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Sent via email to COVIDUpdates@ontariohealth.ca

September 1, 2020

Joint Centre for Bioethics
University of Toronto
155 College Street, Suite 754
Toronto, ON M5T 1P8
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Dear Members of the Bioethics Table:

Re: ARCH Disability Law Centre's Submissions Regarding Ontario's Triage Protocol Draft dated July 7, 2020 Following Meetings with Bioethics Table

The within document is the written submission of ARCH Disability Law Centre (ARCH)¹ flowing from several meetings² between the Bioethics Table and a select number of persons and organizations representing persons with disabilities (the Bioethics Table Meetings).³ We provide these submissions in addition to our previous submissions dated

¹ ARCH would like to especially and sincerely thank members of its Advisory Committee for engaging in extensive discussion and providing thoughtful guidance and expertise on the important issues raised by the Triage Protocol. ARCH's Advisory Committee, in alphabetical order, includes: Chris Beesley, Executive Director at Community Living Ontario, Laura LaChance, Interim Executive Director at Canadian Down Syndrome Society, Trudo Lemmens Professor, Scholl Chair in Health Law and Policy at University of Toronto Law School, David Lepofsky, Chair of the AODA Alliance, Leanne Mielczarek, Executive Director of Lupus Canada, Elizabeth Mohler, Board Member at Citizens With Disabilities – Ontario, Roxanne Mykitiuk, Disability Law, Health Law, Bioethics and Family Law Professor at Osgoode Hall Law School, Tracy Odell, Executive Director of Citizens with Disabilities – Ontario, Dr. Homira Osman, Director of Knowledge Translation & External Engagement at Muscular Dystrophy Canada, and Wendy Porch, Executive Director at the Centre for Independent Living Toronto.

² Specifically, these meetings have taken place on the four following occasions: July 27, 2020, July 29, 2020, August 17, 2020 and August 24, 2020.

³ As ARCH has made it clear in its submissions dated April 2020, May 2020 and July 2020, these meetings have been narrow and under-inclusive. We continue to call upon the Bioethics Table to meet and consult with a broad base of communities that are being disproportionately impacted by COVID-19 and will be disproportionately impacted by the Triage Protocol. This includes holding broader consultations with

May 13, 2020⁴ and July 20, 2020⁵ and not in substitute of them.

Much of the discussion at these meetings has focused on the Clinical Frailty Scale (CFS) and other discriminatory exclusionary criteria in the first draft of the Triage Protocol⁶ and the continued reliance on the CFS and other discriminatory exclusionary criteria in the second draft of the Triage Protocol,⁷ in the face of opposition from disability communities and human rights experts.⁸ Accordingly, these submissions will solely focus on the concerns arising from the Triage Protocol's use of the CFS and discriminatory exclusionary criteria. To be clear, this does not imply that the outstanding concerns raised by ARCH in the May and July submissions and that remain unaddressed are no longer in issue. Rather, we trust that the Bioethics Table will consider the culmination of all of ARCH's submissions and give each concern and corresponding recommendation due weight.

Purpose of ARCH's Involvement

Prior to turning to our submissions, it is important to clarify ARCH's involvement and role at the Bioethics Table Meetings: ARCH advances the interests of persons with disabilities across Ontario. Accordingly, our role in these meetings has been to defend the rights of persons with disabilities, given the resources and time permitted. Our role in these meetings was to provide the perspective of persons with disabilities for the authors of the Triage Protocol to consider. We provide the following submissions in furtherance of this role.

members from the disability community, the Black community, Indigenous community, and persons from other racialized communities.

⁴ ARCH submissions, dated May 13, 2020 [ARCH May Submissions].

⁵ ARCH Submissions, dated July 20, 2020 [“ARCH July Submissions”]

⁶ Critical Care Triage for Major Surge in the COVID-19 Pandemic, dated March 28, 2020 [“Triage Protocol 1”].

⁷ Critical Care Triage for Major Surge in the COVID-19 Pandemic: Updated Recommendations, delivered and dated July 7, 2020 [“Triage Protocol 2”].

⁸ See ARCH May Submissions, *supra* note 4 and ARCH July Submissions, *supra* note 5 addressing other problematic aspects of the Triage Protocol.

A. The Clinical Frailty Scale is *Prima Facie* Discriminatory

Any triage protocol that the Government chooses to implement in response to the pandemic, must comply with the *Charter*⁹ and the Ontario *Human Rights Code*.¹⁰ The development of the Triage Protocol, and the tools and metrics on which it proposes to rely to determine a patient's prioritization or access in receiving critical care, must be considered through this lens.¹¹

One metric employed in this assessment is the Clinical Frailty Scale (CFS). It is our position that the CFS cannot be employed in the manner in which it is proposed, or in any manner, for the purposes of triage as it discriminates against persons with disabilities.

ARCH has previously demonstrated how the CFS will have a disproportionate adverse impact on persons with disabilities if it is applied to them during triage. For example, persons with disabilities are more likely to score higher on the CFS score, because of their general disability-related care needs and reduced activity.¹² If they score higher, then they are more likely to be deprioritized from receiving critical care.¹³ The CFS also deems some persons with disabilities as “severely frail” on the basis of their use of a mobility device and having a support person assisting them with activities of daily living.¹⁴

Unfortunately, these concerns have not been assuaged following meetings with the Bioethics Table. Rather, they have been amplified. Case in point: the simplified CFS decision tree.¹⁵ The stated purpose of which was to assist doctors in applying the CFS during triage. As such, it provides valuable insight into how the CFS will operate in practice.

