



Australian
National
University

Australian Capital Territory COVID-19 Intensive Care Triage Principles and Process Consumer, Carer, and Community Consultation Report

29th September 2020

The Australian National University

Acton ACT 2601 Australia

T 61 2 6125 5753

E brett.scholz@anu.edu.au

Recommended Citation: Scholz, B., Kirk, L., & Mitchell, I. (2020). Australian Capital Territory *COVID-19 Ethical Decision-Making Framework: Consumer, Carer, and Community Consultation Report*. ANU Medical School, The Australian National University, Canberra.

Prepared by: Dr Brett Scholz^a, Ms Lucy Kirk^a, and Prof Imogen Mitchell^b

^a ANU Medical School, The Australian National University, Canberra, Australia

^b Clinical Health Emergency Coordination Centre, Canberra, Australia

Brett Scholz, ANU Medical School, ANU College of Health and Medicine

+61 2 6125 5753

brett.scholz@anu.edu.au

 @brett_scholz

The Australian National University

Canberra ACT 2601 Australia

www.anu.edu.au

Contents

Executive Summary	1
ES.1 Methodology	1
ES.2 Recommendations	1
1. Background	2
1.1 Other COVID-19 Ethical Decision-Making Frameworks	2
1.2 Consumer, Carer, and Community Engagement in Ethical Decision-Making Frameworks.....	4
1.3 The ACT as a Human Rights Jurisdiction	5
2. Clinical Ethics Committee Consultation.....	9
2.1 Theme 1: Ethics and Discrimination Concerns.....	9
2.2 Theme 2: Triage Considerations and Processes	10
2.3 Theme 3: Governance.....	11
2.4 Format.....	11
3. Consultation Process.....	12
3.1 Preparation	12
3.2 Background	12
3.2.1 Philosophical Approach.....	13
3.3 Phase 1: Primary Consultations.....	15
3.3.1 Modality 1: Forum Discussions.....	17
3.3.2 Modality 2: Written Submissions	17
3.3.3 Modality 3: Individual Discussions.....	18
3.4 Phase 2	18
3.5 Analytic Framework	18
4. Outcomes of the Consultation.....	19
4.1 Theme 1: Compatibility of triage with Human Rights	19
4.2 Theme 2: Approaches to triage	20
4.3 Theme 3: Discrimination	22

4.4 Theme 4: Beyond COVID-19	23
5. Recommendations.....	24
5.1 Recommendations for an Ethical Decision-Making Framework.....	24
5.1.1 Ensure Primacy of Human Rights.....	24
5.1.2 Embed Non-Discrimination in Triage.....	25
5.1.3 Base Triage on immediate health-related concerns	25
5.1.4 Ensure Triage Processes Minimise Bias.....	26
5.1.5 Ensure Transparency	26
5.2 Recommendations beyond COVID-19	27
6. Evaluation of the Principles and Processes.....	28
6.1 Addressing the Final Round of Concerns	28
6.2 Concluding Remark	30
Acknowledgements	31
Reference List	32
Appendix A: Conversation Guide.....	36

Executive Summary

The ACT Clinical Health Emergency Coordination Centre engaged the research team in May 2020 to conduct a review of the ethical decision-making processes for allocating critical care resources should demand exceed supply during the global COVID-19 pandemic.

ES.1 Methodology

The methodology for this review broadly included undertaking a scoping review of ethical decision-making frameworks in other jurisdictions; a systematic review of consumer, carer, and community engagement in ethical decision-making frameworks; and a series of consultative processes. The outcomes from each of these activities were then integrated into the ACT Ethical Decision-Making Framework which had been drafted by the Clinical Ethics Committee of Canberra Health Services earlier in the pandemic.

Based on a 'Scoping Review of Ethical Decision-Making Frameworks' and a 'Systematic Review of Consumer Engagement in Ethical Decision-Making Frameworks', a consultation process was developed whereby relevant consumer, carer, and community groups from across the ACT region were given a range of opportunities to provide input into what principles should form the basis of ethical decision-making in the context of COVID-19 should demand for acute care resources exceed capacity.

ES.2 Recommendations

The recommendations developed through analysis of the consultations are:

1. There should be a primacy of Human Rights underpinning decision-making processes,
2. Non-discrimination should be embedded in triage,
3. Triage should be primarily based on immediate health concerns (that is, with no assumptions or value judgements about people's health conditions),
4. Triage processes should *minimise* bias, and
5. Triage processes should be transparent.

1. Background

The current COVID-19 pandemic has led to incredible demands on critical care services in hospitals around the world – in several jurisdictions these demands have exceeded conventional contingency surge strategies. Jurisdictions have begun development of triage systems to best allocate available critical care resources. With appropriate surge planning, it is hoped that the need for such a triage system would be rare. However, failing to prepare triage systems could have serious, if unintended, consequences.^{2,3}

The COVID-19 Ethical Decision-Making Framework aims to support ACT clinicians who are required to make such decisions about the ethical allocation of acute care and critical care resources when demand exceeds capacity during the public health emergency caused by the global COVID-19 pandemic. In March 2020, the Canberra Health Services COVID-19 Taskforce sought rapid guidance from the Canberra Health Services Clinical Ethics Committee. This resulted in the development of two documents (one outlining the ethical principles of triage, and one providing clinical guidance on these principles; summarised in section 2) which outlined a framework for ethical decision making and a COVID-19 guideline to enact the framework. This was an important first step in providing clinicians across the ACT with guidance intended for the purposes of caring for and triaging patients during COVID-19 – particularly in the context of demand for acute care resources exceeding capacity.

With the establishment of the ACT Clinical Health Emergency Coordination Centre in late March 2020, there was a need to progress the work of the Clinical Ethics Committee into a Territory-wide Framework for Ethical Decision-Making. The Canberra Health Services guideline was produced rapidly with *some* community consultation, but in May 2020 the COVID-19 situation afforded such that there was an opportunity to revisit the work and include a greater degree of consumer, carer, and community consultation.

1.1 Other COVID-19 Ethical Decision-Making Frameworks

Internationally, there has been some prior development of frameworks and guidelines for allocation of scarce resources, particularly following SARS in 2003, and H1N1 in 2009. Some of these documents have been published prior to the global COVID-19 pandemic or have now been published without amendment, some have been amended for the global COVID-19 pandemic, and other jurisdictions or facilities have developed new frameworks and guidelines specifically for COVID-19. These can be broken up into two main types of documents; those with the primary purpose of guiding the ethics of decisions made in a pandemic, and those that specifically designed to guide the practical process of allocation of scarce resources during a pandemic.

In regard to ethics of decision making during a pandemic, many decisions are likely to cause controversy and disagreement. Ideally, decisions should be made in a way that is; **fair**, with mechanisms to voice concerns, **inclusive** of relevant stakeholders and views, **transparent** with appropriate communication, **reasonable** given the context, urgency and information available, **accountable**, and **responsive** to the situation as it evolves.⁴⁻⁷ Many of these documents also discuss the rationale that in a pandemic, the focus of decisions changes from individuals to making decisions based on the benefit of the whole of society, as in, take a primarily utilitarian stance of aiming to achieve the greatest “good” for the largest number of people possible.^{5, 8-11} Whilst the traditional medical ethical principles of **autonomy**, **beneficence**, **non-maleficence** and **justice** should be upheld, there is also discussion of additional principles such as **duty to care** (obligation to our patients), **duty to steward resources**, **equity** and **fairness**, **proportionality**, and **reciprocity**.^{4, 5, 7, 10, 11}

With a utilitarian stance in mind, the triage systems set out to try to prioritise ventilators to those who are sick enough to die without one, but well enough that they will likely survive with one. The systems are primarily either based on **likelihood of short-term survival alone**, or **short-term survival and consideration of long-term prognosis**. Allocation based on short-term survival most commonly uses the Sequential Organ Failure Assessment (SOFA) score as a predictor of short-term mortality, with higher priority given to patients with a *lower* SOFA score.¹²⁻¹⁵ Some systems also included an initial exclusion criterion based on very poor short-term prognosis (eg. out of hospital cardiac arrest or unresponsive to defibrillation, malignancy with predicted mortality in <1 month, significant and irreversible neurological events, and severe burns patients of advanced age).^{14, 15} Some triage systems place greater emphasis on trying to increase the overall number of life-years saved, and thus include co-morbidities and longer-term prognosis in their triage allocation (including clinical frailty scoring and conditions include dementia, malignancy, heart failure, chronic lung disease, cirrhosis and chronic kidney disease).^{12, 15-19}

