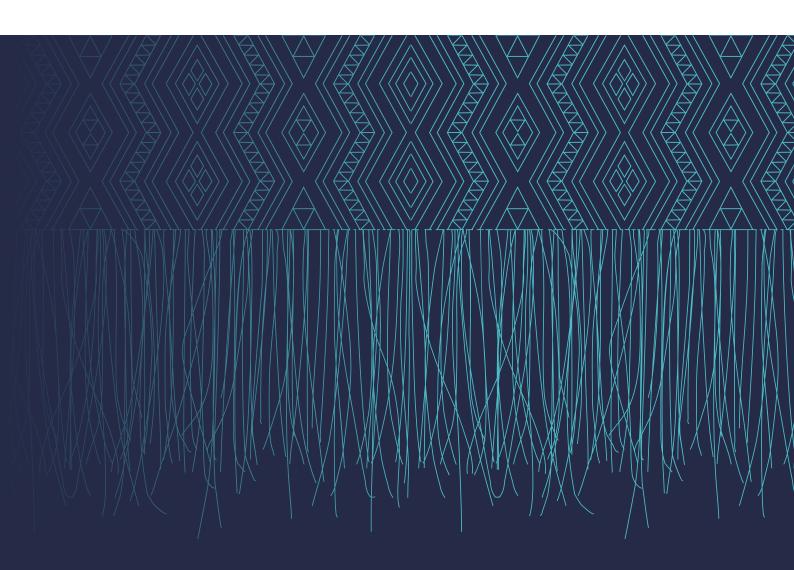


Evaluation of two tools used for waitlist prioritisation for planned care in Health New Zealand – Te Whatu Ora

Appendix 2: Briefing: The ethics of factoring equity into clinical priority-setting

March 2024



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Contents

Introduction	2
Section one	3
Obligation to provide for	
health needs	3
Right to nondiscrimination	4
Positive and negative rights	4
The ethical importance of prioritisati in Aotearoa New Zealand:	on
A context analysis	6
Section two	9
Alternatives to the equity adjustor	9
Justice	9
Principles for prioritising between	
candidates for treatment	10
The need to account for	
underlying injustice	14
Tikanga and kawa	15
Levelling up and levelling down	16
Proportionality	18
Procedural justice	18
Accountability for Reasonableness	18
The need to tackle the	
causes of inequity	19
Conclusion	20
References	22

Introduction

In February 2023 Te Whatu Ora Te Toka Tumai Auckland introduced an updated equity adjustor tool to guide its ordering of patients on waitlists for surgical services. The tool takes multiple factors into account when determining an individual's priority on the waitlist, namely clinical priority, time spent on the waitlist, Māori and Pacific ethnicity, residence in an area of high deprivation, and isolated geographical location. It represents an attempt to counter known inequities in access to healthcare, the social determinants of health and health outcomes in Aotearoa.

Equity is a widely recognised ethical value, but efforts to equitably distribute public goods (such as access to healthcare) can be contentious, especially when we can see the effects of the process upon individuals. When one person or group is prioritised over another, questions are raised about fairness. The inclusion of ethnicity in the equity adjustor tool has attracted particular controversy because some perceive this to suggest that the health of some (prioritised groups) is seen to matter more than others.

This briefing presents a response to the view that it is unfair to take considerations such as ethnicity into account when prioritising patients for services such as surgery. We argue that, in a world in which access to opportunities for health (including healthcare) are unfairly distributed, fairness requires that we allocate resources to mitigate the effects of an unjust distribution. It is because everyone's health matters equally that it would be wrong to ignore the fact that some groups have better prospects for enjoying health than others. Equity adjustment tools are by themselves inadequate to address the underlying injustices they respond to and cannot substitute for the transformational structural measures required to address those injustices. However, they can form part of an overall programme of responses.

Attempts to correct for existing inequities express a commitment to the equal moral status of all. Judgement is required to ensure that inequities are identified and proportionately factored into equity adjustor tools and that they are reviewed at regular intervals for effectiveness and continued relevance. It is important that these judgements are made by a properly constituted, representative group via a procedurally just process. In Aotearoa New Zealand, Te Tiriti o Waitangi requires that Crown agencies work with Māori as equal partners and that Māori are able to exercise tino rangatiratanga, including in respect to matters concerning hauora. Accountability and transparency are key values that should inform how prioritisation decisions are made, applied and communicated to the public.

This briefing is intended to inform the deliberations of the Executive Leadership Team at Health New Zealand – Te Whatu Ora as it evaluates Te Toka Tumai Auckland's equity adjustor tool. It may also be utilised in the writing of any report that arises from this evaluation or published as an appendix or alongside other reports. Here we elucidate ethical considerations relating to equity adjustment for waitlist priority-setting: we do not comment on the specifics of Te Toka Tumai Auckland's tool or its application.

Section one

Obligation to provide for health needs

Any ethical discussion around the equity adjustor must take place within the broader discussion of the obligation to provide for health needs. This is intricately related to the right to health, and the associated right to receive healthcare services. There are a number of international instruments that create a framework within which ethical discussions of the right to health take place.

The Universal Declaration of Human Rights (1948) sets out in Article 25(1) that "Everyone has the right to a standard of living adequate for health and well-being" and specifically includes "medical care" as important to attain this. The International Covenant on Economic, Social and Cultural Rights (1966) provides that State Parties recognise the "right of everyone to the enjoyment of the highest attainable standard of physical and mental health" (Article 12(1)). It then goes on to describe steps to be taken to achieve the full realisation of the right, which include those matters necessary for "the creation of conditions which would assure to all medical service and medical attention in the event of sickness" (Article 12(2)(d)).

