

Ethical Issues Arising from the COVID-19 Pandemic

Consumer Position Statement

May 2020

Background

On 5 May 2020 the National Health and Medical Research Council (NHMRC) convened a workshop with clinical, research and consumer experts to discuss a range of ethical issues arising from the COVID-19 pandemic. The outcomes of the workshop will be presented to the National COVID-19 Health and Research Advisory Council (NCHRAC) for consideration. The workshop was hosted at the request of the NCHRAC. Workshop participants included members of the NHMRC Australian Health Ethics Committee (AHEC), the NCHRAC and co-opted consumers nominated through the Consumers Health Forum of Australia (CHF) and the state-based consumer peak organisations.

This Position Statement was developed through the collation of extensive work undertaken at a state and federal level and incorporates the views of:

- workshop participants,
- state-based consumer peak organisations,
- other CHF organisational members spanning cancer, rare disease, and other disease-specific organisations, aged care, disability and mental health organisations,
- CHF affiliate organisational members with a focus on quality in healthcare,
- CHF consumer representatives, and
- CHF Special Interest Groups.

Framing

The Position Statement summarises the key ethical and policy issues from a consumer perspective against the following six themes which framed the NCHRAC's discussion paper:

1. Resource allocation
2. Implementation of public health measures
3. Issues faced by health care providers
4. Impact on Aboriginal and Torres Strait Islander people and communities
5. Research ethics
6. Emerging from the pandemic and future planning.

Overarching principles

From the consumer perspective, there are a broad range of ethical issues that have arisen throughout the COVID-19 pandemic which are discussed in more detail below.

First and foremost, Australians have a fundamental right to healthcare and principles of fairness, justice and transparency must apply even when resources are scarce.

The principles should be used to inform decisions across all these issues and are themed around an ethical decision-making process and a broader economic and social pathway to recovery:

Ethical decision-making process

- The community's views are a critical ingredient into the development of an ethical decision-making framework that the community will value and trust. Public cooperation and compliance are a function of social licence: communities not only understanding what needs to be done, but why.
- Decisions about whether care is provided and in what form must be informed by the preferences of patients as well as clinical judgement. Shared decision-making practices between a treating team and patient (patients as partners in care) should be standard practice. Patients should be actively involved in decisions about their treatment and care to the extent they wish to be, and they should be supported to do so.
- Decisions based on factors such as age or disability should not be determining factors in the allocation of resources.

Pathway to recovery

- The health and welfare of individuals and the community should be valued over the economy as decisions are made on how to navigate through the COVID-19 pandemic.
- Every effort should be made to reduce existing inequalities through the response to COVID-19 as the impacts of public health restrictions are inequitably distributed and place the greatest burden on those who have the greatest need of social and structural supports.
- Consumers, through their lived experience and contribution to discussion, must be partners and co-designers at all stages of decision-making and involved in the ongoing governance of the pandemic response and recovery plan. The meaningful involvement of diverse voices is vital including people living in rural and remote areas, people with disabilities, First Peoples, people with limited access to digital technology and people from culturally and linguistically diverse backgrounds.

Issues and Next Steps

Theme 1: Resource allocation

Topic	Issue
Resource Rationing	Efforts should be made to ensure enough personal protective equipment (PPE), intensive care unit (ICU) beds and respiratory equipment are available to all Australians requiring such support, throughout all stages of the pandemic. Should resource constraints arise, rationing should not be determined on a purely utilitarian basis. Allocation based on survivability and notional life expectancy only will disadvantage those with comorbidities or shortened longevity expectations.

