



Health Issues Centre
Consumer voices for better healthcare

COVID-19 FORUM

“Who Makes the Call?”



April 2, 2020

Executive Summary

The grim reality of rationing intensive care resources as a result of COVID-19 has recently been witnessed or predicted in several countries (e.g. Italy, USA). Whilst social distancing measures introduced within Australia to ensure our health system is not overwhelmed have thus far been successful, there is considerable (and understandable) anxiety among those with complex conditions and vulnerabilities that they may be denied intensive care should the situation escalate. If that occurs, multiple patients will be subject to triage and clinicians will be in the invidious position of having to make difficult life and death choices. If these choices are not guided by social as well as clinical considerations, they will default to utilitarian choices and that does not bode well for vulnerable individuals. Although some debate is occurring in this space, to date the discussion has been driven by clinicians, academics and policy advisors. A key omission in the discussion has been the voice of the consumer.

In response, on Thursday 2 April 2020, Health Issues Centre (HIC) hosted an online forum to initiate discussion around an ethical decision-making framework for triage during the COVID-19 epidemic. The forum aimed to explore the following:

- A group view as to whether or not a utilitarian approach to triage can be expanded to include social justice and health equity criteria.
- If so, key principles and considerations that should inform a guiding Statement of Principles.
- If not, does it mean social justice and equity considerations are irrelevant or are they applied only to end-of-life management principles?
- How should vulnerable communities be informed if this turns out to be the case?

One hundred and seventy-four people participated in the forum (208 registrants), providing a valuable opportunity to share concerns and perspectives of highly vulnerable groups (condition and population specific). The forum involved experts from the fields of intensive care, ethics, geriatric medicine, ageing and cancer survival giving a series of informative and thought-provoking talks. The video of the plenary session can be viewed at: <https://hic.org.au/covid-19-forum-video/>. The presentations were followed by breakout groups where participants were asked to generate key insights, statements, concerns and/or principles. These statements were compiled into six salient themes - community participation, communication, information/education, clinical guidelines, health workers and ethical framework – and a post-forum survey was conducted to gauge the level of group consensus/endorsement.

Key findings

Whilst the initial intention of the forum was to establish the key elements of an ethical framework in the face of resource scarcity, the outputs of the day were more preliminary in their nature. It was clear from the responses to the keynote speakers, live chat and other feedback, that the forum served firstly as an opportunity to clarify aspects of COVID-19 infection and treatment that have been subordinated by the current public health focus on transmission prevention. The opportunity to voice concerns and ask questions related to specific vulnerabilities was highly valued. The most reiterated theme was a desire for more precise, consistent, transparent and accessible information and communication - not just on hygiene and social distancing but on PPEs, treatment options, outcomes and resource constraints.

This document provides an overview of the content presented and brings together the questions, comments and recommendations of those who contributed to the forum. The resultant statements presented as part of this report represent a community input into processes intended to deliver a nationally consistent ethical framework.



Forum overview

The forum was conducted online via Zoom and consisted of a plenary session with five expert guest speakers. This was followed by breakout groups to enable more detailed discussion among participants. It was facilitated by Health Issues Centre CEO, Danny Vadasz. The forum was recorded and the plenary session can be viewed at <https://hic.org.au/covid-19-forum-video/>. Questions and comments were encouraged via livechat (see Appendix 1) throughout the plenary. Due to time constraints, speakers were not able to answer all questions in the session.

Plenary session

The following highlights the key points made by each of the speakers:

Professor Charlie Corke – ICU perspective

Key points:

- Outlined doctors' concerns of providing treatment where the downside significantly outweighs the upside and that decisions about this is for patients rather than for doctors.
- Stated that people are not keen on prolonged, burdensome treatment that has poor chance of a good outcome.
- Highlighted experiences of frontline staff:
 - "What we do to patients with this personal, protective equipment on when everyone is terrified of you, doesn't want to touch you, doesn't want to go near you, has to wear all this stuff – it's pretty dehumanising."
- Discussed experience of triage and that making clinical decisions is not new:
 - "senior clinicians already make these decisions especially in winter. And these are the considerations that happen frequently in organ donation, how to ration scarce resources."
- Provided information on clinical aspects of the disease (e.g. inflammatory reaction) and ICU outcomes. Explained the need to focus on aspects of care other than just ventilators.
- Reassured that there was reason to be optimistic.

"But I was impressed not by the one third mortality but the two thirds who didn't die; and a lot of them had very mild symptoms. So I think we can all take away that there is the opportunity with this disease to be lucky and (dying is) not an inevitability."

Cathy Mead (board member and former president of Council on the Ageing - COTA) – At-risk population perspective

Key points:

- Acknowledged existing inequities in the system and stated that managing the crisis would require a mind-shift from clinicians:
 - "We are in the process of adding to the duty of care; the duty to manage scarce resources and that's a shift that clinicians are going to have to make.....and we make the shift by saying 'all patients are eligible for care' and then we consider how to prioritise that care."
 - "Inequity is already a part of the process but we are trying not to add to those inequities....co-morbidities are not evenly distributed across the population. They increase with age, they are higher with particular population groups, like Indigenous people. They also increase with lower socio-economic status and are not evenly spread geographically. So this background of inequity already exists."

"There should be no social criteria for exclusion from treatment but there may be some social criteria for inclusion and priorities. For example, we might want to give priority to healthcare workers. We might want to give priority to indigenous people."