Perhaps most well-known is the right enshrined in the constitution of the World Health Organization, which provides for the "enjoyment of the highest determinable standard of health" as one of the fundamental rights of every human being.

Specific rights relate to children, disabled persons, and Indigenous groups. In relation to children, Article 24 of the Convention of the Rights of the Child provides "State Parties recognize the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health." The Convention goes on to additionally impose on State Parties the obligation to ensure that "no child is deprived of his or her right of access" to healthcare services. (Article 24(1)).

Note there is some difference in the wording of these documents, with the World Health Organization and Convention of the Rights of the Child referring to the right to 'health', while the Universal Declaration of Human Rights provides for the related, but not identical right to 'medical care'.

Right to nondiscrimination

International instruments also provide for the rights to be provided in a nondiscriminatory manner. Article Two of the Universal Declaration of Human Rights provides that everyone is entitled to the rights "without distinction of any kind, such as race colour, sex...national or social origin." The International Convention on the Elimination of All Forms of Racial Discrimination (1965) provides that State Parties undertake to prohibit and eliminate racial discrimination and "guarantee the right of everyone, without distinction as to race colour or national or ethnic origin, to equality before the law" including in relation to the right to public health and medical care (Article 5).

The United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP) provides in Article 21 that Indigenous peoples have the right to "the improvement of their economic and social conditions, including ... health...". It is envisaged in UNDRIP that Indigenous peoples have a pivotal role to play in determining and developing priorities and strategies for exercising their rights, including in relation to health (Article 23). A right to access "without any discrimination" all health services is set out in Article 24, which also states:

"Indigenous individuals have an equal right to the enjoyment of the highest attainable standard of physical and mental health. States shall take the necessary steps with a view to achieving progressively the full realization of this right." While these international instruments do not create binding obligations in the Aotearoa New Zealand context (with the exception of the Convention on the Rights of the Child 1989, which has been ratified by the New Zealand government), they do create an umbrella of ethical standards which are relevant to the current discussion.

For our discussion it is important to consider how the equity adjustor interacts with these international instruments and ethical obligations. This analysis must be grounded in the context of deep-seated disparities in New Zealand's healthcare system, and obligations to Māori guaranteed under Te Tiriti o Waitangi.

Positive and negative rights

Any rights-based analysis must take into account the complex nature of rights, which can be categorised as positive or negative. The right to health can be seen as both a negative right (a right not to have interference with one's health for example in the form of medical experiments, unconsented research, forced sterilization, or inhumane or degrading treatment or punishment) and a positive right (a right in which there is a related obligation on the State to provide for and protect that right).

A positive right to health or healthcare would contain entitlements to a health system that provides an opportunity for the prevention of ill health, the treatment and control of diseases, access to medicines, maternal and child health, and timely access to health services including the provision of health-related education and information. (See discussion in Office of the United Nations High Commissioner for Human Rights and the World Health Organization, n.d.). While the right to health does not mean there is a right to be healthy, a right to health does encompass obligations on the State to facilitate health and access to healthcare services in a fair and equitable manner.

Equity adjustors are becoming more frequently utilised as a tool to address inequities in health systems. New Zealand is not alone in experiencing disparity in health outcomes across lines of gender, ethnicity, socio-economic, and regional boundaries (see for example Moir & Barus, 2022). Other jurisdictions are also grappling with innovative approaches to address deep-seated and systemic inequities in their health systems (Shenoy, 2023).

The equity adjustor operates as a specific allocation tool applied to address inequity in the context of distribution of surgical procedures. It can therefore be seen as interacting with the positive right to receive treatment. It could also, however, be considered by some (on a short-term understanding) to deny the right to receive treatment for nonprioritised groups. On that understanding the equity adjustor would be seen as a discriminatory approach that would prima facie breach the ethical obligation not to discriminate in the provision of healthcare services (see discussion below: 'Levelling up and levelling down').

We do not consider this a valid critique when considered in the broader context of Aotearoa New Zealand's health system and systemic disparities, particularly with regard to health outcomes for Māori. In making this assertion we draw on a wellestablished ethical principle known as the "Difference Principle" first espoused by philosopher John Rawls in his seminal work on distributive justice A Theory of Justice (Rawls, 1971). While not without its critics, Rawls' Difference Principle provides one way of thinking about what makes a distribution just. Rawls argues that if we were choosing how to allocate resources in optimal conditions (under the veil of ignorance) we would choose for resources to be allocated equally, but with an extra weighting for those who are worst off. The extra weighting for those who are worst off is intended to make the positions of the worst off in society as good as possible.

Simply put, using this understanding as a basis for resource allocation, we would be required to address the *specific context* within which the equity adjustor operates in New Zealand. If (and only if) there is inequity in the health system, would it be morally justified to use an equity adjustor to address disparities.

The ethical importance of prioritisation in Aotearoa New Zealand: A context analysis

While any health system must provide for individual needs in a just way, scarcity of resources means that some form of prioritisation is necessary. Prioritisation is important because it determines how long a person must wait to receive treatment, and sometimes it can also determine whether a person receives a given treatment at all. New Zealand's health system currently allocates scarce resources by a number of means, one of which is a 'point system' (Clinical Priority Assessment Criteria – CPAC) that rations surgical services based on clinical criteria. (For a review of the introduction into New Zealand of the booking system see Derrett, 2005.) The CPAC system at its heart, has a utilitarian ethos, namely one which aims to provide for the greatest outcome for the greatest number of people.

