



ETHICAL DEBATE

Ethical considerations for paediatrics during the COVID-19 pandemic: A discussion paper from the Australian Paediatric Clinical Ethics Collaboration

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Purpose

Children have not been severely affected by SARS-CoV-2-related illness but are vulnerable to the economic and social deprivation arising from the pandemic.¹ This document describes unique risks and burdens for children and their care givers during the COVID-19 pandemic.

The principles for the allocation of health-care resources apply to the whole population; however, there are particular paediatric considerations. The experience internationally is that paediatric intensive care resources are being utilised to support adult services during the emergency. Ethical tensions also arise from decisions about usual service restriction as a strategy for controlling the pandemic.

This guidance provides a framework for health services and authorities to ensure paediatric concerns are considered during the development of COVID-19 related guidelines and decision-support tools, when resources may be constrained by the emergency response. It was developed by a working group of paediatric clinical ethicists, and intensive care and other specialty clinicians. This document is an extension to the other general documents available.²⁻⁴ It is intended to be read by clinicians and executive of paediatric and general hospitals, and by health-related government departments.

Should Paediatric and Adult Health Resources Be Shared in an Emergency?

Yes. Health-care resources support the whole community and children are a part of the community. Resource constraints should be shared to ensure that maximum benefit can be obtained from collective resources. The spirit of community

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solidarity in an emergency would be undermined by ring-fencing resources for sections of the community. Nevertheless, it is important to consider the impact of constrained resources on the services of vulnerable sections of the community, such as paediatric health care, and aim to ensure that constraints are equitably distributed across the community.

Challenges for Children and their Families during the COVID-19 Pandemic

Children flourish in an environment of supportive relationships. Family is central to this, and development is enhanced by access to quality education and a supportive school environment. Because of their developmental dependence on relationships, children are uniquely vulnerable to family stress. Social restrictions in Australia have been associated with an increased demand for child protection and family violence support services.⁵

What effect does reducing elective, outpatient and community care have on children and their families?

Many elective health services for children are developmentally time-critical. For example, hearing screening allows for early intervention such as hearing aids. Delay of even a few months can negatively impact speech, language and social development.^{6,7}

Children routinely participate in prevention programmes, such as immunisation, that not only prevent disease and promote health, but also allow opportunities to assess child welfare and provide early support to vulnerable families. Reduction in attendance removes a safety net for tracking child welfare.

Telehealth appointments minimise the risk of SARS-CoV-2 transmission and increase access to health care for many families particularly in remote areas. However, telehealth is only suitable for some health-care assessments. Paediatric care relies heavily on physical examination, interaction, and observation of interactions with care givers. This is especially important with non-verbal children. Decreased access to in person care risks a

disproportionate reduction in quality of assessment and therapeutic intervention.

Families with established therapeutic relationships, who are reliant on the support of their child's health team, could find adjusting to an alternative model of care difficult. In particular, children with autism spectrum disorders and other intellectual disabilities rely heavily on routine and consistency in their therapeutic relationships. Changes in care delivery as a result of the need for social distancing may profoundly increase care burdens for this group.

Service restrictions are necessary as part of a national strategy to manage the pandemic. It is equally important to review and reassess the risks and benefits of restrictions frequently.

Are there impacts on acute care delivery for children?

Fear in the community about the risk of SARS-CoV-2 infection may delay presentation to hospital for children who require acute care. Paediatric emergency departments around Australia have seen dramatic decreases in presentations in the weeks since social distancing restrictions have been in place. This was also described in Italy, and resulted in increased paediatric mortality from non-COVID-19 illnesses.⁸ This has also been described for adults.⁹

