

# Chapter 10

## Afterword



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**Abstract** This casebook offers a window into important aspects of the ethical landscapes that researchers, communities, health professionals, policy makers – and ethicists – had to navigate during the first 15 months of the COVID-19 pandemic. The cases presented in this casebook are inevitably a selection informed by and constrained by the processes through which they were sought, and by the pandemic itself. Additional cases could valuably complement all the thematic chapters in this casebook. In addition, this casebook calls for a broader approach to research ethics, both in terms of the issues to be considered, and the range of stakeholders having ethical responsibilities relating to the conduct of research. However a broad range of stakeholders have differing values, remits, authorities and capacities to exercise power in pandemic contexts, and in many situations, exercises of power, and their impact on research, are not direct and explicit. As such they are less amenable to clear representation in real-world cases, highlighting the importance of complementing discussions of the cases in this casebook with conceptual literature. Reflection on the research that has not been conducted is also critical. The COVID-19 pandemic has reemphasized that global health emergencies are never only about health. The wide-ranging impacts of the pandemic on economies, employment, education and a range of socially and culturally important activities, accentuates the importance of an equally comprehensive research agenda, which goes beyond a narrow conception of ‘health’, and addresses a broad range of pandemic impacts on populations. A further way in which we believe debate on pandemic research ethics both could and should be broadened is in relation to aspects of pandemic science beyond those relating to ‘response’. Inevitably, in the

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context of an emerging and continuing pandemic, scientific research attention has tended to focus on interventions that can enable more effective responses. However pandemic science can be thought of as divisible into four interdependent and overlapping domains: prevention, preparedness, response, and recovery. Research is essential to the development, evaluation, and deployment of interventions in each of these domains and effective, valuable, trustworthy and trusted research will require ethical questions to be identified and addressed. This chapter concludes by inviting the connection of additional cases and conceptual resources to this case-book, to enhance and expand the themes and topics covered.

**Keywords** COVID-19 pandemic · Research ethics · Public health emergency response · Public health emergency preparedness · Public health emergency prevention · Public health emergency recovery

## 10.1 Introduction

The COVID-19 pandemic has had – and continues to have - an unprecedented global and ‘whole of society’ impact (Miyah et al. 2022; Elavarasan et al. 2022). The critical ethical importance of conducting timely, rigorous and responsive research to inform public health and clinical responses to the pandemic, and to ensure that lessons are learned to inform responses to future emergencies, is inarguable (Swaminathan et al. 2022). So too is the evidence that pandemics raise a number of distinctive and profound challenges for the conduct of such research. Health emergencies are contexts in which effective and informative research conducive to well-founded public trust and confidence is desperately needed. They are also, however, almost by definition situations that are radically non-ideal for such research (Nuffield Council on Bioethics 2020).

Many of the challenges arising when conducting research in emergencies have an ethical dimension. From the very beginning of the COVID-19 pandemic, there has been a complex, rapidly evolving and at times contested literature addressing a range of ethical issues arising in pandemic health research. A comprehensive list is not feasible, but examples of areas in which such issues have been discussed include: decisions about prioritising, funding, suspending and halting biomedical and social science research; accelerated research and vaccine development pathways; adapting and adaptive research; research exceptionalism, quality and misconduct; monitored emergency use of unregistered and investigational interventions; adapted and expedited ethics review pathways, and adaptations to governance and oversight mechanisms for national and multi-national studies; unprecedented rates of scientific pre-publication, publication and retraction; participant protection and inclusive approaches to recruitment; curation, analysis and sharing of phylogenetic, surveillance and research data; and research using mobile apps and social media data. This literature has made an important contribution to public and academic debate and to the development of policy. However, it has, at times, been inadequately informed by an in-depth understanding of practical ethical issues arising on the ground in

research contexts around the world. To address this deficit, in December 2020 we issued an open global call to researchers, reviewers and academics to contribute case-studies and co-create a capacity building resource informed by, and responsive to, lived experiences. The 44 cases within this casebook, drawn from Africa, Asia, the Americas, Europe and Oceania, provide contextually rich examples of practical ethical issues arising as health-related research was conducted during 2020 and early 2021. While this means that casebook provides a critical insight into lived experiences and complex challenges on the ground from a broad range of settings, it is not possible for such a compilation to be exhaustive. This is true in at least two important respects – it not possible to represent all the contexts and settings in which research has taken place, nor to investigate all the ethical dimensions of the multiplicity of biomedical and social science research approaches undertaken in the context of the COVID-19 pandemic.