There are some significant ongoing points of contention regarding these triage systems. The first is **categorical exclusion** of certain patient groups with particular conditions. This is due to the fact that it may be seen as a judgement of a life “not worth saving” and is also likely to be too rigid for the rapidly changing nature of a pandemic.^{12, 18} Another important issue is that of both **direct** and **indirect discrimination** for vulnerable groups such as those of advanced age, people with a disability, those who are homeless, refugees and Aboriginal and Torres Strait Islander people, and those from other marginalised backgrounds.¹¹ It is recognised that the risk of comorbidities is influenced by social determinants of health, and whilst not all systems explicitly include comorbidities as part of their triage, comorbidities will impact physiological health and thus, will likely be reflected in their SOFA score.¹⁰ A third significant point of contention is the **reallocation of**

ventilators from patients who were initially well enough to receive one, but then deteriorate or fail to improve.^{14, 20} Lastly, an important issue to consider is the mechanism that will be used to differentiate between patients in the same triage priority if there are not adequate ventilators – ie. **“tie-breakers”**. Suggested factors for consideration include; patient age, carer responsibilities, healthcare workers involved in the COVID-19 response, first-come-first-served, random allocation, and those in disadvantaged or vulnerable groups.^{12, 14, 18}

Since the initial publication or development of these triage systems in the earlier stages of the COVID-19 pandemic, there has been increasing critique and commentary. This is in particular reference to triage systems that may be discriminatory and the incongruence of such systems with Human Rights.^{21-26 27}

1.2 Consumer, Carer, and Community Engagement in Ethical Decision-Making Frameworks

Community consultation regarding allocation of scarce resources during an influenza pandemic has occurred in both Australia (specifically, South Australia) and overseas (primarily Canada and the United States of America).²⁸⁻³² This has ranged from online surveys, to in-depth “town hall” style meetings and deliberative democracy forums. Throughout these consultations in a range of settings, there were some strong reoccurring themes.

The first was regarding the importance of **transparency, public awareness** and **consultation** regarding development and implementation of an allocation framework.^{28, 33} In the majority of consultations, participants sought to **solve the issue of scarcity** before being willing to consider the moral dilemmas posed, and they highlighted their desire for local and national pandemic planning.^{30, 33} There was often concern regarding the feasibility of **use of any single ethical principle** with **significant uncertainty** and **deliberative struggle** in regard to participants justifying allocation systems or coming to consensus.^{28, 30, 33} Participants often had concern regarding **biased decisions** and that the system may **perpetuate existing health inequities**.^{28, 33} The most commonly preferred ethical principle in the majority of consultations was a system that would **save the greatest number of lives** (“survive current illness”, ie. Short-term mortality), over other systems such as saving the most life-years (“live longer”, ie. Long-term prognosis), random allocation, or first-come-first-served systems.^{30, 31, 33} However, some individuals more strongly valued equitable treatment or treating those with the greatest need.³⁰

Overall, there are significant recurring themes from community consultation regarding allocation of scarce resources during an influenza pandemic. However, results of any consultation during COVID-19 are yet to be made available, and there is a paucity of

published results from specific consultation with those likely to be impacted due to being vulnerable or marginalised in society.

1.3 The ACT as a Human Rights Jurisdiction

In 2004, the ACT Legislative Assembly enacted the Human Rights Act 2004, establishing the ACT as a Human Rights jurisdiction. The Act requires Human Rights considerations to be taken into account in all public decisions.

International leaders in Human Rights issues acknowledge that “the scale and the severity of the COVID-19 pandemic clearly rises to the level of a public health threat that could justify restrictions on certain rights.”³⁴ However, attention to specific rights and principles can support the COVID-19 response and limit harms arising from response measures. These rights and principles include:

- ‘The right of everyone to the enjoyment of the highest attainable standard of physical health and mental health’ (*International Covenant on Economic, Social and Cultural Rights* 1966, art. 12)³⁵
- ‘All humans are born free and equal in dignity and rights’ (*Universal Declaration of Human Rights* [UDHR] 1948, art. 1)³⁶
- ‘Every human being has the inherent right to life. This right shall be protected by law. No one shall be arbitrarily deprived of his life.’ (UDHR 1948 art. 3, *International Covenant on Civil and Political Rights* [ICCPR] 1966 art. 6.1)³⁷
- ‘No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment. In particular, no one shall be subjected without his free consent to medical or scientific experimentation.’ (UDHR 1948 art. 5, ICCPR 1966 art. 7)
- Human Rights should be applied ‘without distinction of any kind, such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status’ (UDHR 1948 art. 2, ICCPR 1966 art. 2.1)
 - This implicitly covers age, disability, gender identity, nationality, marital status and sexual orientation.
- ‘Parties shall take all appropriate measures to eliminate discrimination against women in the field of health care in order to ensure, on a basis of equality of men and women, access to health care services, including those related to family planning.’ (*Convention on the Elimination of All Forms of Discrimination Against Women* 1979, art. 12.1)³⁸
- *Convention on the Rights of the Child* [CRC] 1989:³⁹
 - ‘Parties recognise that every child has the inherent right to life.’ (art. 6.1)
 - ‘States Parties recognize that a mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self-

reliance and facilitate the child's active participation in the community.' (art. 23.1)

- 'States Parties recognize the right of the disabled child to special care and shall encourage and ensure the extension, subject to available resources, to the eligible child and those responsible for his or her care, of assistance for which application is made and which is appropriate to the child's condition and to the circumstances of the parents or others caring for the child.' (art. 23.2)
- 'Recognizing the special needs of a disabled child, assistance extended in accordance with paragraph 2 of the present article shall be provided free of charge, whenever possible, taking into account the financial resources of the parents or others caring for the child, and shall be designed to ensure that the disabled child has effective access to and receives education, training, health care services, rehabilitation services, preparation for employment and recreation opportunities in a manner conducive to the child's achieving the fullest possible social integration and individual development, including his or her cultural and spiritual development.' (art. 23.3)
- 'States 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. States Parties shall strive to ensure that no child is deprived of his or her right of access to such health care services.' (art. 24.1)
- *Convention on the Rights of Persons with Disabilities* [CRPD] 2006:⁴⁰
 - The principles of the Convention are (art. 3):
 - 'Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons; non-discrimination; full and effective participation and inclusion in society; respect for difference and acceptance of persons with disabilities as part of human diversity and humanity; equality of opportunity; accessibility; equality between men and women;'
 - 'Parties must undertake: to take into account the protection and promotion of the Human Rights of persons with disabilities in all policies and programmes.' (art. 4.1.c)
 - 'Parties shall prohibit all discrimination on the basis of disability and guarantee to persons with disabilities equal and effective legal protection against discrimination on all grounds (art. 5.2). In order to promote equality and eliminate discrimination, States Parties shall take all appropriate steps to ensure that reasonable accommodation is provided.' (art. 5.3)
 - 'States Parties recognize that women and girls with disabilities are subject to multiple discrimination, and in this regard shall take measures to ensure the full

and equal enjoyment by them of all Human Rights and fundamental freedoms.’ (art. 6.1)

- ‘States Parties shall take all necessary measures to ensure the full enjoyment by children with disabilities of all Human Rights and fundamental freedoms on an equal basis with other children.’ (art. 7.1)
- ‘States Parties reaffirm that every human being has the inherent right to life and shall take all necessary measures to ensure its effective enjoyment by persons with disabilities on an equal basis with others.’ (art. 10)
- ‘States Parties shall take, in accordance with their obligations under international law, including international humanitarian law and international Human Rights law, all necessary measures to ensure the protection and safety of persons with disabilities in situations of risk, including situations of armed conflict, humanitarian emergencies and the occurrence of natural disasters.’ (art. 11)
- ‘Every person with disabilities has a right to respect for his or her physical and mental integrity on an equal basis with others.’ (art. 17)
- ‘States Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. States Parties shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation. In particular, States Parties shall:’ (art. 25)
 - ‘(a) Provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons, including in the area of sexual and reproductive health and population-based public health programmes;
 - (b) Provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, including among children and older persons;
 - (c) Provide these health services as close as possible to people's own communities, including in rural areas;
 - (d) Require health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent by, inter alia, raising awareness of the Human Rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care;

- (e) Prohibit discrimination against persons with disabilities in the provision of health insurance, and life insurance where such insurance is permitted by national law, which shall be provided in a fair and reasonable manner;
- (f) Prevent discriminatory denial of health care or health services or food and fluids on the basis of disability.’