Utilitarian justifications for actions can ignore individual rights or values such as justice. CPAC also fails to account for systemic discrimination within the health system or the impact of comorbidities which may exist due to systemic racism.

New Zealand's booking system has operated for decades to govern access to elective services in New Zealand. Elective services refer broadly to those of a nonurgent nature (i.e. not acute), but cover services that are 'time critical', without which a person may die (such as cancer surgery and cardiac operations). It is important to acknowledge, therefore, that in the allocation of elective surgery we may be making choices about who will live and who will die. In the context of New Zealand's health system, which is at a stress point (in terms of meeting the needs of the population), who gets surgery is not just a matter of delay by a few weeks, it may be a matter of who receives treatment at all. Surgeons have voiced concerns with the current system, and it is against this reality that the equity adjustor must be measured (see Gordon, 2022).

The CPAC allocation tool has been challenged for creating a focus on maximising benefit from healthcare services at the expense of seeking equity. It is well recognised that there are significant health disparities existing in New Zealand of a systemic nature – most notably those affecting Māori, rural populations, and Pacific people. In the context of allocation of scarce resources following COVID-19, the National Ethics Advisory Committee identified 4 overarching principles in its 2021 report 'Ethics and Equity Resource Allocation and COVID-19':

- All people are equally deserving of care
- Getting the most from the resources
- Minimising harm and health protection
- Achieving equity

In 2020 a review of the health and disability system was undertaken to understand the drivers of inequities within the system that have been perpetuated over many years. The *Health and Disability System Review* (known as the Simpson Report) identified serious inequities at the heart of Aotearoa New Zealand's health system, and made a series of recommendations to address them, noting that:

"Improving the equity of the health outcomes achieved in New Zealand requires first that we acknowledge that current inequities are not acceptable, that we understand better what is contributing to that inequity and the health and disability system becomes more determined to operate differently so that inequities are addressed." (Health and Disability System Review: 4)).

The Waitangi Tribunal in its 2019 report Hauora (WAI2575), drew attention to the systemic inequities in our healthcare system that lead to disparities for Māori. This led them to recommend an additional set of principles applicable to the New Zealand healthcare context (discussed below). The Tribunal in WAI2575 makes several observations about the findings of previous reports that provide context for a measure such as equity adjustment, stating that: The Tribunal in the Napier Hospital and Health Services Report stated that, while the principle of active protection does not automatically 'privilege Maori as a group', the existence of significant health disparities requires the Crown to implement positive steps to provide for the pursuit of Māori health equity. The Crown's obligation of active protection is heightened where 'adverse disparities in health status between Maori and non-Maori are persistent and marked'. Thus, in such circumstances, active protection may compel the Crown to target more resources according to need 'in order to reduce structural or historical disadvantage".

In its inquiry into Tauranga Moana post-raupatu claims, the Tribunal also considered the Crown's Treaty obligation of active protection with regard to Māori health, and it concluded that the persistent Māori health disparities evident in that inquiry should have compelled the Crown to 'do all it could' to achieve Māori health equity. The Tribunal also observed that, given the Crown's knowledge of the persistence of Māori health disparities since the mid-twentieth century, it would be reasonable in Treaty terms to expect the Crown to implement positive steps to reduce these disparities." (Waitangi Tribunal 2019: 32-33).

There is a plethora of evidence that Māori and Pacific people experience a disparity in standard of health and access to healthcare in New Zealand. There is also evidence that access to health is affected by urban/rural location and socioeconomic status (See Health and Disability System Review, 2020).

We therefore adopt for this report the fundamental premise that at multiple levels in the systemic provision of healthcare in Aotearoa, there are factors operating to create a system in which discrimination occurs which affects – for some groups at least – the right to the 'highest attainable standard of physical and mental health' and/or access to medical care.

In an effort to address ethical implications of disparity and achieve equity in our health system, the National Ethics Advisory Committee has utilised the additional principles from the Waitangi Tribunal's *Hauora* report and incorporated them into New Zealand's ethical ecosystem. These additional principles are based on Te Tiriti o Waitangi:

- The guarantee of tino rangatiratanga: relating to positioning Māori as key decision makers in the design, delivery, prioritisation, and monitoring of health services
- The principle of options: requiring the state to provide for and properly resource kaupapa Māori health services

- The principle of active protection: requiring the state to act "to the fullest extent practicable" to achieve equitable outcomes for Māori
- The principle of partnership: requiring Crown and Māori to work together as co-designers of health services
- The principle of equity: requiring the Crown to be committed to achieving equitable health outcomes for Māori

The principles outlined above can therefore be seen to apply to any discussion of right to health or access to healthcare in the New Zealand context, creating a unique framework for New Zealand that leads the way in terms of Indigenous rights to healthcare.

It should be acknowledged that domestic legislation also exists in relation to healthcare services, which should be taken into account in tandem with this advice. Rights to health and healthcare are grounded in national legislation and codes and decisions.

Section two

Alternatives to the equity adjustor

The right to healthcare and health is a fundamental right that is enshrined in ethical principles and international instruments which must carry weight in the determination of the equity adjustor. We have established that there is a right not to be discriminated against in the recognition of these rights. Aotearoa New Zealand's healthcare system fails to deliver health for all, suggesting that at some level the system contains entrenched discriminatory practices.