Scientific knowledge about SARS-CoV-2 is emergent and best practice guidance is rapidly evolving in terms of diagnosis, clinical management and the prevention of health-care worker (HCW) infection. Keeping pace with this is challenging, particularly for acute care clinicians with mixed practice who need to keep abreast of adult and paediatric literature. Thresholds for instituting aerosolising therapies such as nebulised medication, high flow oxygen therapy and non-invasive ventilation have changed.^{10,11} Likewise, recommendations for the management of patients during transport, in particular a lower threshold for invasive ventilation, have altered due to the risk of COVID-19.^{10,11} These changes in practice disproportionately affect children because they have a high prevalence of acute respiratory illness presentation¹² but their symptoms are less likely to be due to infection with SARS-CoV-2. Some paediatric guidelines reflect this, recommending fewer changes to usual practice.¹³ Guidelines written for adult patients should clearly direct clinicians to the corresponding paediatric guidelines. While staff protection is of the utmost importance, strategies such as rapid testing should be used where possible to mitigate the risks of changing evidence-based care pathways for common illnesses.

Are there impacts on children admitted to hospital?

Restricting visitors to hospital is distressing for all patients, but particularly for younger children because of their developmental dependence on family relationships. The hospital environment is frightening for children, especially when clinicians and parents wear personal protective equipment.

Clinical decision-making in paediatric practice is made in partnership with parents in the best interests of the child, with consideration given to their developing autonomy. In contrast, clinical decision-making for adults is done directly with the patient, or if the patient lacks capacity, their family members

should make surrogate decisions based on that person's known character and wishes. There are challenges with decision-making in all spheres, but the burden of decision-making that parents have is arguably higher, and it may take more time to build shared understanding and agreement with the health-care team. Restricted visiting and the need for telehealth conferences can impact the development of these therapeutic partnerships.

Are there special paediatric considerations for research during the pandemic?

It is vital to carry out research during a pandemic, to develop insight into the prevention and management of a novel disease. Usual research processes and ethics approval should be adhered to. There may need to be restrictions to some ongoing research projects due to risks associated with the current pandemic. Similar to restrictions to routine health services, restrictions to research projects should be frequently reviewed and reassessed with the resumption of usual research as soon as is safe.

Paediatric Intensive Care Resources

In Australia, we are fortunate that intensive care resources usually match or slightly exceed demand. When assessing a child for admission to intensive care the primary consideration is whether intensive care therapy will benefit that particular child. Deciding not to embark upon intensive care unit (ICU) therapy is not usually a rationing decision, but a decision made to respect the child's best interests. The number of critically ill adults may exceed both paediatric and adult intensive care capacity during the COVID-19 pandemic. It will then be necessary to make allocation decisions that maximise value for all. This means that some children who may have benefited from intensive care therapy will not receive it.

Ethical resource allocation considerations common to adult and paediatric ICUs and are explored elsewhere.^{1,2,4} This section expands on issues specific to paediatrics.

How should children's intensive care resources be allocated to critically ill adults?

In usual practice, the age of the patient defines access to intensive care resources - up to age 16–18 years for paediatric intensive care units (PICUs) and up to 4 weeks post gestational age for neonatal units. These criteria are based on practical considerations for the best use of resources, including specialised skills of the staff. They can be adjusted in different contexts.

The best method of repurposing paediatric critical care resources for adult care will vary between institutions and states. Options include redistribution or reorganisation of staff; centralising paediatric patients in children's hospitals to create capacity at mixed institutions; or admitting adults to paediatric units. Neonatal units may consider accommodating older infants to create capacity for paediatric ICUs to care for young adults.

Reallocation of resources is not simple in practical terms. There is increased risk to patient safety and overall expenditure efficiencies in extending the scope of staff practice, in extending the systems supporting the model of service of a unit, and in the

requirement for transfer of increased numbers of patients between institutions.

How should we decide who is admitted to ICU?

We recommend the processes already described in general documents to support decision-making and the ethical allocation of resources during the COVID-19 pandemic.²⁻⁴ It is recommended that intensivists undertake a comprehensive clinical assessment of the patient to determine eligibility for intensive care admission. If there are more eligible patients than there are ICU resources to treat, the second step is to prioritise between those who are eligible for admission. The allocation of intensive care resources applies to all patients needing ICU, not only those with COVID-19, and it applies to the whole population, from newborns to the elderly.

