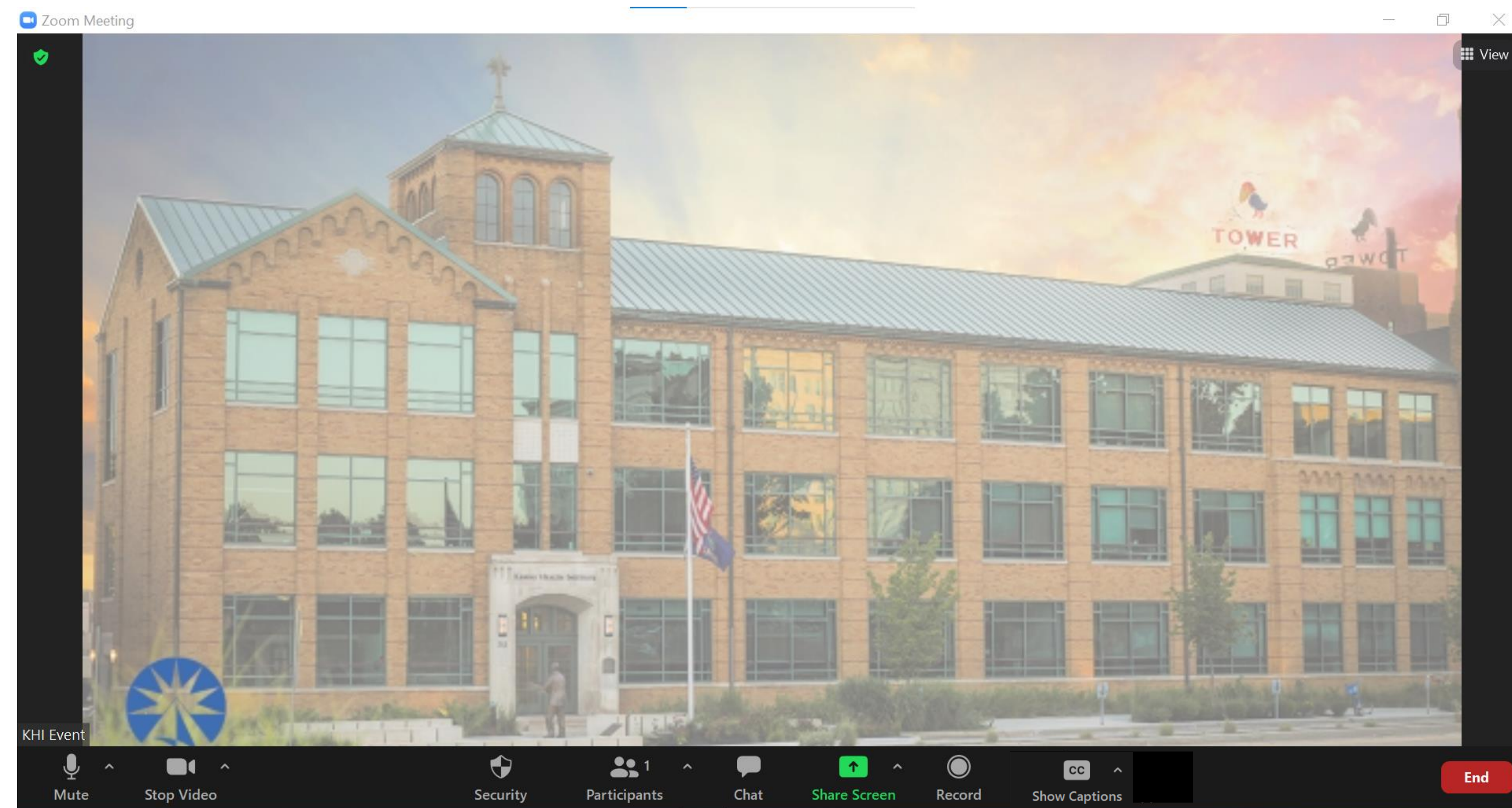
KANSAS HEALTH INSTITUTE

Kansas Crisis Standards of Care Guidance

Phase II: Joint Meeting

January 20, 2023



View: Switch between Speaker and Gallery view.

Helpful Hints for Zoom Meeting

Technical questions about your Zoom connection or functionality?

> Find **'KHI, IT Help'** in the Participants list to connect for assistance.

Mute

Video: Stop or start your individual video

Participants listing: Find a participant to message

Chat: Use this feature to enter questions and comments.

Closed Captions: Option for participants

Who We Are

- Nonprofit, nonpartisan educational organization based in Topeka.
- Established in 1995 with a multi-year grant by the Kansas Health Foundation.
- Committed to convening meaningful conversations around tough topics related to health.

