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Decision-making for pandemics: an ethics framework

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1. Introduction

The COVID-19 pandemic presents unprecedented challenges that have required, and will continue to require, rapid and well-considered decisions by public health experts and policy-makers and by leaders in the community sector. In any pandemic, decisions are required at the local and national level that are most appropriate for the population. One of the key issues is to ensure that those who are the most vulnerable to the impact of a pandemic are engaged and involved in the decision-making process. The management of other pandemics, such as Ebola and H1N1, has demonstrated that collaboration, engagement and buy-in by governments, clinicians, researchers and members of the community lead to effective pandemic management.

Purpose

The purpose of this framework is to guide ethically informed decision-making and policy development on health-related issues during the current COVID-19 pandemic and in future pandemics, both in the planning and management phases. To support and facilitate this, the framework offers a structured, reflective process grounded in a set of core values and procedural principles.

The framework does not lead the user to a definitive conclusion or argue for any particular ethical value over others. Reliance on any individual value is correlated with the strength of the claims arising from the context—the needs, decisions and actions—to which it applies. There may be times when values and claims conflict and, when this is the case, it will be necessary to weigh them against each other.

This framework encourages users to reflect on the assumptions and judgments they make in response to the difficult and often competing priorities that present themselves during a pandemic. Any decision-maker will need to justify the processes and methods they use to make their decisions, consider the possible harms and benefits and other ethical implications of their actions, and accept responsibility for these decisions and actions. It also encourages decision-makers to engage with others in discussion and evaluation of individual decisions and of the decision-making process itself.

Scope

The framework offers a facilitative approach by setting out processes that aim to generate clear and justified outcomes of decision-making. An effective response requires that potential benefits and harms for all those who may be affected by a decision are carefully considered. This is particularly important, as any response to a pandemic requires that actions are taken in the interests of the whole community and requires that no individual or group is further disadvantaged.

This framework is a form of ethical guidance that does not, on its own, have legal standing. It is written in a way that makes it compatible for use with other ethics frameworks, including those that have been developed by professional societies and Australian jurisdictions to help guide the delivery of health care and the allocation of resources during a pandemic. This framework does not aim to assist with clinical care decision-making or with the ethical review and approval of research, although some of the discussion used in the framework may assist in the reflective process in those contexts.

Users of the framework should make themselves aware of applicable laws and regulations and the constraints that these may place on policy options or other actions that might be identified when using the framework.

Intended audience

The intended audience for this framework is those with responsibility for decision-making during a pandemic. These decision-makers include:

- Government officials, public health experts and health care administrators
- Community leaders with authority to make decisions on behalf of the community they represent.

It is recognised that every sector of society is affected by a pandemic. However, some populations and individuals, particularly those who were in precarious situations prior to the pandemic, will be more adversely affected as a result of the pandemic. Many groups and organisations at a range of different levels in the community will be planning and making decisions for how best to manage the pandemic in the context of their local arrangements. It is hoped that the framework will be a useful tool for community-based decision-making more generally.

Structure of the framework

The framework begins with an outline of the values and procedural principles that underpin the key issues in this framework. These values and principles are commonly found in the literature that discusses the range of complex ethical decision-making required in a pandemic. This section is followed by a series of steps and questions that inform the decision-making process and help guide the process of formulating, justifying and implementing proposed decisions.

Selected worked examples are provided to demonstrate how to apply the values and principles and the decision-making steps. These worked examples are illustrative and are not intended to be comprehensive. The framework also includes selected ethical issues potentially arising during and after a pandemic (Appendix A) and a list of additional resources (Appendix B).

2. Values and procedural principles

The following values and procedural principles aim to guide the reflective processes, decisions and actions of decision-makers. They do not represent all of the relevant values or principles, but are often seen as the most important in the context of a pandemic.

Not every value will be applicable in every circumstance. To that extent, these values are not absolute. When making decisions during a pandemic (or in planning for it), they will, inevitably, need to be balanced or weighed against one another. Judgment will be required to decide which values are relevant, and to what degree, and which take precedence in cases of conflict. This means that none of the values, such as 'liberty', 'solidarity' or 'community well-being', should be ignored in the decision-making process, although there will be times when they don't all apply.

In contrast, the procedural principles guide how to implement the decision based on the values. They are all important when making significant decisions or taking actions that have a meaningful impact on individuals, distinct communities and Australian society as a whole.

Values

Respect – recognition of the equality and dignity of all individuals and their communities.

- **liberty** – affirming the exercise of self-determination and individual choice, including the right to privacy.

Justice – the need to prioritise resources appropriately – e.g. on the basis of need, efficiency and/or equality – to meet the standard of a high level of universal care and well-being.

- **equity** – the distribution of resources and benefits with the aims of achieving equal outcomes for and responding to the impact of the social determinants of health on individuals and specific population groups.
- **diversity –** respect for, and fair representation of, differences including age, gender, sexual orientation, ethnicity, levels of literacy, and differing world views, beliefs, expertise and lived experience.
- **advocacy by and for the most vulnerable –** ensuring that the needs of vulnerable communities and individuals are prominent in any decision-making.

Solidarity – recognition of, and respect for, duties and mutual obligations that exist on international, national, local community and interpersonal levels.

- **reciprocity –** the commitment to offer support to those who take on greater risks and/or burdens.

Common good/stewardship – the need to take care of the health of a society as a whole, in addition to its component parts, as well as the natural environment.

- **community well-being** – the need to ensure that the well-being of communities is considered even when prioritising individual or group interests.

Procedural principles

Transparency – openness about what decisions are being or have been made, for which reasons, and in accordance with what criteria. Transparency also requires the disclosure of relevant interests, where applicable.

Accountability – being answerable to the public for the type and quality of decisions made or actions taken.

Inclusiveness – inclusion and engagement of all relevant stakeholders in decision-making processes ranging from consumers and community groups to medical, public health or scientific experts. Inclusiveness should be based on collaboration and partnership and promote culturally appropriate decision-making.

Verifiability – the potential for independent assessment of the validity of the evidence used in decision-making.

Responsiveness – establishment and use of mechanisms for ongoing review of decisions and any necessary revisions.

Proportionality – that the action is appropriately calibrated to the relevant needs.

Using the values and principles to inform your decision-making should not be formulaic. An ethically defensible decision on policy, strategy or any other matter is the outcome of a complex process requiring reflection, integration and balancing of multiple imperatives and demands.

The steps and questions in Section 3 are intended to promote and facilitate thoughtful and pragmatic decisions that can be justified by reference to the values and principles in Section 2.

3. Steps and questions

Having read and reflected on the values and principles, the steps below demonstrate how to make and reflect on decisions made in response to pandemics.

