



Summary of Submissions

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

Citation: Ministry of Health. 2020. *Summary of Submissions: Consultation on the Draft Ethical Framework for Resource Allocation in Times of Scarcity*. Wellington: Ministry of Health.

Published in October 2020 by the Ministry of Health PO Box 5013, Wellington 6140, New Zealand

ISBN 978-1-99-002941-7 (online) HP 7473



This document is available at health.govt.nz



This work is licensed under the Creative Commons Attribution 4.0 International licence. In essence, you are free to: share ie, copy and redistribute the material in any medium or format; adapt ie, remix, transform and build upon the material. You must give appropriate credit, provide a link to the licence and indicate if changes were made.

Contents

Background	1	
The National Ethics Advisory Committee	1	
Developing the Framework	1	
Update of Getting Through Together	2	
NEAC Members	2	
Consultation process	3	
Dissemination	3	
Consultation design	3	
Public meetings	4	
Consultation meetings	4	
Profile of submissions	5	
Number of submissions	5	
Categories of respondent	5	
Analysis	7	
Introduction	7	
Themes	8	
Support for the Framework	9	
Balancing and weighting of principles		
Context – existing landscape and dominant values		
Visibility and acknowledgement of groups		
Human rights	11	
Scope, structure and purpose	12	
Decision-making group	13	
Ethical principles	14	
Equity	14	
Treaty principles	15	
Intensive care units	16	
Personal protective equipment	17	
Vaccines	17	
Use of quality-adjusted life years as a tool for resource allocation	18	
General allocation guidance	18	
Wider issues	19	

i

Background

The National Ethics Advisory Committee

The National Ethics Advisory Committee (NEAC) is an independent advisor to the Minister of Health. NEAC was established in 2001 by section 16 of the New Zealand Public Health and Disability Act 2000.

The National Ethics Advisory Committee's statutory functions are to:

- provide advice to the Minister of Health on ethical issues of national significance in respect of any health and disability matters (including research and health services)
- determine nationally consistent ethical standards across the health and disability sector and provide scrutiny for national health research and health services.

The Ministry of Health provides policy staff and other resources to support NEAC, but the Committee remains independent of the Ministry and its work.

Developing the Framework

The Framework was developed in response to COVID-19 but has wider application

NEAC's Draft Ethical Framework for Resource Allocation in Times of Scarcity (the Framework) is a high-level guidance document for the health and disability sector that helps health workers and policy makers consider ethics when allocating resources in the context of the COVID-19 response.

Importantly, NEAC notes that, in this context, in some instances people will need to prioritise one value over another, as values will sometimes be incompatible. The Framework helps decision-makers identify ethical tensions and recommends the establishment of decision-making groups to work through these tensions and uphold transparency of decision-making.

NEAC's framework includes Te Tiriti principles and equity as a core principle

The Framework sets out four essential ethical principles and four Te Tiriti principles that medical staff, service planners and policy analysts should consider when responding to pandemics.

The ethical principles have been developed on the basis of international literature. NEAC has adopted the Ministry of Health's definition of equity, which recognises that different people have different levels of advantage and so require different approaches and resources for them to gain equitable health outcomes.

In a resource allocation setting, health workers and policy makers should consider how resources can be allocated to mitigate the adverse consequences of pandemic response measures while avoiding or minimising growth in inequity.

Update of Getting Through Together

NEAC recognises that the current Framework only addresses a small part of pandemic ethics, and is currently focused on COVID-19. It intends to revise the Framework to be applicable to pandemics more generally, as part of its planned review of its 2007 document *Getting Through Together: Ethical Values for a Pandemic (Getting Through Together)*.

Getting Through Together considers ethical issues that may arise during any pandemic. NEAC believes it needs to be updated for two reasons. First, it needs to consider further ethical issues, including use of digital technologies, specific guidance on public health interventions and the impact of a pandemic on routine standards of care and consideration of equity. Second, its structure needs amendment. Experience from the COVID-19 pandemic revealed that the current document is difficult to use. The target audience of a pandemic ethics document is wide, and includes decision-makers, government and the public. Accordingly, the document should be clear and easy to navigate.