2. Clinical Ethics Committee Consultation

The Clinical Ethics Committee (CEC) draft framework was sent to a range of relevant consumer, carer, and community organisations and peak bodies (see list in Section 3.2). While this process was distinct from the consultation presented in this document, most of the feedback received – generously within 48 hours from each team – remains relevant and is strongly aligned with the discussions forming the basis of the current document. As such, this section presents a thematic analysis (using the same process as discussed in Section 3.4) of the feedback on the CEC document.

2.1 Theme 1: Ethics and Discrimination Concerns

Clarity of ethical premise

Several of those responding to the CEC document noted that because the purpose of the framework is about triage, the intent of triage needed to be “clearly defined early in the document.” There was a call for discussion “beyond a statement against discrimination” in regards to practically preventing discrimination against potentially vulnerable groups such as people with a disability. In other words, non-discrimination was considered to be an important principle of any such framework, and merely a brief mention of discrimination would not be sufficient.

Reference to Human Rights

Respondents noted that discrimination “is the heart of the discussion that is needed” and that incorporating reference to “the ACT as a Human Rights jurisdiction” should underpin the framework. They emphasised that “value judgements about the lives of people with disability, women and older people” should not be part of the framework.

Concerns about frailty scoring and the implications for people with disabilities

Respondents were “concerned by the potential for certain...groups to be denied treatment on the grounds that their outcomes tend to be poorer” including people with disability (but also with implications for other marginalised groups, those in lower socio-economic groups, people with mental health concerns, and others). As with other findings from this theme, respondents highlighted that “more thought is needed on” the broad issues facing people in vulnerable communities. Ableist assumptions as to quality of life should not be part of the decision-making process.

Several comments received in the consultation process raised concerns about “people with disability [being] considered frail and therefore less likely to receive treatment.” Suggestions to resolve this included adding “a note to the top of the document to be used by ACT staff that it is only to be used for patients over 65 without pre-existing medical conditions” and ensuring that the clinical decision be based “not on assumptions about the person’s age, disability, capacity” but rather on clinical presentation.

Access and Communication Barriers

Another common concern related to a range of access and communication barriers (often correlated with discrimination and marginalisation as already discussed). Respondents called for “accurate, authoritative and timely communication...in simple accessible English and in other languages”. Reflecting that several respondents worked with people with disabilities, there was particular concern about communication issues where individual consumers “may not be able to state their preferences” without support, about people receiving healthcare inequitably based on who is able to communicate their needs, and about what would happen in cases where consumers rely on advocates or family carers who may not be able to be present due to COVID-19 related limitations.

2.2 Theme 2: Triage Considerations and Processes

More thought to advance care planning and consumer wishes

There was generally positive support for the CEC document’s discussion of the need for increased resources for palliative care in the home or community. Some hoped there would be more support for consumers to ensure that their “values, wishes and preferences” could be taken into account in medical decision-making.

Transparency

Respondents asked that decisions about critical care resource allocation be transparent and clearly documented to ensure that decisions were consistent with guidelines. “An appeal or review process built into the triage processes” was suggested as a way to ensure comfort with and trust in the system.

2.3 Theme 3: Governance

More consultation

Respondents asked for more consultation on this process – a call which has been in part the reason behind this current process.

National process

Multiple respondents thought that “nationally consistent work” done on developing an ethical decision-making framework would be useful. (Our understanding is that a national guideline for ethical decision-making in the COVID-19 pandemic is unlikely – and the findings of the consultation discussed overleaf suggest the ACT has particular obligations as a Human Rights jurisdiction that might not sit well with a national process).

2.4 Format

Clarity in purpose and structure

Respondents asked that the framework be clearer about its purpose early on in the document. Similarly, a clearer structure was considered to be beneficial so that information about resources, information about COVID-19, and information about patient outcomes could be easier to follow.

3. Consultation Process

3.1 Preparation

Partners from the ANU Medical School at The Australian National University synthesised **academic literature** on triage in the COVID-19 context, **existing frameworks** of triage from other jurisdictions, and **The ACT Global Pandemic COVID-19 Guideline** drafted through the Canberra Health Services Clinical Ethics Committee.

3.2 Background

Engagement of consumers at all levels of decision-making in health organisations is emphasised in contemporary health policy within and beyond Australia. There are international calls to involve consumers in decision-making processes for equitable governance of health care.⁴¹ Indeed, Australian National Health Standards now *require* consumer engagement in health service planning, design, delivery, and evaluation.⁴²

There are numerous important benefits of engaging with consumers in developing health services. The context of the COVID-19 pandemic only underscores the importance of these benefits, including:

1. **Better quality care.** Health systems that meaningfully engage with consumers in systemic decision-making are more likely to be placed to provide more relevant care that better meets consumer needs.^{43, 44}
2. **Improved social justice.** Care that is based on and respects the knowledge and experiences of consumers provides better opportunities for empowerment and better supports consumers with particular needs.^{45, 46}
3. **Greater innovation.** Consumers have unique perspectives of health systems,⁴⁵ likely due to their more holistic understanding of health system use that other health professionals (endisciplined into specific areas of health service provision) would not be able to share.
4. **Increased trustworthiness.** Even prior to the COVID-19 pandemic, one of the *urgent health challenges for the next decade* was considered to be earning consumers' trust.⁴⁷ Now – even more so than before the pandemic – one of the steps towards earning public trust is better engagement with the communities served by health services.

Given all these important benefits, an approach that would non-tokenistically engage with the development of a decision-making framework in the context of COVID-19 was adopted.

3.2.1 Philosophical Approach

We aimed to develop the decision-making framework for COVID-19 in the ACT in as collaborative a manner as possible within the constraints of the pandemic and the large body of stakeholders to the work (although this report focuses only on the consultation processes with consumer, carer, and community groups, the nature of the decision-making framework also required engagement of many other groups including the Clinical Health Emergency Coordination Centre; clinicians from across the disciplines of intensive care, emergency care, and palliative care and beyond; government solicitors; human rights experts; and bioethicists). We were also constrained by time: we were acutely aware of the need to have a framework developed ahead of possible COVID-19 transmission in the ACT and of the uncertainty about if and when such transmission would occur; and funding: we were unsuccessful in securing funding for consumer researcher collaborator(s) for the project.

These limitations impacted the extent to which we were able to achieve co-production across the development of the framework. As seen in *Figure 1*, co-production requires collaboration across all phases of an initiative, from planning, through design and evaluation, to delivery. *Table 1*, below, outlines the way in which collaborative approaches with consumer, carer, and community organisations underpinned the work contained in this report and the framework that was developed more fully.

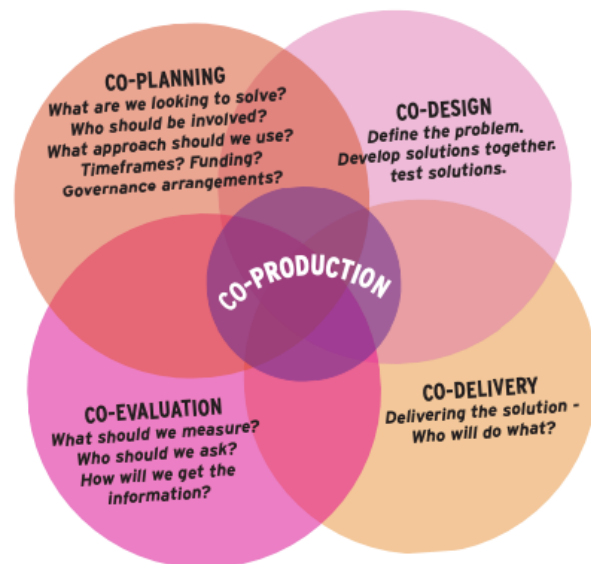


Figure 1. What does co-production involve? (Reproduced from Roper, Grey and Cadogan, 2018)¹