Step 1: Specify the Issue and Identify/Assess the Options

- What problem or issue do you need to address?
- What action/s are you considering and what are the possible alternatives that you should consider?
- In considering your options, determine with whom you need to consult and how (see step 3).
- What are the pros and cons of each option and what uncertainties should you consider?
- What facts are relevant to your decision? Is there evidence for/against the available options? What is the nature and quality of that evidence?
- Is there additional information that you require to make a decision?

Step 2: Propose a Decision and Provide Reasons

- For any action that is proposed, what are the reasons that justify that action?
- Looking to the values in section 2 of this framework, which of these support/do not support your proposed action?
- Is your decision-making process or planned approach consistent with the procedural principles set out in section 2?
- Have you considered the ethical implications of your proposed action and identified the risks in taking this action?
- Have you identified the ways the risks might be resolved, managed or reduced?
- Have you identified how you will weigh the identified risks and balance them against any benefits?

› **Based on the values and principles that you have applied and the reasoning that you have used, state clearly your preferred action and the ethical argument(s) that support(s) it.**

Step 3: Consult and Revise

- Who are the key individuals/groups/communities that will experience the greatest impact (benefits or harms) of your proposed action?
- How will you engage with them and involve them in the decision-making process?
- Is this individual/group/community able to engage in consultation in the way that you propose and can they be supported to do so in a manner that empowers them?
- How will you make the process of engagement with stakeholders and subsequent decision-making transparent?
- With whom will you need to coordinate and collaborate in finalising and implementing the decision?

› In light of the feedback that you receive, **consider revision of your preferred action and the reasons that support it.**

› **Check any proposed revisions via a return to previous steps (if needed).**

Step 4: Act and Review

- What is/are the most appropriate way/s to implement and communicate the decision (for example: official statement, media release, policy, guidance, regulation, community event)?
- When and by whom will the decision be communicated and implemented?
- How will the impact of decisions be monitored?
- What would trigger review or additional action?

› **Establish an arrangement for review of the action.**
› **Implement the proposed action.**
› **Collect any evidence about the impact of the action.**
› **Consider what lessons you have learned from the success, failure and implications of the action (including unintended consequences).**
› **Keep actions under review and return to the previous steps (if needed).**

4. Worked examples

The worked examples below are provided to assist decision makers in using this framework. They do not encompass the full range of ethical issues or decision-making challenges that are likely to arise during a pandemic. The analysis that follows each worked example is intended to raise questions or issues that must be considered, not to resolve those questions or issues.

The framework attempts to provide a systematic set of steps to help decision makers take into account the complex factors that are relevant to a decision or to the decision-making process. The examples illustrate how those who make and implement decisions might use the framework to help them make necessary choices.

Worked Example 1 – Messaging for Indigenous communities

This example considers messaging for Indigenous communities. The ethics framework provides decision-makers with a robust process for decision-making, enables them to articulate an ethically defensible rationale for the decisions that they have made, and guides them to put in place a process of consultation and review of these decisions.

As COVID-19 began to spread across many communities in Australia, ensuring that public health messaging was reaching the whole population and finding ways to properly engage with Indigenous communities was of critical importance.

Sammi lives in an Indigenous community in a rural area. Sammi is connected into social media networks and is receiving information about the pandemic from the local Aboriginal Health Service. Sammi is very worried about the health of her relatives and other kin, who are spread around a large geographical area and for whom access to digital media is patchy. In particular, Sammi is concerned for her father, who is unwell and needs regular access to medical services. When he can't get to those services, Sammi cares for him herself. She is aware of the need to maintain physical distancing and to wear a mask when this is not possible, as well as the need for frequent hand washing and monitoring for any symptoms of COVID-19.

While the novel coronavirus has not reached Sammi's community, the community is aware that doctors and nurses visit the town from more populated parts of the state and Sammi is worried that it is only a matter of time before the virus arrives in the community. She is also concerned that some of her relatives may not fully understand the potential for infection. She wonders how she can assist her relatives and the community to understand what they have to do to stay safe during the pandemic. Sammi is particularly concerned about the older members of her community. Like others in her community, she recognises the critical importance of these older members of the community, both as community leaders and as custodians of cultural memory.

Using the framework to help make decisions

In this example, we illustrate how messaging in a pandemic may need to be modified to meet the needs of specific communities.

STEP	EXAMPLE	VALUE	PROCEDURAL PRINCIPLE
	Messaging for Indigenous communities		
Step 1 Specify Issue/ Identify & Assess Options	Policy makers, state/territory governments (including departments of public health) and Aboriginal health services need to determine how best to provide culturally appropriate, accurate and comprehensive information and advice to Indigenous groups.	Respect Diversity Solidarity	Inclusiveness Proportionality
	Consider: • Identifying groups at risk of being isolated due to lack of resources and/or language barriers. • Which biases, conscious or unconscious, may be influencing decision-making. • Whether the voices and preferences of Indigenous people are being sought, heard and incorporated into the decision-making process. • How best to build relationships and empower the community to make decisions.	Respect Justice Equity Diversity Solidarity Community well-being	Transparency Inclusiveness Advocacy
	Consider the pros and cons of each possible decision.		Accountability
	Consider what evidence/advice/guidance exists to support your decision and the quality of that evidence/advice/guidance.		Verifiability
	Ask: What else do I need to know to make this decision?		

STEP	EXAMPLE	VALUE	PROCEDURAL PRINCIPLE
	Messaging for Indigenous communities		
Step 2 Propose Decision/ Provide Reasons	For each proposed decision, consider how to explain and justify your decision.		
	Consult with community leaders to identify their information needs and co-design best ways to communicate in a culturally sensitive manner.	Respect Diversity	Inclusiveness
	Employ a range of approaches (digital and non-digital) to providing information to these communities (see, e.g. Resources | National Indigenous Australians Agency (niaa.gov.au)).	Respect Diversity	Inclusiveness
	Recognise the need for rapid implementation of urgent measures and the potential delay in successful dissemination of information, with the consequent impact on understanding and compliance.		Proportionality
	Identify Sammi and community members like her as partners in identifying the information needs of their community and the best ways to communicate in a culturally sensitive manner, and engage them in this communication process.	Equity	Advocacy
	With the community leaders of the rural Indigenous community, consider whether the critical importance within the community of its older members should influence treatment decisions involving them.	Justice Diversity Community well-being	Inclusiveness Advocacy
	State the values in the framework that underpin your decision and any balancing of these that has been required (e.g. prioritisation of community well-being over justice or vice versa).		Transparency
	Ask yourself whether you have considered the ethical implications of your decision and whether you have attempted to reduce the risks and burdens to an appropriate degree.	Justice	Proportionality

STEP	EXAMPLE	VALUE	PROCEDURAL PRINCIPLE
	Messaging for Indigenous communities		
Step 3 Consult & Revise	Conduct further consultation with community leaders on how actions can be community-led and how communication strategies and resources can be co-developed and implemented.	Justice Equity Diversity	Inclusiveness
	Check to make sure that your decision (and the decision-making process) is consistent with the framework's procedural principles (e.g. transparency, inclusiveness, proportionality).		
	Remain open to revision based on changing circumstances and input from those involved in and impacted by the decision.		Inclusiveness Responsiveness
Step 4 Act & Review	Establish a mechanism and timeframe for review of the action/s.		Responsiveness
	Monitor implementation of the decision to ensure that those responsible for the action (or its component parts) are doing what they are supposed to be doing.		Transparency Accountability
	Revise and modify as necessary.		Responsiveness
	Conduct a review of what worked and what didn't and why.		Responsiveness
	Consider how to incorporate lessons learned into future decisions and actions.		

