Crisis Standards of Care: Focus Group and Interview Findings

May 5, 2022

25TH ANNIVERSARY
KANSAS HEALTH INSTITUTE
Informing Policy. Improving Health.

BACKGROUND

KEY COMPONENTS

Community Advisory Board

Up to 15 individuals - Consumer advocacy groups, patients and other individuals with live experience

Technical Advisory Panel

Up to 25 individuals - Clinicians and those with technical knowledge, including representatives of hospitals of various sizes

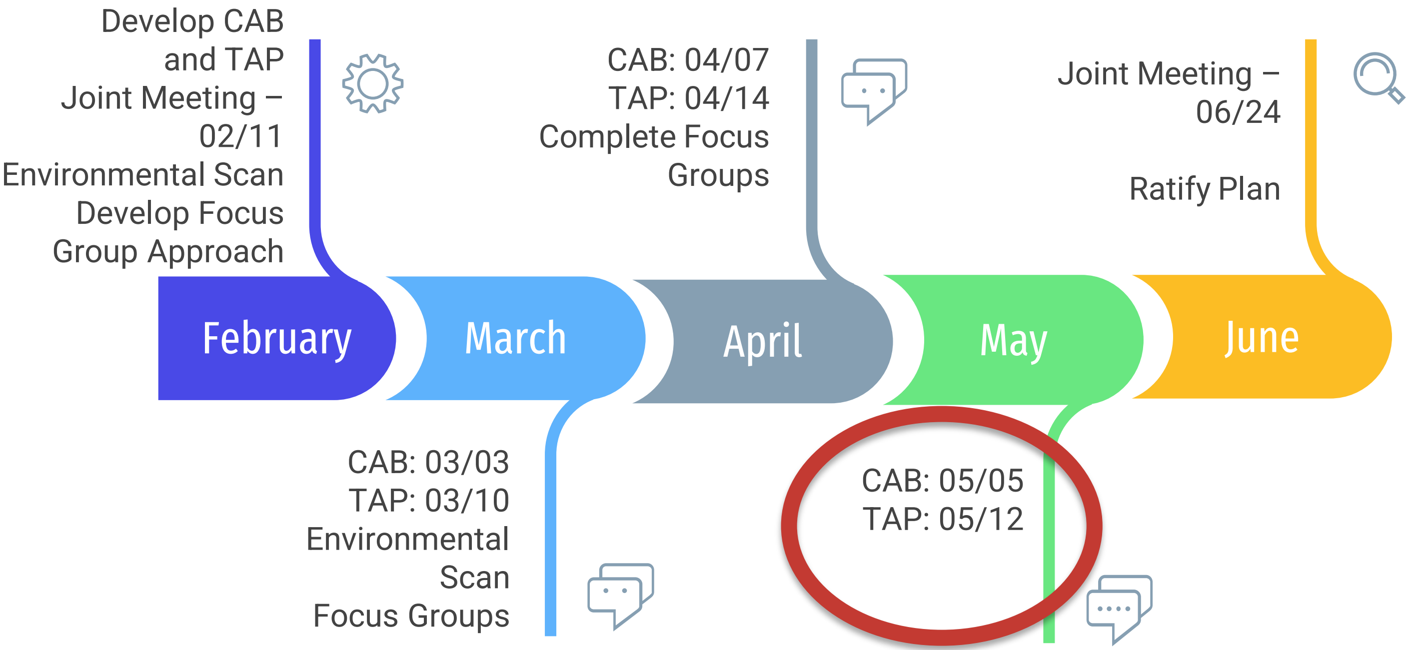
Environmental Scan

Address key questions to support discussions

Focus Groups

Identify considerations around allocation of scarce resources during emergencies (e.g., safety net clinics and facilities, consumer advocacy, patients)

CSC PLAN TIMELINE



February

Develop CAB and TAP
Joint Meeting – 02/11
Environmental Scan
Develop Focus Group Approach