TODAY'S AGENDA

9:00 a.m.	Welcome
9:05 a.m.	KDHE
9:25 a.m.	Project Overview
9:40 a.m.	Review of Phase 1
10:00 a.m.	Speaker
10:30 a.m.	Breakout Rooms
11:45 a.m.	Report Out
11:55 a.m.	Wrap-up
12:00 p.m.	Adjourn

Kansas Department of Health and Environment
Division of Public Health

Acknowledgements

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PREPAREDNESS PROGRAM

KANSAS DEPARTMENT OF HEALTH AND ENVIRONMENT

Kansas Crisis Standards of Care Guidance Development: Phase II – Introduction

Edward Bell | January 19, 2023

AD ASTRA PER ASPERA
Kansas
Department of Health and Environment
Division of Public Health

When We Last Met

Through the joint efforts of the members of the Community Advisory Board (CAB) and the Technical Advisory Panel (TAP), built the *Kansas Crisis Standards of Care Guidance* (KSCSCG) by:

- Identification of questionable sections of the 2013 KSCSCG and COVID-19
- Group, team and ad hoc meetings to discuss the direction of the new KSCSCG
- Collaborative activities to build a new KSCSCG, referencing other state KSCSCG
- Professional and productive conversations on difficult topics
- Development of leveled scoring guidance based on CAB input
- Careful re-imagining of the resource scarcity sections of the KSCSCG
- Positive and positivity critical analysis of the new KSCSCG through the build process Mutual understanding experienced by both groups

Where Do We Stand Now?

- Has been reviewed by the Kansas Department of Health and Environment (KDHE) Legal Department
  - Minor changes were adopted, mostly grammatical and document flow
- Has been reviewed by State Health Officer
  - Questions for both the CAB and TAP
- Was submitted to Administration of Strategic Preparedness and Response (ASPR) for review in September 2022
  - Approval by leadership was not part of the grant requirement
- Presently?
  - KSCSCG is being reviewed by the Division of Public Health Deputy Secretary and then on to the KDHE Secretary for final review

PREPAREDNESS PROGRAM

KANSAS DEPARTMENT OF HEALTH AND ENVIRONMENT

Kansas Crisis Standards of Care Guidance Development: Phase II - Level Setting Topics

AD ASTRA PER ASPERA

Kansas

Department of Health and Environment

Division of Public Health

Level-Setting: This Iteration's Goals

- Review of the complete materials to see if there is something the group wishes to change
- Explore the development of Hospital messaging to the Public into the KSCSCG
- Explore the integration of Long-Term Care, which includes Skilled Nursing, Assisted Living and Nursing Homes, into the KSCSCG
- Exploring the development of possible procedures providing guidance on Resource and Patient Load Leveling concepts across the state into the KSCSCG

Review of the Current Kansas Crisis Standards of Care Guidance

- General review by both the Community Advisory Board (CAB) and the Technical Advisory Panel (TAP)
- While being reviewed by KDHE leadership, this annual review by the board and panel will serve the following:
  - Internal check balance on the document
  - A fresh look might reveal something that needs changing
  - A review by new Board and Panel members
  - A good review for all board and panel members
  - A look at the copyedited version
  - A look at some critical notes and questions from KDHE that were better answered by this group rather than KDHE Preparedness and KHI

Development of Hospital Messaging to the Public

- Chosen due to the number of times concerns were raised about:
  - Complicated medical terms- translation please?
    - Excessive use of medical and technical jargon
    - Conveyance of the underlying concept of the Crisis Standards of Care
  - How does a healthcare facility make that conversion?
  - How does a healthcare facility make that information public without loosing the potential threat or impact on society?
  - Sometimes it's simply "What does that mean?"

- A work group will cover the development and building of this annex

Integration of Long-Term Care in to the KSCSCG

- Questions were asked about how Long-Term Care fits into the CSC. This group will look at the following:
  - The workability of bringing Long-Term Care into the CSC?
  - What training would be needed to educate employees?
  - What special messaging will be needed to keep residents informed?
  - How does Long Term Care differ from Post-Acute Care?
  - What potential issues would a Long-Term Care Unit, Skilled Nursing, Assisted Living, see that would warrant inclusion or a stance in the KSCSCG?

- A work group will cover the development and building of this annex

Resource and Patient Load Leveling

- At the end of the last session, concerns regarding Resource and Patient Load leveling was raised:
  - Need to develop from Lessons Observed from COVID-19 resource impacts
  - Suggested policies that need to be developed:
  - How levels are reported
  - How resources are shared and what triggers are needed
  - How patients are moved between facilities
  - How the use of EMResource could better help this
  - Are Memorandums of Agreement (MOAs) and Memorandums of Understanding (MOUs) enough to combat this challenge?
  - This annex as the potential of being the most important annex created for the KSCSCG
- A work group will cover the development and building of this annex

Questions?

PREPAREDNESS PROGRAM
KANSAS DEPARTMENT OF HEALTH AND ENVIRONMENT

Kansas Department of Health & Environment
www.KSPrepared.org

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Project Overview

KANSAS HEALTH INSTITUTE

Informing Policy. Improving Health.