New Zealand has developed ethical principles based on obligations in Te Tiriti o Waitangi that apply in the context of right to health and the provision of healthcare:

- Tino rangatiratanga
- Options
- Active protection
- Partnership
- Equity
- (Waitangi Tribunal, 2019: 163-4)

The ethical question we ask in Section Two of this report is as follows: How does the equity adjustor measure up against alternative methods to allocate resources?

Justice

Considerations of justice or fairness (we will use these terms interchangeably) are invoked whenever we distribute goods or services between individuals (distributive justice).

Although ideas about justice permeate many of our judgements about situations, it can be difficult to explain what we take justice to require. One challenge is that there are competing principles of justice, and no universally accepted way of adjudicating between them. But one idea about justice is widely accepted, and it provides a starting point for thinking about the ethics of equity adjustment. It comes to us from Aristotle.

Aristotle's formal principle of justice states that equals should be treated equally and unequals unequally, in proportion to their relevant inequalities (Aristotle, *Pol* 3, 1280a). Treating people fairly is partly a matter of consistency across cases. To give effect to justice, we need to know what makes people equal for the purpose of setting priorities on a health service waitlist. We must look not for any old similarities and differences, but for similarities and differences that are relevant for the purposes of healthcare priority-setting (Bærøe, 2009). Here we consider three widely

promulgated principles for priority-setting between patients: clinical need, costbenefit measures and order of presentation (see, for instance National Ethics Advisory Committee, 2021; Norwegian Ministry of Health and Care Services, 2017; Curtis et al., 2010; National Advisory Committee on Core Health and Disability Support Services, 1993; Daugherty-Biddison et al., 2019). Whilst these are relevant considerations and can appropriately inform priority-setting, they require nuanced application and supplementation. In order to treat equals equally, we must also take account of underlying structural inequities that result in reduced access to healthcare and poorer health outcomes for some groups.

Principles for prioritising between candidates for treatment

Clinical need

Perhaps the most apparent dimension of difference between candidates for treatment is the extent of their clinical need. The relevance of this consideration to healthcare priority setting is clear: we only have to prioritise access to treatment because clinical need exists. So the first cut is, in principle, easy: clinical need is a relevant difference that justifies putting some (those with clinical need likely to be served by treatment), and not others (those without need) on a waitlist. Prioritising greater over lesser clinical needs is sometimes expressed in terms of vertical equity (Macinko and Starfield, 2002).

The introduction of waitlists reflects the fact that available services cannot meet the clinical needs of all people who present to health services. If some patients will have to wait to receive services, further decisions are required to determine whose needs should be met first. Urgency of needs supplies a defensible basis for prioritisation. If two patients are referred to a service on the same day, one of whom is more likely than the other to experience an adverse outcome if their need is not met with urgency, placing that person higher on the waiting list is not unfair to the less seriously ill person. By attending to more urgent needs first, we increase the likelihood of being able to meet the needs of all, thereby treating equals equally. Severity of need is also a relevant consideration: if one person will suffer more than the other or experience greater risk of loss of function or onset of further symptoms if their condition is not treated promptly, it would be fair to prioritise them.

Urgency and severity of clinical need are important considerations when priority setting, but their assessment is not always straightforward. Criteria may be ill defined (Curtis et al., 2010) and there is evidence that prioritisation systems based entirely upon clinical need accord a high level of discretion to clinicians to advance the claims of some patients over others with what might be regarded as similar or greater clinical needs (Holm, 2000).

Application of discretion can distort the fairness of priority setting, as doctors weigh the interests of their patients, or patients they see as particularly deserving, or who campaign most effectively, against those of others on the list (Bærøe, 2009; Bruce & Tallman, 2021; Hadorn & Holmes, 1997).

There is evidence of practices that might undermine the fairness of prioritisation for elective surgery taking place in Aotearoa New Zealand. McLeod and colleagues (2004a) reported strategies employed by general practitioners to elevate the priority assigned to patients they referred for surgery, along with decisions not to refer patients with clinical need due to perceived length of waiting times. Some surgeons reported only assigning the highest or lowest CPAC scores, whilst others followed guidance 'by the book'. At times, secretaries or booking clerks assigned CPAC scores that should have been determined by doctors (McLeod et al., 2004a). McLeod and colleagues (2004b) asked general practitioners and surgeons about their perception of equity in access to elective surgery: whilst some participants recognised that Māori and Pasifika patients faced more barriers to receiving surgery, including racism within the health service, others denied that ethnicity was ever a factor in prioritisation. In contrast, Seddon et al. (2006) found that the clinical priority assigned to Māori and Pacific men with severe coronary artery disease did not always reflect their high CPAC scores, suggesting that ethnicity may impact upon priority-setting based on clinical needs.

In summary, whilst clinical need is a proper ground for priority-setting, assessments of clinical need can vary between practitioners and are susceptible to gaming and expressions of bias. Systems for priority-setting may not always accomplish the intended end of ensuring that the most urgent and severe needs are met.

Cost-benefit measures

When resources are insufficient to meet all needs, attention often turns to how to extract the most value from the resources available (Emanuel et al., 2020, National Ethics Advisory Committee, 2021). If two patients with comparable clinical need have been referred for the same treatment and one is more likely to make a good recovery and be ready for discharge quickly (call them the "low risk" patient), whilst the other (the "high risk" patient) has a higher probability of experiencing complications, treatment failure or death, or may require more intensive management or a longer stay, some would advocate for treating the "low risk" patient first. This preference is typically underpinned by utilitarian logic: try to produce the greatest good for the greatest number.

