

4 February 2021

The Honourable Shannon Fentiman MP
Attorney-General, Minister for Justice, Minister for Women and Minister for the Prevention of
Domestic and Family Violence
GPO Box 149
BRISBANE QLD 4001

Via email: attorney@ministerial.qld.gov.au

Dear Attorney-General,

I write to respectfully request that you consider making a reference to the Queensland Law Reform Commission to examine the law that applies to clinical decisions about the allocation of finite health resources during a period of high demand, such as a pandemic. I outline my reasons for seeking this reference below.

The COVID-19 pandemic required the Queensland government to make many difficult decisions to protect the health and safety of Queenslanders.

Queensland Health was very active in its efforts to consult with a range of stakeholders to inform its responses to the pandemic. From the early days of the crisis I have been an active participant in two Queensland Health-led working groups, the COVID-19 Working Group – Residential Aged Care and the COVID-19 Working Group – Disability supports in the Queensland community.

One particular policy that I was consulted on as a member of these working groups was the *Queensland ethical framework to guide clinical decision making in the COVID-19 pandemic* (the ethical framework), developed by Queensland Health (attached).

Documents such as the ethical framework are of critical importance to every Queenslanders who may be infected with COVID-19 or connected to someone who is, and for whom decisions will need to be made about their clinical care and access to potentially limited beds, equipment and other health resources.

The purpose of the policy is to provide medical practitioners with a broad framework for considering how to ethically allocate resources to certain patients during times of high demand during the COVID-19 pandemic. The policy includes a 'threshold test' which is intended to create an 'equitable triage process and assist in identifying patients most likely to benefit from critical care treatments AND provide a rationale for excluding those who, in the current context, are less likely to survive and enjoy a reasonable quality of life.'

I write to you because I have a number of concerns about the ethical framework relating to its development, content (including the principles or values guiding the decision-making), authority and legal status.

Underpinning my concerns is a recognition of the magnitude of the decisions made daily by clinicians — life and death decisions. A decision to withhold or withdraw access to health facilities and services to a person is a decision to override that person's right to life and right to health services under sections 16 and 37 (respectively) of the *Human Rights Act 2019*:

16 Right to life

Every person has the right to life and has the right not to be arbitrarily deprived of life.

37 Right to health services

(1) Every person has the right to access health services without discrimination.

- (2) *A person must not be refused emergency medical treatment that is immediately necessary to save the person's life or to prevent serious impairment to the person.*

Hospital and health services are often delivered in an environment requiring rapid decision-making and responses to people's health needs. This is particularly the case when people are critically ill and during events such as the COVID-19 pandemic. While recognising the demands of these environments, it remains necessary, before a person's right to life and to health services can be overridden, to ensure that the ethical framework relied upon to guide these decisions has community acceptance, uses transparent decision-making processes and includes all necessary considerations to make such a decision.

Engagement with legal and human rights issues

The primary concern with the policy is that it appears to have no clear legal basis. Although there is legal precedent regarding the refusal of medical treatment based on the concept of 'futility', my understanding is that there is no legal justification in refusing treatment based upon considerations around the allocation of resources to other patients, including potential patients that may seek treatment during the height of a pandemic.

Such a decision would also be a direct contradiction of section 37 of the Human Rights Act 2019, the right to health services.

The Executive Summary of the ethical framework outlines the extensive consultation undertaken to develop the document to its current iteration, including with 'clinicians, consumers, academics and ethicists and lawyers' to 'determine the 'shape' of the framework'. While it is clear a great deal of effort was invested in the consultation process, it is concerning that there was no specific consultation with human rights agencies or advocates from the earliest stages of development, particularly considering the types of critical health and human rights issues that are impacted by the decisions the framework is intended to guide.

The ethical framework makes a passing reference to the *Human Rights Act 2019* and the *Anti-Discrimination Act 1991*, however, the principles that underpin those Acts are not referred to in the ethical framework, when they should actually be key considerations in the 'Ethical considerations' section of the document. Clinicians making these decisions need to be informed that they must not take into account irrelevant or discriminatory considerations such as gender, sexual orientation, religion, disability, social status, personal connections, wealth, citizenship, ethnicity or race.