⁹ *Canadian Charter of Rights and Freedoms*, Part 1 of the *Constitution Act, 1982*, being Schedule B to the *Canada Act 1982* (UK), 1982, c 11 [*Charter*]; *Canadian Doctors for Refugee Care v Canada (Attorney General)*, 2014 FC 651 para 506; see also generally, *Eldridge v British Columbia (Attorney General)*, 1997 CanLII 327 (SCC) [*Eldridge*].

¹⁰ RSO 1990, c H19.

¹¹ ARCH May Submission, *supra* note 4.

¹² ARCH May submissions, *supra* note 4.

¹³ *Ibid.*

¹⁴ *Ibid.*

¹⁵ Simplified CFS Decisions Tree provided by the Bioethics Table on July 29, 2020. [“Simplified CFS”].

The simplified CFS asks two especially problematic questions.¹⁶ Namely, question 2 asks if the patient being assessed can perform Basic Activities of Daily Living (BADLs) *without assistance*; question 3 similarly asks whether the patient can perform Instrumental Activities of Daily Living (IADLs) *without assistance*.

These questions are *prima facie* discriminatory and exemplify the very shortcomings of the CFS from a disability rights lens. Many persons with disabilities require assistance with BADLs and IADLs. This assistance is referred to as a disability-related accommodation.

Elementarily, the purpose of accommodation is to ensure that all persons have access to equal opportunities, access and benefits.¹⁷ As the Ontario Human Rights Commission explains:

The duty to accommodate stems, in part, from recognition that the “normal ways of doing things” in organizations and society are often not “neutral” but rather may inadvertently disadvantage, privilege or better meet the needs of some groups relative to others. Instead of giving special privileges or advantages, accommodations help to “level the playing field” by ensuring that all Ontarians are equally included and accommodated.¹⁸

The questions posed by the simplified CFS reflect an ableist perspective of disability, specifically that disability is an “anomaly to normalcy.”¹⁹ This perspective has historically

¹⁶ It was made clear at a Bioethics Table meeting that the assessor would ask both questions of the patient regardless of whether the first question – does this person have a terminal illness with an expected mortality in <6 months – was answered in the negative or in the affirmative.

¹⁷ This comment is in relation to preventing discrimination based on creed, but applies equally to discrimination based on disability. Ontario Human Rights Commission, Policy on preventing discrimination based on creed, (2015) at 54, online: http://www3.ohrc.on.ca/sites/default/files/Policy%20on%20preventing%20discrimination%20based%20on%20creed_accessible_0.pdf

¹⁸ *Ibid.*

¹⁹ Ontario Human Rights Commission, Policy on ableism and discrimination based on disability (2016) at 10, citing Marcia H Rioux & Fraser Valentine, “Does Theory Matter? Exploring the Nexus Between Disability, Human Rights, and Public Policy,” in *Critical Disability Theory: Essays in Philosophy, Politics, Policy, and Law*, (Vancouver: UBC Press), 2006, 47 at 51-52. The authors write that the “human rights approach to disability...identifies wide variations in cognitive, sensory, and motor ability as inherent to the human condition and, consequently, recognizes the variations as expected events and not as rationales for limiting the potential of persons with disabilities to contribute to society.” This approach recognizes “the condition of disability as inherent to society, not some kind of anomaly to normalcy.”

been used to rationalize the marginalization and exclusion of persons with disabilities from their ability to access services on an equal basis.²⁰ The CFS, as demonstrated by the simplified CFS, asks questions based on a normative way of doing things, neglecting the fact that some persons can complete the tasks in question with accommodations in place.

Accommodations in place for BADLs and IADLs further the right of persons with disabilities' to live independently in the community.²¹ To note, living independently is not to be interpreted solely as the ability to carry out daily activities by oneself.²² Rather, it contemplates assistance as a tool for independent living.²³ Persons with disabilities using accommodations to complete tasks to facilitate their ability to live independently are treated as less-than by the simplified CFS. The fact that they can complete these tasks with accommodations in place is of no significance to the CFS – it will score them higher on the scale as they cannot complete these tasks *unaided*.²⁴

The discrimination flowing from the application of the CFS is well exemplified when considering a case scenario provided by the Bioethics Table. The case scenario contemplated a 74 year old woman, who among other characteristics, received assistance with her finances. This need, however, was contextualized during the discussion as follows: she may not require assistance to do her finances because of a disability-related need, but rather because of her socio-economic status whereby she never learned how to do her finances. As such, the conversation continued, she *chose* to have someone assist her, rather than *required* for someone to assist her.

²⁰ *Eldridge*, *supra* note 9 at para 56.

²¹ *Convention on the Rights of Persons with Disabilities*, art 19, GA Res 51/106, 76th plen Mtg, UN Doc A/Res/61/106 [adopted by consensus at the UN on Dec 13 2006] [*Convention*].

²² Committee on the Rights of Persons with Disabilities, General comment No. 5 (2017) on living independently and being included in the community, 27 October 2017, online: <http://docstore.ohchr.org/SelfServices/FilesHandler.ashx?enc=6QkG1d%2fPPRiCAqhKb7yhsnbHatvuFkZ%2bt93Y3D%2baa2q6qfzOy0vc9Qie3KjjeH3GA0srJgyP8IRbCjW%2fiSqmYQHwGkfikC7stLHM9Yx54L8veT5tSkEU6ZD3ZYxFwEgh>.

²³ *Ibid*, at para 16(d).

²⁴ The application of the CFS further violates the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability, *Convention*, *supra* note 21, art 25, and the right to life, *Convention*, *supra* note 21, art 10.