Key Components

Community Advisory Board

Up to 20 individuals - Consumer advocacy groups and individuals with lived experience

Technical Advisory Panel

Up to 25 individuals - Clinicians and those with technical knowledge

Environmental Scan

Address key questions to support discussions

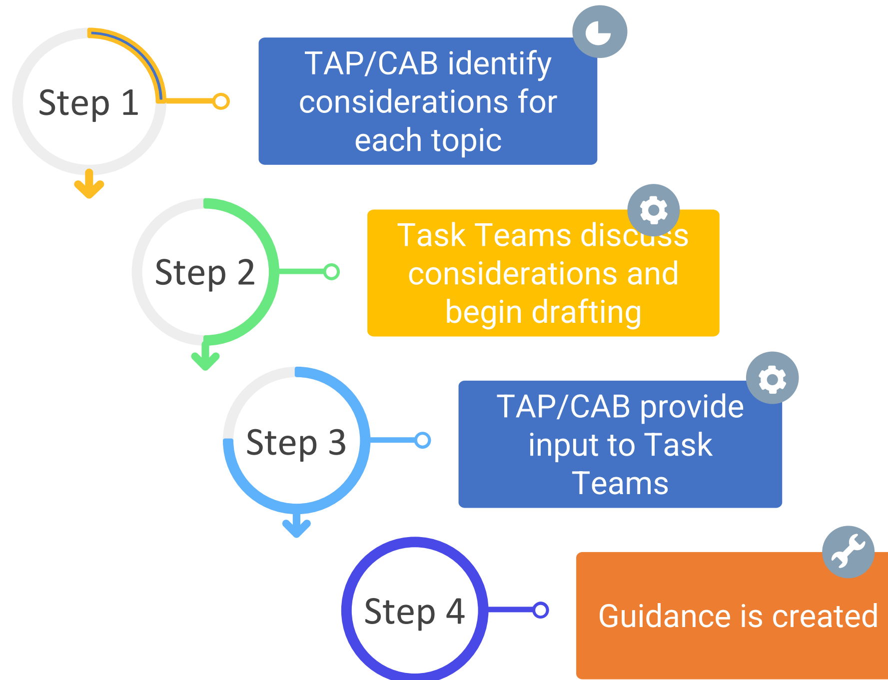
Task Teams

3 task teams (one for each topic area) - Assess considerations recommended by the CAB and TAP and develop guidance

Focus Groups

Identify considerations around allocation of scarce medical resources during emergencies

CSC Plan Process



Additional sources of information:

- Environmental scan
- Focus groups
- Information collected between meetings from Task Teams, TAP, and CAB members (e.g., survey)

CSC Phase II Timeline

January	February	March	April	May	June
1/20: Convene CAB and TAP groups	2/23: CAB & TAP Joint Meeting	3/23: CAB & TAP Joint Meeting	4/27: CAB & TAP Joint Meeting	5/25: CAB & TAP Joint Meeting	6/22: CAB & TAP Joint Meeting
Assemble Task Teams	2/2: RLB TT Meeting	3/2: RLB TT Meeting	4/6: RLB TT Meeting	5/4: RLB TT Meeting	6/15: Task Teams Meet (if needed)
Environmental Scan	2/9: LTC TT Meeting	3/9: LTC TT Meeting	4/13: LTC TT Meeting	5/11: LTC TT Meeting	Finalize Guidance
	2/16: Comms TT Meeting	3/16: Comms TT Meeting	4/20: Comms TT Meeting	5/18: Comms TT Meeting	
	Publish Environmental Scan	Draft Outline	Draft 1	Draft 2	
	Conduct Focus Groups/Interviews	Analyze and Share Focus Group Data			

RLB: resource load balancing; LTC: long term care; Comms: public communication; TT: task team

Meeting Commitments

Group Agreements

- Be present
- Listen with curiosity
- Come ready to discuss and compromise
- Don’t hesitate to ask clarifying questions
- Balance between listening and talking
- Keep remarks succinct and on topic
- Lean into discomfort and courage
- Keep it confidential

Roles

Technical Advisory Panel (TAP)

- Meet once a month virtually from January-June 2023.
- Participate in a structured process to update the Guidance.
- Provide meaningful participation and assess evidence-based information to contribute to the Guidance.
- Assess and incorporate considerations recommended by the Community Advisory Board.
- Contribute to and provide feedback on the Guidance.

Roles

Task Teams

- Meet once a month virtually from February-May 2023.
- Participate in a structured process to create new sections of the Guidance.
- Provide meaningful participation and assess evidence-based information to contribute to the Guidance.
- Assess and incorporate considerations recommended by the CAB and TAP.
- Contribute to and provide feedback on the Guidance.

Feb 2023	March 2023	April 2023	May 2023	June 2023
Review other state plans Gap analysis	Outline draft sections Writing assignments	Draft 1	Draft 2	Final Guidance