March

CAB: 03/03
TAP: 03/10
Environmental Scan
Focus Groups

April

CAB: 04/07
TAP: 04/14
Complete Focus Groups

May

CAB: 05/05
TAP: 05/12

June

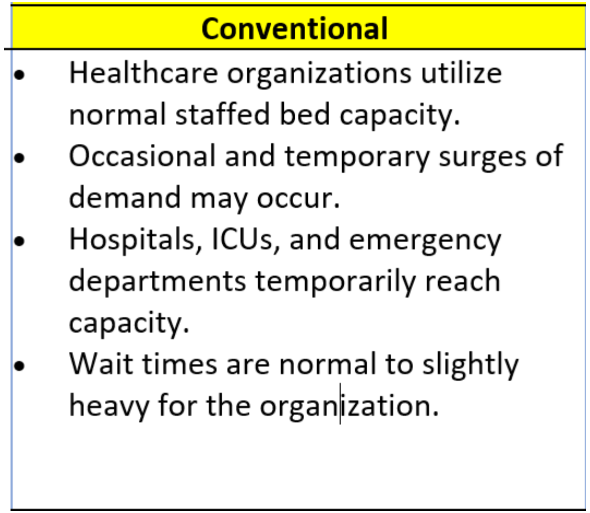
Joint Meeting – 06/24

Ratify Plan

2.

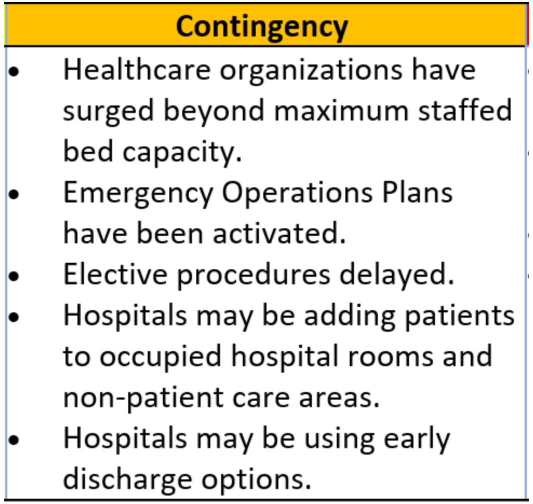
REVIEW OF DRAFT RECOMMENDATIONS

SURGE STATUS



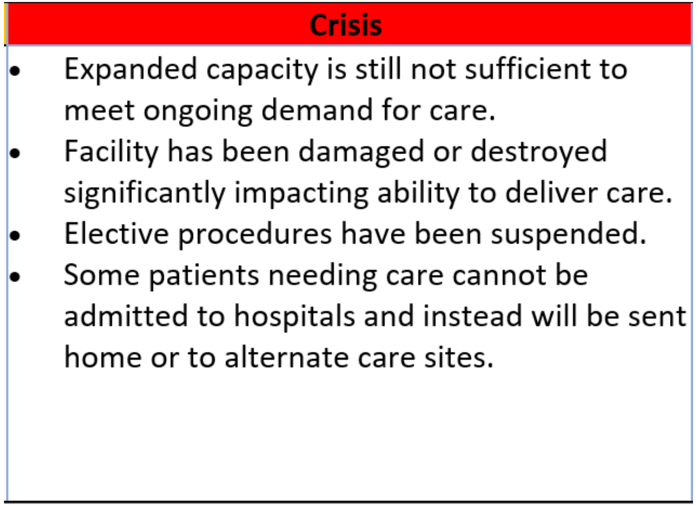
Conventional

- Healthcare organizations utilize normal staffed bed capacity.
- Occasional and temporary surges of demand may occur.
- Hospitals, ICUs, and emergency departments temporarily reach capacity.
- Wait times are normal to slightly heavy for the organization.



