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Supplementary ethics submission to the Aotearoa New Zealand Ministry of Health's National Ethics Advisory Committee

Consultation on the Draft Ethical Framework for Resource Allocation in Times of Scarcity

August 2020

About The Royal Australasian College of Physicians (RACP)

The RACP trains, educates and advocates on behalf of over 18,000 physicians and 8,500 trainee physicians, across Australia and New Zealand. The RACP represents a broad range of medical specialties including general medicine, paediatrics and child health, infectious diseases, cardiology, respiratory medicine, neurology, oncology, public health medicine, infectious diseases medicine, occupational and environmental medicine, palliative medicine, sexual health medicine, rehabilitation medicine, geriatric medicine, and addiction medicine. Beyond the drive for medical excellence, the RACP is committed to developing health and social policies which bring vital improvements to the wellbeing of patients.

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Introduction

The RACP welcomes this opportunity to provide a supplementary submission on the National Ethics Advisory Committee's (the NEAC) Consultation on the Draft Ethical Framework for Resource Allocation in Times of Scarcity (the Framework).

This RACP submission is supplementary to the RACP's previous submission on the draft Framework[1] which highlights that Te Tiriti o Waitangi is an absolute commitment to pursuing health equity for Māori, which should not be subsumed under other concerns.

This supplementary submission focuses specifically on the ethical issues outlined in the NEAC Framework and has been developed by the RACP Ethics Committee. It should be read in conjunction with the previous RACP submission.

We congratulate the NEAC for the development of this valuable draft document and offer recommendations and suggestions to strengthen its ethical focus.

Feedback on the draft Framework

General comments on the draft Framework

- The draft Framework would benefit from an Executive Summary as well as definitive framework for actioning allocation of resources and describing these mechanism of review.

- The Summary guidance sheets from the 2007 NEAC document, *Getting through together – Ethical values for a pandemic,* clearly articulate the ethical values for a pandemic which recognise the values in "Māori tikanga or kawa (the right or correct ways of acting)". Inclusion of these guidance sheets in this Framework should be considered as they identify widely shared ethical values. Importantly they highlight inclusiveness and openness, respect, fairness and unity. In addition, they can be "applicable to health and disability settings other than those of a pandemic" and importantly can relate to community health care settings and not just the intensive care setting as the newer document highlights, specifically around ICU treatment. The guidance of pandemic ethics is also clear and highlights the ethical tensions that occur in pandemic situations. These include restrictions in movement, and visiting restrictions; and questions that arise during overwhelming demand or in situations of resource scarcity. The summary sheets are concise and clear and could be added to the background/introduction of the current document.

- The draft Framework is titled *Resource allocation in times of scarcity*, however, throughout the document there is overlap of information in relation to ethics of resource allocation, ethics of scarcity, ethics of pandemics and COVID-19 as a specific ethical issue. The title suggests that it could be applicable more broadly to other situations of scarcity which arguably exist all the time, for example, allocation of organs, allocation of budget for new diagnostics or therapies, etc. Further, even if the scope of the draft Framework was limited to pandemics, much of the current content refers specifically to COVID19 and some of the information is not applicable more broadly. For example, modified SOFA scores are irrelevant to many other infectious diseases that continue to place large burdens on low to middle income countries (e.g. HIV/AIDS, XDR-TB, malaria). While there is no doubt that similar ethical issues apply in all resource allocation, it would seem that it would be better to focus the document on either pandemics generally or on COVID-19 specifically whilst pointing out that ethics is generalisable across other settings.

- The Framework appears to have adopted the Pittsburgh-style SOFA score but there is little to no mention of the triage-officer/triage team approach where 2-3 senior staff make urgent decisions for

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reporting and review by a larger body. We would recommend adding this team approach to strengthen this aspect of the Framework.

- The draft Framework states at the onset that its focus is on equity, however, it is not clear how this is consistent with the remainder of the document which lays out the need to balance ethical principles and does not outline why the focus should not equally be on care as well as equity or why equity should take precedence over care and respect.

- While the Framework makes a strong initial commitment to partnership, cultural respect and Te Tiriti o Waitangi and recognises that disease, including COVID-19 is a marker of injustice and inequity, it does not clearly outline how it proposes to take the impact of social determinants into account and how injustice should be redressed. In saying this, we acknowledge that other frameworks internationally, notably in the US, have also failed to make clear whether social determinants of health should be taken into account, for example, in the access to allocation of ICU beds and ventilators. Indeed, this draft Framework would appear to support clinical status/capacity to benefit as the major determinants of decision-making in times of scarcity. To address this, we would recommend the draft Framework lays out how social justice could be achieved or state clearly and honestly that it is not possible in the current context for decisions with regard to ventilation to be made whilst taking social justice concerns into account and that systematic inequities need to be addressed at different points and in different ways. Without such clarity the initial commitment to equity and the principles of Te Tiriti o Waitangi Tiriti may appear superficial and could arguably undermine trust.