- “(age) should be no social criteria for exclusion of treatment but there may be some social criteria for inclusion, for example health care workers and Indigenous people”
- Highlighted the importance of communication and language:
 - competing points of views and competing communications creates confusion, as does alarmist language and that language matters and needs to be more nuanced.
- Mentioned currently prioritisation is looking at:
 - Role of co-morbidities – how do we think of these (whilst it may sound harsh, helps to give consistency)
 - How the individual responds to the virus. Still looking for early identification markers.

Professor Paul Komesaroff – Ethical perspective

Key points:

- Highlighted and examined ethical decision strategies including more nuanced and complex considerations that inform decision making. More complex considerations include:
 - Rigorous discussion about treatments
 - Detailed analysis of technical issues
 - Flexibility and readiness to adapt
 - Does NOT involve rigid rules
- Discussed key principles of allocation:
 - All patients given best care in circumstances
 - Discussions open and transparent
 - All alternatives examined
 - Decisions based on need, prognosis and likely success
 - Age can be included as a signifier
 - Decisions not based on “social worth”

“We will be judged by future generations on how we respond to the present crisis. We need to keep our ethical nerve.”

“If we have values worth defending, this is the time we need to fight for them”

Sophy Athan (Health Issues Centre Board Chair) – At-risk condition specific perspective

Key points:

- Consulting the community was a vital part of developing an effective response to a major health crisis and she hoped this discussion would inform future planning and preparedness.
- “We need to not only engage in the conversation but we actually need to have these policies in place for the future.”
- “There’s been discussion over the last ten years that we are anticipating a pandemic ... so we have had sufficient warning. My question is, could we have prepared a little bit better? This is the beginning of potentially some further health crises that could be emerging in the future. Maybe there are lessons to be taken from that.”

Professor Vasi Naganathan – Geriatric medicine perspective

Key Points:

- Shared some oddly prophetic research he had been involved in that studied how Australian and New Zealand residents felt triage decisions should be made in the event of a flu pandemic. (<https://www.ncbi.nlm.nih.gov/pubmed/28866976>). The research showed consumers had a clear preference for doctors to make triage decisions (both New Zealand and Australia) – informed by present circumstances – with guidelines from health departments as a close second (Australia).
- Explained the importance of discussions about the balance between realistic optimism but also preparation and discussion about what people would want if they got sicker and the question of critical care.



- Discussed assessment tools and their limitations in assisting clinicians in making critical decisions:
 - “Age does come into it because older people are more likely to have health problems, multiple diseases and frailty. So do you use a tool for frailty? Do you use a tool to determine how sick someone is?”
 - “The problem with all tools is they’re not particularly accurate for the individual and a lot of people forget that. One of the concerns that geriatricians have is that the tools that are used for older people will be used for people with disability ... and it’s important to not think about people with disability in the same way as older people with co-morbidity and frailty.”
 - “But there is an appetite for using tools because people feel that it provides some clear guidance for what people should do.”
- Examined the concept of independent panels of 3 people to take the onus off medical staff in making ethical decisions - however stated that these too will have biases
- Discussed issues of co-morbidities:
 - “I intrinsically have a problem when the message seems to be that if you have chronic lung disease and you get COVID you’re going to die. That’s somewhat factually incorrect and it’s important it’s communicated clearly. I just imagine I’m that person sitting at home thinking if I get COVID I’m going to die, it’s a terrible existence. I feel terrible for people sitting at home in isolation with that fear. Because it’s not an accurate fear. They’re at increased risk but that’s not the same as you’re going to die if you get COVID.”
- Believes it is “important to have guidelines and tools and involve people from outside the box because in a vacuum the danger is local hospitals will develop their own protocols, which is already happening.”

Break-out groups

Following the plenary session, attendees then divided into 12 break-out groups with approximately 6 – 8 people per group. The groups were tasked to discuss key insights, concerns, statements and/or principles/recommendations for consideration in developing an ethical framework. Due to time limitations, the break-out groups were unable to share their discussions with the broader group and were encouraged to return their comments to HIC via email. Feedback was received from 9/12 groups.

Development and testing of statements/recommendations

Based on the break-out group feedback, several statements/recommendations were proposed. Approximately 37 statements were drafted by the groups. These were condensed to reduce duplication (22 resultant statements) and grouped into six salient themes - community participation, communication, information/education, clinical guidelines, health workers and ethical framework. A post-forum survey was conducted to gauge the level of group endorsement/consensus. Participants were invited to rate each of the statements/recommendations on a 5-point scale from strongly agree to strongly disagree. Eighty-eight responses were received (51% return rate) and results are discussed below.



Outcomes and key areas of focus

An analysis of the day's discussions (including both the plenary and breakout groups) indicates that participants focused on the following:

Community participation

Included the rights of consumers, as key stakeholders, to participate at all points of COVID-19 planning and preparation as well as in decision making around their own health choices. There was acknowledgement and dismay that there has been little to no community consultation and input into key areas including governance, the inclusion of community perspectives in framing policy, the development and testing of consumer materials, or the facilitation of consumer involvement in informed decision making around their own care, let alone consideration of an ethical approach to rationing critical resources.

"We will be judged by future generations on the decisions we make in response to this crisis."

Participants cited the suspension or deferral of existing consultative bodies (particularly advisory committees and clinical governance bodies) and the experience of being uninvited where those committees continued to operate. There was a sense that just at the time when community input was most crucial the system had reverted to a top-down, non-inclusive, non-consultative decision-making approach. Lack of consumer input also led to concerns about government transparency and accountability.

"This should be considered an opportunity to strengthen patient-centred care throughout the healthcare system, including resource allocation decisions."

