



Center for Public
Representation

April 9, 2020
By electronic mail

Governor Charles Baker
Lt. Gov. Karyn Polito
Secretary Marylou Sudders
Attorney General Maura Healey
Senate President Karen Spilka
Speaker of the House Robert DeLeo

Dear Governor Baker and other distinguished State officials:

We appreciate the Administration's ongoing response to the COVID-19 crisis, including development of the recently released Massachusetts Crisis Standards of Care (hereafter "MA CSC"). This letter contains specific alterations and additions we believe are required in order for the MA CSC to comply with federal law, and to be implemented consistent with the Administration's principles surrounding rationing of care.

First, we want to support, and underscore the importance of, feedback the Administration has already received from individuals included in the Attorney General's call on April 6, 2020, including written correspondence from the Disability Policy Consortium. We fully support the suggested elimination of life-limiting co-morbidities, and long term prognosis as factors in the triage scoring protocol. We address those items in more detail below, along with other specific recommendations intended to ensure the Commonwealth's guidance: 1) is consistent with federal law and the recent OCR bulletin; 2) avoids criteria which would lead to discriminatory assumptions or unconscious bias in the provision of lifesaving care,¹ and includes safeguards against such influences in triage decisions; and 3) upholds the Administration's intention to avoid inequities in the allocation of care to individuals based on disability, age, race, or other protected status.

These recommendations focus on, and are intended for inclusion in, Section V of the MA CSC, titled "Strategies for Maximizing Critical Care Resources (Allocation Framework)."

¹ The prevalence of unconscious bias in the provision of health care generally is well documented. See <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5333436/> (meta-analysis of 49 articles on the impact of implicit race and gender bias in the provision of medical care concludes that "healthcare professionals exhibit the same levels of implicit bias as the wider population" and that bias is "likely to influence diagnosis and treatment decisions and levels of care in some circumstances . . .;" see also <https://www.aafp.org/afp/2017/0801/p192.html> ("[f]alse assumptions about patients' quality of life can affect prognosis" and even "result in premature withdrawal of life-preserving care."))

1) Include an explicit statement prohibiting consideration of disability independent of its impact on short term survivability;

In addition to the global statement of criteria that will not be factored into triage assessments, the MA CSC should explicitly reference as binding on Commonwealth hospitals the US Health and Human Services' Office of Civil Rights Bulletin prohibiting disability discrimination in HHS funded health programs, including the delivery of lifesaving care during the COVID-19 outbreak.² This and other key principles outlined in that Bulletin should be enumerated in the opening paragraph of Section V as "core triage principles" to which all facility protocols must adhere.

2) Make more explicit that all individuals are qualified for, and eligible to receive, lifesaving care, regardless of diagnosis, functional impairment or ADL needs;

Although the MA CSC does not exclude patients based on diagnosis, it does rely heavily on maximization of efficiency in allocating lifesaving resources, with the stated goal of saving life years. Both of these principles can be operationalized in ways which discriminate against people with disabilities and other protected classes.

Consistent with the "Pittsburgh model," MA CSC should explicitly state: "No patient should be disqualified from life-saving treatment solely because of underlying disabilities or co-morbid conditions. All individuals should be eligible for, and qualified to receive, lifesaving care."³ This language should be among the "core triage principle" required under Section V of the MA CSC.

3) Emphasize that all triage decisions must result from individualized assessments based on objective medical evidence;

Even validated medical assessment tools can be vulnerable to unconscious bias in their application. For instance, if Massachusetts allows the SOFA to lower an individual's priority for life saving care based solely on the presence of chronic, but stable underlying conditions, like diabetes, developmental disability or acquired brain injury, it risks running afoul of federal antidiscrimination laws and directives from the Office of Civil Rights.

Massachusetts CSC should include the following statement with regard to use of the SOFA in triage scoring: "Triage teams must avoid penalizing individuals with chronic but stable underlying conditions, including individuals with disabilities, when calculating SOFA scores. Baseline levels of impairment, prior to the acute care episode, should not increase SOFA scores unless objective medical evidence, interpreted by a medical professional with expertise necessary

² This bulletin is available at <https://www.hhs.gov/sites/default/files/ocr-bulletin-3-28-20.pdf>; see also, <https://www.disabilityscoop.com/2020/03/30/trump-administration-says-disability-no-reason-to-deny-covid-19-care/28065/>.

³ See, <https://ccm.pitt.edu/?q=content/model-hospital-policy-allocating-scarce-critical-care-resources-available-online-now>

to exercise professional judgment under usual standards of care, demonstrates that those conditions directly impact an individual’s short term survivability with treatment.”

4) Replace vague criteria that are likely to screen out or disparately impact people with disabilities;

As noted above, Massachusetts should eliminate triage criteria which score patients based on “*life-limiting co-morbidities*” or “*long term prognosis*.” These criteria dramatically increase the likelihood that individuals with disabilities will be denied lifesaving care based on discriminatory assumptions about their quality of life, or overall life expectancy. Even validated instruments like the SOFA can only begin to assess short term survivability – namely survivability to discharge.

The proposed triage guidelines provide no objective, reliable or consistent means of informing decisions on intermediate or long term prognosis. Additionally, populations whose health and longevity are already negatively impacted by inequities in access to care (people with psychiatric disabilities; communities of color; LGBTQ individuals) will be doubly harmed by these criteria, undermining the Administration’s goals of equity, transparency and fairness in the rationing process.⁴

Therefore, we recommend the MA CSC eliminate the above criteria and include the following statement: “Intermediate or long term prognosis should not be factors in determining priority for emergency lifesaving treatment. Attempts to predict long term prognosis, especially for persons with disabilities, can lead to erroneous, inconsistent, and subjective decision-making in violation of federal antidiscrimination laws. Triage decisions should be governed by individualized assessments of the patient’s potential for survivability to discharge.”