	<p>Allocating resources is highly value laden. For health consumers, above all, the process must be a fair and visible to those affected. A fair process for all health consumers includes the following attributes: inclusivity; fairness; reasonableness; accountability; responsiveness; and transparency.</p> <p>The issue is broader than who gets to live and die in ICU. It is system wide and includes issues such as, but not limited to, access to PPE and equity of access to emergency, acute, palliative, and ongoing community care including for non-COVID patients. Consideration will need to be given to how access to emerging treatments and a vaccine, should one become available, occurs. If supply is staged and whole of population vaccination is not possible in the first instance, access should not be left to the market. A transparent plan based on key access criteria should govern decision-making.</p>
Logistical issues	<p>Logistical issues need to be addressed to ensure equitable distribution of and access to resources such as PPE and medicines, especially for vulnerable or disadvantaged consumers. Even when national supplies are available there will be localised supply issues, particularly in rural and remote areas. Equitable pricing that is not affected by remoteness is preferred in these critical times.</p>
Bias and discrimination	<p>Age, disability, cultural diversity or other characteristics should not be used to determine if resources are allocated – the focus should be on health status and health need. Conscious or unconscious bias need to be acknowledged and addressed by having decision-making focussed on individual health status and health need. For less common diseases, the role that families and carers play in the daily management of disease should be acknowledged and providers should work with their knowledge: this can facilitate more responsive and appropriate services.</p>
Residential aged care	<p>Specific consideration needs to be given to the treatment decisions of people with COVID-19 infections living in residential aged care facilities to optimise health outcomes, including:</p> <ul style="list-style-type: none"> • How it is determined if aged care patients should be transferred to hospital? • Consideration of access to palliative care • Are systems in place to support residents to make advanced care directives, including those under guardianship? Ideally these are in place on admission and not as a result of a crisis such as a pandemic? • Where advanced care directives are in place, are they being followed? • Early communication with families and carers about the processes and procedures that will affect them during a pandemic, including their involvement in care decisions.
Usual care	<p>The pandemic has caused significant concern for many people affected by chronic and/or terminal illnesses. Many may be at increased risk of infection, and for some with conditions such as cancer, at risk of both a more severe infection as well as disease course if infected. Ensuring access to usual care and the continued delivery of optimum care pathways for consumers with these conditions must continue throughout the pandemic.</p>
Palliative care	<p>Access to palliative care must not be forgotten about in times of resource constraint. Palliative care needs an increase in resourcing including</p>

	specialist palliative care and better support for case conferencing with families and loved ones when the decision has been taken to provide palliative care rather than active treatment. Advanced care directives must be respected, and end of life discussions must be done in an ethical and culturally safe way.
Mental health and related services	Significant resources will need to be invested into mental health and related supports including welfare, mental health services, and drug and alcohol services. We are already seeing reports of deteriorating mental health across the community, rising alcohol consumption and disturbing increases in disclosures of family violence or child safe issues, and the resulting increase in demand for these services. Leading mental health services providers report that young people will be disproportionately impacted by the pandemic yet the number experiencing mental illness and mental ill-health presenting to mental health services for care and treatment has declined substantially during the pandemic. A further reason for low mental health service use by young people is that services are not always tailored for young consumers. Providing a voice to young people will ensure that services are relevant and young people are not disproportionately impacted by COVID-19.
Topic	Next step
National framework for ethical decision making	The development of a national framework for ethical decision-making for policy and practice consistency and transparency is urgently required for application in a second COVID-19 wave as well as incorporation as annexes into revised national pandemic plans. Such a framework should be guided by the outputs and principles expressed in recent forums (e.g. Qld Clinical Senate, Health Issues Centre (HIC) Forum), as well as international best practice such as the UN Emergency Response Framework. Co-design with consumers and the community is critical to ensure their views shape the framework and they can trust how it is applied. Where they don't exist, the development and use of critical care guidelines to inform Australian hospitals and clinicians during the pandemic is essential. The impact on chronic disease management needs to be factored into resource decision-making and prioritised. As the peak of COVID-19 cases passed (or does not occur), the risk to long-term health may be greater than the risk of the pandemic.
Advanced care directives	Efforts to increase the uptake of advanced care directives across the board should be taken as well as to ensure the introduction or updating of advanced care directives with vulnerable populations without reinforcing anxiety or risking coercion. Undertake an audit of care received in residential aged care facilities and identify how often people are receiving care in line with advanced care directives and to confirm systems are in place to support the preparation of an advanced care directive.

Theme 2: Implementation of public health measures

Topic	Issue
Governance	There has been a lack of community input into the suite of public health measures implemented to date, which have resulted in unintended consequences, particularly to vulnerable groups within our society.