There are several dimensions of this approach to consider. Take benefit first: a positive health outcome may be more likely to eventuate from the treatment of the "low risk" patient than from the treatment of the "high risk" patient. The benefit conferred through treatment may also be greater for the "low risk" patient, if we judge the size of benefit in terms of how good the health state achieved through treatment is (note that it is far from clear that we should assess health benefits in this way). Utilitarian logic emphasises the importance of ensuring that value is gained from the use of scarce resources. The idea that a loss to one person can be offset by a gain to someone else reflects the notion, central to utilitarianism, that it is the overall quantum of good created by an act or policy that matters, not its distribution.

The second dimension is that of resource intensiveness. Some patients may respond readily and require less treatment and support to attain a given clinical benefit, thus freeing up resources to devote to other patients. Providing the same clinical benefit to other patients may require more resources (a longer hospital stay, more intensive care, lengthier rehabilitation, etc), thus reducing the total number of people who can be treated with a given amount of health resource.

On this approach, equals are defined as those who are equally likely to gain a certain clinical benefit from treatment from a certain resource expenditure. Cases are unequal, and should accordingly receive different priority when they vary according to probability of clinical benefit and anticipated resource intensiveness of treatment.

Prioritising between patients on the basis of likely benefits and anticipated costs is sometimes seen as morally neutral or objective, because of its focus on treatment outcomes rather than characteristics of the individual. But this appearance of neutrality can be deceptive. Predicted treatment outcomes vary according to a host of socially determined facts about an individual's (perceived) characteristics and the ways society distributes opportunities, privileges, and disadvantages on the basis of those characteristics. Unjust social disparities and the ongoing effects of colonisation culminate in greater health burdens for disadvantaged groups. Members of those groups are more likely to be evaluated as high risk and resource intensive.

Schmidt, Roberts and Eneanya (2022) illustrate how, despite an appearance of neutrality, prioritisation frameworks built around clinical markers can replicate and compound broader patterns of social advantage and disadvantage. During the COVID-19 pandemic, when health systems in many jurisdictions were preparing to ration ventilators, use of the SOFA (Sequential Organ Failure Assessment) tool, amongst other measures, was advocated as a basis for predicting likelihood of survival. In the event of scarcity, candidates for ventilation with lower SOFA scores, indicating higher predicted survival, were to be preferred over those with higher SOFA scores. SOFA scores model for kidney function by incorporating a measure of the waste product creatinine in blood. Higher creatinine levels, which indicate loss of kidney function, are more common amongst Black Americans, a phenomenon that has been attributed to social inequities arising from persistent structural racism (Eneanya et al., 2022). If SOFA scores are utilised to determine access to ventilators in the event of scarcity, Black Americans will be less likely to receive the care they need. Whilst SOFA scores might seem to encapsulate objective clinical markers, they do not escape from, but rather enter into, the murky world of social advantage and disadvantage.

In their guidance on resource allocation in the context of the COVID-19 pandemic, the National Ethics Advisory Committee (NEAC) observes that the principle of getting the best out of resources, which is included in their framework, can be in tension with the principle of equity:

Giving priority to individuals who have the most chance of benefiting from treatment in ICU may achieve the aim of saving the maximum number of lives. But greater ability to benefit is often associated with wider determinants of health, such as higher socioeconomic status. Socioeconomic status in turn may be systematically distributed to some groups and away from others. As a result, a socioeconomically advantaged group may be more likely to be represented among those individuals selected for ICU. Where reduced ability to benefit by reason of socioeconomic disadvantage is linked to injustice, this results in a tension with the value of equity (NEAC, 2021: 37).

NEAC draws attention to the unjust social distribution of comorbidity and multi-morbidity, which would tend to heighten the complexity and risk associated with surgical care. A priority system based entirely on maximising benefit from available resources would disadvantage those with comorbidity and multi-morbidity. In Aotearoa New Zealand, rates of multimorbidity are close to twice as high amongst people who identify as of Māori and Pacific ethnicities as amongst non-Māori and non-Pacific ethnicities (Stanley et al., 2018). There is evidence across a range of health conditions of associations between experiences of racism and poorer health outcomes and reduced access to healthcare (Talamaivao et al., 2020).

First come, first served

So far, we have looked at two prioritisation principles that capture important ethical ideas (meet needs, confer benefits) but cannot reliably produce equitable outcomes. Another attractive approach is simply to meet needs in the order in which they present. This strategy creates a clear order of priority and has an air of moral neutrality, as it requires no evaluation of patient's claims beyond the chronological. It suggests that we treat people fairly by treating them in turn. Unfortunately, this approach is also prone to baking in the social inequities which permit some but not others to seek healthcare earlier in the development of a condition, and which hasten diagnostic and referral processes for some but not others. The order of presentation reflects existing unjust distributions of advantages and disadvantages, so relying entirely on this order to formulate waiting lists risks perpetuating those injustices.

Data from the 2021/2022 Health Survey indicates that adults with a disability and those living in the most deprived neighbourhoods are more likely to have experienced a health need in the past year for which they did not seek GP care due to cost (Ministry of Health). People of Māori ethnicity and people with a disability were more likely to have unmet need due to their fear or dislike of their GP. Māori, people with a disability, and people living in the most deprived neighbourhoods were more likely not to have sought primary care due to unpaid accounts with their primary care provider. Māori and Pacific people, those with a disability, and men were more likely to have foregone primary care because of a lack of transport. People of Pacific and Asian ethnicities and those in the most deprived neighbourhoods were less likely to have been referred to specialists than the general population. Adults with a disability were significantly more likely to have been unable to access specialist care in the previous five years due to the hospital declining their referral.