NEAC Members

- Neil Pickering
- Maureen Holdaway
- Kahu McClintock
- Wayne Miles
- Liz Richards
- Hope Tupara
- Dana Wensley
- Mary-Anne Woodnorth
- Gordon Jackman
- Dr Penny Haworth
- Cindy Towns
- Dr Vanessa Jordan

For more information on members, please see https://neac.health.govt.nz/aboutus/committee-members

Consultation process

NEAC called for public submissions on the Framework on 16 June 2020. The consultation ran for four weeks; it closed on 15 July 2020. However, NEAC accepted late submissions; the final submission was received on 29 July 2020.

Dissemination

The consultation document was available online on the Ministry of Health website and NEAC's website. The document was tweeted by the Ministry of Health and shared on LinkedIn by members of the Ministry of Health Ethics team. The document, and a link to the online consultation form, was emailed to an initial list of 75 email addresses. The email requested that recipients forward the consultation widely, and provided a list of target stakeholders. The email list was generated from suggestions from NEAC and the Ministry of Health Secretariat. During the consultation the email was also sent out on an ad hoc basis, as NEAC took suggestions for interested stakeholders from those responding.

Some submitters who had a strong interest in the consultation provided feedback that they had not been directly contacted to participate. In response, NEAC notes that it will make use of the submitters who responded as a baseline for future consultations and will take steps to build its stakeholder engagement contact list.

Consultation design

The consultation was designed using Citizen Space, an online consultation tool. Submitters also used Citizen Space to make their submission.

The consultation asked submitters:

- 1. whether the Framework captures the ethical tensions involved in resource allocation in times of scarcity
- 2. whether the Framework helps decision-makers understand the ethical implications of making decisions
- 3. whether the Framework helps decision-makers consider equity when responding to COVID-19
- 4. what they thought about the Te Tiriti principles and their application to resource allocation decisions
- 5. to specify any further comments they had, and suggested changes for NEAC to consider for the final draft
- 6. the ethical issues or areas of work submitters thought should be covered in a substantial review of *Getting Through Together*.

Submitters were asked to respond using Likert scales for questions 1–3. The Secretariat contacted those submitters who did not respond using Citizen Space by email to seek their submission. NEAC also received some submissions through the post (see 'Number of submissions' below).

Public meetings

There were no public meetings held for this consultation, due to COVID-19. All submitters were offered Zoom meetings with NEAC and or the Secretariat.

Consultation meetings

NEAC held five consultation meetings with submitter groups as follows:

- 1. Capital & Coast District Health Board (DHB) intensive care unit and palliative care clinicians
- 2. Waitemata DHB Clinical Ethics Advisory Group
- 3. Rare disorders NZ
- 4. Capital & Coast DHB Clinical Ethics Advisory Group
- 5. Te Ropū Whakakaupapa Urutā (the national Māori pandemic group).

Profile of submissions

Number of submissions

A total of 34 submissions were received using email, post and the Citizen Space tool. Five submitters opted not to have their submissions published and publicly disseminated.

Categories of respondent

Consult **Organisation/individual** Category number 1 Consultant haematologist - Wellington Blood and Clinical **Cancer Centre** 2 Royal Australian and New Zealand College of Clinical Obstetricians and Gynaecologists 3 Capital & Coast DHB Clinical Ethics Committee Clinical/ethics 4 IHC Disability/consumer 5 Asian, Migrants and former refugees of the Planning Consumer and Funding, Waitemata and Auckland DHBs Asian Support Services of Waitemata DHB 6 Rare Disorders NZ Consumer 7 Alzheimers New Zealand Consumer 8 New Zealand College of Midwives Clinical Public health 9 Individual - Ministry of Health 10 Leeston Medical Centre Clinical 11 Milford Family Medical Centre Clinical 12 Independent general practitioner Clinical Australasian College for Emergency Medicine 13 Clinical 14 Perioperative Nurses College of New Zealand Clinical 15 University of Otago, Christchurch Clinical/academic 16 Capital & Coast DHB intensive care unit pandemic Clinical triage working group 17 Waitemata DHB Clinical

Basic details of submitters are set out below.