Phase	Notes on Collaboration
Planning	<p>The need for a framework for decision-making in the context of the COVID-19 pandemic was realised by the Clinical Health Emergency Coordination Centre of the ACT. The ANU team was engaged to develop a plan for partnering with community for devising the framework.</p> <p>In the <i>planning phase</i>, the ANU team worked together with colleagues from the Health Care Consumers Association of the ACT who provided invaluable insights into how a consultation process might</p>

	<p>occur, and how to challenge the barriers faced in the context of COVID such as not being able to meet face-to-face and working with an already-fatigued sector.</p>
Design	<p>There were several stages in which the design of the framework was collaboratively produced.</p> <p>First, a proto-version of the document was produced by the Clinical Ethics Committee of Canberra Health Services and then sent out to a number of consumer, carer, and community groups for input.</p> <p>Second, a series of forum discussions was held in which a broad group of members of consumers, carers, and community groups were invited to take part in developing solutions to the issue of how to make decisions about care in COVID-19.</p> <p>Third, consumer, carer, and community groups were also invited to make written submissions or to engage the ANU research team in individual discussions. These modalities were offered in addition to the forum discussions to increase flexibility and accessibility, and to provide a space for people to discuss difficult issues in whatever way made them feel most comfortable.</p>
Evaluation	<p>A draft of summary of the solutions developed in the design phase was written by the ANU research team. This was then sent for evaluation to each organisation from the previous phase, as well as some other key organisations identified, <i>and</i> to groups of clinicians for input on how the principles might be put in place in the clinical setting. At this stage, people were invited to either insert track changes to the document (i.e., providing people with the opportunity to have direct input in the framework), to provide written feedback, or to discuss any issues.</p>
Delivery	<p>The framework was provided to a steering group comprised of relevant parties including representation from consumer groups. Specifically, the steering group comprised the Clinical Director COVID-19 at the Clinical Health Emergency Coordination Centre, the Calvary Public Hospital Bruce Medical Director, the ACT Human Rights Commissioner, the Community Co-Chair of the ACT Disability Reference Group, the Executive Director of the ACT Health Care Consumers Association, and a bioethicist from The Australian National University.</p> <p>Representation from the Health Care Consumers Association, ACT Disability Reference Group, ACT Human Rights Commission, and bioethicist was particularly important for the collaborative input during this phase.</p> <p>The steering group met to discuss a draft version of the framework, and collaboratively evaluated concerns to be addressed. These concerns were noted, and respective changes were incorporated by the ANU research team. The steering group met again to evaluate the updated version of the framework, with some further minor changes</p>

	noted at this stage. The steering group then presented the final framework to the Clinical Health Emergency Coordination Centre for endorsement.
--	--

3.3 Phase 1: Primary Consultations

The aim of this stage of the project was to consult widely and deeply with consumer, carer and community stakeholder groups, to maximise understanding of consumers' needs for and perspectives of ethical decision-making frameworks. Invitations were sent to a range of peak bodies and relevant organisations, and each of these was asked to engage with their staff or membership (depending on what would be appropriate within their specific context), and to provide them with support to engage with the consultation processes.

The organisations invited were:

	Provided Written Feedback to the Original Clinical Ethics Committee Document	Invited to Take Part in the Consultation Processes Outlined in this Section	Represented in the Consultation Processes Outlined in this Section	Invited to Take Part in the Final Feedback Processes for the Framework	Participated in the Final Feedback Processes for the Framework (see Section 6, page 28)
A Gender Agenda		√	√	√	
ACT Council of Social Services	√	√	√	√	√
ACT Disability Aged Carer Advocacy Service	√	√	√	√	√
ACT Down Syndrome Association	√	√	√	√	√
ACT Human Rights Commission	√	√	√	√	√
ACT Aboriginal and Torres Strait Islander Elected Body				√	
ACT Mental Health Consumer Network	√	√		√	√
Advocacy for Inclusion		√	√	√	√
Alcohol Tobacco and Other Drug Association ACT		√		√	

Calvary Public Hospital Bruce Aboriginal Liaison Officer Team				√	
Canberra Health Service Aboriginal and Torres Strait Islander Liaison Office				√	
Canberra Multicultural Community Form	√	√		√	√
Carers ACT	√	√	√	√	
Companion House		√		√	
Council of the Ageing ACT		√		√	
Gugan Gulwan				√	
Health Care Consumers' Association ACT	√	√	√	√	
Hepatitis ACT				√	
Mental Health Community Coalition ACT	√	√		√	
Meridian	√	√		√	
National Disability Service (ACT)		√	√	√	
People with Disabilities ACT	√	√		√	
Sexual Health and Family Planning ACT	√	√		√	
Winnunga Nimmityjah	√	√		√	√
Women with Disabilities ACT	√	√		√	√
Women's Centre for Health Matters		√			

Please note that a lack of representation at the consultation processes (as depicted in the fourth column above) does not necessarily indicate a lack of engagement with the material. For instance, we had correspondence with the team from the Women's Centre for Health Matters who were happy to have us engage with others from the community sector with particular relevant expertise as they did not have capacity and did not feel they had the same stake in the conversation as other particularly marginalised groups.

We also acknowledge this was a particularly busy and stressful time for many groups we contacted who were often busy supporting their members and communities deal with

some of the concerns that had been arising during physical distancing measures for COVID-19. Similarly, technological issues did arise during some of the sessions which meant that participant's internet connections did not always let them into Zoom. In these instances, we were able to arrange separate phone calls with those we knew were unable to access the online platform – but there may have been others unable to connect that we were not able to follow up with.

A multimodal approach to consultation was adopted to try and maximise accessibility of the process as well as make consumers, carers, and community members or groups feel comfortable to engage in at least one of the following modes.

3.3.1 Modality 1: Forum Discussions

A series of Forum Discussions were held in the first week of June. Due to the restrictions on meeting face-to-face, these discussions were facilitated online through Zoom by the ANU Medical School team. Although there were some difficulties with the online platform including technological issues as well as not being able to see and communicate with participants in person, there were some positive aspects to this too. The added flexibility of being able to participate from home (while also potentially isolating) seemed to improve accessibility.

Another benefit was that the Zoom platform was able to provide a written transcription of recordings. This was beneficial not only because it allowed the research team to engage more during the discussions (rather than being concerned with writing down key issues from the discussions), but also because some participants wanted to go back and check their transcription to see if they had successfully conveyed their thoughts.

Of the organisations listed in 3.3, above, those whose team or members participated in the forum discussion sessions were: A Gender Agenda, ACT Disability Aged Carer Advocacy Service, Carers ACT, Health Care Consumers' Association ACT, and National Disability Service (ACT).

3.3.2 Modality 2: Written Submissions

Another option for individuals who wanted to contribute but could or did not wish to take part in the forum discussion sessions was to provide written submissions to the research team.

Of the organisations listed in 3.3, above, those whose team or members participated in the forum discussion sessions were: ACT Disability Aged Carer Advocacy Service, and Advocacy for Inclusion.

3.3.3 Modality 3: Individual Discussions

The ANU Medical School research team also set aside appointments for individuals to have one-on-one discussions about consumer, carer, and community perspectives and needs for the ethical decision-making framework. Appointments were flexible and aimed to allow people to engage in more in-depth discussions about concerns relevant to specific consumers, carers, community members or groups.

Of the organisations listed in 3.3, above, those whose team or members participated in the individual discussion sessions were: ACT Down Syndrome Association, ACT Human Rights Commission, and Health Care Consumers' Association ACT.

3.4 Phase 2

A thematic analysis (see section 3.5 for further details) was conducted on the data from Phase 1. This was a deductive – or theory-driven – analysis whereby existing literature on COVID-19 ethical decision-making frameworks (see section 2.1) and the Human Rights implications (see section 2.2) formed the lens through which the thematic analysis was conducted.

The preliminary outcomes of this thematic analysis (which formed the basis for the Outcomes of the Consultation discussed in section 4 of this report) were then shared with senior representatives from each consumer, carer, or community group to have the chance to ensure the synthesis addressed key issues, and to comment on any necessary changes. Clinicians were also consulted during this phase to determine the appropriateness of the the guide to support clinical decisions.

3.5 Analytic Framework

Data were analysed using the principles of thematic analysis based on the steps outlined by Braun and Clarke.⁴⁸ This process involves repeated and iterative reading of the data for familiarisation and to generate initial codes. These codes were then applied to the data and refined and reviewed as the data are coded. Related codes are then grouped into provisional themes that are refined as data related to each theme is assessed for fit (or lack of fit) with the theme. The approach was both theory-driven (informed by the previous ethical decision-making frameworks; see sections 2.1 and 2.2) and data-driven (so that the analysis could capture novel information that might not have been anticipated from existing work).