"Public need a sense of control and understand that they will be part of decisions about their own care and treatment"

Communication

Included the need to translate official data, infection prevention guidelines, financial support packages and other government information into easily understood messages differentiated according to audience needs. The point was made that there is a significant difference between public health announcements and messaging – the translation of data and regulatory information into comprehensible communication that accounts for the differentiated realities, literacy levels and information needs of different populations.

"There is a difference between govt reporting and public messages - needs to be much more public messaging as part of the communication strategy - nationally and locally."

Participants emphasised the need to enrol community organisations in messaging given they best know the appropriate style, content and channels that are appropriate for their stakeholders.

"Communication HUGELY important - especially considering the various forms of accessible communication people with disability may need"

Information/Education

While understandably information to date has focussed on caseloads and infection prevention measures, there is important information regarding disease progression, treatment options, the complicating impact of pre-existing conditions and scarce resource allocation policies that haven't been explained to the public.

"The more we as a society know about the facts of ICU treatment the better prepared we will be to discuss whether it is the right option for someone."

Health workers

Participants acknowledged the need to support and protect health workers from vicarious trauma and the moral burden of having to make and feel responsible for life and death decisions.

Ethics

Participants expressed concern that susceptible communities (whether population groups or condition specific groups) will be disadvantaged once triage decisions are required. The speakers were able to address some of these concerns – providing factual information on how many people survive the disease and reassurance that care is not based on individual criteria (e.g. age) in isolation of other considerations.

Statements/recommendations

The 22 statements/recommendations as proposed by participants are listed below.

A score for the level of consensus was determined for three different groups:

- Group 1 - total respondents
- Group 2 - consumer and community group (included concerned users of the health system, representatives of community groups, charities, non-government organisations, consumer representatives)
- Group 3 – medical and health group (included medical professionals, non-medical health system staff, government staff)

The ‘Strongly agree’ and ‘Agree’ responses were combined to determine the score. The following table gives an overview of the results (for more detailed survey results, please see Appendix 2).

Table 1: Statements/recommendations and level of consensus from survey respondents.

Statement/Recommendation	Level of consensus		
<p>Key - Level of consensus (includes Strongly Agree and Agree responses)</p> <p> > 90% 80 – 89% 70 – 79% 60 – 69% 50 – 59% </p>	Group 1 Total (88 respondents)	Group 2 Consumers/ community (53 respondents)	Group 3 Medical professionals and health system staff – (30 respondents)
Community participation			
1. Governments and health services need to demonstrate an appetite for public engagement in process, decision-making (including resource allocation) and public messaging.	>90%	>90%	>90%
2. Consumer organisations should be enlisted to disseminate information to their communities.	>90%	>90%	>90%
3. There is a need for open and transparent accountability from government and health services and this must include a place for consumers/community groups (especially high-risk communities) at the table.	>90%	>90%	>90%
4. That it is a consumer’s right to have their unique circumstances and health issues taken into consideration and to be part of the decision-making around their treatment and care.	>90%	>90%	>90%
Communication			



5. That the government recognises that consumer and community organisations are best placed to process and distribute information to the groups they represent (e.g. may include road-testing of messages).	80-89%	80-89%	70-79%
6. That messaging must be concise, consistent, in plain English (or other community languages) and illustrated.	>90%	>90%	>90%
7. Recognise that current messaging may actually discourage vulnerable groups seeking care (particularly older people, people with disabilities and people with chronic conditions).	80-89%	80-89%	70-79%
8. Develop specific messages of reassurance for groups who have experiences of healthcare discrimination (e.g. lower socioeconomic groups, Aboriginal and Torres Strait Islander people) that they will receive care as needed.	>90%	>90%	>90%
Information/Education			
9. There needs to be public education about the reality of intensive care (e.g. treatment and morbidity)	>90%	>90%	>90%
10. There is a need to reassure people (particularly high-risk people) that primary and acute healthcare “below” intensive care will be available to them.	>90%	>90%	>90%
11. That there is a need for statements emphasising that whilst vulnerable groups are at increased risk, treatments are available, and outcomes are often positive. (eg old age is not a death sentence nor are young people indestructible).	>90%	>90%	>90%
12. That given the plethora of unreliable information, it is important to credential the authenticity and currency of sources and that superseded information is revoked.	>90%	>90%	>90%
Clinical guidelines			
13. Triage Officers should be made available to support staff in all ICU and high dependency settings, including makeshift settings.	80-89%	>90%	80-89%
14. That for those who do not want hospital admission, “hospital in the home care” is provided as an alternative.	80-89%	80-89%	80-89%
15. That when a positive COVID-19 test result is given, GPs should be empowered to initiate a discussion with the patient and their family on what might happen next (eg 15% may need hospitalisation, 5% may need intensive care) and the type of care they want.	>90%	>90%	>90%
16. Advance care planning discussions should be initiated and documented where appropriate.	>90%	>90%	>90%
Health workers			

17. Need to acknowledge vicarious trauma of health workers and provide appropriate support.	>90%	>90%	>90%
18. Need consistent protocols to assist health care workers balance their responsibility to care for their patients with the responsibility to look after themselves (eg impact of PPE shortages).	>90%	>90%	>90%
Ethical framework			
19. Acknowledge that current ethical frameworks address the question of futile treatment but need to be strengthened (incorporating consumer perspectives) to deal with the potential need to ration scarce resources.	>90%	>90%	>90%
20. If there is a need to ration resources, the focus needs to be on fair allocation of resources using multivalued and involving the community.	>90%	>90%	80-89%
21. That consideration be given to resource allocation from a random allocation perspective to reassure the community that everyone has equal opportunity to the resources.	50-59%	60-69%	50-59% (medical professionals only – 27%)
22. Establish an independent panel that is accessible nationally, so any health care professional anywhere (remote, rural, metro, etc) will have the support they need for decision-making, and to potentially help arbitrate difficult situations with families.	80-89%	80-89%	70-79%