	Consumer input is a critical ingredient for successful and inclusive policy design and implementation.
Design	Public health measures introduced during the pandemic that target vulnerable groups, for example, housing or income support, need to be maintained and strengthened to help reduce health, social and economic inequalities.
Isolation and access to care, including preventive services	<p>Physical distancing, while necessary, impacts on a) mental health, loneliness and isolation; and b) access to usual health care, both of which risk poor social and health outcomes and lead to heightened demand for services at a later point.</p> <p>The impact of COVID-19 on families and carers cannot be underestimated, with restrictions in place exacerbating loneliness and isolation and mental health challenges, especially for those supporting people with complex needs and in end of life care.</p> <p>There are real concerns and evidence that people with complex and chronic conditions have had disruptions to their usual care and have experienced a deterioration in their condition/s as a result. At risk communities also require heightened prevention measures. Identification of this risk issue should be referenced in localised business continuity plans. While telehealth bridges some of the gaps and provides supplementary services, not all consumers are computer literate. Poor or no access to the internet and the 'digital divide' are associated equity and ethical issues. Telehealth is not appropriate in all situations and the best interests and choices of the patient must be considered in all decisions regarding whether telehealth should be used.</p>
Health literacy and messaging	<p>Poor public health messaging during the pandemic has created a level of community fearfulness which has deterred people from seeking care and/or maintaining their health, evidenced by the drop in the number of routine pathology tests and GP visits. Inconsistency in messaging is also a concern, with some consumers avoiding regular care due to perceived risk or not wanting to be a burden on the system. Consumers should be involved in the development of messaging including information in other languages.</p> <p>More nuanced public health messaging is required to complement the universal pandemic safe practices messages. These should remind people that health maintenance and self-care during the pandemic is equally as important as social distancing and hygiene. They should be delivered in appropriate settings such as workplaces, general practice and other health care settings, and schools, and with varying levels of health literacy and patient activation taken into account.</p> <p>Attention must be paid to people with complex communication needs, including those who communicate in ways other than speech and have limited capacity to make decisions about their healthcare. This includes people who are especially vulnerable such as those with intellectual disabilities, aphasia from a stroke or head injury where patients' ethical rights and potentially legal issues can arise in relation to medical decision-making if the provision of appropriate aided and unaided communication tools has not occurred.</p>
Balancing public	Tracing and tracking using technology (e.g. via the COVIDSafe app) has the potential to negatively impact individual privacy and human rights. Creating

health and privacy rights	a sense of a 'social contract' with the community where public health is valued and balanced with assurances of privacy protection is critical, particularly in an environment where there is typically low trust in governments and institutions. This also applies to the use of apps for mental health and wellness that can also contain private information.
Topic	Next step
Mental health and social support	A robust service investment is needed for populations which have seen the greatest equity impacts from the pandemic. This should include mental health and social support services (e.g. family and domestic violence services, community legal centres) in the context of the Australian Government's response to the Productivity Commission Inquiry into Mental Health and the Victorian Royal Commission into Mental Health. There is an urgent need to build the capacity of the system to provide assertive outreach, through mobile home and community care teams and other alternatives to inpatient facilities such as Hospital in the Home. Effective modelling and ongoing data monitoring and research must be a central part of a mental health response plan.
Social prescribing	There is scope to innovate, learning from leading practice in the United Kingdom, Canada and New Zealand, including through the roll out of a national social prescribing program.
Coordinated, consistent messaging	Coordination and development of all public health messaging across levels of government in collaboration with consumers and the community. Increasing government support for consumer-driven campaigns through existing community and health advocacy groups and profession-led campaigns such as the RACGP #expertadvicematters initiative.
Telehealth	Further research into the patient experience of telehealth to better understand its value and utility to individuals and flow-on effects on the system is required e.g. anecdotal evidence suggests that attendance at outpatient clinics has improved with reduced 'do not attends'. Retain, extend and continue to promote telehealth as a vital adjunct to face-to-face service delivery in primary, hospital, specialist and other care settings by GPs, pharmacists, specialists, allied health and other service providers. Invest in telehealth equipment and infrastructure to support a long-term sustainable model.