Having said this, the cases in this casebook are not intended to capture all ethical dimensions of challenges arising when conducting research, nor are they necessarily intended to be representative. Our aim here has been much more limited. We have sought to compile a diverse and inclusive range of cases and thematic commentaries with the potential to be used to prompt discussion and reflection on the ethical issues presented both by these specific cases and beyond them. It is our hope that readers will make links between the cases discussed here and those challenges arising in their own experience or elsewhere and reflect upon the relevance, and the limitations, of the commentaries presented here for those situations.

## 10.2 Looking Forward

It is important to reflect both on areas that have received less attention in this casebook, and to emphasise the importance of conducting further work into the broad range of important ethical issues arising during research conducted in the differing contexts of global health emergencies. An initial consideration is that for many of the themes addressed in the casebook, *additional cases could provide an important resource to prompt more nuanced consideration of relevant ethical dimensions*. For example, the collection and analysis of case studies of research with migrant or refugee populations would form a valuable complement to the discussions of vulnerability, inclusion and protections in Chaps. 8 and 9, and prompt discussion of further relevant ethical issues, including those associated with roles and responsibilities of community ‘gatekeepers’ in emergency contexts. Many other examples could be given and we would love to see this resource connected to others that enhance and expand the themes and topics covered.

In addition, the breadth, complexity, and at times inter-relatedness of the ethical considerations arising in the majority of cases prompt (and are intended to prompt) consideration of a wider range of ethical issues than those associated with traditional accounts of research ethics. Chapter 1 calls for readers to take a broader approach to research ethics – both in terms of the issues to be considered, and the actors having

ethical responsibilities relating to the conduct of research in pandemics and other health emergencies. Examples include the nature of responsibilities to address systemic inequities in capacity to rapidly pivot and originate and conduct responsive research, and rollout effective interventions in pandemics. Important questions also arise about the supra-research roles and responsibilities of research organisations in pandemic contexts, including for example, supporting national COVID-19 testing and pathogen sequencing initiatives and the provision of healthcare.

Global health is inherently a complex field of social, political, economic, and scientific relationships in which a broad range of stakeholders have differing values, remits, authorities and capacities to exercise power. Issues relating to the exercise of epistemic power are important to consider, as this is a space within which questions of expertise, what constitute reliable sources of information and evidence, and the role and responsibilities of the media, are inevitably contested. Within complex global health landscapes, the COVID-19 pandemic has both emphasised and exacerbated global health and epistemic inequities, demonstrating the importance of critically reflecting on the roles and responsibilities of powerful actors in international and national pandemic research and response. Such stakeholders are sometimes far from the ethical issues experienced by researchers and reviewers, but their decisions profoundly influence which research is conducted and the options available to researchers and the communities in which they work.

While the cases in Chap. 1 directly address the consequences of decision-making by national and multinational stakeholders, *in many situations, exercises of power, and their impact on research, are less direct and explicit, and are thus less amenable to clear representation in real-world cases.* In the context of the COVID-19 pandemic for example, unprecedented political, economic and social pressures to develop and implement effective responses have had significant implications for accelerated vaccine development pathways. National and multinational interests have profoundly influenced processes for emergency use authorisations of COVID-19 vaccines, including the design and implementation of COVID-19 vaccine studies, the fairness of research collaborations, and approaches to pre-publication and the sharing (or not) of research data. Such interests also had profound implications for both enablers and barriers to the collective action required for post-trial access to vaccines, and global vaccine equity. These and other exercises of power highlight the importance of complementing discussions of the cases in this casebook with an appreciation of the relevant conceptual literatures focusing on the responsibilities of a range of stakeholders when research is conducted in pandemics and other health emergencies.

The COVID-19 pandemic has also reemphasized that global health emergencies are never only about health. The wide-ranging impacts of the pandemic on economies, employment, education and a range of socially and culturally important activities, accentuates the importance of an equally comprehensive research agenda, which goes beyond a narrow conception of 'health', and addresses a broad range of pandemic impacts on populations. While the cases in this casebook promote consideration of the ethical issues arising in the research conducted during the first 15 months of the pandemic, *reflection on the research that had not been conducted is*

*also vital.* As discussed in Chap. 2, further work is needed to explore what a comprehensive research agenda in a public health emergency should comprise, the values that should inform such decision-making, and inclusive and procedurally fair approaches to developing research that is responsive to population burdens. It is important to explore effective approaches to developing research priorities which leave no-one behind in pandemic contexts where systemic inequalities and inequities are exacerbated and have broad ranging impacts both on health, and on social determinants of health. This includes exploring the impacts of pausing and halting research into pre-pandemic health priorities, and the impacts such revisions have had, for example, on the research populations involved, and on development of evidence to inform effective approaches to addressing their health needs.