Based on this distinction, the Bioethics Table explained, the 74 year old patient would be marked lower on the CFS in the first instance (choice) and less likely to be deprioritized for critical care, but higher on the second instance (need) and more likely to be deprioritized for critical care. This is exceptionally problematic because both patients require assistance, but only one is deprioritized for receiving critical care. This, of course, is discriminatory.

Notably, the Triage Protocol cites the Disability Rights Education & Defense Fund's (DREDF) guiding principles for Avoiding Disability Discrimination in Treatment Rationing²⁵ to demonstrate that "there is published guidance on how triage systems can minimize risk of discrimination based on factors unrelated to a patient's clinical needs and mitigate discriminatory application of such frameworks in practice."²⁶ We direct the Bioethics Table's attention to the third guiding principle which advises: "The fact that an individual with a disability requires support (minimal or extensive) to perform certain activities of daily living is not relevant to a medical analysis of whether that individual can respond to treatment."²⁷

B. Discriminatory Exclusionary Criteria

It was suggested by some members of the Bioethics Table that perhaps the adoption of the wording employed by the National Institute for Health and Care Excellence (NICE) in its COVID-19 rapid guideline: critical care in adults²⁸ may address the issue of discrimination. In particular, NICE explicitly states that the CFS should not be applied to persons with stable long-term disabilities.²⁹

Unfortunately, adopting NICE's wording does not cure the Triage Protocol of all of its discriminatory effects. The assurance that the CFS will not apply to persons with long-

²⁵ Disability Rights Education & Defense Fund, Applying HHS's Guidance for States and Health Care Providers on Avoiding Disability-Based Discrimination in Treatment Rationing, April 3, 2020, online: <https://dredf.org/avoiding-disability-based-discrimination-in-treatment-rationing/> [DREDF]; See also: Evaluation Framework for Crisis Standard of Care Plans, April 8, 2020, online: http://www.bazelon.org/wp-content/uploads/2020/04/4-9-20-Evaluation-framework-for-crisis-standards-of-care-plans_final.pdf.

²⁶ Triage Protocol 2, *supra* note 7 at 2.

²⁷ DREDF, *supra* note 25.

²⁸ NICE, Covid-19 rapid guideline: critical care in adults, 20 March 2020, online: <https://www.nice.org.uk/guidance/ng159/resources/covid19-rapid-guideline-critical-care-in-adults-pdf-66141848681413> [NICE Guidelines].

²⁹ NICE Guidelines, *ibid.*

term, stable disabilities still leaves a group of persons with disabilities vulnerable to the discriminatory impacts of the CFS – namely, persons with progressive disabilities.

Drawing a distinction between “stable” disabilities and “progressive” disabilities still constitutes discrimination.³⁰ It is unsatisfactory, from a legal perspective, to defend the discriminatory application of the CFS to one group of persons with disabilities by pointing to another group of persons with disabilities not being discriminated against.³¹ The Triage Protocol cannot exclude a particular group of persons with disabilities from access to critical care if those disabilities may not prevent them from benefitting from treatment of the very condition (COVID-19) that the Protocol seeks to treat.³²

The foregoing is of especial significance when the exclusion of persons with progressive disabilities is not justified and overbroad. In effect, persons with disabilities, and in this specific context persons with progressive disabilities, have a higher threshold to meet in order to be able to access critical care. They will always find themselves deprioritized to those patients who do not have disabilities – which is in direct contravention of human rights law.³³

In effect, the Triage Protocol adopts the absence of a pre-existing disability as a qualification for prioritization in accessing critical care.³⁴ The way in which the Triage Protocol currently operates, a person with a disability is much less likely, if ever, to be prioritized above a person without a disability. This concern is further exacerbated by the fact that a broad categorization of disabilities – progressive disabilities – is a criteria upon which a patient will be denied access to critical care.

Accordingly, it is our position that even if NICE’s wording is adopted and the CFS is not applied to persons with long-term stable disabilities, this change does not render the

³⁰ *Charter, supra* note 9, s 15.

³¹ Samuel R Bagenstos, “May Hospitals Withhold Ventilators from COVID-19 Patients with Pre-Existing Disabilities? Notes on the Law and Ethics of Disability-Based Medical Rationing” (2020) 130 *Yale Law Journal Forum* forthcoming, online: https://papers.ssrn.com/sol3/papers.cfm?abstract_id=3559926#.

³² *Ibid.*

³³ *Ibid.*

³⁴ *Ibid.*

Triage Protocol non-discriminatory. The CFS is a discriminatory standard when applied to persons with disabilities – progressive or otherwise.

C. Questioning the Available Data on CFS

Some members of the Bioethics Table provided a number of studies³⁵ in support of the position that the CFS is an accurate predictor of mortality and, as such, is the most appropriate tool for the purposes of the Triage Protocol. We have reviewed these studies and, with respect, question the conclusions of the Bioethics Table.