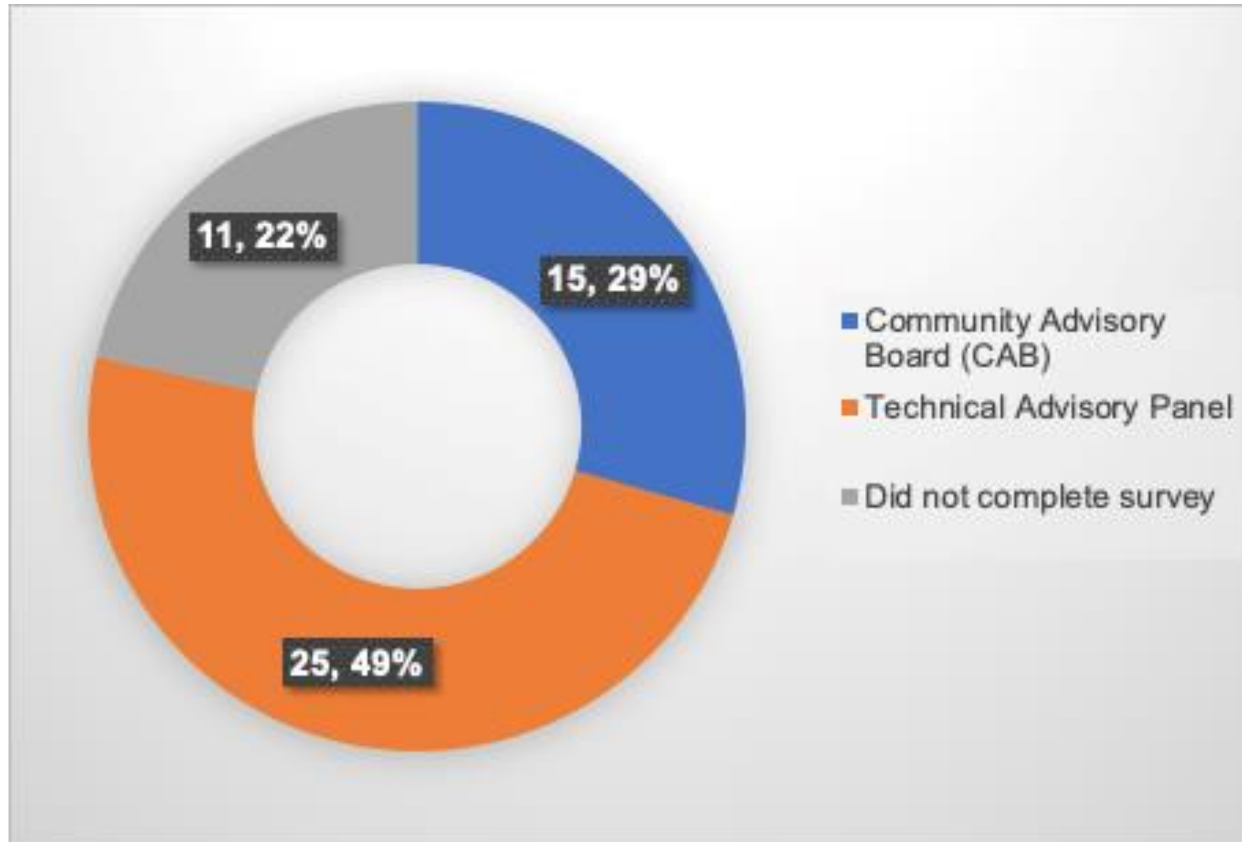
Roles

Community Advisory Board (CAB)

- Meet once a month virtually from January - June 2023.
- Participate in a structured process to create the Guidance.
- Share considerations regarding different topics examined during the development of the Guidance.
- Inform the development and implementation of focus groups to gain community insights regarding considerations around the development of the Guidance.
- Contribute to and provide feedback on the Guidance.

Registration Survey Results: Member Makeup

Percentage of Survey Respondents



Note: Numbers for CAB and TAP indicate those who completed the survey. Number of total CAB and TAP members = 51.
Source: KHI Summary of the Kansas Crisis Standards of Care Phase 2 Registration Survey, 2023.

Areas CAB and TAP Members Serve

NW 1
NC 4
NE 13
SW 1
SC 2
SE 1

Statewide
29

Legend

Kansas Perspective: 29 out of 47 members serve statewide. See the blue outlined box.

Regions: 18 members serve in regions across Kansas. Some members serve multiple regions. See region names and associated numbers on the map.

Counties: **14** members serve a variety of counties. See ◆ on the map.

Note: Members were asked to identify region(s) and counties they serve. Thus, the numbers on the map may not be equal to the total number of members. Members also identified counties in which they serve or have experience. Those counties are indicated with a diamond symbol. One diamond symbol could represent more than one member that identified a particular county. Members may have regions, areas or counties they serve that are not yet indicated on the map.

Source: KHI Summary of the Kansas Crisis Standards of Care Phase 2 Registration Survey and Recruitment files, 2023

Member Makeup

Characteristic	Results
Age	17.6% Aged 25-44 **47.1% Aged 45-64** 13.7% Aged 65 and Older 21.6% Missing or Declined
Gender Identity	**45.1% Identify as Female** 29.4% Identify as Male 2.0% Identify in Other Categories 23.5% Missing or Declined
Education Level	2.0% Some college but no degree 5.9% Associate's Degree 23.5% Bachelor's Degree **47.1% Graduate degree or higher** 21.5% Missing or Declined

Note: Number of total CAB and TAP members = 51, including nine individuals without response.
Source: KHI Summary of the Kansas Crisis Standards of Care Phase 2 Registration Survey, 2023.

Member Makeup

Characteristic	Results
Race	**64.7% White** 5.9% Black or African American 5.9% Two or more races 23.5% Missing or Declined
Hispanic, Latinx or Spanish origin	2.0% Hispanic, Latinx or Spanish origin **76.5% Not Hispanic, Latinx or Spanish origin** 21.5% Missing or Declined

Note: Number of total CAB and TAP members = 51, including nine individuals without response.
Source: KHI Summary of the Kansas Crisis Standards of Care Phase 2 Registration Survey, 2023.