Worked Example 2 – Allocation of resources in acute care hospitals

This example considers the allocation of resources in an acute care hospital in two scenarios: the first involving the outbreak of a virulent influenza and the second involving the outbreak of a slow-progressing novel virus. As in the previous examples, the ethics framework provides decision-makers with a robust process for decision-making, enables them to articulate an ethically defensible rationale for the decisions which they have made, and guides them to put in place a process of consultation and review of these decisions. An interesting feature of this example is that the use of this framework leads decision-makers in the two scenarios to different decisions.

Scenario 1: Virulent influenza

An influenza virus spreads throughout Australasia and, within a few weeks, hundreds of thousands of people are seriously ill. The virus is considerably more virulent than influenza viruses previously encountered and, while the symptoms are standard flu symptoms, this virus has a high fatality rate.

Following from prior experience, public health authorities and government departments of health have well-developed plans in place for a flu outbreak; however, the virulence of this virus means that the health care systems of most countries are quickly overwhelmed. Those in charge of critical clinical care resources scramble to maintain orderly delivery of services and some resources quickly run out or are 'captured' for use with identified patient populations who have been badly affected by the virus. In particular, ICU beds and nursing staff are insufficient to meet the needs of both those infected with the virus and those with other health conditions who also need access to intensive care.

Clinical ethics committees and other review committees are established or activated at many health care institutions and at several levels of government.

Disagreements amongst staff begin to increase about how to prioritise individual patients for access to intensive care. The principal issue is how people with equal projected outcomes of care are being prioritised if some of them are over 90 years old or are living with significant health issues that are likely to reduce their life span. Some facilities are not factoring in this variable while others are, either explicitly or implicitly.

Unit managers are also noticing that residential facilities for the aged or people living with disabilities seem to be employing very different approaches to transferring people within their care to hospitals.

Additionally, review committees in different institutions or government agencies are reaching decisions that are frequently not aligned with one another.

Scenario 2: Slow-progressing novel virus

A novel virus of unknown character and aetiology emerges in discrete areas of tropical Australasia. Within a few months, thousands of people have become sick and many die. The rates of virus transmission are relatively low at first and then gradually increase until the WHO declares a regional pandemic. The virus spreads to more populated regions, but cases are not appearing in any significant numbers outside of Australasia. Fatality rates are very high.

Following from the COVID-19 experience, public health authorities and government departments of health in the affected countries have well-developed plans in place for a virus outbreak; however, these plans are skewed towards management of known virus types, such as coronavirus and influenza, and diagnostic services capacity to address the novel virus is not sufficient to meet the need. Moreover, the virus is producing a constellation of symptoms that are not limited to one or two medical specialities and necessitate significant coordination between clinical services.

Those in charge of critical clinical care resources rapidly organise diagnostic testing and multi-disciplinary and cross-specialty teams. However, many hospitals in affected areas do not have access to necessary diagnostic or clinical specialty services and are reluctant to re-allocate the resources they do have, as these are needed to treat patients with common health conditions. They are also contending with objections from patients' families to transferring those afflicted with the virus to major tertiary hospitals in distant cities.

Using the framework to help make decisions

In this example, we illustrate how the framework might apply to different decision-making processes and outcomes under two related scenarios with distinctive fact patterns.

Scenario 1: Virulent Influenza

STEP	EXAMPLE	VALUE	PROCEDURAL PRINCIPLE
	Allocation of resources in acute care hospitals		
Step 1 Specify Issue/ Identify & Assess Options	The core decision for policy makers, hospital administrators and clinicians is how to allocate scarce or limited resources fairly and efficiently.	Justice Equity Solidarity	Transparency Inclusiveness Advocacy Proportionality
	Consider: • Which variables are determinative, which are relevant to a decision and which should not be given weight in an allocation decision. • How social determinants of health and systemic inequities should be taken into account when allocating resources. • Which biases, conscious or unconscious, may be influencing decision-making. • Whether the voices and preferences of commonly disenfranchised groups of people are being sought, heard and incorporated into the decision-making process.	Justice Equity Diversity	Transparency Inclusiveness
	Consider the pros and cons of each of these possible decisions.		Accountability
	Determine who is responsible for developing and coordinating allocation policies and making individual allocation decisions.		Transparency Accountability
	Consider what is different, if anything, about this scenario versus the norm.		Proportionality
	Consider what evidence/advice/guidance exists to support your decision and the quality of that evidence/advice/guidance.		Verifiability
	Ask: What else do I need to know to make this decision?		

STEP	EXAMPLE	VALUE	PROCEDURAL PRINCIPLE
	Allocation of resources in acute care hospitals		
Step 2 Propose Decision/ Provide Reasons	For each proposed decision, consider how to explain and justify your decision. For example, if you have decided to prioritise treatment of virus-infected patients at the expense of other critically ill individuals needing access to intensive care.	Justice, Equity	Transparency
	Your reason could be that this choice is necessary to prevent the infection from spreading further in the community via relatives and hospital staff and that recovery from the virus is more likely than from other health conditions requiring intensive care. If so, then any policy or explanation of your decision should include this rationale. Providing reasons for a proposed action helps to clarify a decision and provides an explanation for why it is appropriate. This explanation can then provide the basis for a justification of the eventual action if the reasons are challenged by others. You should be prepared to be challenged, especially if exceptions are made or the policy is applied inconsistently.	Liberty Community well-being	Transparency
	State the values in the framework that underpin your decision and any balancing of these that has been required (e.g. prioritisation of community well-being over justice or vice versa).		Transparency
	Ask yourself whether you have considered the ethical implications of your decision and whether you have attempted to reduce the risks and burdens to an appropriate degree.	Justice	Proportionality
Step 3 Consult & Revise	Consider who needs to be involved in making the decision and implementing the action (e.g. government health department, institutional executive, clinicians (including nursing and allied health), clinical ethics committee or consultant or other review committee, patients, and relatives).	Respect Equity Diversity	Inclusiveness Accountability
	Develop an implementation plan, including a communication strategy and a response if circumstances shift (e.g. the numbers of patients requiring intensive care increases or decreases significantly).		Accountability Responsiveness
	Check to make sure that your decision (and the decision-making process) is consistent with the framework's procedural principles (e.g. transparency, inclusiveness, proportionality).		
	Remain open to revision based on changing circumstances and input from those involved in and impacted by the decision.		Inclusiveness Responsiveness

STEP	EXAMPLE	VALUE	PROCEDURAL PRINCIPLE
	Allocation of resources in acute care hospitals		
Step 4 Act & Review	Establish a mechanism and timeframe for review of the action/s.		Responsiveness
	Monitor implementation of the decision to ensure that those responsible for the action (or its component parts) are doing what they are supposed to be doing.		Transparency Accountability
	Revise and modify as necessary.		Responsiveness
	Conduct a review, collecting evidence of what worked and what didn't and why.		Responsiveness
	Consider how to incorporate lessons learned into future decisions and actions.		