What is clear, overall from the studies, is that formal assessment of frailty is a newly developing area in critical care³⁶ with studies as recent as 2019 questioning the reliability of frailty assessments in the ICU.³⁷ It is clear from the literature that the studies in this

³⁵ Eighteen studies were provided to ARCH including, Abraham et al, “Validation of the clinical frailty score (CFS) in French language,” (2019) 19 BMC Geriatrics 322; Sean M Bagshaw et al, “Association between frailty and short- and long-term outcomes among critically ill patients: a multicenter prospective, cohort study.” (2014) 186:2 CMAJ E95 [Bagshaw et al, “Association”]; Nathan E Brummel et al, “Frailty and Subsequent Disability and Mortality among Patients with Critical Illness” (2017) 196 American Journal of Respiratory and Critical Care Medicine 64; Shannon M Fernando et al, “Frailty and associated outcomes and resource utilization following in-hospital cardiac arrest” (2019) 146 Resuscitation 138 [Fernando, “Frailty and Cardiac Arrest”]; Shannon M Fernando et al, “Frailty and Associated Outcomes and Resource Utilization Among Older ICU Patients with Suspected Infection” (2019) 47 Critical Care Medicine E669 [Fernando, “Frailty and ICU Patients”]; Hans Flaatten et al, “The impact of frailty on ICU and 30-day mortality level of care in very elderly patients (≥ 80 years)” (2017) 43 Intensive Care Med 1820; Bertrand Guidet et al, “The contribution of frailty, cognition, activity of daily life and comorbidities on outcome in acutely admitted patients over 80 years in European ICUs: the VIP2 study” (2020) 46 Intensive Care Med 57; David Hewitt & Malcom G Booth, “The FRAIL-FIT study: Frailty’s relationship with adverse-event incidence in the longer-term, at one year following intensive care unit treatment – A retrospective observational cohort study” (2020) 21 Journal of Intensive Care Society 124; Aluko A Hope et al, “Surrogates’ and Researchers’ Assessments of Prehospital Frailty in Critically Ill Older Adults” (2019) 28:2 American Journal of Critical Care 117; Carmel L Montgomery et al, “Implementation of population-level screening for frailty among patients admitted to adult intensive care in Alberta, Canada” (2019) 66 Canadian Journal of Anesthesia; John Muscedere et al, “The impact of frailty on intensive care unit outcomes: a systematic review and meta-analysis” (2017) 43 Intensive Care Med 1105; Richard J Pugh, Chris M Thorpe & Christian P Subbe, “A critical age: can we reliably measure frailty in critical care?” (2017) 21 Critical Care 121; Richard J Pugh et al, “Reliability of frailty assessment in the critically ill: a multicenter prospective observational study” (2019) 74:6 Anesthesia 758 [Pugh et al, “Frailty observational study”]; Melissa Shears et al, “Assessing frailty in the intensive care unit: a reliability and validity study” (2018) 45 Journal of Critical Care 197; Ralph KL So et al, “The association of clinical frailty with outcomes of patients reviewed by rapid response teams: an international prospective observational cohort study” (2018) 22 Critical Care 227; Gary Tse et al, “Frailty and mortality outcomes after percutaneous coronary intervention: a systematic review and meta-analysis” (2017) 18:12 The Journal of Post-Acute and Long-Term Care Medicine 1097; and, Chris Wharton, Elizabeth King & Andrew MacDuff, “Frailty is associated with adverse outcome from in-hospital cardiopulmonary resuscitation” (2019) 143 Resuscitation 208.

³⁶ Pugh et al, “Frailty observational study”, *supra* note 35 at 759.

³⁷ *Ibid.*

area have neither been broad nor inclusive; with studies raising more questions than providing answers. While it is understood and appreciated that the purpose of medical studies is to raise further issues to investigate, it is our submission that the current and available data on the application and use of the CFS is too unresolved to deem it the most appropriate or reliable tool for the purposes of the Triage Protocol.

i. The CFS has not been Tested in a Pandemic

We question the broad proposition that the CFS is an appropriate tool for triage decisions. None of the studies provided³⁸ contemplate the use of the CFS within a pandemic setting, for the purposes of a Triage Protocol, or as a tool by which to **exclude** a wide range of patients from accessing critical care.³⁹ Rather, a number of studies, either explicitly or implicitly, state that should the CFS be applied it would be for the purposes of **providing** better, more tailored care.⁴⁰

For example, one study suggested the diagnosis of frailty could improve prognostication and identify a population that might benefit from follow-up and intervention,⁴¹ while another study advised of the importance of clinicians' awareness of frailty in order to inform prognosis, aid with counselling, attend to special needs, and plan for appropriate discharge planning.⁴² One of the larger studies speculated that by using the CFS, doctors can improve upon their dialogue with the patient on the expected course of recovery

³⁸ We note that Dr. James Downar, who kindly provided the set of 18 studies, indicated that there are currently more than 1000 published studies involving CFS. However, for the purposes and scope of this document, we focus on these 18 studies (with a few more that we introduce into these submissions ourselves) as Dr. Downar has indicated their findings are likely to reflect current standards of care.

³⁹ One study does contemplate how frailty should factor into deciding whether "very old intensive care patients" (VIPs) should be admitted into the ICU based on their chances of survival. This study, however, was limited to 5021 patients with a median age of 84. See: Flaatten et al, *supra* note 35 at 1821. Another study found that the CFS was "feasible" in circumstances of rapid processing of the decision making to admit or refuse a patient in ICU. However, again, this study was limited to patients with a median age of 84 years old with a cohort of 3920 patients. See: Guidet et al, *supra* note 35 at 67.

⁴⁰ Sean M Bagshaw et al, "A prospective multicenter cohort study of frailty in younger critically ill patients" (2016) 20:175 *Critical Care* at 8 [Bagshaw et al, "Prospective multicenter"]; Shears et al, *supra* note 35; So et al, *supra* note 35.