Survey key points

High level of consensus

- There was a high level of consensus across all six themes for 21/22 statements.
- Sixteen statements received a score > 90% and 5 statements received a score between 80% - 89%.
- No disagreement (included both 'Disagree' and 'Strongly disagree' responses) was noted in 10/22 statements. These statements were:
 - including consumers 'at the table' as part of transparent processes (#3)
 - the need for up to date, authentic messaging that is clear, concise and accessible (#6, #12)
 - the need to provide information that reassures vulnerable groups about positive outcomes and treatment options that will be available to all (#8, #10, #11)
 - acknowledgement of vicarious trauma of health workers and the need to provide support and consistent protocols to ensure their safety (e.g. adequate PPE) (#17, #18)
 - clinical issues around availability of triage officers to support ICU settings (#13) and support for empowering GPs to initiate discussion with patients (#15).

"It is important to ask the consumer what message they are NOT receiving."

"There is a need for good quality resources aimed at helping people have these conversations with family and friends as well as health professionals. Many of us are supporting older (and younger) family members and friends with chronic health conditions and some of us will be thrust into acute care at home for people with COVID-19."

Low level of disagreement

- Where there were responses indicating disagreement, it was generally low (<5%).
- Comments regarding Hospital in the Home facilities noted the need for appropriately resourced community health services to ensure safety for the patient and health care workers.
- The main exception to this was the statement about random allocation (#21 – see following).
- There was also a slightly higher level of disagreement for Statement #22 - establishing an independent panel for decision making support (6% disagreement, 11% neutral).

Low level of consensus

- Statement #21 – *'That consideration be given to resource allocation from a random allocation perspective to reassure the community that everyone has equal opportunity to the resources'* – had the lowest level of consensus (approx. 52% in total but 27% for medical professionals only) and the highest number of neutral (27%) and strongly disagree/ disagree responses (22% disagreement). This is consistent with the research presented by Prof Vasi Naganathan that demonstrated a low level of support for random allocation of resources in a pandemic situation.

Differences (and similarities) between medical and consumer responses

The consumer responses on average were mostly stronger than those of the medical group (i.e. consumers rated more responses as 'Strongly agree' compared to Agree'). However, despite some minor differences, the importance and willingness of people to work together to tackle this 'wicked problem' was evidenced throughout the forum and in response to the following two statements.



Table 2: Level of consensus on ethical framework statements

Statement	Consumer group	Medical group
Acknowledge that current ethical frameworks address the question of futile treatment but need to be strengthened (incorporating consumer perspectives) to deal with the potential need to ration scarce resources (#19).	96%	90%
If there is a need to ration resources, the focus needs to be on fair allocation of resources using multivalued and involving the community – 83% medical and 92% consumers (#20)	92%	83%

“Consumers MUST be kept in the centre of health care and this includes full disclosure by health professionals of risks and options.....We might mean well as health professionals but we are NOT the patients experts. The patients are often NOT the condition experts. We need each other, in this world of consent to complex health care.”

Although the majority of statements (16/22) received high levels of agreement when combining ‘Strongly agree’ and ‘Agree’ statements (>90%), there were several interesting differences. The medical group responded more strongly on only one of the statements – advance care planning discussions (see Table 3).

Table 3: Differences between groups in ‘Strongly agree’ responses

Statement	Consumer group	Medical group
Advance care planning discussions (#16) – need to initiate and document plans	60%	80%
Establishing an independent panel to support decision making (#22)	85%	77%
Governments and health services need to demonstrate an appetite for public engagement in process, decision-making (including resource allocation) and public messaging (#1)	73%	43%
Open and transparent accountability from government and health services including a place for consumers/community groups (especially high-risk communities) at the table (#3)	81%	50%
That it is a consumer’s right to have their unique circumstances and health issues taken into consideration and to be part of the decision-making around their treatment and care (#4)	82%	57%

Conclusion

Allocation and triage decisions are made every day in hospital settings. However, the speed of events related to COVID-19 sharpened people’s thoughts about the potential of this pandemic to result in resource shortages and difficult triage decisions. As has been witnessed overseas, these shortages and decisions can disadvantage some of the most vulnerable in our community. Health Issues Centre wanted to ensure that the voice of the consumer was included in discussions about how such decisions may be made in the event that our hospital system becomes overwhelmed.

Although the forum aimed to predominantly discuss ethical issues in triage, it was apparent throughout that consumers are still very much looking for more/better information that is directly relevant to them. Whilst time was a limiting factor on the day, the conversation was very keenly based around gaining further clinical information and the risks associated with different vulnerable groups. It may be that a greater understanding of existing triage frameworks and practice may be needed to assist in prompting further community-based discussions. Although an important conversation to conduct, the recent success in ‘flattening the curve’ may also have moved interest and enthusiasm in pursuing this topic at this time.

The 22 recommendations that arose from the forum and were tested for consensus were largely accepted (excluding the recommendation for random allocation of resources). Although preliminary, these can provide a valuable community input into any development work on ethical frameworks being undertaken at a state or national level. Health Issues Centre will actively engage with State and Federal governments to include your voices.