People of Pacific ethnicities and those from the most deprived neighbourhoods were significantly more likely to have been unable to attend a specialist appointment because of work commitments. These findings point to the kind of disparities that mean that some groups join the queue for treatment further into the development of a clinical condition than others.

This is not to say that order of presentation should count for nothing. One element of what makes equals equal is how long they have spent waiting to have health needs met. Prolonged delays to receive care can have significant psychological, health and quality of life impacts, and communicate that one's needs are accorded little significance by the health system. Given that these burdens are imposed by the system's constraints, it is right that the system takes responsibility for them by according some priority to meeting the needs of those who have waited longest. But order of presentation may be an inadequate proxy for time spent with unmet health needs, as some people have unmet needs long before they ever present for healthcare or are placed on a list.

The need to account for underlying injustice

Each of the principles reviewed so far captures something important about healthcare priority-setting but they do not correct for the injustices that drive patterns of social disadvantage, ill health, dislocation from health services and insufficiently responsive healthcare for some groups. Unless a prioritisation method accounts for underlying inequities, it will not be able to treat equals equally and unequals unequally; that is, it will not be able to prioritise fairly.

It can seem counterintuitive to prioritise the health needs of some patients based upon factors like ethnicity, gender, socioeconomic status, and so forth. We often think that justice requires that we do not differentiate between people based upon such characteristics. This thought is motivated by a fundamental commitment to human equality: as we all have equal moral status regardless of our ethnicity, or where we live, and so forth, we should not treat people differently based upon such characteristics. But equity adjustments do treat people differently based upon such characteristics, so it is easy to see why some consider them to be inherently unjust. It seems that equity adjustments that factor in characteristics such as ethnicity depart from principles of justice that we should all accept and be guided by.

The justification for factoring characteristics such as ethnicity into priority-setting lies in the context. The fact is that characteristics such as ethnicity, rurality, status and living with a disability do mediate opportunities for health in Aotearoa New Zealand. This is not fair, but it is true. If we do not recognise and try to correct for existing inequities, they will remain. When we prioritise for treatments, we are prioritising to ensure that, insofar as is possible, people have equal opportunities for good health. Ensuring equal opportunities requires us to account for the broader context in which opportunities are offered to some and withheld from others. The motivating claim is not that some groups deserve or matter more or have greater moral status, but rather that we all matter the same, which means that biases and system failures that affect us differently need, as a matter of justice, to be corrected. Equity adjustor tools are applied too far into a patient's health journey to fully correct for injustices that have led them to the point of referral for treatment. Measures to address the unjust distribution of the social determinants of health are sorely needed. But equity adjustment can mitigate for as yet uncorrected inequities, thereby creating a more equal distribution of opportunities for health than would pertain without adjustment.

Tikanga and kawa

Mātauranga Māori is rich in ethical reasoning that should be brought to bear in health policy and practice in Aotearoa New Zealand. As tauiwi, we are not the proper people to make definitive statements about how tikanga might apply to equity adjustment. It is, however, important to acknowledge the need to reflect upon what tikanga and kawa require when prioritysetting and to ensure that processes accord with these requirements, whilst recognising that tikanga and kawa arise from a value and knowledge system (mātauranga Māori) built on foundational assumptions and values that differ in important respects from those that underwrite our national health system and its processes.

There are a number of tikanga-based (Ngā Tikanga Paihere; Te Mata Ira; Te Ara Tika) and blended tikanga and western ethical frameworks (NEAC's *National Ethical Standards for Health and Disability Research*) to support decisionmaking in different domains. These offer possible starting points for thinking about how tikanga might apply in healthcare priority-setting. Here we explore the framework created for public health practice: the Public Health Association of New Zealand's *Te Ture Whakaruruhau*.

Te Ture Whakaruruhau situates aroha and charity at the heart of its model, pervading the other principles: whanaungatanga, kotahitanga, manaakitanga, rangatiratanga, solidarity/ social capital, beneficence/competence, justice/equity and honesty. Te Tiriti o Waitangi provides the grounding for the relationships in which public health is enacted according to these tikanga/ principles. All tikanga/principles have equal weight. The framework suggests applying either the tikanga or the western principles to work though an ethical challenge. If practitioners draw upon certain tikanga/principles more fully than others, the framework calls upon them to be clear about their reasons for doing so.

The tikanga encapsulated in *Te Ture Whakaruruhau* offer a way of understanding our obligations to those who are most vulnerable, and those whose mana is least likely to be upheld within the health system. As an illustration, whanaungatanga speaks of:

'the rights and reciprocal obligations consistent with being part of a collective. It is the principle which binds individuals to the wider group and affirms the value of the collective. Whanaungatanga is inter-dependence with each other and recognition that the people are our wealth' (Public Health Association 2012:5).

Tikanga are not principles that can be pulled out to support a pre-determined policy. Giving proper expression to tikanga requires entering and maintaining relationships in the right spirit from the outset. Although a commitment to protect the most disadvantaged seems to us to harmonise with tikanga, the question of its application to equity adjustment requires careful and expert consideration. The guidance of Kaumātua, Kuia, Māori philosophers and Māori health specialists is required to ensure that any equity adjustment tools that are developed and applied accord with tikanga.