Contingency

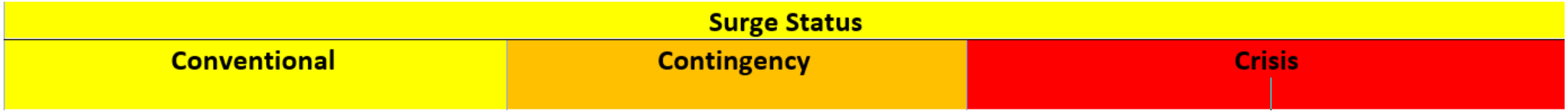
- Healthcare organizations have surged beyond maximum staffed bed capacity.
- Emergency Operations Plans have been activated.
- Elective procedures delayed.
- Hospitals may be adding patients to occupied hospital rooms and non-patient care areas.
- Hospitals may be using early discharge options.



Crisis

- Expanded capacity is still not sufficient to meet ongoing demand for care.
- Facility has been damaged or destroyed significantly impacting ability to deliver care.
- Elective procedures have been suspended.
- Some patients needing care cannot be admitted to hospitals and instead will be sent home or to alternate care sites.

OVERALL RECOMMENDATIONS

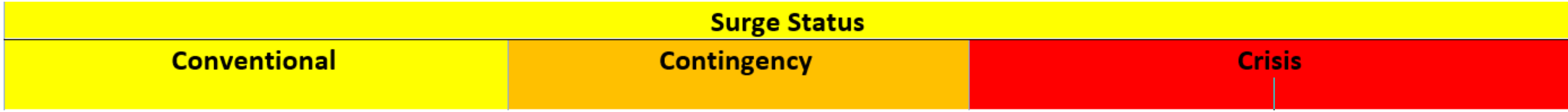


Surge Status		
Conventional	Contingency	Crisis

1.1. The implementation of Crisis Standards of Care commits to the dual goal of public health emergency: improving health outcomes and reducing inequities in distribution of health benefits.

1.2. Guidelines should prioritize making equitable decisions that create a level-playing field for individuals that have experienced systemic barriers rather than prioritizing fair decisions that treat everyone the same regardless of the inequities they may have experienced.