4. Outcomes of the Consultation

Participants across the 3 modalities received a Conversation Guide prior to the discussions (Appendix A). However, the communication sent with Conversation Guide itself, and the preamble to each consultation pointed out that although the discussion would be based loosely on the questions in the guide, participants were encouraged to critique the questions themselves, propose other questions, or to raise other issues more important to the discussions as they saw fit.

4.1 Theme 1: Compatibility of triage with Human Rights

Our consultation questions were largely informed by practical approaches to triage – e.g., questions dealing with demand/supply and allocation of resources in the context of acute care in COVID-19. Many participants in the consultation processes critiqued this approach – suggesting that before even considering triage, there were two considerations that should come first: a) stressing the importance of avoiding situations where demand exceeds capacity for acute care (this aligns with the findings of our review of community consultations in section 1.3), and b) the primacy of Human Rights in these discussions.

Importance of Avoiding Capacity vs Demand Situation

Participants emphasised the importance of trying to avoid a situation whereby this ethical decision-making framework would be used at all – a sentiment which health services and clinicians would echo. There was some concern that governments were not pressured enough to ensure that we have enough resources to cope with demand. Some participants also discussed their experiences of being health service users during the COVID-19 pandemic and noting that it is not only COVID patients who are impacted by decisions about capacity and care during this time.

Primacy of Human Rights

The other aspect of this theme related to participants' concerns that in presenting a utilitarian question about allocating resources, Human Rights principles were already being violated by even considering that a triage system might privilege one person over another. This was an issue that was raised in most consultation sessions, with participants emphasising how “every life is of value, and every life is important”. It was generally considered that the conversations should start by suggesting that ‘we’ would “try our hardest to have enough resources to treat everybody” and then move to a Human Rights framework that discussed Human Rights rather than questions about resources.

Theme 1 Summary

Participants' concerns about the mismatch between a triage approach and Human Rights reflects that "compatibilizing the reality of triage and Human Rights" has not yet received significant attention.⁴⁹ Nonetheless, the message from the consultation sessions is to *begin* with Human Rights principles.

4.2 Theme 2: Approaches to triage

Although participants' discussion about issues discussed in Theme 1 often related to how triage was considered incompatible with Human Rights, the overall aim of the process was to better understand consumers', carers', and community members' needs and perspectives in relation to triage. Indeed one of the participants said that this talk about how health care should be allocated was "one of the most important discussions a society can have." The sub-themes related to approaches to triage were focusing specifically on immediate COVID-19 factors, and processes.

Focusing on Patient's Immediate Health Issues

When asked about what considerations should not form part of decision-making processes, several participants suggested that it would be problematic to consider anything other than concerns specific to their immediate health issues. In other words, if clinicians are to "focus on the immediate health needs" of the patient, then that would be an appropriate approach to triage. There was concern that using any "attributes about a person" other than their immediate health condition in decision-making processes would lead to discrimination.

In a similar vein, participants emphasised that if a patient required a reasonable adjustment to their care (e.g., requiring extra support for an existing comorbidity), that should not be taken into consideration about whether or not they should receive treatment.

Triage processes

Participants generally did not answer the questions about how triage should determine who receives critical care. However, they did discuss other aspects of the triage system that they thought were critical. For instance, some were concerned with a model which used a separate triage team to make the decision. The model would exclude the treating team, which might mean a reduced understanding of a person's care needs.

Some were concerned that there was a risk that bias about who should receive critical care could be present even though most health service providers would have good will.

There was also discussion about how some triage systems implied that a consumer would either be treated and receive critical care, or would be triaged into a palliative care stream. Acknowledging that palliative care is important, these participants were concerned about how palliative care would be framed in any guidelines produced – they thought that palliative care is the right treatment to offer those for whom there was no other treatment, but that offering palliative care should not remove the obligation to treat patients where viable treatment might exist.

Other participants raised concerns about whether the triage system should be a “medical decision” at all, noting that medical doctors should not have a monopoly on ethical decision making and in fact have competing interests given that they work within a system with inadequate resources. These participants suggested that the onus should be on politicians to explain their public funding in detail (reflecting the opinion that any lack of resources is not the fault of health professionals).

Several members of the conversation forum felt comfortable with a ‘first-come, first-served’ model where there was a need for triage of acute care resources. If a resource was available when a patient needed it, they would be allocated that resource. In such a system, if resources were not available at the time that a patient needed them, they would not be able to access that resource (i.e., the resource could not be re-allocated unless another patient using it no longer had a medical need for it).

Participants emphasised that discussions should be had about care and values early on so as to accommodate a person’s needs within decision-making processes. It was noted that there would need to be sufficient time and resources and clear communication in order to have such discussions (and in a Super Surge context, such time would likely be stretched).

Theme 2 Summary

That our discussions touched on this tension between non-discrimination and triage systems is perhaps unsurprising – and it is noteworthy that it reflects broader discussions from early on in the pandemic. One of the important principles from participants’ accounts is that **immediate health concerns** should be the main focus of a triage system. The second approach endorsed by some forum discussion participants is a ‘first-come, first-served approach’ as it was perceived to minimise discrimination. However, there are concerns that it would still “disadvantage the more vulnerable in society with the worst access to healthcare.”⁵⁰

As in Theme 1, discussion about triage and Human Rights seem to indicate a lack of compatibility. Theme 2 extends this discussion by highlighting that consumers, carers, and community members want non-discrimination to underpin whatever triage approach is adopted. A Human Rights-driven triage “would have to identify a minimum level of entitlement that may never be restricted even in the presence of resource scarcity. Exactly what this minimum should be is something that can only be decided through a democratic process, but some such level must be defined.”⁴⁹ While the conversation guide did seek to find out what these minimum levels of entitlement might be, several participants of the consultation process called for a democratic process (see section 4.4; Theme 4) after the COVID-19 pandemic to revisit these questions when we have time and the ability to do so.

4.3 Theme 3: Discrimination

Discussion about particular forms of discrimination and how particular consumer, carer, and community groups experience discrimination was another important theme of the findings of the consultation discussions. Overall, participants wanted clinical decisions to be made independent of “any factor of people’s lives” (most often in terms of assumptions and value judgements about quality of life) outside of the context of their immediate health issues.

Age

One of the areas of discrimination in the COVID-19 pandemic relates to age – and this was brought up by participants in the consultation discussions. As one participant said, “if this process reinforces the idea that our community values older people less than it values younger people, it would not be a good idea anywhere in Australia” (let alone within the ACT Human Rights jurisdiction). Participants were concerned that the ways that the other jurisdictions had set up their pandemic triage systems were inherently discriminatory towards older people (but noted that sometimes these could be euphemistic such as through particular clinical severity of illness scoring systems).

Managing Discrimination

Some participants suggested that those clinicians using triage tools must be educated about discrimination by those who likely to be impacted by it.

Individuals' own equipment

Some participants were concerned that the question in the conversation guide about reallocating a ventilator from a patient using it to another person who needed it, might imply that we were asking about taking a consumer's own ventilator off them to reallocate to someone else – we had not realised the question might be interpreted this way but it underscores the discrimination that people with disabilities are used to experiencing that this question could be taken in this way. They pointed out that there was no circumstance in which a person's own ventilator should be taken.

4.4 Theme 4: Beyond COVID-19

Participants tended to acknowledge that these discussions were being held in an unusual time (during a pandemic) and in an unusual way (online rather than face-to-face because of physical distancing requirements and health concerns), and that such discussions fit into broader discourses and practices in our society about how life is valued, how we allocate health care resources, and discrimination across these intersecting issues. As such, participants noted that it might be useful to have a more deliberative democratic discussion about allocation of health care resources during a time less fraught and limited as we are in the context of COVID-19. Indeed, as one participant noted that it is “one of the most important discussions a society can have” it seems that more stakeholders need to engage with it.

Some participants expressed hope that the lessons we are learning during COVID-19 (such as the importance of valuing life and the issues discussed throughout this document) would not be forgotten after the pandemic is over. In terms of talking about death and dying and advance care planning, participants suggested that these were aspects of health care that have not been dealt with as broadly by society as they have to be in the threat of being overwhelmed by a pandemic. Certainly discussing issues like advance care planning should be done even during non-pandemic times, but the pandemic has brought the issue to the fore.