Appendix 1: Questions and comments from the live chat

Questions	
Clinical	<p>Questions</p> <ul style="list-style-type: none"> • How many patients that go into the serious ICU care/ventilators with COVID are coming out? • Are there any early patient/COVID related predictors about who will get an uncontrolled inflammatory response? • Re the discussion on inflammatory response. Does this mean those with other inflammatory conditions are at increased risk? • For people who do recover is there any permanent damage to the body? • Should patients be encouraged to take blood thinners? • Are those with background respiratory disease more likely to have an overwhelming inflammatory response to COVID-19 or is this an unknown currently? • How many days are seriously ill persons with COVID-19 spending in ICU. That will help people think about what they want for themselves and their loved ones. • Do you see these types of inflammatory responses in ICU often? • Does COVID-19 have a doubling effect on asbestos & silica sufferers on inflammatory conditions? • Realistically, when making a decision about an individual patient, how much time do clinicians have for discussion and consultation in general? • Can a frailty tool be used for younger persons living with chronic conditions and multiple co-morbidities? • For advocates of persons who may have some ongoing medical issues that impact their health generally, should we be advising them to push to have early treatment if this is not being provided, given that early oxygen treatment seems to be important in managing the condition? (Answer CC - I think it is very reasonable to use oxygen as soon as it is required) <p>Comments</p> <ul style="list-style-type: none"> • Thank you - the information that ventilators may not be the answer is new to me and extremely important • Keep Government out of it - why hasn't 'clotting' been mentioned - the emphasis on ventilators • Yes, the more we as a society know about the facts of ICU treatment the better prepared we will be to discuss whether it is the right option for someone • Agree with your comments re: public communication about ICU treatment. GPs / primary care health workers are a great resource to have these discussions. I wonder if there is capacity to provide appropriate teaching to these clinicians by people such as Charlie and Vasikaran and then provide telehealth consults for people to speak to their doctors about their specific health fears and disseminate information? Thoughts?
Communication	<p>Comments</p> <ul style="list-style-type: none"> • Charlie's message is powerful: "all patients are eligible for care". ICU is not better care if that's not what the person wants.

	<ul style="list-style-type: none"> • All people are eligible for CARE -- the Treatments may be different. • Nice Charlie. I wish such a simple explanation of what was going on could be given to the general public. • Communication HUGELY important - especially considering the various forms of accessible communication people with disability may need (easy read, AUSLAN, braille....) • Communication a real issue for people with limited English proficiency - interpreters! • Great discussion. Such emphasis on messaging and the importance of ensuring to maintain public trust • Chief Medical Officer should be in this forum to learn how to communicate to the ordinary non-medical person • I hear that a lot in the community, need to improve the messaging • There is a difference between govt reporting and public messages - needs to be much more public messaging as part of the communication strategy - nationally and locally • The way to get the messages out there is through all of us to get good quality messages out to the people we work with • Actually wish the presenters were able to make their knowledge and simple explanations available to the general public. We need more people in the public eye sharing sensible clear information and represent the broad issues well • I think that that is the message (<i>COVID as a death sentence?</i>) that many in the public have taken away from the public messaging. There is insufficient accurate information and it's caused a level of unreasonable fear. • That message needs to get out there, as I absolutely have been of the belief that anyone with a lung condition has a big problem if they get COVID • Thank you to all speakers for sensible and sensitive presentations. So important to have open and honest communication with consumers about their preferences for medical treatment and not assume that everyone will want intensive treatment. • Seems to me that we have an ethical vacuum currently given the government messaging is to build ICU capacity to manage everyone. • Australia is seeing the benefit (slowing of rate of new infections) of notifying the public of a shortage of ventilators. Fact: those that need help need respiratory help. Fact: if we have an increase in numbers, there WILL be a shortage of ventilators. I believe we need to be careful in how we notify the public of what the outcomes may be. • We need to be very careful in the public discourse about how to allocate finite resources as some people may actually resist seeking medical help or decline access to care because they may see themselves as not being deserving
Ethical issues with triage	<p>Questions</p> <ul style="list-style-type: none"> • Wondering if first come, first served actually does favour those with underlying health conditions? • Should children's needs always trump those of adults if there is a competing need for the same resources?

	<ul style="list-style-type: none"> • It seems like we are talking about a situation where everyone lines up for ventilators at the same time, and deciding who gets it first. But reality is all ventilators might be used up but then you get a new patient in with better prognosis - will they get to take the ventilator of a person who has less chance of recovery? <p>Comments</p> <ul style="list-style-type: none"> • Enlisting a committee to make treatment allocation decisions when escalation plan gets to dire stage takes a mental load off the bedside clinicians. This has been a big issue for clinicians' mental health in Italy and USA • There is also some ethical relevance to a person's life cycle stage and the proportional time and associated wellbeing of those available years • Quality of life IS very subjective, and ableism in health is ubiquitous I think... • I remember a few years back NZ tried to limit access to dialysis for people under 70 years. Did not go down well with the public • It's interesting to know what the situation is like when a person reaches the point where end of life decisions need to be made... I wonder whether there would be some way to have the general public determine whether they want critical care, similar to other medical decisions, like organ donation, or do not resuscitate? • It seems that there are so many issues that need to be addressed in great detail to ensure we cover everything. Perhaps we need at this time given the urgency that may be needed in some situations that we entrust our clinical ethicists to help make these decisions? • Given the level of distrust of our political leaders over the last decade I think that expert clinicians input into discussions will be vital. Polls have been quick to default to medical guidance during this pandemic to counter this distrust in the public.
Advance Care Plans/ treatment	<p>Questions</p> <ul style="list-style-type: none"> • Will people be explained the options and encouraged to complete Advance Care Plans if they are in the group more likely to be affected? <p>Comments</p> <ul style="list-style-type: none"> • It seems like this is the time we need to educate people to have discussions with their family about what they want should an escalation be required, and then getting those plans documented in a resource that is accessible by the clinicians. • It will be helpful if we all think about the care we would want if we were to become seriously ill with COVID-19 and to share our thoughts with family members • Advance Care Plans should be encouraged at this stage • No advance care plan ever considered Covid 19 • Advance care directives requesting CPR, dialysis etc can't mandate that the treatment be provided if that treatment is considered futile • Really good to have Advance Care Planning aspect as part of HIC communication ..as stated here