The narrowness of the focus and consultation in the development of the document is demonstrated in statements such as the one below:

To develop a relevant ethical framework to aid clinical and shared decision-making in the time of a pandemic there is a need to have a clear understanding of the nature of the disease, the health and social implications upon a community, as well as knowledge of ethical principles both at individual and population health levels.¹

This statement suggests that the set of considerations listed is all of the relevant considerations for the development of such a document. There is no mention of the need to understand and apply the law around health and end-of-life decision-making, the operation of human rights principles in this context or the need to ensure decisions are not influenced by considerations that would amount to discrimination.

Nor is the legal status or authority of the ethical framework made clear. It is presented as an 'aid' to clinical and shared decision-making. However, it is unclear, whether compliance with the framework would provide legal protection to a clinician who was challenged over a decision based on the approach of the framework, or whether failing to apply the framework would expose the clinician to allegations of unprofessional or unlawful conduct.

¹ Queensland Health, *Queensland ethical framework to guide clinical decision making in the COVID-19 pandemic*, V2_ July 2020, p 3.

Broad public consultation and education required

The ethical framework has potentially far-reaching impacts for members of the Queensland community. Ultimately, it is intended to guide life-and-death decisions for people infected with COVID-19, and will impact many other people in the community connected to them.

Accordingly, there should be broad community education and consultation about the issues raised by the framework and a process by which this can be reflected in the document.

Most Queenslanders are unlikely to be aware that such documents or policies exist until they are directly affected by decisions made by clinicians using them. Many people would correctly question the authority of the health system and clinicians to develop these documents and make life-and-death decisions based on a set of rules and values about which the community has not been broadly consulted or informed and do not appear to be underpinned by any formal legal framework.

When the government is considering the development of laws and policies dealing with sensitive and emotive issues relating to the right to life, they must be driven by conscience and morality. Broad public consultation is critical to ensuring community acceptance of such laws and that they are based on shared community values.

Many of the considerations in this ethical framework are relevant to the legal, health and social issues considered by the Parliamentary Committee that conducted the Inquiry into Aged Care, End-of-Life and Palliative Care, and Voluntary Assisted Dying. While historically, the community has not been particularly interested in public discussions about these types of issues, it was clear from the submissions made to that Committee, that many members of the Queensland community are well-informed and have strong views about these issues, and can positively contribute to the development of public policy about these matters.

Transparency and accountability

It is critical that there is transparency and accountability in clinical decision-making about these issues. Documents such as the ethical framework should be available to the public and members of the community should have information about how and why end-of-life decisions are made by clinicians under the framework. I understand that the ethical framework was posted to the Queensland Health website in April, 2020, but has since been removed. It remains on the AMA Queensland website.²

The currency and legal authority of the ethical framework is also unclear. There is no information about whether the framework is currently in use in Queensland Health facilities, or through what process and under whose authority that may have occurred. Nor is there information about the legal status of the document or decisions made under it.

It is of concern that a document which could have such far-reaching impacts for Queensland citizens could be developed and apparently adopted by clinicians in Queensland Health, without going through any formal public consultation or legislative process.

I am aware of other ethical frameworks, such as the 'Guiding principles for complex decision making during Pandemic COVID-19' issued by the Australian and New Zealand Intensive Care Society³ which also appear to be in use across Australia. This document at least includes a principle that clinical decisions must not be based on irrelevant and discriminatory considerations. However, there is no reference to broader human rights principles and their relevance to decisions potentially made under the document. Again, the legal status of the document and the decisions made under it is unclear. It is also unclear which document would take precedence and in what circumstances.

² <https://community.amaq.com.au/search?executeSearch=true&SearchTerm=ethical+framework&l=1> accessed on 24 August 2020.