Determining eligibility for ICU admission

Eligibility for ICU is based both on the clinical need of the patient and their likelihood of benefit from intensive care.

A comprehensive patient assessment to determine clinical priority should be undertaken by senior intensivists and should include discussions about goals of care, the family and child's preferences, and the opinions of other clinicians involved in the patient's care. It also includes an assessment of co-morbidities, independent prognoses, the predicted resource consumption required for the patient to recover, and the likely effect on holistic outcome in the short and long term.

It is important to explicitly separate comorbidity from disability. Quality of life should be defined by the person living that life, or elaborated through their proxy. If a person perceives their own quality of life to be good, and intensive care treatment is likely to return a person to their baseline functioning, they should have as much claim to that resource as someone who does not live with disability. The medical frailty associated with some disabilities is relevant when assessing a child's likelihood to benefit from ICU therapy, but the disability alone is not. Assessing the quality of life is especially challenging in children. Any assessment must give weight to the opinions of the family, and where able, the child's.

Eligibility for ICU should not be based on discriminatory characteristics such as disability, ethnicity and socio-economic status.

Prioritising between those eligible for ICU

If the demand for intensive care overwhelms capacity, then admission to ICU is prioritised on the clinical need of the patient and their likelihood of benefit from intensive care. If there are patients with equal clinical priority, prioritisation will then be on the basis of value claims.

To determine clinical priority, the sole use of categorisation tools such as severity of illness scores, is not recommended.² There are no tools that are validated for this purpose, and none that have been developed for both children and adults. Applying tools outside the recommended context may result in inappropriate prioritisation. For example, frailty scores are designed with age-related frailty in mind. Many children have baseline dependence but enjoy good quality of life. If expected frailty at discharge is calculated using an adult frailty score, it will de-prioritise some children on the basis of their baseline functioning. Likewise, some children with baseline profound disease, such

as hypoplastic left heart, will score erroneously favourably with some scores. There is evidence in the adult literature that clinician judgement is superior to scoring tools for predicting outcome.¹⁴

Prioritisation decisions are ethically difficult. Ethically permissible ways to prioritise that have emerged from the general literature include: prioritising younger people, adults with caring responsibilities, HCWs, or prioritising particularly vulnerable or disadvantaged groups.³ There are two key extensions to these which support giving children as a group some special priority.

- 1 Prioritising younger people generally prioritises children. However, life cycle considerations may need to be interpreted differently for children with life-limiting illnesses. While the total years of life left may be less, it can represent a large proportion of their overall life-span. It may be more just to consider prioritising based on 'life cycle', rather than on the raw years of life left.
- 2 Children as a group are often not considered vulnerable or disadvantaged, likely because most children are well cared for by families and carers who advocate for them. Notwithstanding this, they are the most vulnerable group in our society. They are physically, financially, and developmentally dependent on their adult care givers, and have no political voice.

How should non-ICU paediatric clinicians prepare for ICU resource scarcity?

In the event of PICU resource limitations, the broader paediatric health community will need to adjust expectations of access to ICU. Children with life-limiting conditions often have advance care plans reflecting their family and primary treating teams' perspective that active resuscitation, intensive care admission, and invasive ventilation would be appropriate in the event of a deterioration. Consequently, children are frequently admitted to ICU, as parents and primary treating teams will identify that 'they made it through last time'. ICU should actively collaborate with other clinical specialties to ensure timely, compassionate goals of care conversations are being held with patients and families. Health services should consider developing communication guidelines to assist in navigating conversations about denial of intensive care due to resource limitation, emphasising that patients will not be abandoned.^{15,16}

Palliative care services should be well resourced and available for all children who could benefit. Particularly in the pandemic setting with limited critical care resources, palliative care surge capacity needs to be part of the overall response, to ensure high quality, compassionate end of life care.¹⁵

What are the paediatric considerations for decision-making in the ethical allocation of resources?