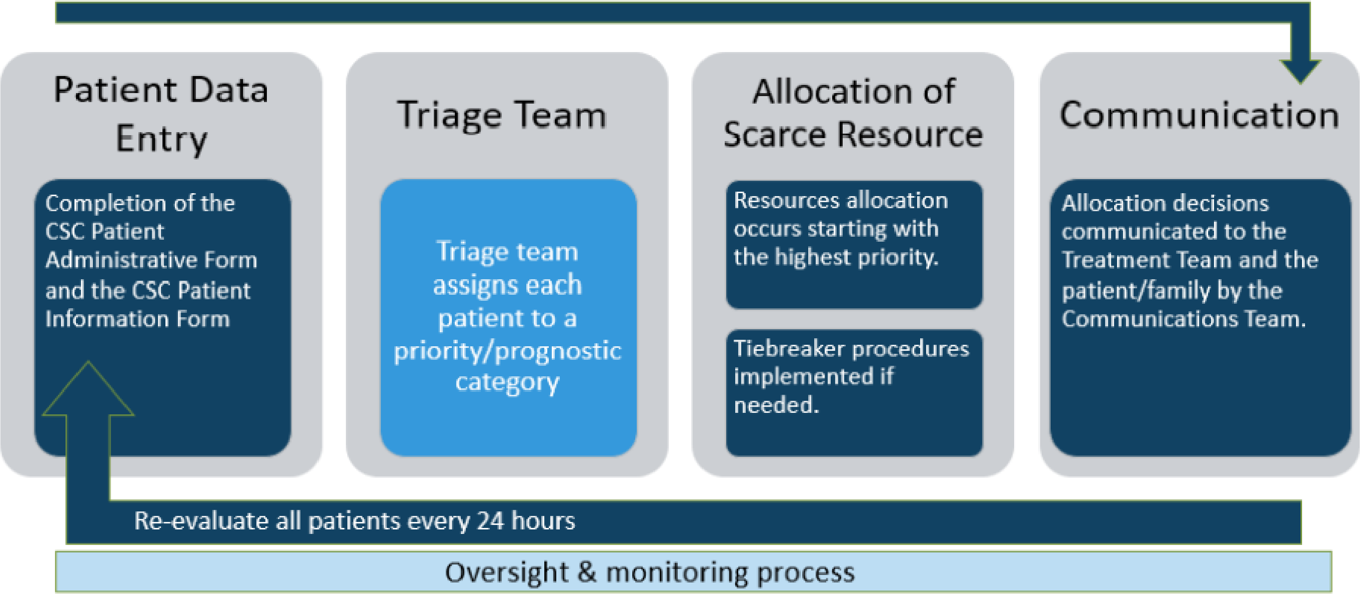
PERSONAL MEDICAL EQUIPMENT



Surge Status		
Conventional	Contingency	Crisis

1.3. Patients who have their personal medical equipment will not have their personal equipment allocated or reallocated to other patients. When a patient with their own (non-hospital) medical equipment is admitted, they **may** continue using their medical equipment (as defined in this CSC Guidance) which is considered to be their personal property. However, when the patient’s status changes and the use of medical equipment provided by the hospital is necessary, the patient will be included for assessment and resource allocation of other hospital equipment according to a triage protocol in place for CSC. Patients' privately-owned, personal medical equipment will remain theirs even if a patient is allocated further hospital equipment.

TRIAGE PROCESS



Patient Data Entry

Completion of the CSC Patient Administrative Form and the CSC Patient Information Form

Triage Team

Triage team assigns each patient to a priority/prognostic category

Allocation of Scarce Resource

Resources allocation occurs starting with the highest priority.

Tiebreaker procedures implemented if needed.

Communication

Allocation decisions communicated to the Treatment Team and the patient/family by the Communications Team.

Re-evaluate all patients every 24 hours

Oversight & monitoring process

TRIAGE PROCESS

Conventional

1.4. To best mitigate implicit bias, each facility should have a group of triage coordinators and a triage team that adequately reflects the diversity of the patient population served by the facility in terms of demographics such as race, ethnicity, disability, preferred language, sexual orientation and gender identity.

1.5. Facilities should have a human resource plan to recruit and retain people from excluded communities so a greater pool of potential team members that reflect the community's demographic are available.

TRIAGE PROCESS

Conventional

1.6. Triage team members and coordinators should receive advanced and ongoing training to prepare them for the role, including training in:

- Applying the allocation framework;
- Communicating with clinicians and families about triage;
- Avoiding implicit bias against persons of color and other marginalized groups;
- Improving cultural competencies; and
- Respecting disability rights.

1.7. Develop a process to resolve any disputes (placeholder).

TRIAGE PROCESS

Crisis

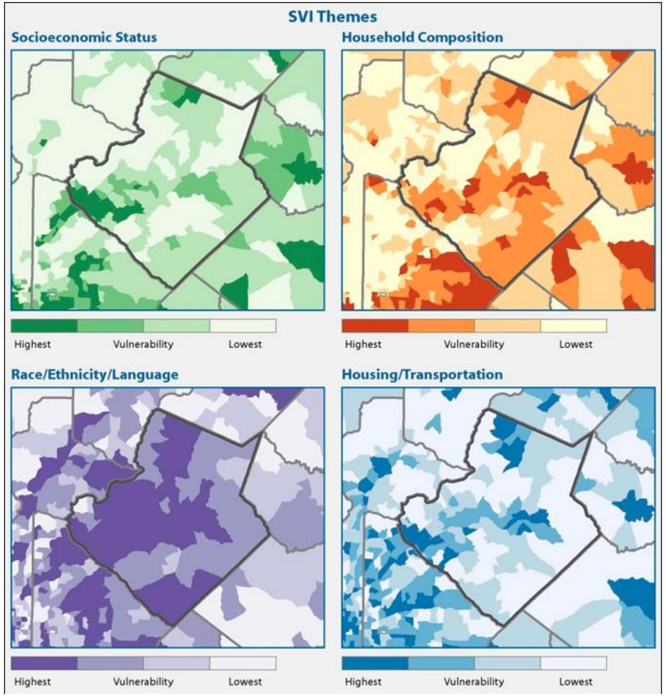
1.8. Clearly communicate triage process to patients and/or their next of kin using plain linguistically and culturally appropriate language to ensure a triage process that manifests respect for persons.