Scenario 2: Slow-progressing novel virus

The information below reflects the similarity between the use of the framework to inform decision-making for this scenario and for scenario 1 (virulent influenza). Additional issues, factors or comments to be considered in this scenario are in **bold** and underlined.

STEP	EXAMPLE	VALUE	PROCEDURAL PRINCIPLE
	Allocation of resources in acute care hospitals		
Step 1 Specify Issue/ Identify & Assess Options	The core decision for policy makers, hospital administrators and clinicians is how to allocate scarce or limited resources fairly and efficiently **not just within a health care institution, but also across institutions that are not similarly situated.**	Justice Equity Solidarity	Transparency Inclusiveness Advocacy Proportionality
	Factors that have to be considered are: • Which variables are determinative, which are relevant to a decision and which should not be given weight in an allocation decision. • Which biases, conscious or unconscious, may be influencing decision-making. • Whether the voices and preferences of commonly disenfranchised groups of people are being sought, heard and incorporated into the decision-making process. • **Whether the objections of relatives to separation from the patient/resident override clinical factors in a transfer decision.**	Justice Equity Diversity	Transparency Inclusiveness
	Consider the pros and cons of each of these possible decisions.		Accountability
	Determine who is responsible for developing and coordinating allocation policies and making individual allocation decisions.		Transparency Accountability
	Consider what is different, if anything, about this scenario versus the norm **– both a more 'normative' outbreak and compared to a non-pandemic scenario.**		Proportionality
	Consider what evidence/advice/guidance exists to support your decision and the quality of that evidence/advice/guidance.		Verifiability
	Ask: What else do I need to know to make this decision?		

STEP	EXAMPLE	VALUE	PROCEDURAL PRINCIPLE
	Allocation of resources in acute care hospitals		
Step 2 Propose Decision/ Provide Reasons	For each proposed decision, consider how to explain and justify your decision. For example, if you have decided **not to** prioritise treatment of virus-infected patients and continue to provide other critically ill individuals with equal access to intensive care.	Justice, Equity	Transparency
	Your reason could be that this choice is justified by the fact that other health conditions requiring intensive care are more prevalent. If so, then any policy or explanation of your decision should include this rationale. Providing reasons for a proposed action can be useful in clarifying a decision and to provide an explanation for why it is appropriate. This explanation can then provide the basis for a justification of the eventual action if the reasons are challenged by others. You should be prepared to be challenged, especially if exceptions are made or the policy is applied inconsistently.	Liberty Community well-being	Transparency
	State the values in the framework that underpin your decision and any balancing of these that has been required.		Transparency
	Ask yourself whether you have considered all of the ethical implications of your decision and whether you have attempted to reduce the risks and burdens to an appropriate degree.	Justice	Proportionality
Step 3 Consult & Revise	Consider who needs to be involved in making the decision and implementing the action (e.g. government health department, institutional executive, clinicians (including nursing and allied health), clinical ethics committee or consultant or other review committee, patients and relatives).	Respect Equity Diversity	Inclusiveness Accountability
	Develop an implementation plan, including a communication strategy and a response if circumstances shift (e.g. the numbers of patients requiring intensive care increases or decreases significantly).		Accountability Responsiveness
	Check to make sure that your decision (and the decision-making process) is consistent with the framework's procedural principles (e.g. transparency, inclusiveness, proportionality).		
	Remain open to revision based on changing circumstances and input from those involved in and impacted by the decision.		Inclusiveness Responsiveness
Step 4 Act & Review	Establish a mechanism and timeframe for review of the action/s.		Responsiveness
	Monitor implementation of the decision to ensure that those responsible for the action (or its component parts) are doing what they are supposed to be doing.		Transparency Accountability
	Revise and modify as necessary.		Responsiveness
	Conduct a review, collecting evidence of what worked and what didn't and why.		Responsiveness
	Consider how to incorporate lessons learned into future decisions and actions.		

Worked Example 3 – Research priorities and the rapid generation, dissemination and publication of research findings

This example considers a situation in which two of the staff at a university – researcher Dr A and Deputy Vice-Chancellor for Research Professor B – have different views about the priority for Dr A's research during a pandemic. Here, the ethics framework provides a respectful and transparent process whereby the opposing views can be examined.

Background

It is the year 2023, and the WHO has declared a global pandemic, the first since COVID-19. The pandemic is a respiratory condition, HIBID-23, that is caused by a highly infectious strain of bacteria. HIBID-23 is particularly prevalent amongst children and older people and is resistant to all available antibiotics. Its aetiology is not yet clear, but the first outbreak occurred in the South Pacific region. The fatality rate is much higher than for COVID-19.

Researchers with relevant skills and expertise, industry, government and academia are working around the clock to organise research infrastructure and debating which research questions to pursue first and where to allocate funding. As in the COVID-19 pandemic, there is tension between collaboration and competition with respect to work on promising treatments. The new Pan-Pacific Research Council, a public-private partnership developed after the COVID-19 pandemic, is the focus of much media attention.

Clinical trial sponsors are being approached by researchers to run trials testing a new therapeutic product that has significant potential, but for which pre-clinical testing has not yet been completed. Journal editors are experiencing a ten-fold increase in the number of manuscripts submitted on the profiles of HIBID-like bacteria and health conditions that may be caused by these bacteria.

Dr A and Professor B

Dr A's expertise is in determining protein structures that aid in the design of pharmaceutical products (a sub-specialty of proteomics). Most of his work has focused on the proteomics of breast cancer cells and he has several large grants from government funding bodies and philanthropies that support his work. Like most researchers, Dr A is trying to determine whether he should postpone his current work and re-direct his resources to HIBID-23.

Dr A has conferred with his research team, colleagues in his field and consumer representatives from the Cancer Council and he has determined that the value of the impact that he could have on HIBID-23 is not sufficient to justify abandoning his cancer research. He is also concerned about the impact of shifting direction on his career, which has only recently stabilised after 20 years in the medical research sector.