5

Consult number	Organisation/individual	Category
18	Te Puni Kōkiri	Māori
19	PHARMAC	Public health/government
20	Royal Australasian College of Physicians	Clinical
21	New Zealand Nurses Organisation	Clinical
22	Hāpai te Hauora Tāpui	Māori Public Health (non- government organisation)
23	Disability Action National Office	Disability
24	Nelson Marlborough District Health Board	Clinical/public health
25	New Zealand Medical Association	Clinical/public health
26	Health Quality & Safety Commission	Quality and safety
27	Australian and New Zealand College of Anaesthetists & Faculty of Pain Medicine	Clinical
28	Human Rights Commission	Consumer
29	Central DHB	DHB community and public health department

Analysis

Introduction

Overall, submissions showed strong support for the general approach and content of the Framework. Most submitters made additional suggestions, including further refinements; some expressed disagreement with certain parts. Overall, the feedback was positive and constructive, and suggestions were helpful.

There was also strong support for the proposed approach to Te Tiriti o Waitangi. The proposed focus on equity, and the need for a New Zealand-centric ethical framework grounded in Te Tiriti, resonated with many people, and the Framework's approach in this context was thought to be helpful, directly and indirectly, to tackling resource allocation issues.

NEAC developed this consultation at the same time that many submitters were dealing firsthand with the subject matter under consideration, namely resource allocation during the COVID-19 pandemic. Accordingly, many lessons drawn from submitters' real-life experience came to light, and will inform the final iteration of the Framework. In particular, NEAC became aware of two significant issues that the Framework will need to address:

- a tension between clinical judgement and the background context of systemic racism that has resulted from colonisation
- issues resulting from the suspension of services that the Government considered non-essential.

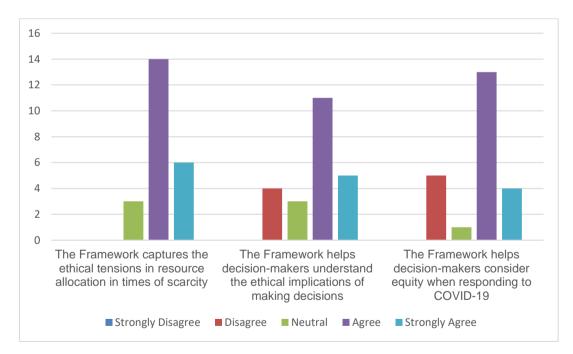
Submitters generally strongly supported the Framework's assumption that pandemics can exacerbate existing inequities, and that different approaches are therefore required to achieve equity. Many people highlighted the interconnection between resource allocation and the wider issue of equity in the context of the COVID-19 pandemic. NEAC acknowledges this, and will address this issue both in the Framework and in its update of *Getting Through Together*.

Themes

We asked submitters to tell us what they thought about three statements on a Likert scale:

- The Framework captures the ethical tensions in resource allocation in times of scarcity
- The Framework helps decision-makers understand the ethical implications of making decisions
- The Framework helps decision-makers consider equity when responding to COVID-19.

Overall, submitters agreed with the statements that the Framework captures the ethical tensions in resource allocation in times of scarcity and helps decision-makers understand the ethical implications of making decisions, but agreed less so with the statement that the Framework helps decision-makers consider equity when responding to COVID-19.



The structure of the remainder of the document contains themes identified by NEAC as emerging consistently throughout the feedback to the Frameworks consultation.

8

Support for the Framework

NEAC heard from submitters that an ethical Framework that specifically addresses equity in a pandemic is very much needed. Overall, most submitters felt that the Framework addressed most, if not all, of the ethical tensions identified, and applauded the explicit naming of the tensions between equity and utility.

Overall submitters agreed that the Framework is helpful and provides guidance on how to apply an equity lens to the allocation of resources. Submitters also agreed with the approach of acknowledging the importance of making decisions that do not exacerbate existing inequities. Most submitters supported the Framework's commitment to achieving equity, and its description of equity issues (with the examples of allocation of personal protective equipment (PPE) in a clinical context). However, many submitters thought the Framework should go further in this regard, and suggested constructive amendments accordingly.