- As outlined in the previous RACP submission, the draft Framework identifies the importance of the implementation of Te Tiriti o Waitangi in health and the mandate that Māori people participate in equal partnership with the Government. The overriding ethical values of 'inclusiveness', 'respect', 'fairness' and unity are applicable to a range of settings, including participation with government, health care workers and policy makers to ensure that there is partnership and that Māori and other citizens are 'active partners in preventing, mitigating and managing the impacts of a pandemic or public health emergency' (p.3 of the draft framework)

- The key to balancing the impact of measures to control COVID-19 against its harms relates in large measure to the point at which they are enacted and applied. This has been a particular issue in Australia where, arguably, triage ethics/decision-making was enacted prior to the expected (first) surge that never came. While the second wave is creating major challenges for the health system in Australia it is unquestionable that many patients who would otherwise have been treated did not receive care during the first wave of COVID-19: radiotherapy units were quiet, angiography didn't happen, cancers were undiagnosed or unstaged, chemotherapy and transplant were deferred or cancelled, etc. This situation will have created significant harm and we would therefore recommend expanding the draft Framework's discussion of the importance of being able to assess when triage is justifiable and when it isn't.

- The draft Framework advocates keeping beds empty for the coming onslaught. This is ethically very fraught if people are denied treatment for an onslaught that never comes. While this approach may be put forward in terms of reducing care such as elective surgery or implementing a 'first-comes first-served' decision-making, it needs to be developed more explicitly or stated in different terms.

- The draft Framework discusses ICU withdrawal largely in terms of individual patient benefit and not so much in the context of another (currently unventilated) patient being judged as more likely to benefit. We would recommend strengthening this aspect of the Framework by advancing a position on the ethics of withdrawal of care in these situations.

- The Framework describes ICU, PPE and vaccines as examples of possible scarce resources, but could perhaps describe the ethical tension in pandemics in general initially i.e. when considering a pandemic situation there is a transition from an individual patient and family focused care, to a broader community/system response – with responsibility to the care of the society, particularly those who are vulnerable. The overarching focus should be on all the community with values of solidarity, stewardship, and care.

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- Limited human resources, particularly health care workers should also be noted as a serious potential scarce resource, thereby further impacting the health care and support of people in the community.

- Linkage of the Framework to the following resources would be useful:
  - The Australian and New Zealand Intensive Care Society (ANZICS) COVID-19 Working Group's Guidelines[2]
  - The Australasian College for Emergency Medicine (ACEM) COVID-19 Guidelines and Resources[3]

- With regard to personal protective equipment (PPE), its use should be based on a risk-based method as this is more likely to ensure consistency across settings and the 'social worth' principle and interpretation is also inequitable.

Specific feedback

- The preamble on the public consultation page for the draft Framework states the following: "NEAC's Framework is a high-level guidance document for the health and disability sector that would help health workers and policy makers consider ethics when deciding how to allocate resources. It sets out four essential ethical principles, and four Te Tiriti principles, that medical staff, service planners and policy analysts should consider when responding to a pandemic." We would recommend replacing the term "medical staff" with "health care or health workers" as the use of the term *medical staff* indicates medical dominance which by inference reduces equity.

- The section on health disparities on p.3 would benefit from a brief discussion of the factors that create vulnerability and limit power. Arguably, it could also be beneficial to add a broad statement about the groups of people who face discrimination and inequity and may lack access to health care, for example, the LGBTIQ+ community, people experiencing mental illness, people who are disempowered (i.e.. refugees, asylum-seekers, people who are homeless).

- In the section titled *Increasing risk through unequal distribution and exposure to determinants of health* on p.3, we would recommend either defining the term "equal moral worth" or using a different term, perhaps the terms "equally deserving of care" included in Table 1.

- We would recommend significantly expanding the section titled *Human rights* on p.4 as it currently only gives a cursory outline of the issue and does not explain or link human rights to ethics, ethical principles, values or to decision-making. We would also recommend including a definition of 'human dignity' in this section.

- The section titled *Tensions between the principles* on p.5 has a strong clinical ethics focus. In our experience, clinicians often struggle with the frameshift in conceptualising decision making in this way. If reading this document is their first exposure to this way of thinking at a time when they are facing resource allocation decisions at the front line in a pandemic response, it may not be readily accessible to them, particularly if they are frontline staff.

- Table 1 of the document outlines four principles to allocate resources and it could be argued that most if not all are different conceptual ways of trying to achieve equity. The priority remains that <u>all</u> people/peoples should be able to access care and this should be clearly articulated. We would also suggest adding a statement that while care should be universal, treatments may differ based upon individual's goals of care, for example.

- Table 2 of the document is very clearly set out. It articulates the principles of how health and disability services should meet obligations under Te Tiriti in 'day-to-day work'. The application to the primary

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[2] Available online: https://www.anzics.com.au/coronavirus-guidelines/ [last accessed 29/07/2020]
[3] Available online: https://acem.org.au/Content-Sources/Advancing-Emergency-Medicine/COVID-19/Resources [last accessed 29/07/2020]

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health care system and to resource allocation describes the importance of partnerships, self-determination, protection and options for culturally appropriate care. Further emphasis of the partnering with all community is important for a general document and recognition and respect for all individuals/families to identify goals of and types of care (i.e. continuing sustainable and supported care in the community, and access to palliative care when escalation of treatment is not desired by the patient/family and if of potential harm with little/no benefit).