Levelling up and levelling down

Recent media coverage of Te Toka Tumai's equity adjustment tool drew attention to its differential effects. Whilst equity adjustment might reduce the waiting times for some, others may end up waiting longer than they otherwise would have (although it may be difficult to estimate the actual effect upon other candidates). Some people may endorse the goals of equity and reduced waiting times for groups that experience barriers to treatment, but object to the corresponding impacts such measures have on others. The worry can be expressed in terms supplied by philosopher Derek Parfit: levelling up and levelling down (Parfit, 1995).

In broad terms, there are two ways to work towards greater equality between groups (or individuals). The first involves improving the position of the worse off, bringing them up to the level of the better off (levelling up). The second reduces the position of the better off so that it is equivalent to that of the worse off. Clearly it is better to do the former wherever possible because this increases equality and welfare.

Equity adjustors will only succeed in their own terms if they result in a different ordering of patients than would otherwise have been the case. If the volume of treatment available in a given time frame could be increased, it might be possible to level up through equity adjustment without imposing significantly longer waits on other candidates. In this way, levelling up could occur without levelling down. If it is not feasible to increase treatment volume, levelling up will result in some people waiting longer than they otherwise would. Levelling up can only occur through levelling down if treatment volumes and throughput remain fixed, although features of the priority-system can restrict the level of disadvantage that this imposes (for instance by placing significant priority on meeting urgent and severe needs, and adjusting for time spent on the waitlist). Despite these protective measures, the involvement of levelling down in equity adjustment is likely to continue to attract controversy.

It is common to experience a reduction in priority relative to a prior state as unfair, because it involves a loss of goods that one was accustomed to regarding as 'one's due'. In fact, the position that one ought to have on a clinical waitlist is not fixed and is determined by many factors, including facts about the health needs of others. Although it can be deeply frustrating, it seems to be widely accepted that a person's scheduled surgery can be delayed if an emergency case arises that is likely to result in the death, suffering or long-standing loss of function of another patient. There is an element of contingency involved in scheduling and providing surgery, so caution is called for when drawing attention to disadvantage wrought by equity adjustments.

Although it may be difficult to identify which candidates are levelled down and by how far, equity adjustment accepts that levelling down will occur. When people are suffering and in need of treatment, it is understandable that equity measures that are perceived as extending unmet need for some are resented. But if equity tools adjust proportionately to operative inequities in opportunities for health, they are not unfair. The level of provision that those who are levelled down might have expected was the result of an unjust distribution. It is not unfair to correct for unjust distributions, even though it is unfortunate and often distressing to feel the loss of an expected benefit.

Notwithstanding the defensibility of equity adjustment, it is important to acknowledge how contentious and resentable health resource allocation is. Contentiousness does not arise exclusively from equity adjustment: those who are currently disadvantaged have reasons now to resent the system that knowingly and systematically fails to take reasonable measures to meet their health needs and provide opportunities for health. Maintaining public trust in the healthcare system requires careful, principles-based priority-setting, fairly applied across the board. There is no way to avoid controversy, but carefully attending to how and what decisions are made and by whom, how the health system monitors and responds to changes in the health needs of groups and individuals, and transparency about all these measures, offers the best chance of allocating resources fairly and in ways that are (largely) seen as fair.

Proportionality

Proportionality is a key aspect of justice. Vertical equity (treating unequals unequally) requires that the extent of prioritisation of one candidate over another is proportionate to the morally relevant differences between their claims. Equity adjustors need to be sensitive to the increment of health loss that prioritised groups experience as a result of social and health inequities: weightings should be tied to that loss. Current evidence about disparities in access and health outcomes is necessary in order to assess whether a weighting is proportionate. Adjustors should therefore be regularly reviewed against information about access and outcomes for the relevant health service. An evidence-based approach is more likely than a 'guesstimate' to deliver an equitable outcome and to withstand public scrutiny, thereby preserving grounds for public trust.

Procedural justice

Equity adjustors raise questions not only about who gets what resources (distributive justice) but also about who decides who gets them, why they decide that way, who gets to know about it, and what can be done if the decision seems wrong. These latter questions address issues of procedural justice. Because resource allocation is so deeply debateable and has such profound effects on individuals and groups, it is essential that decision-making processes are fair. In Aotearoa New Zealand, fair decisionmaking about public goods necessarily involves the Crown and Māori acting together as Te Tiriti partners. The principles of te Tiriti bind the Crown to secure mana taurite (equitable health outcomes) for Māori and to ensure that Māori can exercise rangatiratanga through making decisions in partnership (pātuitanga) about how health resources are prioritised. It is the responsibility of the Crown to ensure whakamarumarutia (active protection) for tangata whenua. Health NZ must therefore engage with Māori leaders, (one route would be via Te Aka Whai Ora), to jointly establish the methods by which inequities will be identified, the principles for according weightings, and to collectively monitor how the system is working, and make necessary adjustments.

Accountability for Reasonableness

Accountability for Reasonableness' (A4R), Norman Daniels and James Sabin's (Daniels, 2008; Daniels and Sabin, 1997) model of procedurally just decisionmaking, is widely regarded as a good starting point for designing publicly legitimate resource allocation processes.

Decisions can be seen as legitimate, even if people do not agree with them, if they are the result of a fair process. Accountability to stakeholders is key to legitimacy. Decision-makers should answer to the public for how they make decisions, and for the decisions they make. This happens through the four elements of A4R.

- 1. **Publicity**: Decisions and their rationales must be made public.
- 2. **Relevance**: Decisions should be informed by considerations and principles that are seen as relevant by people who seek to cooperate in reasoning through issues together.
- 3. **Appeals and Revision**: Decisions must be subject to appeal, and principles and frameworks underpinning them subject to revision when warranted.
- 4. **Regulative**: Decision-makers should be subject to a regulative mechanism through which their performance in the previous three elements is assessed.