	<ul style="list-style-type: none"> Contemporary advance care plans do ask what is important to you and what outcomes people would find unacceptable - so they are not unsuitable for COVID-19. An ACP does consider an illness that may require aggressive or ineffective treatment and the values of the person in terms of recovery and ongoing quality of life. COVID19 is just one of many even though currently it appears overwhelming.
Age	<p>Questions</p> <ul style="list-style-type: none"> If age is used as a signifier of something else that is relevant, why not use the something else and leave age out of it? What is the purpose of using age, and what does it add – could you please clarify? Does this risk reinforcing implicit age-based decision making? If age is included just because it is a correlate with other underlying risk factors, why include it at all and instead not just include those underlying factors. Surely even the mention of age would reinforce potential and real biases. Paul, I completely agree with you. Can you please clarify how to consider age in the overall assessment? While I too am very concerned about age alone being used as an indicator of worse clinical response and therefore reinforcing ageism throughout our community, is it not the case that our immune systems do become less effective as we age especially against new pathogens in which case then when all other variables are equal would age perhaps not need to come into the equation? <p>Comments</p> <ul style="list-style-type: none"> Many, many "older" Australian live independent, healthy lives and are self-funded retirees who have never relied on the Govt for any kind of financial support. To discriminate against people over a certain age is very "un-Australian" We need also to provide appropriate care and safety for gaps at risk (eg in aged care) but failing to value and meet their social needs - eg people in lock down in aged care facilities without any interaction with families and support network. Examples of people experiencing significant cognitive deterioration without such interaction Only 1 visit per day of up to 2 people allowed in aged care facilities (for those who are following national requirements rather than inventing their own rules) and those 2 includes a doctor Also please be aware that older people living at home are starting to refuse services they have been receiving as part of their Aged Care Home Care Package for fear of letting another person into their home
Other vulnerable groups	<p>Questions</p> <ul style="list-style-type: none"> What do we tell families friends of people with dementia (or other cognitive impairments) about what to expect, what can be done, how health services will be delivered? They need to be informed so that they can make decisions especially in residential care where they are already limiting family visitors? What about people who have been diagnosed with dementia or live with a long-term mental illness?

- People with dementia are already stigmatised as being unable to participate in problem solving and decision making. So will current tools & protocols adequately ensure their participation??
- How will the decisions re ICU beds - and end of life issues - be made for people with dementia? This is a cohort who are not only people with a terminal illness, but many who live at home and are people with acquired disabilities, but where a great many are living very productive and meaningful lives.

Comments

- I represent a very comprised community group in Victoria of asbestos and silica sufferers of all ages from their 30s - their 90s - so it looks like to me that my people will be put to one side as a lost cause
- The multifactorial health co-morbidities and the pervasive health and social inequities of the Aboriginal and Torres Strait Islander population present significant challenges which require redress in creating equitable ethical guidelines in this current environment. Clearly our First Australians / Traditional Land owners need to be robustly included in this discussion and provide additional guidance
- In WA our greatest concern is how Aboriginal and Torres Strait Islanders living in remote communities access care at all when their communities can be more than a 10 hour drive from a hospital facility. It is now a more urgent consideration than before as we have positive COVID cases in several remote communities in the Kimberley and Pilbara
- The point that tools will not tell you about the individual, rather it will group people based on stereotypes or groupings. In practice it would seem that the tool approach runs the risk of by default having an ageist approach to rationing.
- Totally agree - people with disabilities need to be supported.
- Many people with disability live healthy, full lives and should in NO way be considered in the same vein as older persons with co-morbidities - but aligned with other able-bodied persons
- The impact for people with significant physical disability who need daily personal care has already been an issue. Whether sick or not, many people are losing their carers and support staff, or when they have them, they are struggling for PPE to keep both themselves and their staff safe. This leaves them even more vulnerable and isolated, and at greater risk
- Very challenging situation for people with dementia in residential aged care right now without easy access to advocates/family.
- That is the message many with dementia are getting, if they have diseases such as asthma or COPD (*COVID as a death sentence*)
- Yes I agree - there are well established ways however these are not applied universally (Vasi's talk)
- We see quite an extent of carer / family exclusion in health cases such as these
- Family conferences are likely to be more difficult in the seriously ill COVID-19 situation
- Please do not forget that people with dementia are people with disabilities...