⁴¹ Bagshaw et al, *ibid.*

⁴² Shears et al, *supra* note 35 at 198.

and/or survivorship expectations that would lead to a clear person-centered high-value treatment plan.⁴³

Of note, there is currently very little data focused on how clinicians should use information gathered from applying the CFS to guide their decision-making prior to getting critical care.⁴⁴ This absence of evidence is concerning as the very purpose of including the CFS in the Triage Protocol is as a determining factor in whether a patient is provided or denied critical care.⁴⁵

ii. The Application of the CFS in Patient Groups Under 65

The proposition that the CFS should or could accurately apply to all patients over the age of 18 is also not supported by the data. Notably, guidance by the Dalhousie Geriatric Medicine Research department on the CFS explicitly states that “The CFS is not validated in people under 65 years of age.”⁴⁶ The cohorts comprising the studies provided support this position, with at least 12 of the studies having a mean or median age of 65 or over.⁴⁷ Further, one of the larger studies advised that while the CFS may be appropriate for the use of persons aged 80 and above, different tools should be used in the triaging of younger patients.⁴⁸

⁴³ So et al, *supra* note 35 at 8.

⁴⁴ Montgomery et al, *supra* note 35 at 1318.

⁴⁵ Triage Protocol 1 *supra* note 6 and Triage Protocol 2 *supra* note 7.

⁴⁶ Geriatric Medicine Research, Dalhousie University, CFS Guidance & Training, online: University of Dalhousie <<https://www.dal.ca/sites/gmr/our-tools/clinical-frailty-scale/cfs-guidance.html>>. See also, the NICE Guidelines, *supra* note 28 at 6 which, after revisions, explicitly states that the CFS should not be used in younger people, people with stable long-term disabilities, learning disabilities or autism.

⁴⁷ See Bagshaw et al, “Association”, *supra* note 35 (mean age of 67); Fernando, “Frailty and Cardiac Arrest”, *supra* note 35 (median age of 65.7); Fernando, “Frailty and ICU Patients”, *supra* note 35 (1, 510 cohorts aged 65 and over); Flaatten et al, *supra* note 35 (median age of 84); Guidet et al, *supra* note 35 (median age of 84); Hope et al, *supra* note 35 (median age of 67.2); Pugh, Thorpe & Subbe, *supra* note 35 (median age of 70.5); Pugh et al, “Frailty observational study”, *supra* note 35 (median age of 69); Smith study (median age of 72); So et al, *supra* note 35 (age of 67); Tse et al, *supra* note 35 (mean age of 69); and Wharton, King & MacDuff, *supra* note 35 (median age of 74). We understand and appreciate that median/mean age represented in these studies indicates that persons younger than 65 were a part of these studies. However, none of these studies were solely focused on the validation of the CFS in persons younger than 65. And most, if not all, of the studies call for further studies. Moreover, at least 5 of the studies had cohorts with a mean or median age ranging between 58.5 to 63.8. See Bagshaw et al, “Prospective multicenter”, *supra* note 40 (mean age of 58.5); Brummel, *supra* note 35 (mean age of 62); Hewitt & Booth, *supra* note 35 (median age of patients diagnosed as frail was 62); Montgomery et al, *supra* note 35 (mean age of 63); and, Shears et al, *supra* note 35 (mean age of 63.8).

⁴⁸ Flaatten et al, *supra* note 35 at 1826.

In light of the evidence, it is clear that the CFS has only been tested on a very small subset of the population – namely, the very demographic for which it was designed. While some studies have explored the potential for applying the CFS for populations younger than 65, this exploration hardly justifies generalizing its application to all adults. One of the studies with a younger population of a mean age of 58.5 called for “further rigorous research in larger cohorts” to confirm its findings.⁴⁹ It is clear studies on the CFS are limited in scope; to use these studies as a basis for widespread application across all ages is a far leap and completely inappropriate. Indeed, members of the Bioethics Table shared that the CFS would not apply to pediatric patients. They later conceded that it was open to narrowing the CFS’ application to an older cohort.⁵⁰

Lastly, in a document that holds as much weight as the Triage Protocol and from which will flow serious, dire and devastating consequences, arbitrariness should be avoided at all costs. The suggestion that the CFS should apply to all patients over 18 is arbitrary. The suggestion that the CFS should apply to all patients over 50 is also arbitrary. Excluding persons over 65 from being able to access critical care during a pandemic is equally arbitrary.⁵¹ However, the metric chosen by the authors of the Triage Protocol stipulates an age cut-off of 65 and over. The authors cannot choose a metric that has been designed for a specific (age) demographic and transpose it into a Triage Protocol to be applied to a completely arbitrary, different and varied demographic.

To be clear, we are not suggesting that triage decisions should be based on age. However, the metric chosen by the authors of the Triage Protocol stipulates an age cut-off of 65 and over. The emphasis on age in discussions surrounding the Triage Protocol arises from the fact that the very metric embedded in the Protocol is only validated for a specific age group. ARCH is allied with advocates for the elderly and believes in the equal

⁴⁹ Bagshaw et al, “Prospective multicenter”, *supra* note 40.

⁵⁰ See discussion above at page 6.

⁵¹ It should be noted here that the Supreme Court of Canada has confirmed that arbitrariness is not a stand-alone test that must be demonstrated by the applicant to established *prima facie* discrimination (See *Stewart v Elk Valley Coal Corp*, 2017 SCC 30 at para 45). However, the existence of arbitrariness is an indicia supporting a finding that a policy violates substantive equality. See: *Al-Turki v Ontario (Transportation)*, 2020 HRTO 392 at para 85 citing *Hay v Ontario (Human Rights Tribunal)*, 2014 ONSC 2858 at paras 88 – 90.

protection of elderly patients and patients with disabilities. Anything less amounts to discrimination.

iii. The Inherent Subjectivity and the Reliability of the CFS

Several of the studies available acknowledge the subjective nature of the CFS,⁵² with one study noting that the CFS may have a higher inter-rater variability than more objective measures of frailty,⁵³ while another study explicitly describes it as a “nine-point scale based on *subjective* assessment of functional status”⁵⁴ and yet another describes it as a “subjective judgment-based screening tool for frailty.”⁵⁵

In their search for an objective clinical tool, the authors of the Triage Protocol have instead chosen one that is inherently subjective. From a human rights perspective this is extremely problematic.