Dr A's laboratory staff and the consumer group support his assessment, but Professor B, the Deputy Vice-Chancellor for Research (DVCR) at his university, strongly advises Dr A to change his research plan and re-direct his work toward HIBID-23 proteomics. Professor B also offers Dr A the opportunity to join a new initiative at Company X to develop a state-of-the-art technology that would both aid researchers all over the world in their HIBID-23 research (including research on the new therapeutic product) and potentially revolutionise proteomics more broadly. Professor B is spearheading a coordinated campaign to fast-track publication of data that show the benefits of the technology and proposes that Dr A co-author several journal papers with Company X researchers. She also informs Dr A that proposed cutbacks at the university are likely to result in the loss of two of his most promising junior researchers, who have been core team members on his most significant breast cancer research projects.

As Dr A is deciding what to do, he discovers that several papers published by Company X researchers have recently been retracted by Journal Y due to erroneous or manipulated data used to support the conclusions. The article that forced the retraction focused on flaws in the peer review processes at Journal Y that were presumed to have been corrected after being exposed during the COVID-19 pandemic.

Using the framework to help make decisions

In this example, we illustrate how individuals with different interests and commitments might use the framework to help them make their decisions.

STEP	EXAMPLE	VALUE	PROCEDURAL PRINCIPLE
	Research priorities and the rapid generation, dissemination and publication of research findings		
Step 1 Specify Issue/ Identify & Assess Options	This example focuses on the competing interests and judgments of those involved in supporting, funding and publishing research. The core decisions are: how to allocate research resources, how to allocate research funding and whether standard processes for review and publication of research should be accelerated or de-emphasised during a crisis such as a pandemic.	Justice Common good	Accountability Proportionality
	Each decision maker has to clarify their interests, commitments, responsibilities and obligations and weigh these against each other. Relevant interests, commitments, responsibilities and obligations include: • Dr A's obligations to his funders and to his staff. • Dr A's interest in his career and reputation. • Dr A's commitments to cancer research and to people with cancer (consumer advisors and others). • Dr A's professional responsibilities as a scientist and researcher to his community and to society in a public health crisis. • Dr A's commitment to the standards of his profession and to the quality of his work. • Professor B's obligations to her university. • Professor B's interests in her career, her reputation and her relationship with Company X. • Professor B's obligations to those under her authority, such as Dr A and his team. • Professor B's professional responsibilities as a scientist, researcher and university executive administrator to her community and to society in a public health crisis. • Professor B's commitment to the standards of her profession. • The interests, prior commitments and responsibilities to society of those making decisions for the funding bodies. • Journal Y's (and other journals') commitment to peer review and publication standards. • The professional responsibilities of peer reviewers to the quality of their work and the integrity of the review process.	Liberty Equity Solidarity Common good Community well-being	Transparency Accountability Proportionality

STEP	EXAMPLE	VALUE	PROCEDURAL PRINCIPLE
	Research priorities and the rapid generation, dissemination and publication of research findings		
Step 2 Propose Decision/ Provide Reasons	For each proposed decision, consider how to explain and justify your decision, for example, if you have decided that it is important that any limited funding is prioritised for HIBID-23 research rather than cancer research or other critical health research.	(Justice, Equity, Community well-being)	Transparency
	Your reason could be that achieving perfect fairness and accommodating all critical research needs is not possible in a pandemic, that difficult funding allocation decisions have to be made and that some important research will have to be postponed. If so, then any policy or explanation of your decision should include this rationale. Be prepared to be challenged, especially if exceptions are made or the policy is applied inconsistently.	(Justice, Equity, Community well-being)	Transparency
	State the values in the framework that underpin your decision and any balancing of these that has been required (e.g. prioritisation of common good over justice or vice versa).		Transparency
	Ask yourself whether you have considered all of the ethical implications of your decision and whether you have attempted to reduce the risks and burdens to an appropriate degree. For example, can the 'buckets' into which funding goes be defined on the basis of both long and short term impact rather than only on urgency/ immediate impact?	Justice	Proportionality
Step 3 Consult & Revise	Consider who needs to be involved in making the decision and implementing the action (e.g. in re-directing resources for research, do consumer advocacy groups who have been previously consulted need to have input into the decision?).	Respect Equity Diversity	Inclusiveness Accountability
	Funding bodies, universities, journals or peer reviewers themselves might need to consider developing a policy or statement if, for example, widespread rapid dissemination or publication of results begins to reveal systemic issues in accelerated peer review or insufficiently supported conclusions.		Accountability Responsiveness
	Check to make sure that your decision (and the decision-making process) is consistent with the framework's procedural principles (e.g. accountability, verifiability, responsiveness).		
	Remain open to revision based on changing circumstances and input from those involved in and impacted by the decision.		Inclusiveness Responsiveness

STEP	EXAMPLE	VALUE	PROCEDURAL PRINCIPLE
	Research priorities and the rapid generation, dissemination and publication of research findings		
Step 4 Act & Review	Establish a mechanism and timeframe for review of the action/s.		Responsiveness
	Monitor implementation of the decision to ensure that those responsible for the action (or its component parts) are doing what they are supposed to be doing.		Transparency Accountability
	Revise and modify as necessary.		Responsiveness
	Conduct a review, collecting evidence of what worked and what didn't and why.		Responsiveness
	Consider how to incorporate lessons learned into future decisions and actions.		

Consumer engagement case study

In addition to the worked examples in this Section, we include the following illustrative case study. The case study reflects an experience of a national advisory group and addresses concerns that are often raised about the extended time it takes to consult meaningfully with communities, and how tight timeframes, such as in a pandemic, accentuate this problem. This case study demonstrates how effective engagement with consumers and community members across Australia can permit the contribution of their perspective on the commencement of rapid research during a pandemic.

Case study

In early April 2020, an invitation was extended to 24 senior consumer and community advocates to join a national community advisory group for COVID-19 research. This group was formed within a week and has 22 members from Western Australia, Queensland, Victoria, New South Wales, Tasmania and the Australian Capital Territory. The invited members have lived experience with disability, infectious diseases, lung and heart disease, Aboriginal health, education, and cancer. Many are serving on high-level committees, while some are also involved in other state and national consumer advocacy roles. They are well-informed, connected with a wide range of community groups, and able to contribute and ask appropriate questions.

At that time, members of this group provided a community perspective on 20 national and international research projects. This perspective included providing advice on how research can be conducted when people are not able to come to the Institute and asking questions about whom the research is targeting and how people from Aboriginal and ethnic communities are being included. This ensures that researchers have these perspectives in mind when developing projects under intense time pressures.

Collectively, this group has contributed over 450 hours to virtual meetings and post-meeting feedback (often at short notice and in different time zones); and covered issues such as consent and patient information, data collection, storage and secondary use of data, study protocols, grant applications, dissemination of research findings and priorities for future research.