With such difficult ethical decisions, it is important to ensure that the process by which decisions are made is fair and that decision-makers are adequately supported.

The agreed decision-making process in children's hospitals should be multidisciplinary and engage with parents, children, and other consumers in its design. As in all organisations,

paediatric services should decide on their process in advance and publicise it. All prioritisation decisions should be made by following the process, be clearly documented and reviewed. The burden of decision-making will be high, and it may be reasonable to develop triage teams to help support frontline clinicians.¹⁷ These teams should consist of appropriate clinicians, and may also incorporate other services such as clinical ethics. Triage teams in general hospitals should have 24h access to specialist paediatric input for prioritisation decisions involving children, and should make the need for this explicit in their local guidelines.

Possible Benefits Arising from Practice Changes for COVID-19

The Australian community has made significant and necessary sacrifices to respond to and prepare for the COVID-19 pandemic. The health, economic, social and emotional consequences of the pandemic will echo long into the future. Many of the restrictions to health services have resulted in some compromise to usual care, but they have also forced creative solutions, which should drive quality improvement into the future. Thoughtful blending of digital and in-person care can maximise access to quality care. Close collaboration of intensive care specialists with palliative care and other specialist colleagues improves quality end of life conversations and care at all times. Collaboration between HCWs and academics, harnessing digital and social media platforms, can accelerate practice improvement. The tragic consequences of inadequate personal protective equipment have situated HCW protection and wellbeing as a central ethical obligation of health organisations. Organisations around the world have reflected on and committed to resource allocation frameworks, the principles of which can be applied to fair allocation of health-care resources at any time. The health-care professions have an obligation to reflect on and harness these benefits to best serve the community into the future.

Recommendations

- 1 There should be frequent review of routine health service curtailment, specifically considering the short-term and long-term detriments to children. Services should be reinstated as soon as is safe.
- 2 Triage criteria for paediatric elective and outpatient care should include psychosocial and developmental considerations.
- 3 Guidelines written for adult patients should clearly direct clinicians to the corresponding paediatric guidelines and paediatric guidelines should be actively promoted to general and paediatric clinicians.
- 4 Paediatric critical care services, in conjunction with adult services, should locally assess the most effective ways to support the adult sector.
- 5 Clinicians working in general hospitals should have 24-h access to specialist paediatric input for prioritisation decisions involving children, and should make the need for this explicit in their local guidelines.
- 6 In prioritising intensive care resources, it is ethically reasonable to consider according children some priority.
- 7 PICU should work closely with general paediatrics, palliative care, and other subspecialty services to optimise timely goals of care discussions and parallel planning. Palliative care surge capacity should be part of the overall strategy to address intensive care resource limitation.
- 8 Decision-making processes for determining ICU eligibility and priority should be designed in a transparent and consultative way. All decisions should be clearly documented and reviewed.
- 9 The health professions and health organisations should actively reflect on the benefits arising from pandemic preparation and practice changes and harness these to improve health-care service delivery in the future.