1.9. Once triage decision has been determined, this information should be clearly communicated to patients and/or their next of kin using plain linguistically and culturally appropriate language per facility protocols.

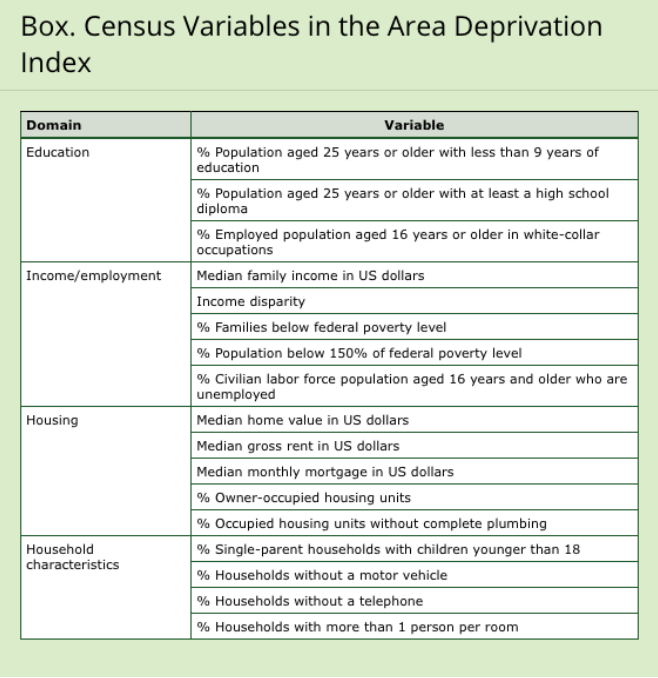
CORRECTION FACTORS FOR SCORING TOOLS (1)

Social Vulnerability Index (SVI)

- SVI uses 15 U.S. census variables to help local officials identify communities that may need support before, during, or after disasters.
- The 15 social factors are grouped into four themes:
  - **Socioeconomic status:** below poverty, unemployed, income, no high school diploma
  - **Household composition and disability**: persons over age 65, persons under age 17, persons over age 5 with a disability, single-parent households
  - **Race/ethnicity and language**: minority status, ability to speak English "less than well"
  - **Housing or transportation status**: multi-unit structures, mobile homes, crowding, no vehicle ownership, group living quarters
- Higher SVI = more social vulnerability = more resources needed to thrive.



CORRECTION FACTORS FOR SCORING TOOLS (2)



Box. Census Variables in the Area Deprivation Index

Domain	Variable
Education	% Population aged 25 years or older with less than 9 years of education
	% Population aged 25 years or older with at least a high school diploma
	% Employed population aged 16 years or older in white-collar occupations
Income/employment	Median family income in US dollars
	Income disparity
	% Families below federal poverty level
	% Population below 150% of federal poverty level
	% Civilian labor force population aged 16 years and older who are unemployed
Housing	Median home value in US dollars
	Median gross rent in US dollars
	Median monthly mortgage in US dollars
	% Owner-occupied housing units
	% Occupied housing units without complete plumbing
Household characteristics	% Single-parent households with children younger than 18
	% Households without a motor vehicle
	% Households without a telephone
	% Households with more than 1 person per room

Area Deprivation Index (ADI)

- ADI is a composite measure of 17 census variables designed to describe socioeconomic disadvantage based on income, education, household characteristics, and housing.
- This is used to show where areas of deprivation and affluence exist within a community on a 10-point scale.
  - A low ADI score indicates affluence or prosperity.
  - A high ADI score is indicative of high levels of deprivation.

CORRECTION FACTORS

Crisis

1.10 Area Deprivation Index (ADI) or Social Vulnerability Index (SVI) data is gathered for all patients at intake so equity adjustments are readily available.