Theme 3: Issues faced by health care providers

Topic	Issue
Access to PPE	Insufficient access to all forms of PPE required to enable health professionals to undertake regular procedures has flow on effects for consumers' experience and quality of care, as well as putting health professionals and their families at risk of infection. This includes access of PPE for carers, disability services, NGO health and community services. There is a need to ensure that all PPE is TGA approved and/or meets required standards.
Mental wellbeing of health care workers	The health and wellbeing of clinicians and health care workers is crucial to their ability to deliver care. Moral distress for health professionals implementing decisions made by others including hospital executives can be an ethical challenge and patient safety matter as a result of burnout, anxiety and fatigue. Consideration needs to be given to the impact of some health

	and care workers being pressured to attend work. Consideration needs to be given to the distress experienced when clinicians and health care workers are unable to provide normal care, including to non-COVID-19 patients. This includes vicarious trauma and the need to provide therapeutic support for front line health workers. Healthcare organisations should undertake surveys of staff to assess their satisfaction with organisational and professional support.
Telehealth	Telehealth has changed the nature of clinical care delivery models and presents a way of reducing the risk of infection for both health care workers and consumers. While there are many benefits, we need to be aware of its limitations and consider how it can be used to best effect. This includes ensuring telehealth doesn't diminish both the choice available to consumers on receiving health services or in the equity of access of health services. Triage systems need to assess a consumer's ability to manage telehealth. Support for consumers to feel comfortable and confident with telehealth is also needed in some cases.
Health professional pipeline	Arrangements needed to support continuation of health professional training and placements to ensure there are enough health workers available after the pandemic and into the future.
Topic	Next step
Mental health support	Investment in mental health supports for clinicians and health care workers, as well as looking at relief models to enable rural and remote clinicians to work sustainably where there are limited or no other services. This will require working with locum agencies about their pool of resources, availability and areas covered.
PPE	Improve the supply chains and availability of PPE, including support for local manufacture.
Health Services	Ensure that there is a balance of health services available to consumers to suit their needs, and that telehealth doesn't diminish the choice of health services available to consumers.
Telehealth training	Training for health professionals in the use of telehealth, both to improve digital literacy and identify techniques to best communicate with consumers during phone and video consults and address issues of physical examinations and assessments.

Theme 4: Impacts on Aboriginal and Torres Strait Islander peoples and communities

Topic	Issue
Equity	We need to make sure people aren't left behind in a rapidly changing situation and that we understand the level of need and what communities require in order to have equitable outcomes. Specific initiatives, developed by ATSI communities, need to be considered that will provide resources to communities with unequal outcomes in a post-COVID environment where funds are limited. These considerations could form part of an Aboriginal Health Priorities Plan which is required for acute service accreditation as well as in business continuity planning.
Gaps in health outcomes	Social determinants of health are known to impact health outcomes. Government policy and the practices of service providers need to ensure that COVID-19 responses and care options do not further exacerbate existing gaps in health outcomes or exacerbate further gaps in services. Examples such as stable housing, internet access or the ability to provide

	home schooling, the ability to isolate or quarantine safely, all become critical.
Trauma	Actions that are developed in partnership with ATSI communities are required to strengthen mental health and wellbeing both at an individual level and within communities. There is a concern that the virus will decimate whole communities and creates a shared trauma. This builds on past trauma including historical feelings about past pandemics and the significant impact which is connected to experiences of marginalisation and racism.
Self-determination in decision-making	Aboriginal and Torres Strait Islander people are often not included in decision-making at the clinical, policy or population levels. The creation of a 'voice' as described in the Uluru Statement would go some way to addressing this. We need approaches that promote agency and don't add to the stigma and racism that is already experienced.
Topic	Next step
Representation	Decision-making and service delivery to be designed and led by local communities and Aboriginal and Torres Strait Islander organisations.
Messaging	Public health messaging must be developed in a culturally sensitive way, using language and imaging that is meaningful to Aboriginal and Torres Strait Islander people (and this also applies for presenting messages in different languages for CALD communities).
Equity in service delivery	Initiatives that reduce existing inequalities and discriminations in the delivery of health services are encouraged including support that allows ATSI to receive priority health services during the pandemic.