NEAC is proud that many submitters supported the Framework's recognition and emphasis of Te Tiriti o Waitangi, its recognition of the need to honor the Governments' obligations to equal partnership and its acknowledgment of Māori rights and interests. While the Framework is concerned with a specific set of circumstances, submitters commended NEAC's acknowledgement that Te Tiriti principles and related decisions sit within a wider context, and require consideration of determinants of health and drivers of inequity.

Submitters agreed that a foundational Framework for decision making will:

- ensure different and competing foundational ethical principles are considered, and any tensions between them identified,
- provide helpful structure for debating complex questions
- facilitate more transparent arguments and reasoning, including through delineating the role of evidence from the role of values in the arguments presented.

Balancing and weighting of principles

NEAC sought submitters' guidance on how to weigh the ethical principles involved and how the tensions, or even contradictions between them, can be managed. While most submitters agreed that the Framework helps decision-makers understand the ethical implications of decisions and that being aware of these tensions was part of good decision-making, a number noted that beyond noting tensions and suggesting a decision-making group, the Framework does not provide clear guidelines on how exactly to weigh, navigate, resolve or address tensions.

One submitter noted that the Framework does not clearly differentiate between the distribution of scarce resources in the clinical setting and that process in the

9

community setting; for example, if affected people decide to stay at home with their whānau instead of going to the hospital.

Context – existing landscape and dominant values

Some submitters provided feedback about the context of the document. This was understood in two ways: first in relation to the existing resource allocation and prioritisation landscape, both institutionally and taking into account existing tools, methods and frameworks, and second in relation to the dominant value system that the framework sits in.

One submitter suggested that the Framework could catalogue approaches to prioritisation and rationing that are already used in the health system.

Submitters highlighted the need to take into account reports that contain existing obligations and expectations; for example, the Health and Disability System Review, and the Government's subsequent commitment to implement its recommendations, has significantly shifted the health care landscape and presents an opportunity to address the structural issues that submitters also raised in this consultation.

A number of submitters queried or discussed how to recognise equity in an unequal society, particularly in the context of health care. One submitter suggested that the cumulative impacts of health care decisions, and existing structural inequities within the health system, reflect the wider societal context, and that this should also be included in the Framework.

Some suggested that the Framework should explicitly state that it operates within an inequitable system, and acknowledge that some of its values will be more embedded in the current system and therefore easier to implement than others, including that of equity. It was noted that the current system prioritises efficiency, and that the tensions caused by valuing both efficiency and equity should be explored in further detail.

One submitter critiqued statements such as 'all people are equally deserving of care', saying that such statements worked in principle but contradicted by the numerous inequities certain groups experience within the health system. Another submitter suggested that such statements should be clarified so they could not be interpreted as prioritising efficiency over equity.

A few submitters observed that the pandemic had highlighted pre-COVID-19 resource allocation inequities, in terms of housing, hospital beds and other resources that are seen as scarce in non-pandemic situations. One submitter expressed an opinion that some existing inequities had been solved as part of the response to COVID-19 (for instance, housing was found for the homeless so that they could meet the requirements of Alert Level 4). This submitter queried the system of pre-COVID-19 resource allocation and whether resources were as scarce as they were historically perceived to be.

Visibility and acknowledgement of groups

There was a strong call from many submitters to lift the visibility of specific groups impacted by a pandemic, either as part of the workforce responding to the pandemic or as a group that has unique needs from a resource allocation perspective.

Submitters suggested that guidance in the Framework should be expanded with reference to a more granular understanding of New Zealand's population make-up. Some noted their opinion that the Framework should include reference to all instances of inequity in New Zealanders, namely Māori; Pacific peoples; Asian people; Middle Eastern, Latin American and African people; Europeans; migrants, former refugees/asylum seekers; older people and people affected by disability. One submitter suggested that the Framework could explore the way ethics interacts with differing age profiles between ethnic groups, and the impact this has on prioritisation.

Submitters noted the importance of building a theme of non-discrimination into the Framework, and suggested that, alongside the Framework, triage protocols should be developed and followed to ensure that decisions are made on the basis of medical needs and the best scientific evidence available, and not on non-medical criteria such as age or disability.