- We would recommend significantly revising the section titled *Clinical resources* for clarity. We recommend removing reference to 'futility' as this is not assessed per se but may be the judgement that is made about a therapy following consideration of its burdens and benefits. We would also suggest that emphasis be placed on 'consideration' rather than assessment. Further, rather than referring to patient autonomy, it may be more appropriate to consider respect and consideration of a patient's preferences, values and health-related goals of care.

- In the section titled *Making decisions*:
  - This is a very important section and the framing outlined in the first paragraph of "the decision-making process" subsection is very accessible.
  - We would recommend expanding on the factors that give policies ethical legitimacy and create public trust. To this end the draft Framework could arguably make reference to fairness (Philosopher John Rawls) or to the Accountability for Reasonableness Framework which identifies reasonableness/evidence-base, inclusiveness, transparency, revisability and fair enforcement/application with some form of appeal process as among the process principles that create legitimacy. The Australian Ethical health Alliance has also laid out ethical principles for collaboration in health which may also be useful.
  - The last sentence on p.11, "Good decision-making processes may be necessary in order to show respect for people and ensure procedural fairness". We recommend rewording this sentence as follows: "Good decision-making processes **are always necessary** in order to show respect for people and ensure procedural fairness".
  - The recommendation of a 'decision-making group' is important and aligns with other international frameworks and recommendations. However, the proposed membership of these groups is large and diverse and the groups are allocated very broad duties which may make them less able to make urgent allocation decisions. We would suggest a clearer delineation of clinical teams charged with urgent decisions and larger policy/case review groups and relationship between the two to address this issue.
  - In addition, we would recommend clarifying the link between procedural fairness and group decision making to bring the clinical leaders along. In our experience, many clinicians dislike 'decision by committee' so this link is critical to bring procedural fairness to the table.
  - With respect to the concern about smaller centres and communities, the use of tele-medicine/technology could connect smaller communities to the larger centres in a health district where support could be available.

- The section titled *General allocation guidance* is valuable and the question/answer format is practical and accessible. Under the question *What are organisations' obligations"* we would recommend adding staff safety and support.

- In the introduction to *Example 1: Intensive care unit allocation*, we would recommend defining the terms "moral injury" and "moral distress". These are known terms for those familiar with clinical ethics but they may not be readily understood by many frontline decision makers.

- In the section titled *Achieving equity:*
  - We would suggest the following sentence on p.16 "For critically ill COVID-19 patients, the primary consideration should be whether ICU care is in the patient's best interest and what other care may be appropriate, including palliative or supportive care." should be placed up-front in this section and, should also emphasise that access to ICU should not be segregated in terms of COVID or non-COVID patients.
  - We would also recommend adding information about the importance of community awareness of outcomes, chance of recovery and the importance of advance care planning/advance health directives prior to an emergent situation. This will have the benefit of family members understanding goals and wishes for treatment and in situations where people elect for

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palliative care, the need for hospitalisation and consideration of escalation of care will be avoided.

- While the document tabulates mechanisms for prioritisation in resource allocation (Table 3), there is no clear recommendation put forward. Prioritisation for frontline workers is inequitable, as is the lottery mechanism. There should be clarity around this and how the 'decision-making group' will work and be reviewed.

- In the section titled *Getting the most from resources* on p. 21, the sentence "'Social worth' is an interpretation of this principle that may be ethically justified in the unique setting of a pandemic" could be complemented by adding considerations of public health ethics which are covered under the section *All people are equally deserving of care* in the following sentence on p.22: "Seniority within the health system or organisational hierarchy is irrelevant to PPE distribution. The only exception would be staff with critical expertise whose absence would disproportionally impact the system's ability to provide adequate treatment. Where this justification is used, the reasoning must be transparent."

- In the section titled *Achieving equity* on p.21, we would recommend including a definition of the term "epistemic authority" and also outlining how it could be applied in practice.

- In *Example 3: Vaccine allocation*, it is unclear whether NEAC is advocating for lottery or random selection for vaccination. We would recommend strengthening this section of the document by including a discussion of prioritisation for health professionals, non-paid carers, workers in essential services and people who are at higher risk of severe illness from COVID-19 including people over 70 and those with medical conditions and compromised immunity. We would also suggest addressing the issue of the potential harm from vaccination where the evidence is limited including the mechanisms that would need to be put in place to compensate people potentially harmed by vaccines with limited evidence during a pandemic.

Many thanks again for this opportunity to provide a supplementary submission on the NEAC's draft Ethical Framework for Resource Allocation in Times of Scarcity. Should you require any further information about this submission, please contact the RACP Ethics Committee Secretariat via Ethics@racp.edu.au.

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