Member Expertise

Which population(s) do you have lived experience with and feel that you represent on this project?

Population	Percentage of Respondants with Experience
OLDER ADULTS	51%
CAREGIVERS	49%
LOW-INCOME INDIVIDUALS	47%
PROVIDERS	47%
INDIVIDUALS WITH DISABILITIES	45%
INDIVIDUALS WITH DEMENTIA OR ALZHEIMER'S…	43%
RURAL COMMUNITIES	41%
INDIVIDUALS WITH MENTAL HEALTH DIAGNOSIS	37%
RACIAL OR ETHNIC MINORITY GROUPS	27%
LGBTQ+	24%
VETERANS	24%
UNHOUSED INDIVIDUALS	18%
TRIBAL COMMUNITIES	8%

0 10 20 30 40 50 60

■ Percentage of Respondants with Experience

Note: Number of total CAB and TAP members = 51, including nine individuals without response.
Source: KHI Summary of the Kansas Crisis Standards of Care Phase 2 Registration Survey, 2023.

Member Expertise

Which organization(s) or facilities do you have lived experience with and feel that you represent on this project?

	Percentage of Respondents with Experience
STATE ORGANIZATIONS	29%
LONG-TERM CARE FACILITIES	22%
ASSISTED LIVING FACILITIES	18%
OTHER	16%
NURSING HOMES	16%
HOSPICE	16%
RURAL HOSPITALS/FACILITIES	12%
COUNTY ORGANIZATIONS	10%
URBAN HOSPITALS	10%
CRITICAL ACCESS HOSPITALS	8%

Other organization experience included:

- Bioethics Center
- Center for Independent Living
- IDD Group Homes
- KS Silver Haired Legislature
- NE & KC Metro HHC
- VA Hospital
- Hospital Association
- Trade Association
- State Non-Profit

Note: Number of total CAB and TAP members = 51, including nine individuals without response.
Source: KHI Summary of the Kansas Crisis Standards of Care Phase 2 Registration Survey, 2023.

Focus Groups

GOAL

The purpose of the focus group is to understand the concerns and considerations of individuals representing long-term care facilities, hospitals, consumer advocacy groups, and caregivers regarding the allocation of medical resources, such as staff, supplies (e.g., beds, medication, personal protective equipment, ventilators), facilities, and health care services in nursing homes and long-term care facilities during the implementation of crisis standards of care.

Timeline

February – March 2023

Focus Groups

Stakeholder Type	Participants	Target Number of Participants
Long-term care facilities	Long–term care providers or administrators	1 focus group - up to 10 individuals from long-term care facilities and up to 5 individuals from hospitals
Hospitals	Individuals who oversee and administer resource load balancing	
Caregivers of individuals in long-term care facilities	Family members of individuals who live in long-term care facilities	1 focus group in English and 1 focus group in Spanish - up to 10 individuals per focus group Up to 10 interviews
Consumer advocacy groups	Representatives from consumer advocacy groups	1 focus group - up to 10 individuals

Focus Groups

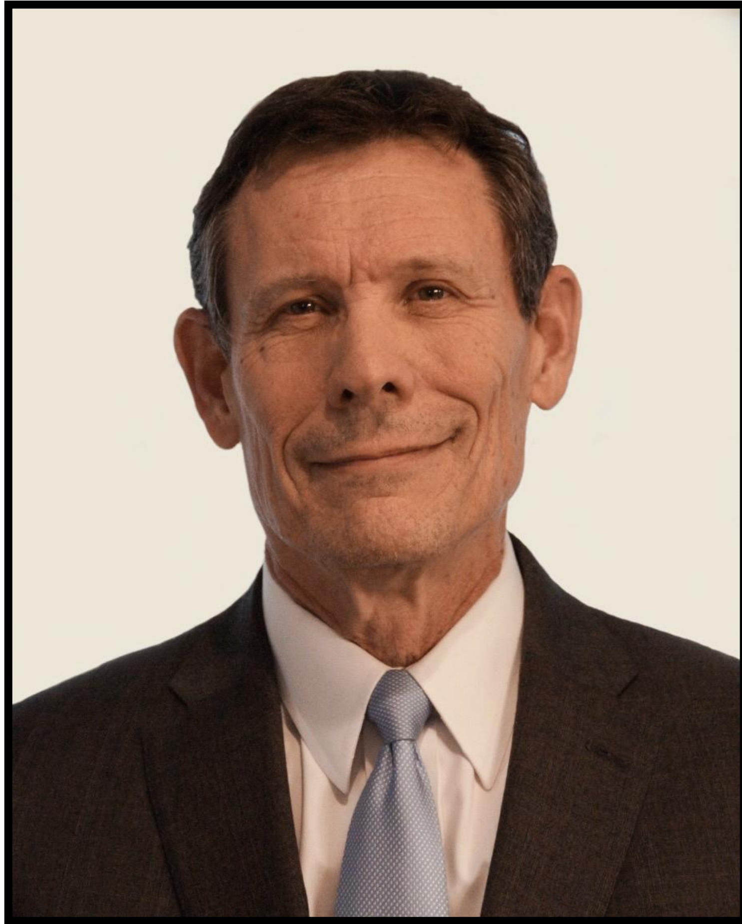
Feedback

- Categories of questions
- Questions
- Terminology/language
- Other considerations?