NEAC heard through a number of submissions that more work should be done to ensure that decisions that stress disability, or alternative descriptions such as frailty, or reliance on support, must not be used as a proxy determinant of clinical prognosis that affects allocation decisions.

Human rights

One submitter suggested that a human rights-based approach concerned with process as well as outcome could work better as the foundation for the Framework, rather than a human-rights as a subset of equity, as currently proposed. This submitter said that, to fulfil such an approach, the Framework could set out more detail on obligations and rights.

It was also suggested that the Framework should acknowledge mention human rights treaties such as the Convention on the Rights of Persons with Disabilities and the recently released Whakamaua: Māori Health Action Plan alongside Te Tiriti and other recognised allocation frameworks.

Scope, structure and purpose

Several submitters noted that the Framework is relevant for pandemics other than COVID-19 and, further, could be relevant for resource allocation outside of the context of pandemics.

Other submitters requested that NEAC should clarify the scope of the document, as a resource specifically for the COVID-19 pandemic, pandemics in general or emergency situations in general, or as a general allocation framework for everyday scarce resources.

It was suggested that the term 'times of scarcity' was too broad, and could be interpreted as applying in times of business as usual in situations in which resource requirements exceed capacity. A few submitters suggested that the title should reflect that the Framework relates to an immediate crisis or emergency situation.

One strong theme was that the Framework should acknowledge the frameworks and structures currently used and prioritised by the health sector; one submitter noted that these should be assessed to justify why they are not sufficient for managing a major surge in COVID-19 disease burden specifically.

A common theme was the need for the Framework's scope to be clarified, including in terms of explaining why a pandemic generates the need for rationing principles that apply beyond the day-to-day rationing that health services already undertake. Some submitters requested extending the approach for addressing resource scarcity to accommodate more 'everyday' challenges. In this context, they wondered why the Framework does not identify how the potential speed and intensity of a rationing crisis related to COVID-19 differs to such a crisis related to other events, such as a natural disaster.

In this regard, submitters recommended that the Framework should note the wider context of the health system, including existing allocation structures. One submitter identified that possible pandemic-specific factors might include intensified time pressure, limitations to wide consultation and, conversely, the need to obtain widespread public agreement with the measures to be taken.

A number of submitters noted that the Framework is both theoretical, providing guiding principles, and detailed, using specific clinical examples to illustrate the implications of the principles. Some found this combination problematic and unlikely to be useful in practice, where others thought the examples effectively illustrated the tensions between the principles and their practical impact.

A number of submitters suggested that the Framework could be more helpful in practice if it included practical flow diagrams or decision trees as appendices, or if additional guidance documents were published alongside it to assist people in practically applying the principles.

The need for more clarity on how to implement or use the guidance was a very strong theme.

Submitters suggested that NEAC should facilitate participation in the Framework by publishing the final iteration in culturally appropriate and accessible formats such as te reo, 'easy read', Braille, audio and New Zealand Sign Language video.

Decision-making group

Overall, there was strong support for the establishment of a decision-making group that would have responsibilities in terms of resource allocation. There were suggestions on how to improve the composition of this group, and feedback on the need for a clear definition of the roles of national and local decision-making bodies respectively. Submitters noted that effective national resource allocation decision-making documents and bodies already exist (for example, PHARMAC), and suggested that the Framework acknowledge these.

One submitter suggested that resource allocation principles be prioritised, to avoid variation in the decision-making process across practitioners, health care settings and DHBs. There was support for local decision-making bodies, such as clinical ethics advisory bodies, although submitters acknowledged that there could be issues with lines of delegation if decision-making were to occur at both the national and local level. Because of this, submitters suggested that the Framework should clarify how the different levels of decision-makers should work together.

A few submitters suggested that it was unreasonable to quickly convene a decisionmaking group in the context of a pandemic, and stressed that the consideration of such a group should not delay the provision of effective medical care where decisions need to be made fast (sometimes within minutes). One submitter suggested an 0800 support number to address this.

There was support for the idea that independent decision-making groups should be responsible for enacting triage plans.