³ https://www.anzics.com.au/wp-content/uploads/2020/04/ANZIC_3367_Guiding-Principles.pdf accessed 26 August 2020.

There were a number of media reports during the height of the pandemic about the lack of transparency around the adoption and application of such policies in Victorian hospitals.⁴

Decisions about whether a patient will receive care that will determine whether they live or die must be transparent and accountable. It is critical that, as a community, we can be confident that these decisions are based on specific, defined, objectively measurable considerations, and not on considerations driven by a clinician's subjective view of a patient's 'value', or their quality of life.

Further, treating doctors may not be the most appropriate people to make decisions about the allocation of limited health resources. These circumstances can raise issues of conflict for doctors. There may be benefit in considering whether these decisions should be referred to an independent decision-maker, for example a panel that may be comprised of clinicians, ethicists and consumers. Considering the need for clinicians to often make decisions urgently, there will of course be challenges involving the practicality of such a model which would need to be considered. However, in my view, the issue of timeliness needs to be weighed against the consequences of the decision. In any event, such decisions should always be transparent and open to public scrutiny.

Recent media reports have cited examples of clinical decisions in regional hospitals in New South Wales, that appear to have been based on a person's age.⁵ It is concerning that these types of decisions may be happening daily in Queensland hospitals without publicly available guiding frameworks or independent oversight.

Not only should there be some system of oversight of the way these decisions are made, they should also be subject to review or appeal. How appeals would operate in practice, when time is of the essence, would need to be worked through as part of the development of any formal decision-making process. Courts and tribunals are frequently called upon to make emergency health decisions for members of the community. These processes are frequently accessed by clinicians and hospitals when there are concerns about decisions made by parents in relation to their children's care, so there are precedents for urgent review of health decisions. Despite the preference of clinicians to make and exercise decisions quickly in these settings, due to the nature of these decisions, it is critical for public confidence in the health system that decision-making is consistent and based on well-understood and accepted principles, and that people are able to question and challenge clinicians' decisions. No decision-maker is infallible or immune from bias.

As a human rights jurisdiction it is essential that Queensland has appropriate laws and processes to support the medical profession to deal with these difficult end-of-life issues, especially during events such as pandemics, and make transparent, defensible decisions.

As already noted, I respectfully suggest that you consider a reference to the Queensland Law Reform Commission to undertake an inquiry into clinical and end-of-life decision-making by medical practitioners, that could:

- propose an appropriate ethical framework to guide clinical decision-making impacting patients' right to life and right to health services, under Queensland law;
- initiate a broad-ranging public discussion and consultation about the content of the ethical framework and the shared community values that should underpin it;
- propose an appropriate legal framework that the ethical framework could be developed under that would give legal status and authority to the framework and provide appropriate protections for those making decisions under it;
- outline a process for the approval and adoption of the ethical framework for use in Queensland's public health system and promotion of it to the Queensland community; and

⁴ Lisa Mitchell, et al 'In Victoria, whether you get an ICU bed could depend on the hospital' *The Conversation* (online, 19 August 2020) <<https://theconversation.com/in-victoria-whether-you-get-an-icu-bed-could-depend-on-the-hospital-144209>>.

⁵ Jessie Davies, 'Elderly patients and carers say age discrimination in NSW hospitals is real and heartbreaking' *ABC News* (online, 16 August 2020) <<https://www.abc.net.au/news/2020-08-16/ageism-in-health-doctors-biased-best-hospitals-for-the-elderly/12395292?nw=0>>.

- recommend systems and processes to ensure transparency and accountability of clinical decision-making that impacts patients' right to life and right to health services, including requiring the keeping of records and reasons for decisions, processes for appointment of independent decision-makers, review and external oversight of these decisions.

I would be pleased to meet with you or your staff to discuss these matters further or clarify any matters raised in this letter. Thank you for considering these matters.

Yours sincerely

A handwritten signature in cursive script, appearing to read "Mary Burgess". The signature is written in dark ink and is positioned above the printed name and title.

Mary Burgess
Public Advocate

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