Last, the need for better connections between medical and other sectors (in particular disability) was an issue raised by participants. Participants noted that there are synergies between sectors, with supports offered outside the medical sector that could support health outcomes. Participants were hopeful that the engagement that there has been (such as in these consultations) would continue beyond the pandemic.

5. Recommendations

5.1 Recommendations for an Ethical Decision-Making Framework

From the findings presented in Section 4, there are a number of key principles we recommend be incorporated into the Framework. These principles include:

- Ensure Primacy of Human Rights
- Embed Non-Discrimination in Triage
- Base Triage on COVID-19-Specific Concerns (i.e., without making value judgements about other aspects of patient's lives such as assumptions of quality of life).
- Ensure Triage Processes Minimise Bias
- Ensure Transparency

5.1.1 Ensure Primacy of Human Rights

Theme 1 (Section 4.1) explores consultation participants' perspectives on whether triage is compatible with a Human Rights approach. Based on the consultation, and the reviews of the triage processes, it seems that that a transparent (see 5.1.5) triage system that minimises bias (5.1.4) and is based on the principles of non-discrimination (5.1.2) can be compatible with Human Rights.

As mentioned in Section 1.3, international Human Rights law guarantees everyone the right to the highest attainable standard of health. In the event that a triage system would need to be adopted to manage demand exceeding capacity for critical care, decision-making should occur in a transparent way, minimising harms from discrimination (see 5.1.2) and a lack of transparency (see 5.1.5). The existence of an ethical decision making framework for triage in surge situations does not remove the obligation of governments to take steps to prevent threats to public health,³⁴ and this is aligned with consultation participants' concerns that governments would need to ensure health care capacity to deal with the pandemic (Section 4.1). The application of such a framework would only be appropriate for the duration of time that COVID-19 has had such an impact on the demand for critical care that capacity cannot meet.

We recommend that the development of the triage system begins with a Human Rights framework before considering issues about resources.

5.1.2 Embed Non-Discrimination in Triage

One of the concerns of many consultation participants was, understandably, discrimination within triage systems. Although a significant public health threat can justify certain Human Rights restrictions,³⁴ non-discrimination is one of the principles which can limit harms arising from COVID-19 response measures. Indeed, part of the aim of the consultation strategy was to consult broadly with groups marginalised in our community to seek their expertise and insights into an equitable triage system. Specific types of discrimination that were of concern – and there are further issues about discrimination not addressed in the consultations but that are nonetheless aligned with this principle – were related to age (and that triage should not reinforce the idea that our community values older people less than it values younger people), disability (and that value judgements should not be made on perceived quality of life of those with disability), gender and sexuality related discrimination.

One of the ways consultation participants felt that triage system could be based in non-discriminatory practices was to adopt a ‘first-come, first-served’ approach to allocation of critical care resources. While this might seem to alleviate non-discrimination, there are concerns that a ‘first-come, first-served’ process is inherently discriminatory in the way that it privileges those with greater health literacy, and access to health care. As such, a system that more meaningfully engages with non-discriminatory practices would be preferable.

We recommend that the triage system adopted should demand exceed capacity in the context of the COVID-19 pandemic be based on principles of non-discrimination.

5.1.3 Base Triage on immediate health-related concerns

Aligned with the principles of the primacy of Human Rights (see 5.1.1) and non-discrimination (see 5.1.2) participants suggested that the most appropriate triage system would not take into account factors of people’s lives outside of the context of their immediate health condition. That is, that triage should not be making value judgements about, for instance, issues related to extra support a person may need, or assumptions about quality of life due to pre-existing conditions or disabilities.

It is important to note that the clinical understanding of COVID-19 is emerging, and thus the understanding about the health concerns associated with COVID-19 is a developing field. As such, adopting a triage system that can be reviewed as these understandings continue to be improved would be prudent.

We recommend that the triage system adopted should avoid input other than that related to an individual patient's immediate health concerns in relation to COVID-19.

5.1.4 Ensure Triage Processes Minimise Bias

Following on from the point that the system should be driven by a Human Rights approach (5.1.1), non-discriminatory (5.1.2), and based specifically on COVID-19 related health concerns (5.1.3) consultation participants acknowledged that a triage system *could* be used to minimise bias. That is, in a situation where demand exceeds capacity for critical care in the COVID-19 pandemic, it is through an appropriate triage system that bias can be minimised. This is reflected by thought leaders in triage and Human Rights for COVID-19, who have suggested that triage needs to be a tool that supports care rather than obstructs it, and that such a triage that is necessary because resources are not available is appropriate (given consideration for the issues raised above in sections 5.1.1-5.1.3).⁴⁹

We recommend use of a triage system that minimises bias through centring Human Rights, a focus on non-discriminatory practice, and being based on specific COVID-19 issues.

Another key issue related to appropriate triage processes was in relation to triage into a palliative care stream. Consultation participants were concerned that a palliative care stream should be offered as a treatment option when it is medically the right thing to do, rather than it being offered because there was no other option. Clarity of communication appears to be critical here so that consumers and carers understand treatment pathways. Acknowledging the importance of quality palliative care at any time – including during a pandemic – **we recommend clarity about triage for palliative care in the context of COVID-19.**

5.1.5 Ensure Transparency

Consultation participants asked that decisions about critical care resource allocation be transparent and clearly documented to ensure that decisions were consistent with guidelines. An appeal or review process was suggested as a way to ensure comfort with and trust in the system. Aligned with the importance of a triage system based on non-discrimination, we agree that transparency is critical.

We recommend a review process be built into the COVID-19 ethical decision-making framework.

5.2 Recommendations beyond COVID-19

Based on the findings of the consultative process, we recommend that:

- discussions about how critical health care allocation be revisited – perhaps in a deliberative democratic process – outside of the COVID-19 context. The current discussions had to be completed with limited time and resources, but we acknowledge that deciding about health care allocation is “one of the most important discussions a society can have”
- we do not forget, after the COVID-19 crisis, the discussions (and the *importance of the discussions*) we are having about facing public health threats. This might include focusing on the importance of Advance Care Planning, and resources for the health system.
- we remember the value of collaborations within and beyond our immediate expertise. Talking with people from across and beyond parts of the health sector, the disability sector, and with all the individuals who participated in the consultative discussions has been invaluable.

6. Evaluation of the Principles and Processes

The recommendations in Section 5, together with the information from the scoping review in Section 1 formed the basis for the principles and process of the Triage Process. Once these principles were written up into the “ACT Global COVID_19 Pandemic: Principles and Ethical Concepts for Triage” and the process was written up into the “ACT Global COVID-19 Pandemic: CHECC Intensive Care Triage Process”, these documents and an earlier version of the current report was sent out for wider review. The review process included the Canberra Health Services Clinical Ethics Committee, the ACT Clinical Leadership Forum, the ACT Solicitor General, the Directors of the relevant clinical areas across the ACT, and all consumer, carer, and community groups listed in the final column of the table on page 15.

By this stage, most of the consumer, carer, and community groups had seen a number of versions of the document. As such, the majority of edits from these groups were for typographical errors, minor nuances, and points of clarification. Some groups did have ongoing concerns to address, and section 6.1 outlines these ongoing concerns with a brief note of how the concerns were addressed.

6.1 Addressing the Final Round of Concerns

Aboriginal and Torres Strait Islander people

One group was concerned that Aboriginal and Torres Strait Islander people were only mentioned once in the earlier version of the documents.

A further paragraph has now been added outlining the extra support available for Aboriginal and Torres Strait Islander patients. This is in the process document to allow access to support when needed: “For those who identify as an Aboriginal and Torres Strait Islander person, they will be offered support by an Aboriginal Liaison Officer. They may be able to provide assistance with supported decision making, and psychosocial support throughout the triage process. The Aboriginal Liaison Officer for each facility is contactable through the relevant switchboard.”

Broader Discrimination

Two groups highlighted that although the triage process is clear about how inappropriate discriminatory factors will not contribute to decision-making in the context of COVID-19, it should not be forgotten that discrimination *does* influence health care more broadly and that vulnerable and marginalised patients may have higher risks of mortality.