Concerns were raised that regional variation arising from the establishment of local decision-making groups could result in 'postcode health care', whereby a person's location determines the care they receive. It was suggested that this could be mitigated through support from clinical ethics advisory groups at each DHB. A few submitters suggested that such groups should be permanent, and not established only in emergency situations.

Many submitters suggested that the Framework should specify terms of reference and requisite competencies for a decision-making group, including mātauranga Māori, human rights and ethics competencies, or specify training to build such competencies.

There was some resistance to the idea of decision-making groups; submitters were concerned that the value of such groups needed to be assessed against structures and processes already in place. Some submitters were concerned that relying on separate health bodies to develop guidelines could lead to further inequities and inconsistencies, and a loss of public trust.

Some submitters recommended that the scope of a decision-making group should include the provision of guidance on which services within a DHB are deferred, and which may continue, during the peak of a pandemic, across alert levels. Submitters noted that this was a particular issue in the emergency department (ED) context; for example, ED workers potentially had to deal with patients in both COVID-19 and non-COVID-19 streams.

Ethical principles

Though the Framework explores ethical tensions between equity and utility to guide decision-makers' consideration of these issues, submitters noted that it includes no guidelines about reaching a decision, and suggested that this element would be helpful.

One submitter recommended that the Framework should explain the utility principle (that is, the aim to save the most lives) in the same detail as it explains the equity principle (that is, the aim to ensure fair outcomes between groups). Submitters also requested some guidance about whether equity and utilitarian approaches were likely to prioritised in the same way throughout a pandemic, or whether prioritisation of either principle would shift contextually. For instance, submitters noted that prioritisation might shift between public health approaches (for example, in the context of vaccine allocation) and primarily clinical approaches (for example, in the context of intensive care unit (ICU) allocation).

One submitter identified that the Framework should expand on relevant principles, including in terms of risk, uncertainty and intergenerational equity, by including a description of the opportunity cost principle, the intergenerational principle and the precautionary principle.

Submitters expressed the view that the principle of 'minimising harm' is worth adding to the list of foundational ethical principles, as it is conceptually distinct from some of the other principles stated and has particular relevance in the context of vaccines, ICU care and PPE use.

Other submitters were of the view that the Framework could define the principle of "prioritising the people in most need" more clearly and provide an explanation of how it differs from other principles listed, stating that, as it stands, the Framework appears to conflate this principle with other principles, and therefore appears at times redundant. Some submitters suggested that this principle be removed unless it could be clearly differentiated in a way that made it practically useful.

Equity

A number of submissions stressed that discrimination exists at systemic and clinical levels within the health system and affects Māori in particular but also other groups in our society. One submitter felt the Framework does not explain equity with enough nuance – this submission maintained that equity was not about everyone receiving the

same benefits, but about recognising that some people might require more benefits to allow them to become equal to another population group.

Submitters indicated that they would like to see the Framework more clearly acknowledge the context of societal values within which it sits, and to provide more explicit guidance for decision-makers in this context, so that they would be able to use the Framework to navigate those values and actively address inequitable outcomes that are highlighted during pandemics.

Some submitters mentioned that they would like to see a Tiriti-based equity approach prioritised in the Framework, noting that a Tiriti-based focus on equity would challenge the ethical principle of utilitarianism and encourage a more equitable distribution of resources across a number of already disadvantaged groups in society, including Māori and Pacific peoples, the disabled community, older people and immigrant communities, who often present with pre-existing health conditions. A Tiriti-based focus on equity is in line with a World Health Organization-endorsed human rights focus that aims to remediate health inequities among different groups.

One submitter requested that the Framework consider issues of intergenerational equity and inter-patient equity from baseline disease states and co-morbidities, as key components of equity.

One submitter expressed a view that the Framework as it stands relied on clinical judgement for decision-making, and could better acknowledge that clinical judgement decisions are not neutral and are influenced by (often unintentional) perceptions related to a clinician's gender, age, ethnicity, race, class and socioeconomic status, while others expressed the view that the Framework appropriately highlights that a narrow focus on survival alone will only increase inequity, as it means that disadvantaged groups will be less likely to be prioritised for intensive care.

