

Submission to Commonwealth Government COVID-19 Response Inquiry

The need for an Australian standing pandemic ethics response capability

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Overview

This submission addresses several of the terms of reference (TOR) of the inquiry, focusing primarily on TOR 2 (key health response measures), but with relevance also to TOR 1 (governance), TOR 3 (broader health supports), TOR 4 (international policies), TOR 7 (community supports) and TOR 8 (mechanisms for future responses).

We argue that the key decisions made, and policies developed in response to, the COVID-19 pandemic involved multiple ethical issues and that important deficiencies in the response derived from failures either to consider these issues adequately or to demonstrate to the community that such consideration had been undertaken. We recommend that a standing body – an “Ethics Advisory Group” – be established as a key integrated component of a proposed Australian Centre for Disease Control to provide systematic capacity to respond more effectively to similar issues should they arise in the management of future pandemics.

Who we are

We are a group of professionals with deep interest and active involvement in the ethical aspects of healthcare and policy. Our group includes senior academics and clinicians from a variety of disciplines and specialties with expertise in ethics, law, public health, medicine, policy development and implementation, community engagement, and the conduct of public ethical dialogues. Collectively, we have been deeply active in all these fields during the course of the pandemic and have contributed directly to the development of social and ethical policies and responses to the challenges facing healthcare services, public health institutions, government and scientific research domestically and internationally. We have advocated in support of specific communities, such as First Nations peoples, people living with disabilities, people in aged care, and socially isolated and vulnerable individuals in the community, and have been deeply engaged in discussions about ethics in the academic and popular press and in professional and public settings.

Key points

1. Every technical, clinical and policy decision during the pandemic involved ethical issues

The COVID-19 pandemic posed major challenges to healthcare systems and societies across the world. These challenges related to public health responses, government policies, healthcare delivery, scientific research and innovation, protection of and support for vulnerable community members, and fostering confidence and solidarity amongst the wider community. Many of these challenges included technical matters including factual circumstances relating to the virus and its health effects, effectiveness of medical treatments, quarantine and lock-down policies, assessment of vaccine safety and effectiveness, all issues that were generally considered by committees and working groups comprised of individuals with high-level technical expertise.

Without exception, every one of these matters also involved ethical issues, often relating to fairness and equity, balancing of risks, harms and benefits, judicious use of scarce resources, protection of vulnerable groups, and delicate questions of communication and explanation that demonstrate respect for diverse views in the community. Indeed, it is not an exaggeration to say that every aspect of the COVID response was inherently both ethical and technical.

2. Ethical deliberations, processes and scrutiny of decisions and policies during the pandemic were inadequate

While the technical questions were usually considered by properly constituted, publicly accountable expert bodies, the responses to ubiquitous ethical issues lacked clarity and were unaccompanied by evidence of a formal process of deliberation or consultation. And even where ethical frameworks or resources were developed with the support of government, these were not made accessible for public or professional use or scrutiny, and were only sporadically adopted or supported by health services or government. In other words, the ethical responses to the pandemic in Australia were deficient, in that they lacked clarity and transparency, were not openly and consistently integrated into policy deliberations or healthcare decision-making, and failed to create confidence in the community that deliberations were being conducted rigorously, in a spirit of openness, flexibility, inclusiveness and responsiveness to community concerns.

Because of these inadequacies, and despite the efforts of the authors of this submission and others, a perception developed among some sections of the community that decisions with profound ethical consequences were often being made without consideration of the community's diverse beliefs and value systems. Arguably, this resulted in the initial widespread support for public policies – for example, regarding mask-wearing, lockdowns, quarantine, and vaccines – turning into a sense of confusion and uncertainty, ultimately fomenting division and conflict. In many cases the opposition to public policy that emerged lacked a coherent factual or scientific basis, suggesting that it was linked to concerns of a social, cultural, or ethical nature rather than to scientific ones.

3. Ethical decisions were taken, even when they were not acknowledged

Despite the absence of a transparent and accountable process for doing so, innumerable ethical decisions were taken in the course of the pandemic response. These included decisions about healthcare itself, rationing of scarce resources, triage in emergency departments and intensive care settings, policies about social distancing, the use of personal protective equipment, lockdowns, school closures, limitations on the operation of work places and public institutions, the conduct of scientific research and the interpretation and dissemination of trial results, vaccines and the implementation of vaccination policies, support for and responses to the needs of more vulnerable people – including First Nations people, people in aged care facilities, and people with disabilities – and the impact of border closures and restrictions on national and international travel.

In many of these cases the ethical decisions carried deep and lasting implications for individuals and communities. While the decisions were undoubtedly taken appropriately and in good faith, the absence of transparent, inclusive and informed attention to ethical principles and values created confusion, uncertainty, and actual suffering.