Existing criteria/ frameworks/ guidelines	<p>Questions</p> <ul style="list-style-type: none"> • Is there criteria developed to determine futility? and are these based on science or on other concepts? • Charlie - Why did you believe the Government would not develop guidelines? • Is it ever the case prior to Covid-19 that ICU's get full? What criteria do they use to decide then? is it hospital by hospital? • Are any of the 'protocols' in a clearing house? • Paul, the bioethics group in Toronto came up with 7 values for decision making after the 2003 SARS epidemic. Are you aware of those and do you think they are too complicated for clinicians to make decisions in a pandemic? <p>Comments</p> <ul style="list-style-type: none"> • Australian Health Sector Emergency Response Plan for Novel Coronavirus (COVID-19) has an "Ethical framework" which is at the level of principles and then no further guidance • I have heard of using a panel of Drs to make a decision in terms of their likelihood of success. I believe that this is already being used in some contexts. • The Commonwealth Dept of Health will be releasing national guidelines for treatment in Prisons sometime today
Planning	<ul style="list-style-type: none"> • Planning for this and having transparent discussions in the community is key! • This shift into maximising value in resource allocation will only occur if our hospital system reaches a designated 'tipping point' in surge demand for resources such as ICU, ventilators and PPE. We hope planning will obviate that necessity. • We should be having these discussions now and formulating decision frameworks before things ramp up, as at that point, decisions will be rushed. • I agree Sophy, this may happen again more because of how the world has opened up so future plans should be set up to possibly act faster
Consumer involvement	<ul style="list-style-type: none"> • It's concerning that consultation does not seem to have been sought and the speakers, as experts should be at the table. • I facilitated two Citizen Juries in February this year where a stratified sample of citizens in two Australian locations deliberated on the issue of privacy and health data. It was powerful. Is there an argument for running Citizen Juries on this topic around the country? The Juries I ran had around 20 citizens who heard expert testimony on Day 1 and then deliberated on Day 2. The outcome was extremely intelligent, intensely nuanced and participants understood the need to filter through the lens of "Public good". I am feeling that there is a need to ask the public who need the best information on which to deliberate on this critical topic. • I think yes, a Citizen Jury would be good, but more people than 20 would be good for Australia. It is a time consuming and expensive undertaking though and not suited to short time frames. • The time factor could be important - these processes take time. • I would love to see these conversations - Citizen Jury conversations - could be held proactively to tackle issues such as the tension between personal privacy and being able to determine if services are actually helping because you need to follow a

	<p>person's journey across a number of systems and data sets. About 6-8 months and \$100K is the rough timeframe and budget to be considered for a Citizen's Jury and I would think about 300 people demographically chosen across Australia would be another consideration for a Citizen's Jury</p> <ul style="list-style-type: none"> • I'm uncomfortable with citizen juries. I would not want to be on one to decide on someone's life. I prefer expert assessment. I understand that the idea is to dilute individual biases, but I still find it concerning
Primary care	<ul style="list-style-type: none"> • GP's won't allow them in offices or do home visits - already happening • People are being told to stay at home until in respiratory distress and not being tested. • No, i think that is the message to the public. stay at home until or unless symptoms worsen. Little information about the role of primary care in this • Currently people displaying symptoms are being told to stay at home and are not being tested until symptoms are severe. GPs are applying telehealth only • GP's can now do telehealth via video or telephone. Access to primary health care should no longer be an issue for those self-isolating or displaying 'flu like' symptoms • Re lack of primary care, home visits the problem is lack of PPE putting GP's at risk. Likewise the problem of carers refusing to provide care. Unless there can be universal testing of all with URTI's these problems are only going to escalate.
General	<p>Questions</p> <ul style="list-style-type: none"> • How can this approach be applied when patients are being told to self-manage at home (with no medical treatment) until they are critical and presenting at ED? With little primary care or discussion before they present in tertiary care? • How can we best manage situations where substitute decision making is required? We require robust and clear guidelines around involvement of carers or family members where impaired decision making capacity is relevant for the person with COVID. This is particularly important in critical / crisis situations • This is a side issue but what is being done about the mental health of health care workers? (I also agree with your thoughts on mental health in healthcare workers - key for keeping our work force healthy to provide best care) • Could the issue be that with stretched resources, there is not the time to have the discussions you would normally have time to have? • So is it just about lowering the bar on those principles based on the lack of resourcing? Is that what we are really working out here? • Perhaps the wrong forum, but is there anything in place to ensure human rights for those living in RSCF's are in place, as no one is able to visit to check the person they advocate for is ok? The information we have from countries such as Italy, would indicate these people are denied not only access to healthcare, but also to best 'care'.

	<ul style="list-style-type: none"> • Would setting up a system for early identification and notification of patients who will not continue to receive limited resources and a clear legal pathway for any challenges, alleviate clinicians having to deal with increased aggression and threats? Perhaps improved training is required across the board <p>Comments</p> <ul style="list-style-type: none"> • We will be judged by our decisions by future generations on the decisions we make in response to this crisis • Great presentation Paul, essential we leave a legacy of collective / shared leadership • Delirium guides are being rolled out in Victoria but that I believe has been placed on hold • Something we will need to consider is how the research that is needed for treatments, etc is also going to be introduced into this space • Would be a great idea to get some podcasts for the PHC workers on this • Just throwing another idea out there (in case anyone has any contacts among the powers that be) - a fixed time of day for the official press conferences would be helpful. It is impossible to keep track of when they are being held.
Where to from here?	<ul style="list-style-type: none"> • What will come out of this forum? Will the responses be provided to the relevant authorities to develop frameworks and policies?