Treaty principles

Overall, submitters reinforced the fundamental importance of Te Tiriti o Waitangi as an enabler for Māori health advancement. Emphasis was placed on the Crown's obligations under Te Tiriti across the health and disability system. Many people supported the proposed Tiriti framework, but some suggested that it could be better integrated within the document.

While submitters agreed that Te Tiriti principles and allocation to resource allocation decisions were appropriate and useful, one submitter asked NEAC to ensure that the Framework:

- clearly explains how it has been constructed in Treaty partnership
- acknowledges, accepts and uses tikanga and te ao Māori values and principles at the beginning, of the Framework to give weight to the same degree and extent other values expressed
- indicate how a focus on health equity could explicitly protect Māori and other communities during pandemics (not just during COVID-19).

15

Some submitters were of the view that a reference to the Waitangi Tribunal's *Hauora* Wai 2575 report findings could strengthen the Framework, as that report provides a description of systemic inequities and their impact on Māori.

Submitters expressed a wish for more explicit guidance on how decision-makers could prioritise active protection for Māori, keeping in mind relevant Te Tiriti obligations, as a way of ensuring that resource allocation decisions do not perpetuate or exacerbate inequities.

Others noted opportunities for the Framework to explicitly link Treaty articles with key principles, to connect key considerations for decision makers. For example, Article 3 – Oritetanga of Te Tiriti could be linked with the Framework's focus equity. Similarly, one response reminded NEAC that Te Tiriti and human rights commitments are complementary, and said that the Framework must acknowledge this, to provide an effective response to COVID-19 and to keep trust and confidence alive within Crown–Māori relationships.

Some submitters were of the view that the Framework would benefit from an expanded consideration of relevant human rights standards, and greater clarity on the legally binding international and domestic human rights obligations that bind decision-makers at any time, including during times of emergency.

Some submitters noted that they would welcome a specific reference to the United Nations Declaration on the Rights of Indigenous Peoples as a way of reinforcing many relevant rights, including the rights to self-determination, to participation in decision-making and to the highest attainable standard of health.

Intensive care units

Overall, submitters were highly engaged on the topic of resource allocation in the context of the ICU; there were many helpful suggestions to improve and clarify this section of the Framework. At the heart of the feedback in this context was the need for clearer guidance about what equity means in the ICU context, and how to achieve it.

Again, in this section, a number of submitters asked for the Framework to include a discussion about the ethics of various triage decision-making tools and approaches. Some submitters felt strongly that the Framework made a strident commitment to equity and Te Tiriti principles, but did not follow through by providing the right guidance to pursue those principles in practice in the clinical setting.

Specifically, NEAC heard that there needs to be clearer guidance about:

- what is meant by equity in the context of ICU triage (that is, whether equity is defined in terms of access, process or outcome)
- whether equity needs to be weighted for in prioritisation. Submitters felt that
 prioritising equity decisions in the context of resources such as PPE and vaccines
 was relatively simpler and ethically justifiable, but that the same reasoning was
 difficult to superimpose upon the ICU context

• the ethics and process of reverse triage.

Submitters proposed nationally mandated and explicit triage plans for ICU bed allocation that are agreed beforehand by a decision-making group to prevent inequity and monitored to ensure they are applied consistently across New Zealand.

Some feedback noted that NEAC's 2007 *Getting Through Together* provided some useful questions that could be reviewed and expanded on and aligned to the Framework.

Personal protective equipment

Overall, submitters were supportive of the Framework's guidance on personal protective equipment (PPE), but thought it could be strengthened by an instruction to decision-makers to prioritise PPE for health and community workers so that they do not inadvertently infect individuals they are caring for.

Submitters were generally in favour of a greater ratio of resource allocation for certain groups, such as those with specific health needs, abilities or ages that made them more vulnerable to illness.

Submitters sought guidance for primary, community and aged residential care sectors to assist them in making decisions about how to use the Framework to prioritise PPE.

Vaccines

NEAC noted that one option for allocation of vaccines that is already widely used in New Zealand is prioritising according to region (for example, in the event of prolonged but localised COVID-19 regional outbreaks) or setting. This approach is consistent with the World Health Organization view on how a COVID-19 vaccine should be allocated: for health care system workers first, then adults over 65 years old, followed by adults with high-risk comorbidities.