The work of this group demonstrates the high level of community interest in research and the role of the pandemic as an enabler for best practice collaboration. Notably, one of the ways that this collaboration was made possible was through the uptake of technology that enabled the group to meet at different times, regardless of location.

This type of national collaboration can be shared and built on to plan for future pandemics. It also demonstrates the importance of establishing strong links with the community sector as part of regular business that can be activated quickly in emergencies. It is one way of addressing the values and principles outlined in this framework.

Acknowledgement

This case study is based on information provided to the consultation on the ethics framework for pandemics by Anne McKenzie, AM, from the Telethon Kids Institute. It was reproduced with permission. It also draws on information published about the work of this committee at the following link: https://www.telethonkids.org.au/news--events/news-and-events-nav/2020/april/advisory-group-community-take-covid-19-research/

Appendix A: Selected ethical issues potentially arising during and after a pandemic

Although we have divided the ethical issues below into three domains: public health, clinical care and research, we recognise that neither these issues nor the domains are independent of one another; rather, they inform each other and overlap, particularly during a pandemic.

As we have seen in previous pandemics in Australia and overseas, addressing these identified issues and others benefits from consulting and engaging with a variety of communities not just as key stakeholders, but as partners at the beginning of the development of strategies to deal with pandemics and in the decision-making processes that have a direct impact on people's lives.

Ethical issues in public health

Ethical issues in public health encompass issues that affect the whole population of a state, country or region and are not limited to specific public health measures. A non-exhaustive list of these issues follows.

1. **The impact of implementation of public health measures** (distancing, hygiene, quarantine, testing, contact tracing, movement/activity restrictions, border closures, surveillance, monitoring and vaccination). Although each of these issues has distinctive characteristics, most or all of them have common features:
   - They are linked with broader social and lifestyle changes (e.g. transportation, organised social, artistic and athletic activity, substance use/misuse/abuse).
   - They may significantly affect the safety, quality and/or stability of family and intimate personal relationships and the mental health of individuals.
   - There may be significant generational, cultural and gender-based differences in how the measures are received, levels of compliance and long-term impact (e.g. on economic status, educational advancement and mental health).
   - They carry the potential for discrimination or stigmatisation and for violations of privacy, principally via unauthorised disclosure of personal information, including sensitive health information.
   - They may disproportionately impact some groups.
   - They are likely to have immediate, short-term and long-term effects and their viability, efficacy and economic, social and environmental impact should be assessed accordingly.
   - Public health measures that seek to redress the likely inequitable impact of the pandemic itself should be implemented. For example, anticipating the disproportionate impact of the pandemic due to existing inequities related to economic structures, social determinants of health or underlying chronic disease is a necessary component of public health planning.
   - The impact of any vaccination program will be affected by community attitudes and rates of participation.
2. **Resource allocation**
   - The unavailability of sufficient personal protective equipment (PPE) and the inequitable and/or ineffective distribution of this equipment present major practical and ethical risks.
   - Once vaccines and other therapeutics have been developed and determined to be safe for general use, their production, supply and distribution raise issues of priority and equitable access that are likely to be contentious and difficult to resolve.

- Although not specific to the pandemic context, the challenge of finding the appropriate balance between resources allocated for public health needs and for clinical care needs is accentuated.
- Although not specific to the pandemic context, allocation of resources to address mental health needs is often insufficient and takes on even greater priority during a public health crisis.

3. **Messaging**
   - The consistency, coordination and accessibility of messaging on public health matters have important implications for the effectiveness of public health campaigns.
   - The risks associated with a public health crisis accentuate the importance of messages from those in authority being adequately grounded in the best evidence available and also developed with input from health care professionals, employers, health consumers and relevant community groups, including culturally and linguistically diverse and Indigenous communities.
   - Messaging related to population health concerns and public health measures must be appropriately targeted and tailored for its audience and include strategies for those who are living with disability, have low health literacy, limited decision-making capacity, reduced access to digital technology and other communication tools and/or are from Indigenous and culturally and linguistically diverse communities.
4. **Issues faced by public health workers, carers and other frontline service providers**
   - Public health workers, carers and other frontline service providers face physical, psychological and moral risks and burdens that exceed those encountered by most members of the community. Consideration of how to recognise these increased risks and burdens is critical. One way to address the increased costs to and burdens on public health workers, carers and other frontline service providers is to provide priority access to essential resources and protection (especially PPE).
   - Ensuring that the community's expectations of public health workers and other frontline service providers are justifiable and proportionate is a key responsibility of those in authority.

Ethical issues in clinical care

1. **Resource allocation**
   - The allocation of resources to address clinical care needs generates ethical concerns related to:
     - the fairness of the supply and distribution of pandemic treatments.
     - prioritising resources for pandemic needs versus other critical care or primary care needs.
     - apportioning resources (drugs, equipment, beds, staff) to intensive care versus other hospital departments as well as within clinical services.
     - recognising the significance of mental health care needs, including increased addictive behaviours.
     - the potential for any focus on primary care needs and the needs of hospitalised patients to result in inadequate resources being provided to those in aged care facilities, those receiving care in the home or those who live with disability or chronic disease requiring health care.
     - the potential for any focus on critical care to result in inadequate resources being provided to those receiving palliative care.

— All analyses of and recommendations for ethically defensible allocation of health care resources must seek to promote decisions that are fair and just. However, different recommendations can arise, depending on the emphasis that is placed on one or more of the values or the weighting of factors that are considered in the analysis. These factors include, but are not limited to non-discrimination (equity), maximisation of utility (efficiency, effectiveness or likelihood of survival or recovery) and prioritisation of need (e.g. medical, economic, risk or severity of harm and/or historical injustice). This framework does not attempt to adjudicate those differences and, instead, focuses on the integrity and the transparency of the decision-making process used to determine the allocation of resources.

