyone was treated equally. Some individuals said they were concerned that this felt like placing a value on someone's life and that it would create new disparities if resources were taken away from one group and given to another. Some participants also said that the doctors would not know the details needed to make these assessments during triage, so a patient's condition and need alone should be considered. A few participants said they acknowledged the impact of historical inequities on some populations' health outcomes but that an emergency situation was not the right context for addressing these. These participants instead suggested system changes around where resources are available and how easy these are to access.

Move resources to the people who need them (system change), rather than prioritize marginalized populations for greater resources

Consumers

Participants, both those who did not want to dedicate greater resources to these populations and those who did, discussed medical resources being made more accessible to populations who needed it as an important long-term change to the health system. Some suggestions for increasing access included providing health coverage to those who are uninsured, telehealth, improved transportation, better childcare, and moving resources to where the people live particularly in rural areas.

No, patients might be responsible for not seeking resources sooner or complying with their providers' medical advice

Providers

Some participants expressed concerns with dedicating greater medical resources based on population access because it is unknown whether individuals within a population had less access based on their social circumstances or simply chose not to seek care earlier. If patients chose not to seek care in advance, participants said this should not count against the patient but were uncomfortable with prioritizing patients based on this. In addition, assessing potential patient compliance was also noted as a potential consideration in distribution of resources.

What are some strategies to augment the staffing necessary to maximize quality of care during rationing of care?

> “I think that some of the bigger hospitals too, well, not even bigger ones, small ones need to look at, relook at their expectations, especially nurses and bedside. Make those states make it a little easier for those certified healthcare workers, the nurses' aides, the med techs, things like that, to come back onto the scene. There's a lot of CNAs out there that have gone on to other things because of pay, not necessarily because they didn't like their jobs, but because of pay and because hospitals went to an all-nursing model instead of using the CNAs. And if they would allow them to get their certification back easier than going through that whole 90-clock hour class again, in situations like this, then they can take that load off of the nurses who are leaving because they are absolutely wiped.” – Provider

Strengthen the system and workforce pre-emergency

Consumer advocates

The focus group participants emphasized the importance of strengthening the system pre-emergency. Specifically, they recommended increasing healthcare workforce and attracting certain professions that are currently scarce and might be critical during emergencies. Another comment highlighted the effects of defunding of public health system over the years and the resulting difficulty with addressing community needs quickly.

To augment staffing, focus on providing trainings, creating a database and making the recertification process easier

Providers

To augment staffing necessary to maximize quality of care during rationing, providers suggested focusing on providing healthcare worker training. Other suggestions included creating a database of individuals who might be available to help during emergencies and making the re-certification process easier for individuals who might want to re-enter the healthcare workforce during emergencies.

What ethical considerations should be used to determine who gets what medical resources?

> "I think we have to put the human element back in medical care. We need to have training for trauma-informed best practices as well as etiquette, just basic human etiquette practices and working with families."- Consumer advocate

Various ethical considerations

Consumer advocates

The focus group participants suggested various ethical considerations:

- Data should be used to make timely decisions
- Immediate need should not be a key determining factor when allocating resources
- Large healthcare systems that were given resources should have a plan how to reallocate them in rural areas if needs arise
- Need cultural humility training, trauma informed care training and training regarding how to work with families
- Put human element back into medical care
- Obey a key principle - not to do greater harm
- Use trauma-informed care principles
- Not ethical to use quality of life

Medical-based guidelines as ethical principle

Providers

Providers noted the importance of relying on medical-based guidelines when making decisions about who gets what medical resources and when. They noted that using this principle will avoid "picking a person" in an unethical way. Furthermore, it was noted that there is "an art in medicine as well as science." Thus, it is important to recognize that there might be "bias behind the science."

Are there any other considerations around who gets what medical resources and when that you feel are important to share?

> “I think it's important to recognize that the standards that are put forward and the process that's built is not going to be perfect. And it's always going to need improvement and always going to need voices to speak into it. And sometimes, in processes like this, there's pride of ownership. And when there's pride of ownership or pride of authorship, there's this idea that this is mine and I don't want it to be touched. But I think it's important to recognize that any process like this is going to be flawed, but it needs continuous improvement.” – Consumer advocate

Crisis Standards of Care Guidance should be a living document

Consumer advocates

The focus group participants suggested that there is a need to recognize that this CSC guidance should be a living document and improvements should be made based on lessons learned. They also recommended developing the same guidance for other areas such as social services.

Make information relevant

Providers

Providers noted that people are not likely to pay attention to the issue or information until they are personally affected. However, they were not sure how to address this issue. On the other hand, providers noted that there might be an opportunity to leverage examples that people can more easily understand or relate to such as decisions about organ transplants. Other suggestions included being honest and transparent with community members about the situation.

What support should the state provide to keep providers informed related to state and federal crisis standards of care guidance?

> “And I just think that for once everybody needs to get on board and work in the community's best interest, in people's best interests.” – Consumer advocate

Consistent messaging among federal and state agencies

Consumer advocates

The focus group participants provided several recommendations, including improving consistency of information among federal and state agencies and ensuring that all efforts and collaboration are done in best interest of communities.

Provide a toolkit, templates and expert advice

Providers

Providers noted that to support the implementation of CSC, the state could provide resources such as a toolkit and templates. A toolkit could include information about the process. Other suggestions included providing information about available supplies and being available to answer any questions or connect to needed resources.

What information could be given to patients to improve communication?

> “I also think it's important that the basic rules need to be public and transparent, that here are the basic rules that every health facility is operating under and that's available to every person.” – Consumer advocate

Promote transparent communication

Consumer advocates

To improve communication, the focus group participants suggested providing information to patients so they can understand their rights, explaining the situation and next steps and being transparent about hospital rules.

Create support systems before and during emergencies

Consumer advocates

The focus group participants also emphasized the importance of creating support systems pre-emergency and during the emergency. Prior to emergencies, the suggestions included building trust in the healthcare system, educating people about their rights and responsibilities as a patient and growing a pool of advocates. During an emergency, the participants suggested making additional staff available to provide more communication to patients and providing access to advocates so they can help patients with their needs.