A number of submissions noted that certain groups in particular (including women, migrant workers, Māori and Pacific people) tend to work in low-paid, essential service roles (for example, in supermarkets, or as midwives), and that this effectively results in those individuals carrying a higher risk of infection. It was suggested that the Framework should consider prioritising these groups in terms of allocation of certain resources, such as vaccines and PPE.

One submitter noted that it would be useful for the vaccine allocation section to mention the principles and practice used in the context of funding for other vaccines, in terms of coherence and whole-of-government approaches to public policy.

Use of quality-adjusted life years as a tool for resource allocation

Overall there was mixed feedback from submitters regarding the Framework's use of quality-adjusted life years (QALYs) as a tool for resource allocation. A QALY is a generic measure of disease burden, including both the quality and the quantity of a person's life. It takes into account age, weight, cardiovascular risk scores, and so on, and is used in economic evaluation to assess the value of medical interventions. One QALY represents one year in perfect health.

Some submitters supported the Framework's assertion that QALYs should not be used in resource allocation decisions, because this can be detrimental to particular groups, such as those with already high health needs.

Others disagreed, arguing that QALYs can either disadvantage or advantage certain groups, depending on how they are used. These submitters thought that the final iteration of the Framework should not conflate the value-free metric of a QALY with its use in allocating resources and were concerned that the Framework's statement on QALYs could be read as a rejection of the need to consider a patient's ability to benefit from treatment.

NEAC acknowledges that this section needs more work, so that it is clear and helpful in practice, and strikes the right balance while also acknowledging that the use of QALYs in itself produces an ethical tension.

Submitters suggested that NEAC should consider referencing other tools in the Framework that balance health needs and equity with the relative effectiveness and cost-effectiveness of health technologies, among other considerations.

General allocation guidance

Submitters suggested that there was an opportunity to widen the context of the Framework from hospital resources to primary care, community care, non-government organisation and whānau settings.

Submitters noted that, during the level 4 lockdown period within the COVID-19 response, health professionals would have benefited from better channels of information, including guidance on the definition of 'non-essential services' and 'essential surgery'. Some submitters called for the Framework to explore the idea of triage consistency, to mitigate the misinformation and harm associated with inconsistency. Submitters noted that the Framework could give clearer guidance to primary care providers and staff working on the frontline in health.

Submitters suggested that the Framework could include information on approaches to advanced care planning and developing shared goals of care that could be

implemented prior to or during a pandemic, to improve the application of the Framework.

One submitter noted that the concept of a 'tipping point' in a pandemic, or more detail on stage of the pandemic and corresponding changes in weight of principles, might be useful in the Framework. For example, the Framework could help clinicians define the tipping point, and state the underpinning ethical principles that can guide that decision.

Wider issues

Overall, submitters felt that the Framework rightly highlights and emphasises the view that equity should be 'at the forefront of decision-making' but also explains why and how this is very difficult to achieve in practice.

Submitters noted that the focus on preparing New Zealand for an overwhelming demand on health services in the context of a pandemic, as experienced by other countries in the context of COVID-19, meant a reduction in 'non-essential' health services. Some submitters felt that the experience of other countries showed that decisions to make reductions of this nature can be premature and further perpetuate inequities and harm. It was suggested that the Framework needs to acknowledge these issues of risk, uncertainty, precaution and consequent opportunity costs.

Many submitters noted that for some whānau, some health care resources are always scarce; consequently, there are disparities in morbidity and mortality. These submitters suggested that this Framework potentially has wider application across health and disability services in New Zealand, not just in times of scarcity. A continued focus on equity in terms of the composition of the workforce, co-design, consumer involvement at all levels of decision-making, is needed.

Similarly, some submitters suggested that long-term underinvestment in the health sector has made the health system vulnerable to future regional and national emergencies, and that without adequate investment the Framework can only assist in ethical decision-making. It was suggested that a social determinants of health perspective be included in the Framework, and that efforts be made to increase the resilience of health systems and better resource them in business-as-usual times, so that they are adequately prepared for future emergencies.