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References

- 1 The Alliance for Child Protection in Humanitarian Action. *Technical Note: Protection of Children during the Pandemic, Version 1*. 2020. Available from: <https://alliancecpha.org/en/COVID19> [accessed 6 April 2020].
- 2 Australian and New Zealand Intensive Care Society. Guiding principles for complex decision making during pandemic COVID-19. *Crit. Care Resusc. J.* 2020. Available from: <https://www.anzics.com.au/coronavirus-guidelines/> [accessed 17 April 2020].
- 3 Dawson A, Isaacs D, Jansen M *et al.* An ethics framework for making resource allocation decisions within clinical care: Responding to COVID-19. *Sydney Health Ethics*. 2020. Available from: <https://www.sydney.edu.au/news-opinion/news/2020/04/08/covid-19-ethics-frame-work-to-help-guide-decision-making.html> [accessed 6 April 2020].
- 4 Irving H, Jones J, Hallahan A, Johnson A, McDonald K. Queensland ethical framework to guide clinical decision making in the COVID-19 pandemic. *Queensland Health* 2020. Available from: https://www.health.qld.gov.au/__data/assets/pdf_file/0025/955303/covid-19-ethical-framework.pdf.
- 5 Women's Safety NSW. *New Domestic Violence Survey in NSW Shows Impact of COVID-19 on the Rise* [press release]. Available from: <https://www.womenssafety.org.au/impact/article/new-domestic-violence-survey-shows-impact-of-covid-19-on-the-rise/> [accessed 2 April 2020].
- 6 Wroblewska-Seniuk K, Dabrowski P, Szyfter W, Mazela J. Universal newborn hearing screening: Methods and results, obstacles, and benefits. *Pediatr. Res.* 2017; **81**: 415–22.
- 7 Ching TYC, Dillon H, Button L *et al.* Age at intervention for permanent hearing loss and 5 year language outcomes. *Pediatrics* 2017; **140**: e20164274.

- 8 Lazzerini M, Barbi E, Apicella A, Marchetti F, Cardinale F, Trobia G. Delayed access or provision of care in Italy resulting from fear of COVID-19. *Lancet Child Adolesc. Health.* 2020; **4**(5): E10–E11. [https://www.thelancet.com/journals/lanchi/article/PIIS2352-4642\(20\)30108-5/fulltext](https://www.thelancet.com/journals/lanchi/article/PIIS2352-4642(20)30108-5/fulltext).
- 9 Rosenbaum L. The untold toll – The Pandemic's effects on patients without Covid-19. *N. Engl. J. Med.* 2020. <https://doi.org/10.1056/NEJMms2009984>.
- 10 The Australian and New Zealand Intensive Care Society (ANZICS). *COVID-19 Guidelines, Version 1.* 2020. Available from: <https://www.anzics.com.au/coronavirus-guidelines/> [accessed 6 April 2020].
- 11 Australasian College for Emergency Medicine. *Clinical Guidelines for the Management of COVID-10 in Australasian Emergency Departments.* V2.2. 2020. Available from: <https://acem.org.au/getmedia/78105c4b-5195-43f6-9c91-25dda5604eaf/Clinical-Guidelines-for-the-management-of-COVID-19-in-Australasian-emergency-departments> [accessed 17 April 2020].
- 12 Acworth J, Babi F, Borland Met *al.* Patterns of presentation to the Australian and New Zealand paediatric emergency research network. *Emerg. Med. Australas.* 2009; **21**: 59–66.
- 13 APLS Australia Statement on Paediatric Resuscitation during the COVID-19 Pandemic. *Advanced Paediatric Life Support.* 14 April 2020. Available from: <https://apls.org.au/sites/default/files/uploadedfiles/APLS%20Australia%20Statement%20on%20Paediatric%20Resuscitation%20during%20the%20COVID-19%20pandemic%20v1.0.pdf>
- 14 Sinuff T, Adhikari N, Cook DJ *et al.* Mortality predictions in the intensive care unit: Comparing physicians with scoring systems. *Crit. Care Med.* 2006; **34**: 878–85.
- 15 Arya A, Buchanan S, Gagnon B, Downar J. Pandemic palliative care: Beyond ventilators and saving lives. *Can. Med. Assoc. J.* 2020; **192**: E400–E4.
- 16 Curtis JR, Kross EK, Stapleton RD. The importance of addressing advance care planning and decisions about do-not-resuscitate orders during novel coronavirus 2019 (COVID-19). *JAMA* 2020. <https://doi.org/10.1001/jama.2020.4894>.
- 17 Truog RD, Mitchell C, Daley GQ. The toughest triage – Allocating ventilators in a pandemic. *N. Engl. J. Med* 2020. <https://doi.org/10.1056/NEJMp2005689>.