Participants

- Suggest individuals for focus groups/interviews by emailing suggestions to Tatiana Lin at tlin@khi.org or completing a survey

Liaisons



Dr. Dennis Cooley, M.D.
TAP Liaison

Ami Hyten, J.D.
CAB Liaison

Phase 1 Review

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Overview

Background

- The intent is to make it a fluid, living document.
- It can be adjusted to current situations and built upon as needed.
- It will be reviewed and edited on a recurring basis with robust input from communities.
- It is a first step in the broader development of guidelines for communities and a commitment to developing capacity in addressing disaster planning.

Purpose

Scope

- Framework for hospital planning
- Dual goal: improving health outcomes and reducing inequities in distribution of health benefits.
- Prioritize making equitable decisions that create a level playing field.

Activation

Facility-Based

- An affected facility or facilities should make the decision when to activate the CSC.
- Statewide activation of a CSC is not allowed due to limitations placed on the authority of public health officials and the state health department.
- The deactivation of the CSC will be at the discretion of the individual hospital(s).

Health Equity

Definition in Phase 1 document

- Authors adopted a recent and commonly referenced definition of health equity published by the Robert Wood Johnson Foundation
- Disallow considerations of life expectancy beyond survival to discharge, quality of life considerations, social worth (aka instrumental value), categorical exclusion of any patient groups, and the removing of personal medical equipment (PME) from patients.
- Equitable treatment by aiming to increase transparency in decision making, strengthening open communication, and deploying “correction factors” in resource allocation protocols.

Health equity, in an applied method, refers to a state “**when everyone has a fair and just opportunity to be as healthy as possible**.”

This requires removing obstacles to health such as poverty, discrimination, and their consequences, including powerlessness and lack of access to good jobs with fair pay, quality education and housing safe environments, and healthcare.

Applying Community Insights

Promising Practices

Steps for preparation in advance of crisis

Conventional Care	The demand for care is less than the supply of resources. Level of care (i.e., spaces, staff and supplies) is consistent with daily practices within the institution.
Contingency Care	The spaces, staff, and supplies used are not consistent with daily practices but provide care that is functionally equivalent to usual patient care. Patients are not impacted by limits to care options available when services are functionally equivalent to usual patient care. The facility's Emergency Operations Plan is activated.
Crisis Care	The demand for care is greater than available resources despite contingency care strategies. Normal standards of care cannot be maintained.

Source: Language from the table has been adapted from HHS Assistant Secretary for Preparedness and Response (ASPR) Technical Resources, Assistance Center and Information Exchange (TRACIE)'s Crisis Standards of Care Brief: Principles.

Applying Community Insights

Promising Practices

- Steps for preparation in advance of crisis
- Triage decisions made by a team of people
- Adjustments of triage score based on frailty, survival until discharge, improvement, and Area Deprivation Index (ADI)
- Use of communication team to clearly communicate final decisions and allocation processes
- Iterations by context (2022 focused on hospitals)

Triage Framework

Process Overview

- Patient Data Entry (on admission)
- Triage Team
- Equitable delivery of Scarce Resources by by Triage
  - Resources allocation with the highest priority
  - Tiebreakers utilized as needed
- Communication (ongoing)

Allocation of Scarce Resources

Promote Justice and Equity

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

Correction for structural inequities using Area Deprivation Index (ADI)

- 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.

Triage Framework

Triage Team Makeup

- Administrative Support
- Experienced Clinicians
- Experienced Nursing Representatives
- Medical Ethicist
- Community Representatives
- Ad hoc consultants

**Palliative care team members should not be placed in the position of both deciding who will be provided with comfort care, rather than life-sustaining treatments, and providing the comfort care. However, the palliative care member of the team can keep the team informed of the capacity of the Palliative Care Team, itself, during the crisis.*

Allocation of Scarce Resources

Promote Population Health Outcomes

- On admission:
  - Baseline chronic illness
  - Pre-hospital impairment

- Ongoing:
  - Prognosis for hospital survival to discharge
  - Change in clinical status in past 24 hours

Allocation of Scarce Resources

Tiebreakers

1. Priority to patients who are pregnant
2. Equal chances

Communication

Communication strategies should be:

- Tailored to the need of various populations (e.g., individuals with limited English proficiency)
- Transparent and timely communication throughout the process (e.g., about resource availability)
- Connect patients with community-based resources
- Easy to understand materials (e.g., FAQs)
- Education and training around the state about the CSC

Example of a Communication Strategy

Communication of Triage and Allocation Decisions

- *If crisis standards of care are declared, the medical team should make patients and families aware of the declaration as early as possible in the admissions process and, if possible, prior to admission to an ICU.*
- *Once a final triage decision and allocation of scarce resources has been determined, the information needs to be clearly communicated to the patient and their family using plain, linguistically and culturally appropriate language per facility protocols.*

Lessons Learned

Health, Equity and Engagement

- Importance of level-setting and plain language
- Defining roles and recognizing power dynamics
  - Equity work must happen before crisis
  - Collaboratively defining equity in context
  - Importance of a liaison between groups
  - Drafting of guidance language in smaller groups
- Consumer perspectives can differ from initially anticipated
- Opportunities for learning from other states

Today’s Speaker

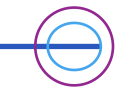
M. Suz Schrandt, J.D.