Bias against persons with disabilities exists within the medical profession.⁵⁶ Implementing a metric that is inherently subjective invites these biases to inform the decisions of medical professionals when assessing patients with disabilities. The devaluing of the lives of persons with disabilities directly contributes to health care inequities experienced by the disability communities.⁵⁷ The medical community cannot seek to rely upon a subjective tool, especially when stigma and inaccurate assumptions about the quality of life of persons with disabilities⁵⁸ continue unaddressed within the profession.

Even arguably objective criteria are prone to an assessors’ subjective notions of the quality of life of persons with disabilities.⁵⁹ Scoring systems that aim to be objective have

⁵² Flaatten et al, *supra* note 35 at 1826.

⁵³ *Ibid.* Muscedere et al, *supra* note 35 at 1112.

⁵⁴ Muscedere et al, *ibid.*

⁵⁵ Bagshaw et al, “Prospective multicenter”, *supra* note 40 at 2.

⁵⁶ Ryan H Nelson, Bharath Ram & Mary Anderlik Majumder, “Disability and Contingency Care” (2020) 20:7 The American Journal of Bioethics 190.

⁵⁷ Catherine L Auriemma et al, “Eliminating Categorical Exclusion Criteria in Crisis Standards of Care Frameworks” (2020) 20:7 The American Journal of Bioethics 28, online: <https://www.tandfonline.com/doi/pdf/10.1080/15265161.2020.1764141?needAccess=true>.

⁵⁸ National Council on Disability, Medical Futility and Disability Bias: Part of the Bioethics and Disability Series, November 20, 2019, online: https://ncd.gov/sites/default/files/NCD_Medical_Futility_Report_508.pdf

⁵⁹ Bagenstos, *supra* note 31.

been described as not necessarily ethically-neutral nor free of bias.⁶⁰ If objective clinical criteria are susceptible to subjective judgments concerning the quality of life of persons with disabilities, then the risk of persons with disabilities being inappropriately and incorrectly excluded from care on the basis of a subjective tool is increased markedly.

Notably, and with regards to the reliability of the CFS, up until 2017 research pertaining to the reliability of the CFS was virtually absent from critical care literature.⁶¹ Another study in 2018 acknowledged that there had never been a formal evaluation of the reliability of the CFS in an ICU setting for clinical or research purposes.⁶² The CFS' reliability remains unproven,⁶³ with a review in 2018 finding little evidence of reliability of frailty assessments of critically ill patients.⁶⁴ It is evident that more research is needed regarding the reliability of frailty assessment tools – including the CFS – before frailty assessments are used to inform clinical decision-making,⁶⁵ and before any recommendations are made concerning its widespread application.⁶⁶

Of interest are the studies focused on inter-rater reliability between health care workers and a family (or surrogates) of a patient.⁶⁷ In Hope et al, surrogates tended to rate their family member (the patient) significantly lower on the CFS scale than the researchers. One inference drawn by the Bioethics table from this finding is that the family's rating is less accurate in predicting mortality which, it is posited, is the more concern pressing concern for the purposes of the Triage Protocol.⁶⁸ With respect, this inference is an oversimplification of a much larger problem with the medical community and how it may assess patients with disabilities.

⁶⁰ Amy L McGuire et al, "Ethical Challenges Arising in the COVID-19 Pandemic: An Overview from the Association of Bioethics Program Directors (ABPD) Task Force" (2020) 20:7 *The American Journal of Bioethics* 15.

⁶¹ Pugh, Thorpe & Subbe, *supra* note 35.

⁶² Shears et al, *supra* note 35 at 198.

⁶³ Richard J Pugh et al, "Feasibility and reliability of frailty assessment in the critically ill: a systematic review" (2018) 22 *Critical Care* 49 ["Pugh et al, "Frailty systematic review"].

⁶⁴ *Ibid.*

⁶⁵ *Ibid.*

⁶⁶ With regards to recommendations concerning widespread application in routine critical care practice. We would submit, however, that this cautious approach applies equally, if not more, to the widespread use of the CFS in a pandemic setting. See *ibid.*

⁶⁷ Hope et al, *supra* note 35.

⁶⁸ Email from Dr. James Downar, Member of the Bioethics Committee, to the ARCH among others, dated July 31, 2020.

A person with a disability or their close family member may deem themselves less frail than a subjective tool applied to them in a hospital setting by a healthcare worker. The issue then is not whether or not a medical professional is accurate in their assessment of frailty – especially if that assessment is coloured by ableism. Rather, the issue is whether the medical professional is undermining a person with a disability’s own self-assessment that is directly based on their lived experience.

It is well-documented that healthcare workers consistently underestimate the self-reported quality of life of persons with disabilities.⁶⁹ This misperception, it has been found, “has negatively influenced physicians’ medical futility decisions and resulted in the withdrawal of necessary medical care from people with disabilities.”⁷⁰ This may also be in part to the paternalism present within the medical community; where there is an absence of understanding and respect for the fact that persons with disabilities are better judges of the quality of their own life than those (including doctors) without disabilities.⁷¹

If, as the Triage Protocol suggests, the CFS is to be applied to a much broader demographic than for whom it was designed, then these issues must be, at the very least, explored further. This is especially considering the fact that none of the studies provided contemplate how, and if, persons with disabilities are assessed differently than patients without disabilities to ensure that they are assessed with their accommodations.

iv. Learning from Past Mistakes

The questionable reliability of the CFS echoes Ontario’s past pandemic errors. In 2006, Ontario released a Triage Protocol in anticipation of the Influenza Pandemic.⁷² The Sequential Organ Failure Assessment (SOFA) was the metric identified by the working

⁶⁹ Nelson, Ram & Anderlik Majumder, *supra* note 56.