Theme 5: Research ethics

Topic	Issue
Vaccine and treatment trials	There are ethical and risk considerations involved in the search for a vaccine and treatments for COVID-19, particularly when it appears that there has been some relaxation of ethics and speeding up of trials in the race for an outcome. Whilst support for fast tracking procedures exists, public confidence in rigorous trials and informed consent by trial participants are of paramount importance.
Non-COVID research and knowledge gaps	<p>Consideration needs to be given to the impact of pausing other research efforts and diverting research to focus on COVID-19. For consumers with other conditions, continuing that research is at least as important as finding a COVID-19 vaccine or treatment. Investment into COVID-19 should not compromise the ongoing research into, and delivery of, optimal treatment and care for chronic health conditions and/or terminal illnesses.</p> <p>Improved modelling and real-time data on mental health incidence rates is required. Currently the lack of data on mental ill-health in Australia is limiting the effectiveness of research informing the mental health response to the pandemic.</p>
Trial participation	Due to the relative success of public health measures, the number of patients eligible to participate in clinical trials will be limited. We may need to think about other kinds of research or recruiting patients from other places to track the long-term health impacts. Given COVID-19 is about all of us, there is likely a whole group of citizens who are experiencing the opportunity to be a research participant for the first time and what this

	might mean for them. Given they may have heightened anxiety, consideration may need to be given to how researchers go about this research beyond the usual ethical guidance.
Topic	Next step
COVID-19 trials and evidence communication and translation	<p>Develop clear guidelines for how COVID-19 trials can be conducted in the current situation, balancing assurances of safety and quality with the need to find a vaccine or treatment as soon as possible. Guidelines should include information for consumers who may participate in trials about any increased risks involved.</p> <p>Inaccurate information and misleading statements about treatments for COVID-19 should be widely corrected and rebutted to protect consumers. The leading work of the National COVID Living Evidence Taskforce should be widely promoted, including the dissemination of emerging evidence of treatments and management in a manner suited to raising public awareness.</p>
Resuming other research	Undertake an assessment of the impact of restrictions on non-COVID research projects and include consumers in conversations about prioritising the resumption of research in other areas.

Theme 6: Emerging from the pandemic and future planning

Topic	Issue
Governance and planning	Consumer engagement and input is a critical ingredient in the development and monitoring of policies and initiatives required to navigate through both the remainder of the pandemic and the post-pandemic environment. This covers all initiatives relating to the current lockdown and includes future measures relating to isolation, tracing and testing. The community voice has not been included in all levels of government decision-making to-date across these dimensions.
Health system	The health response to the pandemic has highlighted the strengths and weaknesses of our health and welfare systems. Key among these is the vital role to be played by primary health care and the need to ensure that we have a sustainable workforce (attention to issues such as supply, training pipeline, clinical placements etc. is critical). Primary care needs to be considered in business continuity planning. The pandemic has also disrupted screening and pathways to early diagnosis. Fresh public health campaigns are required to re-engage the community that it is safe and advisable to seek out preventive and early intervention services.
Coordinated care	The deficiencies in access to services for people such as those with disabilities, older Australians and young people, has been further exposed by the pandemic. Fragmented services are a problem for all these groups, and it is increasingly common for them to present with complex needs which require case coordination across health, disability, education, vocational support, community services and aged care settings. Equity of service access is further compounded when these consumers have minimal experience in navigating a complex service system. Reforms including workforce reforms are required e.g. digital navigators are an emerging concept that should be explored.
Future planning - vaccinations	Public health messaging to date suggests it is assumed that a safe and effective vaccine and/or treatment will be available at some point, but this is not necessarily the case. There is a need for community engagement in