1.11. When patients subject to triage are identified, patient profiles will include a correction factor into patients' triage scores to reduce the impact of baseline structural inequities using Area Deprivation Index (ADI) and Social Vulnerability Index (SVI) upon intake. Collectively, ADI and SVI take into considerations factors, including education, income/employment, household composition and disability, race/ethnicity, language, housing and transportation status.

HOW TO CONSIDER SURVIVAL

Crisis

1.12 Use hospital survival to discharge.

1.13 Quality of life judgments or long-term life expectancy will not be used as factors in the allocation and reallocation of medical resources.

3.

FOCUS GROUP FINDINGS

FOCUS GROUPS: OVERVIEW

- **Goal**: Understand stakeholder perspectives and concerns associated with decisions related to who gets what medical resources and when during the emergencies.

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

FOCUS GROUPS: OVERVIEW

- **Feedback:** Received and incorporated feedback
- **Questions:** Subset of questions – same for consumers and providers
- **Terms**: For purposes of some of the questions asked in this focus group, we use the term rationing of care. 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.

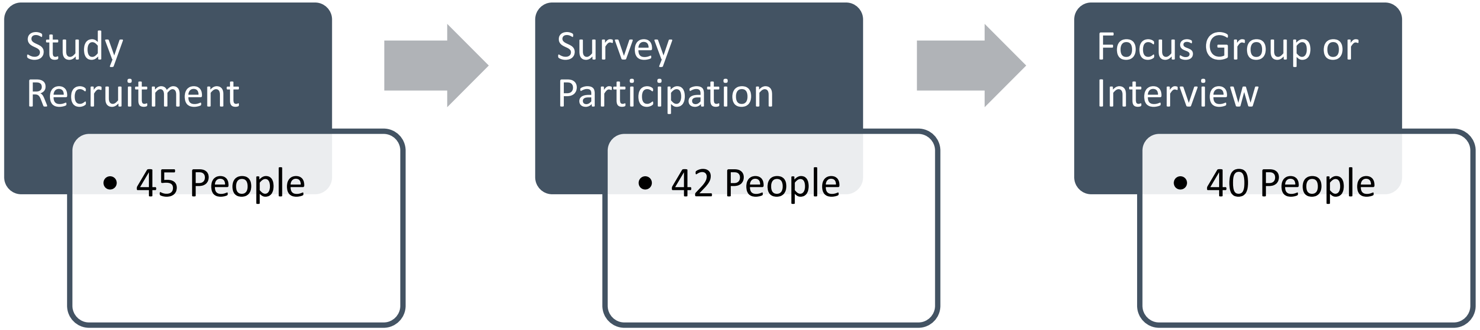
FOCUS GROUPS

1. What is the first thing that comes to mind when you hear the word “rationing of care”?
2. If your local hospital had to ration medical care, what would worry you most?
    - How might this impact your decision to seek medical care?
3. How should people find out their local hospitals are facing shortages and may need to ration care?
4. When medical resources are limited, what do you think would be the best way to decide who gets what medical resources and when?
    - Who should be the one to make that decision?
    - What information should be available to those making the decision?
    - What do you think the role of community members like yourself should be in that decision?

FOCUS GROUPS

5. Is it possible to make fair decisions about who gets what medical resources and when? Why or why not?
6. What groups of people could be at greatest risk of not having all their medical needs met when care is being rationed?
7. 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?
8. Are there any other considerations around who gets what medical resources and when that you feel are important to share

RESPONSE RATE



Study Recruitment

- 45 People

Consumers: 16
Providers: 10
Advocates: 19

Survey Participation

- 42 People

Consumers: 14
Providers/Advocates: 28

Focus Group or Interview

- 40 People

Consumers: 14
Providers: 9
Advocates: 17

DEMOGRAPHICS

Characteristic	Percent of Respondents (14 consumers and 28 providers /advocates)
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, 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