⁷⁰ *Ibid.*

⁷¹ Bagenstos, *supra* note 31.

⁷² Critical Care During a Pandemic: Final Report of the Ontario Health Plan for an Influenza Pandemic (OHPIP) Working Group on Adult Critical Care Admission, Discharge and Triage Criteria. April 2006. [OHPIP] online:

https://www.researchgate.net/publication/273203603_Critical_Care_During_a_Pandemic_Final_report_of_the_Ontario_Health_Plan_for_an_Influenza_Pandemic_OHPIP_Working_Group_on_Adult_Critical_Care_Admission_Discharge_and_Triage_Criteria. To note, OHPIP was never triggered by a surge in Ontario and, as such, was not implemented during the Influenza Pandemic.

group as the most appropriate for the purposes of triage in OHPIP at that time.⁷³ Since then, however, the accuracy of SOFA, especially for the purposes of triage, has been questioned.⁷⁴ And yet, at the time, the scientific data available to deem SOFA valid for the purposes of triage in 2006 was arguably more comprehensive and tested than what is currently available for the CFS.

For example, the SOFA was widely tested on a range of patients.⁷⁵ The same cannot be said about the CFS. The SOFA was also lauded as an accurate predictor of mortality and, as such, appropriate for the purposes of pandemic triage.⁷⁶ Further, even though SOFA had not been previously employed for the purposes of allocating scarce resources, it was designed for that very purpose.⁷⁷ The CFS, of course, was not designed for this purpose.

And yet, subsequent studies demonstrate that the predictive value ascribed to the SOFA outside of a pandemic, may not be directly transferrable to a pandemic/triage context.⁷⁸ For example, a study out of the UK implemented the triage criteria set out in the OHPIP and found that it failed to adequately prioritize patients who would have benefitted from intensive care.⁷⁹ In fact, alarmingly, the study found that of the 46% of patients who would have been withdrawn from critical care, or denied critical care at all based on SOFA scores, 61% actually survived hospital discharge.⁸⁰ It was further found that despite some studies claiming an association between a SOFA score of greater than 11 with a mortality

⁷³ *Ibid* at 8.

⁷⁴ Sheri Fink, "Ethical Dilemmas in COVID-19 Medical Care: Is a Problematic Triage Protocol Better or Worse than No Protocol at All?" (2020) 20:7 *The American Journal of Bioethics* 1 [Fink, "Ethical Dilemmas"]; T Guest et al, "An observational cohort study of triage for critical care provision during pandemic influenza: 'clipboard physicians' or 'evidenced based medicine'?" (2009) 64 *Anaesthesia* 1199; Khan Z, J Hulme & N Sherwood, "An assessment of the validity of SOFA score based triage in H1N1 critically ill patients during an influenza pandemic" (2009) 64:12 *Anaesthesia* 1283; McGuire et al, *supra* note 60.

⁷⁵ OHPIP, *supra* note 72 at 8.

⁷⁶ *Ibid* at 9; the Triage Protocol reported that patients with a SOFA score of greater than 11 had a mortality rate of 90% even with full critical care during a normal period.

⁷⁷ *Ibid* at 8, citing FL Ferreira et al, "Serial evaluation of the SOFA score to predict outcome in critically ill patients." (2001) 286:14 *JAMA* 1754. Despite the assertion by the authors of OHPIP and Ferreira et al. that SOFA was designed for this purpose, others have argued the opposite, i.e. that it was designed for purposes unrelated to triage, see: Matthew K Wynia & Peter D Sottile, "Ethical Triage Demands a Better Triage Survivability Score" (2020) 20:7 *The American Journal of Bioethics* 75.

⁷⁸ Fink, "Ethical Dilemmas", *supra* note 74 at 5. See also: Sheri L Fink, "Worst case: rethinking tertiary triage protocols in pandemics and other health emergencies" (2010) 14:1 *Critical Care* 103.

⁷⁹ Guest et al, *supra* note 74.

⁸⁰ *Ibid* at 1204.

predictability at 90%, Guest’s study only reported a mortality predictability of 29%.⁸¹ Another study focused on the admission of H1N1 patients to the ICU.⁸² That study concluded that the inclusion of the SOFA score in triage could lead to withdrawal from life support in critically ill patients who could have otherwise survived.⁸³

Reflecting on the questionable applicability of SOFA begs the question whether future studies will draw similar conclusions on the application of the CFS. In light of the limited data on the CFS, the Bioethics Table should proceed more cautiously by keeping in mind that whatever harm flows from the application of the CFS will disproportionately impact persons with disabilities. The issues Guest’s study identified in the Ontario’s 2006 protocol as problematic equally apply to the current Triage Protocol. This includes Guest’s finding that using SOFA as a tool creates a method by which “patients are assessed not by individual clinical examination and judgment, but according to a rigid binary method (i.e. certain signs or criteria are present or absent).”⁸⁴

It is important to note that some have argued against the use of SOFA in COVID-19 protocols because it has not been validated within that context.⁸⁵ With respect, the same rationale must apply to the CFS which has also not been validated for the purposes of triaging during COVID-19. Another criticism equally applicable to the CFS is that while such scoring systems can be alluring, their seemingly objective criteria creates the risk of “false precision,” meaning that doctors will look to this criteria to claim that two patients have a different risk of mortality where the reality is that they are clinically indistinguishable.⁸⁶

As at least one critic has warned, it may be time to consider “profound conceptual changes to the triage guidelines.”⁸⁷ This is especially pertinent considering the current

⁸¹ *Ibid* at 1205.