5) Clarify that individuals will not be subject to the withdrawal or removal of personal lifesaving equipment;

Individuals who own and routinely use ventilators in the community may require acute hospital care during the pandemic. Given concerns around the country regarding the discriminatory removal of ventilators from these individuals,⁵ the MA CSC should include the following statement: “Individuals presenting for hospital level of care will not be subject to the automatic withdrawal, removal or redeployment of personal lifesaving equipment, including ventilators, based on discriminatory assumptions about their intensity of need or likelihood of recovery.”

⁴ See, [COVID-19 Triage and Disability: What Not to Do](http://www.bioethics.net/2020/03/covid-19-triage-and-disability-what-not-to-do/). Joseph Stramondo, PhD, Bioethics.net, March 30, 2020, available at ...<http://www.bioethics.net/2020/03/covid-19-triage-and-disability-what-not-to-do/>

⁵ OCR Complaints filed against the states of Washington, Alabama, Kansas, Tennessee and others can be found at <https://www.centerforpublicrep.org/covid-19-medical-rationing/>

6) Require that reasonable accommodations/modifications of the triage protocol be considered for people with disabilities;

Certain triage criteria, such as limitations on how long patients may stay on a ventilator without demonstrated improvement, may have a disproportionate, negative impact on individuals who are no less likely to recover, but may do so more slowly due to a pre-existing disability.⁶ The MA CSC should make clear that federal laws requiring reasonable accommodations remain in effect even when crisis standards of care are invoked. We recommend including the following statement: “Treating doctors and triage teams must consider reasonable accommodations to triage protocols for individuals with disabilities, including the extension of ventilator trial periods, when patients are expected to recover, but may require additional time to demonstrate effective progress because of their disability.”

7) Provide disabled patients with effective methods of communication;

Patients with disabilities may require specific accommodations in communicating their needs and preferences regarding treatment, including access to interpreters and specialized assistive technology. It is critical that all reasonable steps be taken to ensure guardians, family members, and health care agents are afforded an equal opportunity to communicate with the disabled individual, their treating clinicians, and the triage assessment team. If necessary, this communication should be facilitated through specialized interpreters, telephonic or video technology that is effective for, and accessible to, the person and their supporters.

The MA CSC also should include the following model language regarding exceptions to visitor restrictions necessary to accommodate the needs of persons with disabilities:

Patients with disabilities who need assistance due to the specifics of their disability may have one designated support person with them. This could include specific needs due to altered mental status, intellectual or cognitive disability, communication barriers or behavioral concerns. If a patient with a disability requires an accommodation that involves the presence of a family member, personal care assistant or similar disability service provider, knowledgeable about the management of their care, to physically or emotionally assist them during their hospitalization, this will be allowed with proper precautions taken to contain the spread of infection.⁷

8) Ensure an accessible, transparent and accountable appeal process;

Although the MA CSC appears to adopt the two stage appeals process laid out in the Pittsburgh model, it does not make clear how information about triage assessments protocols and appeal

⁶ See <https://www.aafp.org/afp/2017/0801/p192.html> (patient with cognitive limitations and chronic conditions “recovering slowly from an acute, temporary illness” mistakenly referred to hospice due to undue concerns reflecting stereotypical assumptions).

⁷ See, e.g. COVID-19 visitor policy of Rush University Medical Center, Illinois, available at <https://www.rush.edu/patients-visitors/covid-19-resources/rush-coronavirus-covid-19-patient-and-visitor-updates>

procedures will be communicated to individuals, families, and health care agents/guardians.⁸ Nor does it require hospital oversight committees to report on the nature, use and outcome of the appeals process adopted at their respective facilities.

In all instances, it is critical that both the triage assessment protocol and the appeal process are shared with the individual and their agents/family. The appeal process should be speedy, transparent and easy to use. Any decision to remove a ventilator must be stayed pending appeal, and the outcome of that appeal explained by the responsible triage officer. Additionally, the MA CSC should require all facilities publish their triage assessment protocols and appeal procedures on their websites, and make these protocols available in alternative formats as needed to accommodate the individual, their families, health care agents and advocates.

9) Require hospital oversight committees to collect and report data

While the MA CSC describes the recommended composition of a hospital triage team, and references the existence of a hospital oversight committee, it does not describe how these committees will monitor and report on the work of triage assessment teams. In the interests of transparency and equity, and to ensure the Administration is aware of the nature and extent of health care rationing during this crisis, it should insist that hospitals establish a clear process for overseeing the accuracy and consistency with which triage assessment decisions are made, and reporting on the outcome of those decisions.

Additionally, the MA CSC should require regular reporting of key demographic information to the Command Center and other responsible public entities, including the total number of individuals denied lifesaving care and their age, race and disability.

We appreciate the Administration's time and assistance with this important matter. Given the urgency of the circumstances, we ask that you respond by 12:00 PM on April 13, 2020, regarding whether the Commonwealth is willing to make the changes requested above.

Sincerely,

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⁸ See, <https://ccm.pitt.edu/?q=content/model-hospital-policy-allocating-scarce-critical-care-resources-available-online-now>, p.4.

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