- Founder and CEO of ExPPect
- Patient and patient engagement advocate with a health and disability law and policy background

Integrating Lived Experience into Process and Guideline Development

Crisis Standards of Care Meeting

M. Suz Schrandt, JD
Founder, CEO, & Chief Patient Advocate, exPPect



exPPect™

Suz Schrandt is a patient engagement engineer with a health and disability law and policy background. She is the Founder and CEO of exPPect, an initiative focused on improving healthcare and research through the expertise and partnership of patients. Schrandt previously served as Director of Patient Engagement at the Arthritis Foundation, and as Deputy Director of Patient Engagement for the Patient-Centered Outcomes Research Institute ("PCORI"). Schrandt serves as an advisor on the FDA's Patient Engagement Advisory Committee, the National Institutes of Arthritis and Musculoskeletal and Skin Diseases Advisory Council, and the Geneva Foundation (for military research) Scientific Advisory Council, and as a Board member for the Innovation and Value Initiative. Schrandt received her law degree from the University of Kansas and has co-authored multiple peer-reviewed articles on health policy and the value of patient engagement.

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Agenda and Objectives

- Agenda
  - Brief background on engagement of people with lived experience
  - Common challenges, potential solutions
  - Demonstration of engagement tool
- Objectives
  - Increase familiarity and comfort with engagement
  - Equip participants with potential solutions for common challenges
  - Build awareness of available resources and supports

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The State of Engagement in 2023

The majority [at least 51%] of the health center board members must be patients[4] served by the health center. These health center patient board members must, as a group, represent the individuals who are served by the health center in terms of demographic factors, such as race, ethnicity, and gender.

Assessing the Financial Value of Patient Engagement: A Quantitative Approach from CTTI's Patient Groups and Clinical Trials Project

Bennett Levitan [1], Kenneth Getz [2], Eric L Eisenstein [3], Michelle Goldberg [4], Matthew Harker [5], Sharon Hesterlee [6], Bray Patrick-Lake [7], Jamie N Roberts [8, 9], Joseph DiMasi [2]

Affiliations + expand

PMID: 29714515 PMCID: PMC5933599 DOI: 10.1177/2168479017716715

Free PMC article

GUIDANCE DOCUMENT

Patient Engagement in the Design and Conduct of Medical Device Clinical Investigations

Draft Guidance for Industry, Food and Drug Administration Staff, and Other Stakeholders

SEPTEMBER 2019

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Patient & Family Advisory Council for Quality & Safety

Patients' roles and rights in research

Full partnership with patients is essential to any modern research enterprise

Paul Wicks *vice president of patient innovation*[1], Tessa Richards *patient partnership editor*[2], Simon Denegri *NIHR national director for patients, carers and the public*[3], Fiona Godlee *editor in chief*[2]

[1]PatientsLikeMe, Cambridge, MA, USA; [2]*The BMJ*, London UK; [3]National Institute for Health Research, London UK; Correspondence to: P Wicks

Patient Engagement refers to “The active, meaningful, authentic and collaborative interaction between patients and other stakeholders across all aspects of the health ecosystem, where decision-making with regard to an activity or process is guided by patients’ contributions as partners, recognizing their unique experiences, values and expertise.”

Source: National Health Council Glossary, https://nationalhealthcouncil.org/additional-resources/glossary-of-patient-engagement-terms/, accessed 01/02/23

For this workstream, a more appropriate term is “people with lived experience”, but the definition still applies:

- Active, meaningful, authentic and collaborative interaction
- Decision-making is guided by their contributions as partners, recognizing their unique experiences, values and expertise

But how?

Concerns and Solutions

1. May lack scientific and medical expertise
2. Pushing for things that are not scientifically sound or based in evidence
3. May not have experience doing this kind of work

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May lack scientific and medical expertise

- Their expertise is their lived experience, which no one else can bring.

May lack scientific and medical expertise

- Their expertise is their lived experience, which no one else can bring.
- In practice:
  - Covid vaccination study example
  - Potential application in crisis standards work

May lack scientific and medical expertise

- That can be valuable to the process

May lack scientific and medical expertise

- That can be valuable to the process
- In practice:
  - Weight-based practices example
  - Potential application in crisis standards work

May lack scientific and medical expertise

- Foundational information or onboarding can be entirely appropriate

May lack scientific and medical expertise

- Foundational information or onboarding is very appropriate
- In practice:
  - Rheumatoid arthritis claims data project
  - Potential applications in crisis standards work

Concerns and Solutions

1. May lack scientific and medical expertise
   A. They bring lived experience no other stakeholders are bringing
   B. The lack of extensive expertise can be valuable to the process
   C. Foundational information or onboarding is very appropriate