2. **Discrimination in provision and allocation of care based on age or disability**
   - — Decision-making related to the prioritisation of care and the allocation and distribution of scarce resources for clinical care may result in discriminatory outcomes. Factors in producing discriminatory outcomes include the explicit use of age, disability or socio-economic status as criteria in determining prioritisation of care. A person's advanced age, lower projected overall life expectancy or quality, or higher degree of disability should not be a criterion for decision-making related to prioritisation of care or allocation of resources.
   - — However, it may be necessary to take into account clinical factors, such as probability or length of survival, or quality of life post-treatment, in making allocation decisions.
3. **Compromised care and mental health issues in institutions and other care and support settings**
   - — Recognition of the potential for the care of those in residential care facilities and other institutional settings (e.g. prisons, detention centres, mental health facilities) and disability support accommodation or home care to be compromised during a pandemic is critical. The potential for increased expression of psychological disorders, conditions or distress in these settings during a pandemic also should be monitored and addressed appropriately.
4. **Lost opportunities for intervention for existing conditions and detection and treatment of new conditions**
   - — A focus on responding to clinical care for those infected in the pandemic is accompanied by the potential for missed opportunities to provide necessary interventions to those who are suffering from existing, non-pandemic-related health conditions and necessary screening, surveillance and treatment of new conditions.
5. **Deficits in respecting health care preferences or in carrying out advance care planning and advance directives**
   - — Responding to health care preferences and adhering to agreed plans and directives for the care of patients in hospitals, or people in residential facilities or at home are likely to be affected by a pandemic and responses to it. The impact could require that people's preferences and plans be adapted to reflect changed conditions caused by the pandemic or by changes in their health status.
   - — Clinicians and other carers should discuss the likelihood of the need for changes in plans and any necessary preparations (including identification of alternate health care decision makers) with individuals receiving care and their relatives prior to and during the pandemic.
6. **Issues faced by health care providers**
   - — Health care and other care providers face risks, burdens and costs that warrant consideration by other members of the community - specifically, how to recognise these increased costs and burdens via priority of access to resources (such as PPE) or other forms of protection and support.
   - — Those in authority have a responsibility to ensure that the community's expectations of health care and other care providers are not unreasonable.

Ethical issues in research

Research during a pandemic and in planning for responses to future pandemics is a critical need and a core responsibility of the scientific and academic communities in coordination with governments, community leaders and industry. Those responsible for the design, funding, review and conduct of research in a pandemic may need to re-orient their priorities and make adjustments to respond to the challenges that arise.

It is essential that standards of research integrity are not compromised by the urgency associated with a public health crisis. While it may be permissible to make procedural and administrative modifications to research or its review, the principles that underpin the review and conduct of ethical research remain constant.

It is imperative that pandemic research be coordinated with and integrated into other responses to a pandemic, while not impeding responses that are necessary to protect the public health. A non-exhaustive list of ethical issues in research follows.

1. **Variations in research design, development, review and conduct to enable pandemic research**
   - The design, development, review and conduct of research during a pandemic are likely to benefit from variations in the requirements, both large and small, that ordinarily govern research. Support for these variations should be conditioned on thorough consideration of each proposed variation by those responsible for the review and governance of research in Australia.
   - The context of a pandemic increases the pressure to expedite research governance and review processes, including ethical review. Responses to pandemics need to ensure that measures to increase the responsiveness or flexibility of these systems do not compromise the quality of review and standards of assessment that are required.
   - The involvement of consumers and community members in the design and conduct of research is as important in a pandemic as in ordinary times. This involvement includes the need to engage the Australian community, particularly Aboriginal and Torres Strait Islander and culturally and linguistically diverse communities. The need for rapid research during a pandemic should not preclude community involvement in research, as there are strong consumer and community networks across the country that are making themselves available to participate or otherwise contribute at short notice.
2. **Research prioritisation, funding and recruitment**
   - Efforts to prioritise research during a pandemic raise several ethical issues: the impact of the likely reduction or freezing of important non-pandemic research, the potential for funding pandemic research with questionable value and the challenges for clinicians and researchers in deciding which research to recommend to potential participants.
   - The availability of additional funds for pandemic-related research during a pandemic has the potential to induce researchers with insufficient qualifications for that research to seek funding for and conduct the research. When this occurs, there are risks that the quality of pandemic research will be sub-optimal and that other ongoing and important research may be abandoned.
   - Although not specific to the pandemic context, the sense of urgency associated with the conduct of research during a pandemic heightens the risk of participant fatigue due to over-recruitment and the conduct of research that is underpowered due to the lack of sufficient eligible candidates for participation.
3. **Premature publication of data and outcomes without adequate peer review**
   - A pandemic provides the incentive for researchers and journals to publish research data and outcomes as quickly as possible, with the consequent risk of publishing this information without adequate peer review having occurred. This phenomenon can have far-reaching effects, including on the health and safety of those requiring care or treatment that relies upon evidence of safety and efficacy provided by recent publications.
   - Public loss of confidence in pandemic research could undermine public trust in research more broadly (i.e. non-pandemic research).

4. **Research into the impact of and responses to the pandemic**
   - Research during and following a pandemic includes research into the impact of the pandemic and into the responses to the pandemic. There are significant ethical issues related to the recruitment of participants and the well-being of participants in this research. These include the potential for participants' capacity to provide valid consent to be compromised as a consequence of experiencing trauma and the urgent need for assistance and resources.
5. **Consent and the risk of therapeutic misconception**
   - Although not specific to the pandemic context, issues related to obtaining valid consent to participation in research are heightened in a pandemic. In particular, the potential for exploitation or coercion is accentuated and participants' ability to properly assess the risks of the research is likely to be impeded. One of the principal ways that the validity of the consent of participants may be compromised is through inadequate attention to the potential for therapeutic misconception (the mistaken view that an intervention is primarily designed to directly benefit individual participants, as opposed to developing generalisable knowledge for the potential benefit of the community as a whole or selected individuals in the future).
6. **The use of interventions with a limited evidence base**
   - In a pandemic, the pressure to use interventions with a limited evidence base is increased. Therefore, it is necessary to collect outcome data and construct safety profiles for these interventions. Failure to do so may result in increased risk to patients and research participants.
   - The use of mechanisms for monitored emergency use of unregistered and experimental interventions (in Australia, via the Special Access Scheme (SAS) and Authorised Prescriber (AP) scheme, commonly referred to as 'compassionate use') is likely to increase during a pandemic. This phenomenon raises the risk that these mechanisms will be employed in the absence of adequate evidence for an intervention or to substitute for rigorous research into their safety and efficacy.
7. **The impact of early negative outcome data**
   - It is vitally important to find the most effective treatment for those who have fallen ill during a pandemic and to establish an evidence base for public health measures to respond to the pandemic. In doing so, investigations of treatments, therapies or strategies are often conducted within narrow time frames. These time pressures can result in outcomes that, under preliminary analysis, show lack of effectiveness. However, if undertaken, later analysis may yield more positive outcomes. Thus, it is important to guard against the potential for early negative outcome data to impede the continued exploration of safety, efficacy or effectiveness in novel or off-label interventions, other therapies and public health strategies.
8. **Use of appropriate pre-clinical models**
   - The accelerated pace of research into effective treatment during a pandemic can present challenges to identifying and obtaining access to appropriate pre-clinical models for research intended to increase confidence in the safety, efficacy and viability of these interventions before human use.
9. **Process variations for research into vaccine development or other interventions**
   - The health and financial significance of developing a safe and effective vaccine for the disease causing the pandemic increases the pressure to introduce uncontrolled process variations for research into vaccine development, such as foregoing standard phases of clinical trials in order to expedite the availability a vaccine. Careful consideration of the risks of these practices and the use of agreed controls is necessary. Similar pressures may be present for development of other critical health care interventions.