	scenario discussions and planning specifically in relation to the rollout of future vaccinations.
Economic and social impact	Even past the peak of the pandemic we will continue to experience ongoing social economic impacts due to the ongoing need for social distancing. These will have flow on effects for people's health and will not be distributed equally. Balancing the health, social and economic impacts of the pandemic will be an ongoing challenge for some time.
Topic	Next step
Health system reform	It will be incumbent on governments to resume and accelerate reform agendas that are presently 'on hold' particularly the 10 Year Primary Health Care Plan and the National Medical Workforce Strategy. Serious responses with appropriate investment to inquiries such as the Royal Commission into Aged Care and the Productivity Commission Inquiry into Mental Health are all essential to a pandemic recovery plan. An integrated care agenda also needs to be pursued. As telehealth becomes embedded, commonplace and continues to evolve, ethical consideration will need to be given in consultation with consumers to Artificial Intelligence (AI) and the clinical governance, quality assurance and evidence base that integrates it into healthcare.
Pandemic review	A review of the National Pandemic Plan should be conducted with structured and systemic consumer and community input. This should address all aspects of the COVID response and what needs to be adjusted or built into future disaster response plans e.g. the need to develop public health messages and sub-messages in consultation with various population cohorts, particularly disadvantaged and vulnerable groups. A program of pandemic simulations for various scenarios should be mapped and implemented.
Economic recovery	Consumers and community groups must be included in discussions about the economic recovery plan and future budget considerations, particularly where cuts to benefits, programs and/or services are being considered. Young people will feel the negative economic impacts of the pandemic for many years to come. They make up a large proportion of the casual workforce in the hardest hit sectors and will be vulnerable to experiencing psychological, financial and housing stress in the short and longer terms.

Recommendations

The following actions should be progressed as a priority:

1. Develop a national framework for ethical decision-making for policy and practice consistency and transparency. The framework should be co-designed and with the community and informed by recent forums and international best practice. The role of consumers in the ongoing monitoring and evaluation of the framework is paramount.
2. To this end, it is strongly recommended that governments and their relevant advisory structures convene with the state and federal peak health consumer advocacy organisations to co-develop an ethical decision-making framework.
3. Establish a mechanism such as a consumer panel with appropriate composition and diversity to include consumer input into the governance arrangements including the design, implementation, monitoring and evaluation of government policy and programs

required to navigate through the remainder of the pandemic and the longer-term pandemic recovery plan.

4. The recovery plan should incorporate specific objectives focused on reducing existing health inequities and discrimination within vulnerable consumer groups supported by fully funded initiatives.
5. Make a robust service investment in mental health, social and legal support services in line with the recommendations of the Productivity Commission Inquiry into Mental Health, the Aged Care Royal Commission and other relevant inquiries.
6. Increase government support for consumer-driven campaigns through existing community and health advocacy groups. This includes strengthening the consumer voice into the development and coordination of all public health messaging across levels of government and with the community sector, including those messages that encourage consumers to continue to access ongoing care and targeted messages to specific communities that are culturally sensitive and accessible.
7. Retain, extend and continue to promote telehealth as a vital adjunct to health service delivery across a range of service settings and by a range of clinicians and health care providers in a format that doesn't diminish the choice for health services available to consumers or in the equity of access of health services more broadly. Improve telehealth availability to those in communities with current barriers to access (such as those for whom travel for treatment is burdensome for practical, physical and psychological reasons) and conduct research on consumer experiences with telehealth to inform future directions.
8. Conduct a public review of the National Pandemic Plan ensuring wide consumer and community consultation.
9. Resume and accelerate reform agendas that are presently 'on hold' particularly the 10 Year Primary Health Care Plan and the National Medical Workforce Strategy.

About the Consumers Health Forum of Australia

The Consumers Health Forum of Australia (CHF) is the national peak body representing the interests of Australian healthcare consumers. CHF works to achieve safe, quality, timely healthcare for all Australians, supported by accessible health information and systems.

CHF does this by:

- Advocating for appropriate and equitable healthcare
- Undertaking consumer-based research and developing a strong consumer knowledge base
- Identifying key issues in safety and quality of health services for consumers
- Raising the health literacy of consumers, health professionals and stakeholders
- Providing a strong national voice for health consumers and supporting consumer participation in health policy and program decision-making

CHF values:

- our members' knowledge, experience and involvement
- development of an integrated healthcare system that values the consumer experience
- early intervention, prevention and early diagnosis
- collaborative integrated healthcare
- working in partnership

CHF 250 + members and member organisations reach thousands of Australian health consumers across a wide range of health interests and health system experiences. Our Special Interest Groups provide targeted advice in areas such as rural and remote health issues, and patient safety, quality and health literacy. CHF policy is developed through consultation with members, ensuring that CHF maintains a broad, representative, health consumer perspective.