4. Better attention to ethical issues generates better outcomes

There is evidence that properly coordinated, transparent and accountable processes for addressing and reviewing the ethical components of decisions produces socially beneficial outcomes, in the form of improved quality and legitimacy of decisions, increased community consensus, and enhanced support for social policies. Such processes increase public confidence in, and compliance with, policies of government and public health authorities. By committing to inclusion and transparency they build trust in government and in healthcare and public institutions and services and increase the perceived legitimacy of public policy in the face of diverse needs, values, and perspectives. By showing flexibility and a readiness to reconsider decisions shown to be incorrect or no longer applicable, they strengthen solidarity and reduce division and conflict. And by demonstrating recognition that purely technical considerations are incapable of encompassing the full range of concerns, attitudes, beliefs, and preferences, they increase tolerance of differing points of view and enhance social conflict resolution more generally.

In responses to crises such as that of the COVID pandemic, it is likely that a clear ethical process would improve the efficiency and effectiveness of clinical decision and policy making and support mature and productive debate within the community, thereby avoiding or limiting hostility, social division and even violence.

5. Ethical deliberation requires expertise and transparent processes

While political leaders and policy makers in some other countries openly acknowledged the importance of ethical issues in responding to the challenges of COVID, it nonetheless often remained the case that they too lacked processes to debate and engage constructively with the diversity of ethical perspectives among their populations. Nevertheless, there *is* wide knowledge and experience about how to respond to ethical challenges in an effective and successful manner that both respects diverse views and sustains social cohesion.

At the broad social level, many policies require acceptance by the community, which can be secured by careful negotiation to establish and maintain a broad consensus. Such negotiation is best achieved in democratic political contexts through the operation of open and transparent social discourse, including the clear articulation of arguments and explanations underpinning particular decisions. Proof is required that contrary points of view have been considered, and provision needs to be made for continuing conversations should new evidence and arguments appear. Decision makers need to be able to rely on, and to obtain advice from, individuals at arm's length from the political process and whose interests and personal commitments are publicly declared and open to scrutiny.

The conduct of such ethical deliberation requires appropriate expertise, as well as careful attention to a protected, demonstrably transparent process. This expertise may include knowledge of ethical argumentation, but more specifically is informed by experience in practical domains of activity that reflect the diverse range of values and perspectives held

within the community. It also includes competency in conducting public dialogues and critically scrutinising decisions, attitudes and points of view.

6. An alternative approach can be readily established

Both the mechanisms for responding to the deficiencies of the pandemic response and the capacity to do so are readily available in Australia. We believe that what is required is the establishment of an “Ethics Advisory Group”, in the form of a standing body that offers a forum for discussion, as well as developing institutional processes and structures and preparing plans in anticipation of future communicable disease challenges.

Such an Ethics Advisory Group would have the general aim of ensuring open discourse, critical reflection, transparency, and flexibility in relation to the ethical issues raised by a public health crisis and, where appropriate, providing advice and guidance to decision makers. It would have three components: (i) an executive or coordinating committee that interacts with government and other decision-making authorities, receives requests for deliberation, and conveys advice, where appropriate; (ii) a forum that brings together individuals with a range of expertise that represents the diversity of Australian culture and values; and (iii) an organisational capacity to facilitate public consultations and dialogues about ethical issues of relevance as they may emerge.

We are supportive of the establishment of an Australian Centre for Disease Control but suggest that it is critical that an Ethics Advisory Group be established as a key integrated component of it to provide ongoing and authoritative ethics capacity and enable consideration, investigation and advice on ethical questions as requested by responsible authorities. We believe that the establishment of such a body would significantly enhance the quality and effectiveness of any future pandemic response, as well as maximise the support and readiness of the wider community to comply with public health measures.

Recommendations

In the light of the above considerations, we recommend:

1. Public recognition of the role in the pandemic response of ethics in all aspects of clinical and social policy decision-making;
2. Acknowledgement that special considerations arise in relation to particular social groups, including people living in aged care facilities, First Nations people, people living with disabilities etc.;
3. Acceptance of the need for formal processes for ethical decision-making that are transparent and accountable, promote key values such as fairness, equity, and protection of vulnerable individuals, and are informed by and engage with the diversity of public values, to inform policy formation and implementation;
4. Establishment of a standing body to undertake, support and guide the development, implementation and review of decisions and policies in relation to communicable diseases that reflects the diversity of perspectives and values within the Australian population and has the capacity to undertake investigations, facilitate debates and provide advice as appropriate, which interfaces with any methods or structures put in place to improve public consultation and communication;
5. Ongoing support for and resourcing of such a body, particularly to ensure appropriate engagement with ethics across the spectrum of pandemic response, encompassing health, economic and social policy-making, clinical and health service decision-making and management, communications and public engagement.

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