Appendix B: Additional resources

There are a substantial number of other ethics frameworks and exemplary cases published by international and Australian organisations, including from peak bodies, professional colleges, academic centres and government agencies. Including a comprehensive list of these is beyond the scope of this document. However, selected recently released or otherwise influential documents are listed below.

1. Australian Government Department of Health – Australian Health Sector Emergency Response Plan for Novel Coronavirus (COVID-19) Including the Management Plan for Aboriginal and Torres Strait Islander Populations at https://www.health.gov.au/sites/default/files/documents/2020/02/australian-health-sector-emergency-response-plan-for-novel-coronavirus-covid-19_2.pdf and https://www.health.gov.au/resources/publications/management-plan-for-aboriginal-and-torres-strait-islander-populations
2. Australian Government Department of Health/TGA/NHMRC – COVID-19: Guidance on clinical trials for institutions, HRECs, researchers and sponsors at https://www1.health.gov.au/internet/main/publishing.nsf/Content/Clinical-Trials
3. Australian Human Rights Commission – Guidelines on the rights of people with disability in health and disability care during COVID-19 (2020) at https://humanrights.gov.au/our-work/disability-rights/publications/guidelines-rights-people-disability-health-and-disability
4. Bedson, Jamie et al. Community engagement in outbreak response: lessons from the 2014–2016 Ebola outbreak in Sierra Leone. BMJ Global Health vol. 4, issue 8. https://gh.bmj.com/content/5/8/e002145.full
5. Consumers Health Forum – Consumer position statement on the ethical issues arising from the COVID-19 pandemic at https://chf.org.au/consumer-position-statement-ethical-issues-arising-covid-19-pandemic
6. Daniels, Norman and James Sabin. The Ethics of Accountability in Managed Care Reform. Health Affairs vol. 17, no. 5. https://doi.org/10.1377/hlthaff.17.5.50 and Accountability for Reasonableness – An Update at https://www.researchgate.net/publication/23309904_Accountability_for_Reasonableness_An_Update
7. Dawson, Angus et al. Key Ethical Concepts and Their Application to COVID-19 Research. Public Health Ethics, Volume 13, Issue 2, July 2020, Pages 127–132 at https://academic.oup.com/phe/article-abstract/doi/10.1093/phe/phaa017/5837670
8. Government of Canada – Public health ethics framework: A guide for use in response to the COVID-19 pandemic in Canada at https://www.canada.ca/en/public-health/services/diseases/2019-novel-coronavirus-infection/canadas-reponse/ethics-framework-guide-use-response-covid-19-pandemic.html
9. Grill, Kalle and Angus Dawson. Ethical Frameworks in Public Health Decision-Making: Defending a Value-Based and Pluralist Approach. Health Care Anal **25,** 291–307 (2017) at https://doi.org/10.1007/s10728-015-0299-6
10. IDEA: Ethical Decision Making Framework at https://trilliumhealthpartners.ca/aboutus/Documents/IDEA-Framework-THP.pdf
11. National Ethics Advisory Committee – Kāhui Matatika o te Motu (NZ) – Getting Through Together Ethical Values for a Pandemic at https://neac.health.govt.nz/system/files/documents/publications/getting-through-together-jul07.pdf

12. Royal Commission into Aged Care Quality and Safety – Aged Care and Covid-19: A special report at https://agedcare.royalcommission.gov.au/sites/default/files/2020-10/aged-care-and-covid-19-a-special-report.pdf
13. Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability – Statement of Concern: The response to the Covid-19 pandemic for people with disability' at https://disability.royalcommission.gov.au/system/files/2020-03/COVID-19%20Statement%20of%20concern.pdf
14. The Hastings Center (Nancy Berlinger, et al.) – Ethical Framework for Health Care Institutions & Guidelines for Institutional Ethics Services Responding to the Coronavirus Pandemic at https://www.thehastingscenter.org/ethicalframeworkcovid19/
15. World Health Organisation – Ethics and COVID-19 at https://www.who.int/teams/health-ethics-governance/diseases/covid-19 and Ethical issues in pandemic influenza planning at https://www.who.int/ethics/influenza_project/en/

Appendix C: Development of the framework

In April 2020, the National COVID-19 Health and Research Advisory Committee was asked by the Chief Medical Officer of Australia to develop advice on ethical issues arising from the COVID-19 pandemic. This advice led to a request for the Australian Health Ethics Committee (AHEC), in consultation with health consumer organisations, to develop an ethics framework for pandemics.

Workshops were held in May, June and August 2020 at which members of AHEC and small groups of stakeholders including representatives of Consumers Health Forum and other consumer groups and selected experts from the AMA and other medical groups provided feedback on the framework. This feedback included the identification of appropriate topics for case studies, which became the worked examples in the framework.

The framework was released for a targeted consultation in October 2020. This consultation included the Commonwealth Department of Health, all Chief Health Officers, select learned academies, all Human Research Ethics Committees, select NHMRC committees, some specialty groups such as relevant Royal Colleges, Council of the Ageing, Australian Network on Disability and workshop participants.

Forty one submissions were received from consumer and disability organisations, individual consumers, hospital systems, health organisations, government, hospital and university HRECs and government agencies. These submissions led to major changes in both the structure and content of the document and greatly improved the framework.

As indicated in the body of the document, the framework employs a pragmatic, question-based model favoured by a number of international ethics organisations. It also emphasises the integrity of the decision-making process and resists making prescriptive statements or taking the place of guidelines that have been developed by many other organisations (see Appendix B: Additional resources). This is an intentional feature of the framework and aligns with the role of AHEC, which is to support and facilitate responsible ethical reflection and decision-making in line with agreed values rather than to recommend government policy.

NHMRC recognises that that some stakeholders may consider that the framework is not prescriptive enough and does not adequately advocate for the needs of those for whom advocacy is considered necessary, with particular reference to the needs of those living with disability, culturally and linguistically diverse (CALD) communities, non-citizens and people receiving palliative care. In response to feedback from the consultation we have added additional content to address the needs and interests of these communities in all of the sections of the framework and in the ethical issues discussed in Appendix A.

We note that several important issues were raised by a number of stakeholders during the consultation on the framework. These issues include: the applicability of the framework to decision-making related to clinical care, the tensions that inevitably arise between values when trying to adhere to more than one or all of them and the importance of making consultation and partnership part of the decision-making process at the earliest stage of the process, not only when a decision has already been made. We refer the reader to sections 1, 2 and 3 of the document, respectively, for evidence of how we have addressed these concerns.

NHMRC thanks all of those who have contributed to and provided feedback on this framework, with special appreciation for the willingness of so many individuals to contribute their time during a year of unprecedented challenges for all Australians.

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