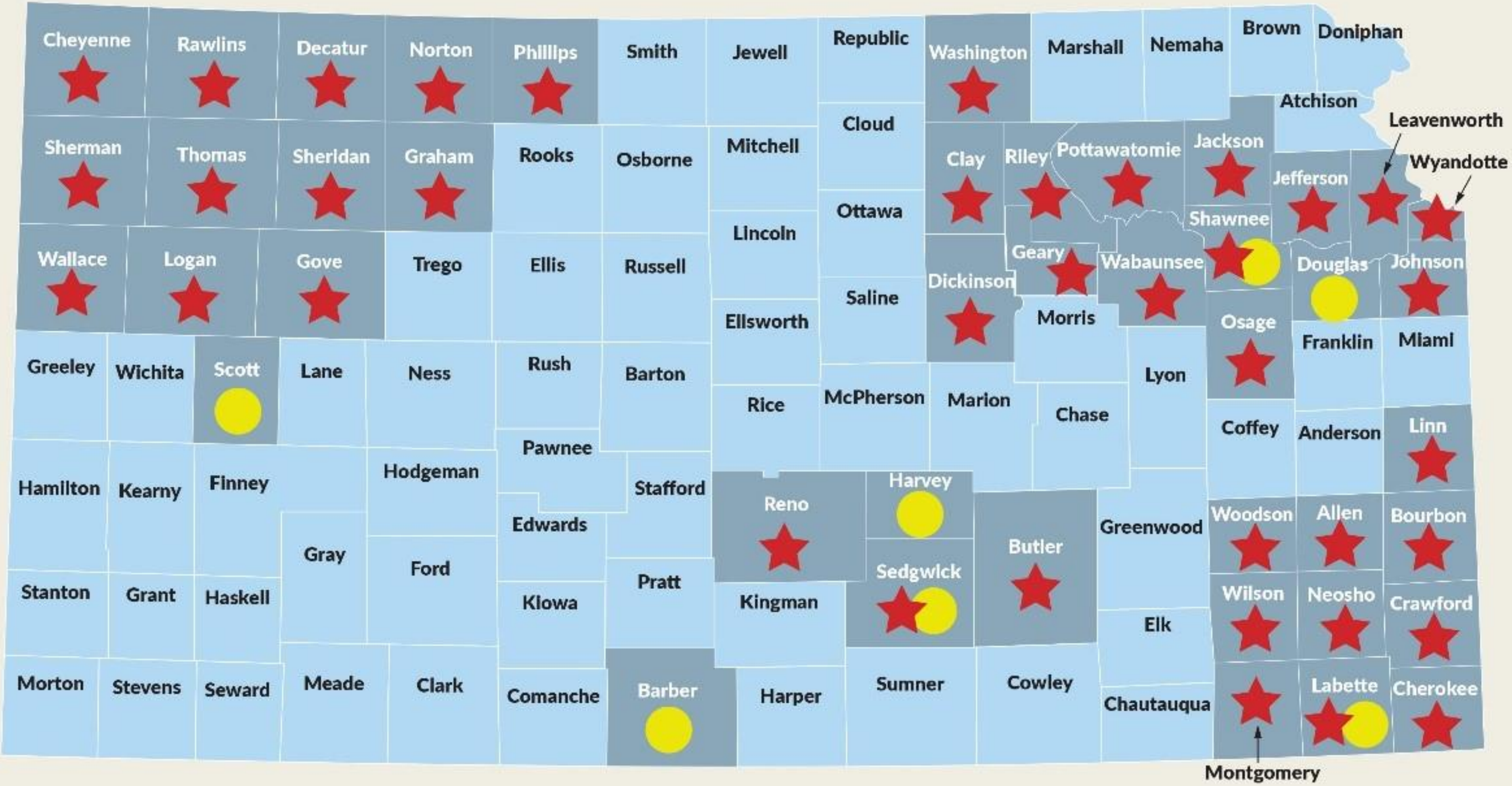
DEMOGRAPHICS

Characteristic	Percent of Respondents (14 consumers and 28 providers /advocates)
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

DEMOGRAPHICS

Characteristic	Percent of Respondents (14 consumers and 28 providers /advocates)
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.

Geographic Distribution of Focus Group and Interview Respondents



★ 28 Providers and Consumer Advocates Responded to the Question:
"From Which Counties Do the Populations You Serve Come?"