Indeed, this triage process has been established only for instances when the ACT is at surge or super-surge capacity in the COVID-19 pandemic. As such, they seek to be non-discriminatory to the extent of their power, but they do not redress ongoing marginalisation and inequities in health outcomes more broadly.

Compatibility of Human Rights with Triage

Most organisations welcomed the way the framework had addressed human rights obligations. There was a group who had ongoing concerns that the “guidelines still work from a position of resource driven triage” which would lead to discrimination and denial of access on the basis of age, disability and other personal characteristics. The group called for reasonable adjustments to be made such that the triage process actively demonstrate how reasonable adjustments will be embedded to enable equitable access to quality of care for all people, including vulnerable people.

In collaboration with the ACT Human Rights Commission, this concern has been addressed in the final principles and processes documents in the following ways:

- Age is no longer part of the triage process. There *had* previously been discussion amongst the Steering Group as to whether age could be included as a tiebreaker. (I.e., if all else was equal between two or more patients in terms of expected clinical outcomes, could we then bring age into the triage process?) However, given these human rights concerns, age is no longer considered in the triage process for COVID-19 in the ACT.
- Reasonable adjustments are now explicitly part of the triage process in several ways. First, reasonable adjustments can be made to the SOFA or paediatric SOFA score. Second, the triage team are to make reasonable adjustments when assessing persons with a disability or otherwise vulnerable to discrimination. Last, the triage team are to be appropriately trained in non-discrimination – of which an understanding of reasonable adjustments is part. These reasonable adjustments might include adapted communication techniques, translation and supported decision-making.
- Although the group was concerned that there was an ongoing impossibility of reconciling a triage approach with the ACT’s obligations as a human rights jurisdiction, no alternatives to a triage approach were developed through any stage of the reviews/consultation processes. Indeed, the triage process has been developed to minimise discrimination and to ensure that decisions are made consistent with human rights obligations.
- To ensure that the triage process is compatible with the ACT’s responsibility to human rights, the Steering Group includes the ACT Human Rights Commissioner.

Oversight of Triage Teams

One group was concerned about the level of skills and experience that triage teams have in working with people with disabilities and accommodating their reasonable adjustments.

This concern has been addressed by:

- Ensuring that triage teams comprise two Triage Officers (a senior intensive care specialist and a senior emergency medicine specialist), a Triage Nurse (an experienced critical care nurse), and administrative staff member, and a specialist palliative care team member.
- Ensuring all triage team members undergo unconscious bias training prior to commencement.

SOFA Score

Most feedback about the SOFA score was that it seemed suitable. One group was concerned that it was suitable *provided* that reasonable adjustments can be made for those with disabilities – which has been addressed as above.

Tiebreakers

After removing age, the only remaining tiebreaker is randomisation as this was the only way to ensure any particular group was not privileged over others. While some other jurisdictions have supported particular groups (such as adults with caring responsibilities and health care workers), the process in the ACT is based on human rights and does not privilege particular groups over others.

6.2 Concluding Remark

Many of the groups consulted acknowledged that although the discussions were at times difficult, they appreciated the opportunity to be involved. A number of individuals from some groups noted that they were not usually – or had never before been – consulted at all in systemic decisions in the health sector; they expressed a hope that if such engagement were possible in the extra challenging context of COVID-19, that ongoing future engagement would be possible.

Acknowledgements

This work has been a collaborative effort and could not have been completed without the patient and wise input from the following individuals and the support from their communities:

Kate Gorman, Health Care Consumers' Association ACT

Lisa Kelly, Carers ACT

Emma Campbell, ACT Council of Social Service

Craig Wallace, ACT Council of Social Service

Lauren O'Brien, ACT Disability, Aged and Carer Advocacy Service

Bonnie Millen, Advocacy for Inclusion

Karen Toohey, ACT Human Rights Commission

Shannon Kolak, ACT Down Syndrome Association

Sue Schreiner, Health Care Consumers' Association ACT

Shelley McInnis, Health Care Consumers' Association ACT

Rey Reodica, National Disability Service

Sel Cooper, A Gender Agenda

Cee Moore, Women With Disabilities ACT

Isobel Shearman, ACT Mental Health Consumer Network

Chin Wong, Canberra Multicultural Community Forum

Ana Herceg, Winnunga Nimmityjah Aboriginal Health and Community Services

Julie Tongs, Winnunga Nimmityjah Aboriginal Health and Community Services

Nadeem Siddique, Winnunga Nimmityjah Aboriginal Health and Community Services

Clinical Ethics Committee, ACT Health

Suzanne Smallbane, Calvary Public Hospital Bruce

Helen Watchirs, ACT Human Rights Commission

Dougie Herd, ACT Disability Reference Group

Benjamin Bramble, The Australian National University.

Darlene Cox, Health Care Consumers' Association ACT

The authors acknowledge the First Australians. These consultations were held on the land of the Ngunnawal and Ngambri people. We respect their Elders, and acknowledge that their people are among those impacted by the marginalisation that this consultation process has tried in a small part to redress by putting consumer, carer, and community perspectives first in the development of the framework.

Reference List

1. Roper C, Grey F and Cadogan E. *Co-production - Putting principles into practice in mental health contexts*. 2018.
2. Rosenbaum L. Facing Covid-19 in Italy — Ethics, Logistics, and Therapeutics on the Epidemic’s Front Line. *New England Journal of Medicine* 2020; 382: 1873-1875.
3. Gandhi R and Patel A. What if Two COVID-19 Victims Need Ventilators and Just One Is Available? <https://blogs.scientificamerican.com/observations/what-if-two-covid-19-victims-need-ventilators-and-just-one-is-available/>: Scientific American, 2020.
4. McDougall R, Sheahan L and Ko D. Planning for and managing COVID-19: Ethical decision-making tool, https://mspgh.unimelb.edu.au/_data/assets/pdf_file/0015/3330060/COVID-ethical-tool-McDougall-Sheahan-Ko-v3.pdf (2020, accessed 5 May 2020).
5. World Health Organization Working Group on Ethics and COVID-19. Ethics and COVID-19: resource allocation and priority-setting, <https://www.who.int/who-documents-detail/ethics-and-covid-19-resource-allocation-and-priority-setting> (2020, accessed 4 May 2020).
6. Thompson AK, Faith K, Gibson JL, et al. Pandemic influenza preparedness: an ethical framework to guide decision-making. *BMC Medical Ethics* 2006; 7: 12. DOI: 10.1186/1472-6939-7-12.
7. Alberta Pandemic Influenza Planning Joint Advisory Committee. Alberta’s Ethical Framework for Responding to Pandemic Influenza, <https://open.alberta.ca/dataset/5ae20e2c-4d4a-4251-bf05-dcdf32d0cd97/resource/5621dbe3-4b27-4c37-9073-58d762312d6f/download/apip-pandemic-ethics-framework-2016.pdf> (2016, accessed 9 May 2020).
8. Savulescu J, Cameron J and Wilkinson D. Equality or utility? Ethics and law of rationing ventilators. *British Journal of Anaesthesia* 2020. DOI: <https://doi.org/10.1016/j.bja.2020.04.011>.
9. Emanuel EJ, Persad G, Upshur R, et al. Fair Allocation of Scarce Medical Resources in the Time of Covid-19. *New England Journal of Medicine* 2020. DOI: 10.1056/NEJMs2005114.
10. Dawson A, Isaacs D, Jansen M, et al. An Ethics Framework for Making Resource Allocation Decisions within Clinical Care: Responding to COVID-19, <https://www.sydney.edu.au/content/dam/corporate/documents/faculty-of-medicine-and-health/research/centres-institutes-groups/she.-clinical-ethics.-resource-allocation-framework.-version-1.-2-april-2020.pdf> (2020, accessed 5 May 2020).
11. British Medical Association. COVID-19 - ethical issues. A guidance note, <https://www.bma.org.uk/media/2360/bma-covid-19-ethics-guidance-april-2020.pdf> (2020, accessed 10 May 2020).
12. White DB and Lo B. A Framework for Rationing Ventilators and Critical Care Beds During the COVID-19 Pandemic. *JAMA* 2020. DOI: 10.1001/jama.2020.5046.
13. Queensland Clinical Senate. Queensland ethical framework to guide clinical decision making in the COVID-19. pandemic <https://clinicaexcellence.qld.gov.au/priority-areas/clinician-engagement/queensland-clinical-senate/publications> (2020, accessed 4 May 2020).