⁸² Khan, Hulme & Sherwood, *supra* note 74.

⁸³ Fink, “Ethical Dilemmas”, *supra* note 74 citing Khan, Hulme & Sherwood, *ibid*.

⁸⁴ Guest et al, *supra* note 74 at 1205.

⁸⁵ McGuire et al, *supra* note 60.

⁸⁶ *Ibid*.

⁸⁷ Fink, “Ethical Dilemmas”, *supra* note 74 at 5.

protocol commits serious human rights violations, to which we have explored in sections # above and to which we now return.

D. The Standard Is Not Justified

In effect, and in its application, the CFS creates a barrier for persons with disabilities from accessing healthcare services, and specifically accessing critical care, largely based on the fact that they have a disability.⁸⁸ This barrier is not justified.⁸⁹

We have raised questions about the strength of the data supporting the use of the CFS in the preceding section. To be clear, our position is that the evidence on which the authors of the Triage Protocol rely fails to demonstrate how the inclusion of the CFS is an appropriate tool for triage decisions.

However, and in the alternative, it is well-established in law that even if a standard, scientific or otherwise, is deemed valid it does not automatically render the discriminatory impact as justifiable.⁹⁰ Rather, once *prima facie* discrimination is established, which has been done with regards to the CFS, then the party proposing the use of the discriminatory standard must demonstrate a *bona fide* reasonable justification for its use – namely that it is minimally impairing and proportional.⁹¹ One need only look to the multitude of studies recommending further study on the CFS coupled with the disparate impact on persons with disabilities to find that no justification exists for the inclusion of the CFS as an triage tool.

E. A Brief Note on Utilitarianism

ARCH has made extensive submissions on the issues arising from the utilitarian framework within which Triage Protocol is developed and applied.⁹² We do not aim to

⁸⁸ This is in violation of section 15 of the Charter of Rights and Freedoms which prohibits discrimination based on protected grounds, including disability, *Charter*, *supra* note 9, s 15.

⁸⁹ *British Columbia (Public Service Employee Relations Commission) v. BCGSEU*, [1999] 3 SCR 3 (“*Meiorin*”).

⁹⁰ *British Columbia (Superintendent of Motor Vehicles) v British Columbia (Council of Human Rights)*, [1999] 3 SCR 868.

⁹¹ *Meiorin*, *supra* note 89.

⁹² See ARCH May Submissions, *supra* note 4 and ARCH July Submissions, *supra* note 5.

repeat these submissions here, but rather provide a brief note specifically regarding the operation of exclusion criteria and the Clinical Frailty Scale within this very framework.

Protocols that emphasize the derivation of maximum benefit from scarce critical care resources have attracted criticism for their employment of simple categorical exclusions to promote the maximization⁹³ of the “good.”⁹⁴ This is because the implementation of categorical exclusions can often disadvantage persons from specific communities, including persons with disabilities,⁹⁵ and can lead to the definitive exclusion of persons with specific disabilities despite the absence of evidence going to same.⁹⁶

A utilitarian framework also neglects to consider socio-economic and other inequities that may make some groups more susceptible to contracting the virus, and therefore more likely to require medical attention, than others. The Triage Protocol expressly recognizes that “critical care triage may have a differential impact on some patient populations who may be disadvantaged due to pre-existing health and social inequities or conscious or unconscious bias in clinical settings.”⁹⁷ While this acknowledgment is important, it is not appropriately addressed by the inclusion of exclusion criteria and a metric that will have an adverse discriminatory impact on marginalized communities. In short, the Triage Protocol embeds⁹⁸ and perpetuates the discrimination, rather than addresses it.

Accordingly, and as others have similarly suggested,⁹⁹ we urge the Bioethics Table to turn its mind to conceptualizing a new framework for triage protocols that rejects tools that disproportionately impact persons with disabilities – as well as persons from other marginalized communities.

⁹³ See, for example Auriemma et al, *supra* note 57.

⁹⁴ Medical Utility in the second draft of the Triage Protocol is defined as creating the maximum good for the maximum number of people.

⁹⁵ Auriemma et al, *supra* note 5793.

⁹⁶ *Ibid.*

⁹⁷ Triage Protocol 1, *supra* note 6 at 2.

⁹⁸ Teneille R Brown, Leslie P Francis & James Tabery, “Embedding the Problems Doesn’t Make Them Go Away” (2020) 20:7 *The American Journal of Bioethics* 109, online:

<https://www.tandfonline.com/doi/pdf/10.1080/15265161.2020.1779864?needAccess=true>.

⁹⁹ See for example, Fink, “Ethical Dilemmas”, *supra* note 7478.

Conclusion

We acknowledge and appreciate that there is a pressing objective central to the Triage Protocol. However, the authors of the protocol are urged to rethink the inclusion of the proposed metric of the CFS for a multitude of reasons, not least that it *prima facie* discriminates against persons with disabilities by drawing distinctions based on disability. The CFS invites ableist and normative assessments of a person's abilities, a concern that is exacerbated by the fact that the CFS is inherently subjective. The questions raised about the CFS data coupled with the clear and inevitable disproportionate impact on persons with disabilities that will flow from its application support the position that this is not an appropriate or reasonable tool whose inclusion or application can be justified within a human rights framework.

Sincerely,

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