Appendix 2: SurveyMonkey results

Statement/Recommendation	Level of agreement Total (88 responses)	Level of agreement (Consumers/ community orgs 53 responses)	Level of agreement (Health professionals – 30 responses)
Community participation			
1. Governments and health services need to demonstrate an appetite for public engagement in process, decision-making (including resource allocation) and public messaging.	SA 62.50 A 31.82 N 2.27 DA 2.27 SDA 1.14	SA 73.58 A 24.53 SD 1.89	SA 43.33 A 46.67 N 6.67 D 3.33
2. Consumer organisations should be enlisted to disseminate information to their communities.	SA 68.98 A 26.44 N 3.45 DA 1.15	SA 71.15 A 25.00 N 3.85	SA 70 A 26.67 DA 3.33
3. There is a need for open and transparent accountability from government and health services and this must include a place for consumers/community groups (especially high-risk communities) at the table.	SA 71.59 A 26.14 N 2.27	SA 81.13 A 16.98 N 1.89	SA 50 A 46.67 N 3.33
4. That it is a consumer's right to have their unique circumstances and health issues taken into consideration and to be part of the decision-making around their treatment and care.	SA 72.41 A 24.14 DA 1.15	SA 82.69 A 17.31	SA 56.67 A 36.67 N 6.67
Communication			
5. That the government recognises that consumer and community organisations are best placed to process and distribute information to the groups they represent (e.g. may include road-testing of messages)	SA 35.63 A 44.83 N 14.94 DA 4.60	SA 39.62 A 41.51 N 15.09 DA 3.77	SA 33.33 A 43.33 N 16.67 DA 6.67
6. That messaging must be concise, consistent, in plain English (or other community languages) and illustrated.	SA 84.71 A 15.29	SA 84.62 A 15.38	SA 83.33 A 16.67



7. Recognise that current messaging may actually discourage vulnerable groups seeking care (particularly older people, people with disabilities and people with chronic conditions).	SA 43.68 A 34.48 N 20.69 DA 1.16	SA 50.94 A 30.19 N 18.87	SA 33.33 A 36.67 N 26.67 D 3.33
8. Develop specific messages of reassurance for groups who have experiences of healthcare discrimination (e.g. lower socioeconomic groups, Aboriginal and Torres Strait Islander people) that they will receive care as needed.	SA 65.52 A 34.48	SA 64.15 A 35.85	SA 63.33 A 36.67
Information/Education			
9. There needs to be public education about the reality of intensive care (e.g. treatment and morbidity)	SA 58.14 A 31.40 N 8.14 DA 2.33	SA 52.83 A 37.74 N 5.66 DA 3.77	SA 66.67 A 23.33 N 10
10. There is a need to reassure people (particularly high-risk people) that primary and acute healthcare “below” intensive care will be available to them.	SA 65.12 A 33.72 N 1.16	SA 66.04 A 32.08 N 1.89	SA 63.33 A 36.67
11. That there is a need for statements emphasising that whilst vulnerable groups are at increased risk, treatments are available, and outcomes are often positive. (eg old age is not a death sentence nor are young people indestructible).	SA 62.79 A 36.05 N 1.16	SA 64.15 A 33.96 N 1.89	SA 56.67 A 43.33
12. That given the plethora of unreliable information, it is important to credential the authenticity and currency of sources and that superseded information is revoked.	SA 78.82 A 18.82 N 2.35	SA 82.69 A 15.38 N 1.92	SA 80 A 20
Clinical guidelines			
13. Triage Officers should be made available to support staff in all ICU and high dependency settings, including makeshift settings.	SA 50.59 A 36.47 N 12.94	SA 56.60 A 33.96 N 9.43	SA 43.33 A 36.67 N 20

14. That for those who do not want hospital admission, “hospital in the home care” is provided as an alternative.	SA 44.71 A 40 N 10.59 DA 3.53 SDA 1.18	SA 41.51 A 43.40 N 9.43 DA 3.77 SDA 1.89	SA 50 A 33.33 N 13.33 DA 3.33
15. That when a positive COVID-19 test result is given, GP’s should be empowered to initiate a discussion with the patient and their family on what might happen next (eg 15% may need hospitalisation, 5% may need intensive care) and the type of care they want.	SA 68.24 A 29.41 N 2.35	SA 64.15 A 33.96 N 1.89	SA 76.67 A 23.33
16. Advance care planning discussions should be initiated and documented where appropriate.	SA 68.24 A 30.59 D 1.18	SA 60.38 A 39.62	SA 80 A 16.67 DA 3.33
Health workers			
17. Need to acknowledge vicarious trauma of health workers and provide appropriate support.	SA 70.24 A 28.57 N 1.19	SA 69.23 A 28.85 N 1.92	SA 68.97 A 31.03
18. Need consistent protocols to assist health care workers balance their responsibility to care for their patients with the responsibility to look after themselves (eg impact of PPE shortages).	SA 72.62 A 25 N 2.38	SA 71.15 A 25.00 N 3.85	SA 73.33 A 26.67
Ethical framework			
19. Acknowledge that current ethical frameworks address the question of futile treatment but need to be strengthened (incorporating consumer perspectives) to deal with the potential need to ration scarce resources.	SA 58.33 A 35.71 N 2.38 DA 2.38 SDA 1.19	SA 60.38 A 35.85 N 1.89 SDA 1.89	SA 53.33 A 36.67 N 3.33 DA 6.67
20. If there is a need to ration resources, the focus needs to be on fair allocation of resources using multivalued and involving the community.	SA 60.71 A 28.57 N 7.14 DA 2.38 SDA 1.19	SA 64.15 A 28.30 N 5.66 SDA 1.89	SA 50 A 33.33 N 10 DA 6.67
21. That consideration be given to resource allocation from a random allocation perspective to reassure the community that everyone has equal opportunity to the resources.	SA 25.30 A 26.51 N 26.51	SA 32.69 A 32.69 N 21.15	SA 16.67 A 13.33 N 36.67



	DA 9.64 SDA 12.05	D 1.92 SD 11.54	DA 20 SDA 13.33
22. Establish an independent panel that is accessible nationally, so any health care professional anywhere (remote, rural, metro, etc) will have the support they need for decision-making, and to potentially help arbitrate difficult situations with families.	SA 54.22 A 28.92 N 10.84 DA 6.02	SA 55.77 A 28.85 N 11.54 D 3.85	SA 53.33 A 23.33 N 13.33 DA 10