14. New York State Task Force on Life and the Law and New York State Department of Health. Ventilator allocation guidelines, https://www.health.ny.gov/regulations/task_force/reports_publications/docs/ventilator_guidelines.pdf (2015, accessed 4 May 2020).
15. Daugherty Biddison EL, Faden R, Gwon HS, et al. Too Many Patients...A Framework to Guide Statewide Allocation of Scarce Mechanical Ventilation During Disasters. *Chest* 2019; 155: 848-854. DOI: <https://doi.org/10.1016/j.chest.2018.09.025>.
16. White D. A Model Hospital Policy for Allocating Scarce Critical Care Resources, <https://ccm.pitt.edu/?q=content/model-hospital-policy-allocating-scarce-critical-care-resources-available-online-now> (2020, accessed 3 May 2020).
17. NICE. COVID-19 rapid guideline: critical care in adults, <https://www.nice.org.uk/guidance/ng159> (2020, accessed 3 May 2020).
18. Warrillow S, Austin D, Cheung W, et al. ANZICS guiding principles for complex decision making during the COVID-19 pandemic. *Crit Care Resusc* 2020 2020/04/17.
19. Arie S. Covid-19: Can France's ethical support units help doctors make challenging decisions? *BMJ* 2020; 369: m1291. DOI: 10.1136/bmj.m1291.
20. Truog RD, Mitchell C and Daley GQ. The Toughest Triage — Allocating Ventilators in a Pandemic. *New England Journal of Medicine* 2020. DOI: 10.1056/NEJMp2005689.
21. Forum ED. Open letter to leaders at the EU and in EU countries: COVID-19 - Disability inclusive response, <http://edf-feph.org/newsroom/news/open-letter-leaders-eu-and-eu-countries-covid-19-disability-inclusive-response> (2020, accessed 7 May 2020).
22. Ne'eman A. 'I will not apologize for my needs', <https://www.nytimes.com/2020/03/23/opinion/coronavirus-ventilators-triage-disability.html> (2020, accessed 7 May 2020).
23. People with Disability Australia. Media Release: Urgent Measures Needed to Support People with Disability During COVID-19 Crisis, <https://pwd.org.au/covid-19-crisis-mr/> (2020, accessed 26 May 2020).
24. Disabled People's Organisations Australia. Statement of Concern - COVID-19: Human rights, disability and ethical decision-making, <https://dpoa.org.au/statement-of-concern-covid-19-human-rights-disability-and-ethical-decision-making/> (2020, accessed 26 May 2020).
25. Disability Rights UK. COVID-19 and the rights of disabled people, <https://www.disabilityrightsuk.org/news/2020/april/covid-19-and-rights-disabled-people> (2020, accessed 26 May 2020).
26. Mello MM, Persad G and White DB. Respecting Disability Rights — Toward Improved Crisis Standards of Care. *New England Journal of Medicine* 2020. DOI: 10.1056/NEJMp2011997.
27. Solomon MZ, Wynia MK and Gostin LO. Covid-19 Crisis Triage — Optimizing Health Outcomes and Disability Rights. *New England Journal of Medicine* 2020. DOI: 10.1056/NEJMp2008300.
28. Daugherty Biddison EL, Gwon H, Schoch-Spana M, et al. The community speaks: understanding ethical values in allocation of scarce lifesaving resources during disasters. *Ann Am Thorac Soc* 2014; 11: 777-783. 2014/04/26. DOI: 10.1513/AnnalsATS.201310-379OC.

29. Braunack-Mayer AJ, Street JM, Rogers WA, et al. Including the public in pandemic planning: a deliberative approach. *BMC Public Health* 2010; 10: 501. 2010/08/20. DOI: 10.1186/1471-2458-10-501.
30. Silva DS, Gibson JL, Robertson A, et al. Priority setting of ICU resources in an influenza pandemic: a qualitative study of the Canadian public's perspectives. *BMC Public Health* 2012; 12: 241. 2012/03/28. DOI: 10.1186/1471-2458-12-241.
31. Bailey TM, Haines C, Rosychuk RJ, et al. Public engagement on ethical principles in allocating scarce resources during an influenza pandemic. *Vaccine* 2011; 29: 3111-3117. 2011/03/08. DOI: 10.1016/j.vaccine.2011.02.032.
32. Docter SP, Street J, Braunack-mayer AJ, et al. Public perceptions of pandemic influenza resource allocation: A deliberative forum using Grid/Group analysis. *Journal of Public Health Policy* 2011; 32: 350-366. DOI: <http://dx.doi.org/10.1057/jphp.2010.49>.
33. Biddison ELD, Gwon HS, Schoch-Spana M, et al. Scarce Resource Allocation During Disasters: A Mixed-Method Community Engagement Study. *CHEST* 2018; 153: 187-195. DOI: 10.1016/j.chest.2017.08.001.
34. Human Rights Watch. Human Rights Dimensions of COVID-19 Response, <https://www.hrw.org/news/2020/03/19/human-rights-dimensions-covid-19-response> (2020).
35. International Covenant on Economic, Social and Cultural Rights (ICESCR). adopted 10 December 1966, 1966.
36. The Universal Declaration of Human Rights (UDHR). 1948.
37. International Covenant on Civil and Political Rights (ICCPR). 1966.
38. Convention on the Elimination of All Forms of Discrimination against Women 1979.
39. Convention on the Rights of the Child (CRC). 1989.
40. Convention on the Rights of Persons with Disabilities (CRPD). 2006.
41. WHO. Engagement and participation for health equity. Copenhagen: World Health Organization, 2017.
42. Australian Commission on Safety and Quality in Health Care. National Safety and Quality Health Service Standards. 2nd ed. In: ACSQHC, (ed.). Sydney 2017.
43. Scholz B, Bevan A, Georgousopoulou E, et al. Consumer and carer leadership in palliative care academia and practice: A Systematic Review with Narrative Synthesis. *Palliative Medicine* 2019; 33: 959-968. DOI: 10.1177/0269216319854012.
44. Scholz B, Gordon S and Happell B. Consumers in mental health service leadership: A systematic review. *International Journal of Mental Health Nursing* 2016; 26: 20-31. DOI: 10.1111/inm.12266.
45. Scholz B, Bocking J and Happell B. Improving exchange with consumers within mental health organisations: Recognising mental ill health experiences as a "sneaky, special degree". *International Journal of Mental Health Nursing* 2018; 27: 227-235. DOI: 10.1111/inm.12312.
46. Scholz B, Bocking J, Platania-Phung C, et al. "Coming from a different place": Partnerships between consumers and health services for system change. *Journal of Clinical Nursing* 2018; 27: 3622-3629. DOI: 10.1111/jocn.14520.

47. WHO. Urgent health challenges for the next decade, <https://www.who.int/news-room/photo-story/photo-story-detail/urgent-health-challenges-for-the-next-decade> (2020).
48. Braun V and Clarke V. Using thematic analysis in psychology. *Qualitative Research in Psychology* 2006; 3: 77-101.
49. Arosemena Solorzano G. Some cautious reflections on triage and human rights, <https://www.maastrichtuniversity.nl/blog/2020/04/some-cautious-reflections-triage-and-human-rights> (2020).
50. Pagel C, Utey M and Ray S. COVID-19: How to triage effectively in a pandemic, <https://blogs.bmj.com/bmj/2020/03/09/covid-19-triage-in-a-pandemic-is-even-thornier-than-you-might-think/> (2020).

Appendix A: Conversation Guide

Question 1

Frameworks in other jurisdictions have suggested many ways of allocating health care resources when there is more demand than supply. Examples include prioritising younger patients (who may have longer to live if they survive), or patients with fewer comorbidities (who may have more chance of survival). In these circumstances:

- o What key considerations do you think clinicians should use to determine who receives critical care support?
- o What considerations should not form part of decision making?

Question 2

Should clinicians be able to remove a ventilator from a patient already using it to give to another person who needs it? Are there any circumstances in which this would be acceptable and what are they?

Question 3

What are the key issues around resource allocation for you or your community in the global COVID-19 pandemic, that you want health services and clinicians to understand and consider if demand for resources exceeds capacity?

Question 4

Are there any key issues that have not been addressed, or that you feel need to be addressed? If so, what are they?