Concerns and Solutions

1. May lack scientific and medical expertise
   A. They bring lived experience no other stakeholders are bringing
   B. The lack of extensive expertise can be valuable to the process
   C. Foundational information or onboarding is very appropriate
2. Pushing for things that are not scientifically sound or based in evidence

Pushing for things that are not scientifically sound or based in evidence

- The goal of engagement is not that people with lived experience have complete power—or that they have no power—it is really about equal partnership

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Pushing for things that are not scientifically sound or based in evidence

- The goal of engagement is not that people with lived experience have complete power—or that they have no power—it is really about equal partnership
- In practice:
  - Control arm example
  - Potential applications to critical standards work

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Concerns and Solutions

1. May lack scientific and medical expertise
   A. They bring lived experience no other stakeholders are bringing
   B. The lack of extensive expertise can be valuable to the process
   C. Foundational information or onboarding is very appropriate
2. Pushing for things that are not scientifically sound or based in evidence
   A. The essence of engagement is collaboration, not letting a single voice lead
   B. Optimal outcomes arise from co-creation between people with lived experience and other experts

Concerns and Solutions

1. May lack scientific and medical expertise
   A. They bring lived experience no other stakeholders are bringing
   B. The lack of extensive expertise can be valuable to the process
   C. Foundational information or onboarding is very appropriate
2. Pushing for things that are not scientifically sound or based in evidence
   A. The essence of engagement is collaboration, not letting a single voice lead
   B. Optimal outcomes arise from co-creation between people with lived experience and other experts
3. May not have experience doing this kind of work

May not have experience doing this kind of work

- Multistakeholder engagement that involves people with lived experience may be new to many (for all stakeholder types!)
- Good news! There are a host of tools, resources, and best practices.

May not have experience doing this kind of work

- In practice:
  - Circulate agenda and meeting materials in advance, in accessible language
  - Develop discussion prompts or “thought-starters” to help team members prepare
  - Designate an acronym and jargon “safe space”
  - Allow members to follow up on items that require consideration or outreach to additional people with lived experience
  - Use skilled facilitators and facilitation tools for meetings

"When I had my stroke, I tried to seek care at my closest hospital, but it was already full. I tried to fight to be seen, but the front desk people told me I would have to seek care elsewhere. I didn't know where to go so I went back home. The next day, I couldn't use my left side, and when I went to the ER I was taken in right away and treated. Now I have permanent damage in my left leg and left hand."

- Sheila M.

This is a hypothetical example

Turning Lived Experience into Action

Whether a negative or positive lived experience, ask:

- Was there a person, system, practice, or set of practices that caused or was a factor in your experience?
- If negative, what could have been done differently by that person, system, practice, or set of practices?
- If positive, what did the person, system, practice, or set of practices do that should be replicated or amplified?
- How can we apply that change (if negative) or that action (if positive) to this body of work?

In closing

- Lived experience *is* the knowledge these project members bring; onboarding or foundational materials can help level the playing field and foster more effective partnership and communication
- The goal is collaboration as equal partners, not ceding complete control to any stakeholder type
- There are a wealth of resources and tools; it is okay to modify and adjust as you go, to determine what methods or tools work best for your group and workstream

Questions?

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Thank you!

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Resource Collections

PCORI Engagement in Health Research Literature Explorer, https://www.pcori.org/engagement/engagement-literature

Campus-Community Partnership for Health Resource Library, https://ccphealth.org/register-3/

National Health Council Patient Engagement Resources, https://nationalhealthcouncil.org/issue/patient-engagement/

Patient Engagement Synapse, https://patientengagement.synapseconnect.org/resources

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Breakout Rooms

5-minute Break

KANSAS HEALTH INSTITUTE

Informing Policy. Improving Health.

Breakout Rooms

TAP Agenda

- Introductions
- Task Teams
- Environmental Scan Questions
- Focus Group Questions Feedback
- Questions for CAB

CAB Agenda

- Introductions
- CAB Scope
- Equity Considerations
- Focus Group Questions Feedback
- Next Steps
- Questions for TAP

Wrap Up

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Upcoming Meetings

January	February	March	April	May	June
1/20: Convene CAB and TAP groups	2/23: CAB & TAP Joint Meeting	3/23: CAB & TAP Joint Meeting	4/27: CAB & TAP Joint Meeting	5/25: CAB & TAP Joint Meeting	6/22: CAB & TAP Joint Meeting
Assemble Task Teams	2/2: RLB TT Meeting	3/2: RLB TT Meeting	4/6: RLB TT Meeting	5/4: RLB TT Meeting	6/15: Task Teams Meet (if needed)
Environmental Scan	2/9: LTC TT Meeting	3/9: LTC TT Meeting	4/13: LTC TT Meeting	5/11: LTC TT Meeting	Finalize Guidance
	2/16: Comms TT Meeting	3/16: Comms TT Meeting	4/20: Comms TT Meeting	5/18: Comms TT Meeting	
	Publish Environmental Scan	Draft Outline	Draft 1	Draft 2	
	Conduct Focus Groups/Interviews	Analyze Focus Group Data			

RLB: resource load balancing; LTC: long term care; Comms: public communication; TT: task team

THANK YOU!

Any Questions?

You can connect with us at: hshah@khi.org or tlin@khi.org