Whilst A4R is an important and influential model of procedural fairness, it has gaps. Annette Rid (2009) argues that A4R should be supplemented by a requirement for decisions to be consistent across cases, and for the decision-making body to be representative of the community to which decisions apply. In a similar vein, Clark & Weale (2012) underline the importance of affected parties participating in decisionmaking processes, to ensure that decisions are properly informed and to secure trust, publicity, and power-sharing. Within a given context, it is also necessary to consider how relevant considerations can be identified and irrelevant considerations excluded (Lauridsen & Lippert-Rasmussen, 2009).

Decision-making processes that enshrine accountability and representative participation help to distribute power between decision-makers and the public, who are able to assess the process and decisions from a more informed standpoint. They can also increase the comprehensibility and predictability of decisions for clinicians, patients and the public, which can allow needs to be more effectively and equitably met.

For equity adjustment to be seen as legitimate and accepted as part of just health resource allocation, it should be governed via a procedurally just process with the characteristics put forward by Daniels and Sabin, adapted to take into account the commentaries of Rid and others, and underpinned by Te Tiriti.

The need to tackle the causes of inequity

Equity adjustors attempt to compensate for injustice in the health system and society more broadly, but they cannot altogether correct for those injustices. The most just system would be one in which everyone was equally well placed to enjoy good health and have their health needs met. Continual efforts and investment to address the social determinants of health and shortcomings of the health system are needed.

Conclusion

In this report we have considered the ethics of using an equity adjustor in the context of Aotearoa New Zealand's healthcare system. We have placed our ethical analysis within the context of Aotearoa New Zealand's health system with its established disparities in health outcomes. Our analysis draws on international and domestic ethical principles in relation to access to healthcare services, and we have also acknowledged that health outcomes are determined by a wide range of factors that must be addressed in any attempts to ensure equitable health outcomes for all.

Our conclusion is that an equity adjustor is not only *ethically acceptable*, but it is also *ethically required* in the context of Aotearoa New Zealand 's current health statistics, which shows marked inequality in healthcare outcomes for some populations. Factoring characteristics such as ethnicity, sociodemographic status and so forth into priority-setting can be justified when:

- it is done in response to existing inequities,
- the extent of inequities and their effects upon health outcomes for the relevant populations is known,
- the weighting is proportionate to the actual level of disadvantage associated with a characteristic,
- there is a reasonable likelihood that it will have a positive impact upon existing inequities,

- decisions about which inequities to adjust for and what weightings to apply are made by a properly constituted, representative body which allows for tangata whenua to exercise rangatiratanga,
- the grounds for decisions are relevant and made public, as are processes for appeal
- equity adjustment settings are regularly reviewed and reported on, and
- equity adjustment is part of a sustained approach to eliminate social inequities.

We note that the equity adjustor operates solely within the context of access to elective surgical procedures. This 'ambulance at the bottom of the cliff' method of addressing health inequities can be critiqued for failing to address the wider systemic causes of the inequities – one of which is inherent racism within the health system that fails to observe and give effect to the obligations to Māori as partners under Te Tiriti o Waitangi.

We are unable to comment on the equity adjustor itself given the lack of specific information provided to us. While an equity adjustor is justifiable in the context of New Zealand's healthcare system, we have no visibility into whether this equity adjustor is justifiable. Reducing health inequities must be a core goal of any government moving forward, and it would be unethical not to consider how an equity adjustor might be used to facilitate equitable provision of healthcare services specifically in relation to the allocation of elective surgery.

Given the ethical sensitivities of resource allocation, we would be concerned if equity adjustment was to occur via an opaque process with little accountability or engagement with the scope of ethical concerns that resource allocation raises. Procedural justice requires that decisions about the disbursement of limited public resources to meet individual needs are made in a transparent and accountable way, via formal processes. It is not known to us the extent to which the current equity adjustor may be utilising artificial intelligence or a self-learning system in a manner that lacks both procedural fairness and engagement with the main targeted groups. Good data is critical to the ethical functioning of any artificial intelligence system, and we have not been given any information as to the quality or quantity of data used to generate the equity adjustor.

The lack of evidence of an ethical analysis being undertaken in relation to the current equity adjustor prior to implementation is concerning, and we encourage a broad ethical analysis to be undertaken based on established ethical principles for resource allocation. We have identified basic ethical principles in this report, drawing on both Western biomedical/political philosophical principles and those from a Te Ao Māori perspective. We recommend a wider discussion be undertaken with key stakeholders around how these can be applied in the context of elective surgery. It may be helpful moving forward to consider how this equity adjustor relates to the Health Equity Assessment Tool "HEAT" (Signal et al., 2008), developed to guide those designing the health system to understand the cause of health inequalities and to promote equity in health in Aotearoa New Zealand through a series of questions and interventions. The "HEAT" tool encourages us to ask questions, such as who will benefit the most, what might the unintended consequences be, and what limitations have been identified in the intervention (and how will these be mitigated) to arrive at a response to inequities. This would encourage a more targeted and transparent process with builtin terms of engagement and measures established to enable any intervention to be evaluated within a set timeline and unintended consequences monitored.

We conclude that while introducing an equity adjustor into the elective surgery booking system is ethically justified in the context of Aotearoa New Zealand's current health statistics, we are unable to determine (on the evidence provided) if this equity adjustor is ethically sound.

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