Respondents could select multiple answers.
13 responded "*We Serve People Statewide.*"

● 12 of 14 Consumers Responded to the Question:
"In What County Do You Currently Live?"

Respondents could select only one answer.
2 respondents chose to not respond to the question.

DISCLAIMER

The following themes were found in analysis of the focus group and interview transcripts. ***For more information about each theme, please refer to the complete document of findings.***

IF YOUR LOCAL HO WHAT WOULD WO IMPACT YOUR DEC

“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

Consumers and Consumer Advocates	● Concerns about discrimination by decisionmaker ● Worries about a quality of life factor being used in decision making ● Worry about a worthiness factor being used to allocate medical resources
Consumers	● Impact of patients’ worry about rationing of care on decision to seek care ● Patients’ worry about understanding CSC process and how to access resources that are available
Consumer Advocates	● Left behind populations
Providers	● Misunderstanding of healthcare resource scarcity by public

WHAT IS TH
WHAT MEDI

> “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

Consumers and Consumer Advocates	● Prioritize those with greatest need and who are most vulnerable
Consumers	● Difficulty making decision about who receives what medical resources ● Participant rejected question itself (favoring a focus on prevention) ● Impact of patients’ use of preventative care on medical resource prioritization ● Allowing patients to self-deny medical resources ● Whether or not to allocate based on patient characteristics (age, disability, race), quality of life, or survival
Consumer Advocates	● Need for objective triage process ● Challenges with COVID-19 resource allocation processes ● Fears about triage process
Providers	● Establish a triage process pre-emergency ● Consideration of certain factors could lead to inequities ● Implement blinded decision-making process and use factors based on type of emergency

WHO SHOULD BE THE ONE TO MAKE THAT DECISION?

> "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

All Stakeholder Groups	● Decision making should involve a team of people
Consumers	● Patients' roles in the decision-making process ● Who should not be making the decision about who gets what medical resources and when

WHAT INFORM THOSE MAKIN

“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

Consumer Advocates and Consumers	• Only pertinent information should be provided to decisionmakers to avoid bias
Consumers	• Decisionmakers should receive all information possible when allocating medical resources
Providers	• Medical-based guidelines should be used to prioritize care

WHAT DO YOU THINK THE ROLE OF COMMUNITY MEMBERS LIKE YOURSELF SHOULD BE IN THAT DECISION?

“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

Consumers	● Community member roles should involve supporting patients ● Community member roles should involve ensuring hospital accountability and transparency
Consumer Advocates	● Need for unbiased decisions ● Role of the family
Providers	● Community member roles could include serving on boards

HOW SHOULD PEOPLE FIND OUT THEIR LOCAL HOSPITALS ARE FACING SHORTAGES AND MAY NEED TO RATION CARE

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

All Stakeholder Groups	● Information should be communicating using multiple communication channels
Consumer Advocates and Consumers	● The public should receive information about the resource shortages, allocation protocols, and guidance for patients
Consumers	● All information shared publicly should be in plain language ● Hospitals, nonprofits, governments, and advocates roles in communication efforts
Consumer Advocates	● Provide information to patients upon entry to hospital
Providers	● Provide easy-to-understand information

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

Consumers and Consumer Advocates	● **Populations at greatest risk of not having medical needs met** (including low-income, people of color, people who are uninsured…)

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

Consumer Advocates	● Need for balance approach between state and local ● Trade offs: State vs. Local ● Voluntary guidance can result in inconsistent implementation
Providers	● CSC should be implemented at local level ● Keep politics out of decisions about crisis standards of care

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

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

All Stakeholder Groups	● Yes, prioritize historically marginalized populations
Consumers	● No, serve everyone equally rather than prioritizing historically marginalized populations ● Move resources to the people who need them (system change), rather than prioritize marginalized populations for greater resources
Providers	● No, patients might be responsible for not seeking resources sooner or complying with their providers' medical advice


THANK YOU

Any questions?

You can connect with us at:

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