During the COVID-19 pandemic, in addition to substantive developments in research pathways for the development of diagnostics, vaccines, and evaluations of novel and repurposed therapeutics, there has been unprecedented implementation of non-clinical approaches to reducing the transmission of infection, sometimes referred to as ‘non-pharmaceutical interventions’ (NPIs). These have ranged from mandatory measures such as national lockdowns, vaccine passports, and school closures, through to interventions such as public information campaigns, the uses of ‘influencers’, and calls for ‘solidarity’. The dramatic impacts of approaches to restrict population movement, and requirements for isolation, social distancing and mask-wearing, demonstrate that vitally important research during pandemics includes social science and public health research on the lessons to be learned from the differing approaches to the rollout and removal of mandated NPIs around the world. These include questions about how trade-offs were made between the importance of averting harms of COVID-19 and the burdens of such approaches. Important questions arise about the nature and magnitude of economic, educational, social, psychological and health burdens associated with NPIs, the distribution of such burdens amongst populations, and the effectiveness of approaches to equitably maximising the benefits of NPIs and ameliorating burdens (Osterrieder et al. 2021; Schneiders et al. 2022). Examples include the impacts of closing schools, and requirements for social distancing and mask-wearing, on education and social development in young children; the impacts of limiting access to social support and health services for vulnerable populations; and the impacts of requirements to self-isolate or enter quarantine on employment, housing, food-security and well-being (Phuong et al. Submitted). All these kinds of research present ethical challenges when undertaken in the context of a pandemic, which are compounded in contexts that are already subject to significant disadvantage. Careful consideration is also needed of the ethical issues that can arise when conducting research into health policies, including, for example, the ethics of conducting cluster-randomized trials to evaluate consequences of relaxing restrictions, and permitting large scale social events to take place as ‘research activities’ to explore effects on COVID-19 transmission rates. Moreover, in addition to the issues relating to surveillance and secondary uses of data addressed in Chap. 7, further work is needed to address the impacts of, and issues arising during, the rapid development and implementation of novel digital surveillance strategies to track and trace populations. These include

issues relating to equitable development and rollout of such technologies and compliance with social mandates for uses of surveillance data.

Chapters 3, 4 and 5 additionally highlight the importance of undertaking further work to determine the advice and support needed to strengthen the capacities of researchers, regulators, ethical reviewers and health authorities to appropriately respond to incomplete, rapidly evolving, and at times problematic and contested research findings and pandemic evidence landscapes. In doing so, it is important to recognise that such landscapes, and accompanying infodemics, impact research agendas and prioritisation, and demonstrate the importance of conducting research into approaches to develop trusted and trustworthy engagement with populations in public health emergencies. (Borges do Nascimento et al. 2022) Such engagement is critical to meet responsibilities to promote public understanding of complex and evolving pandemic contexts, enable populations to take effective measures to promote their health and wellbeing, and mobilise the collective action approaches which are key to implementing effective whole of society responses to the whole of society impacts of pandemics. As discussed in Chap. 6, the COVID-19 pandemic also prompts further research into the practical ethical issues arising when implementing approaches to rapidly accelerating and adapting research review and oversight processes, in ways which seek to maintain substantive requirements to protect participants appropriately. Further work is also needed to explore stakeholders' roles and responsibilities to govern and co-ordinate research efforts in contexts where multiple small scale and potentially poor quality studies may be developed in response to perceived pressures to 'do something' to alleviate pandemic burdens, and where the purported social value of addressing pandemic burdens can be an exceptional multiplier in analyses of the potential benefits of research.

### 10.3 Beyond Pandemic Response

A further way in which we believe debate on pandemic research ethics both could and should be broadened is in relation to aspects of pandemic science beyond those relating to 'response'. Inevitably, in the context of an emerging and continuing pandemic, scientific research attention has tended to focus on interventions that can enable more effective responses. As illustrated in the cases presented in this casebook, this can include scientific research on the development and evaluation of diagnostics, vaccines, and therapeutics, and social science research on the impacts of NPIs. This tendency to focus on response is reflected in the cases collected for this casebook, which are concerned primarily with the ethics of research of this type. However, despite the importance and the urgency of developing and implementing effective responses, it is clear that pandemic science is or ought to be concerned with questions beyond those related to effective pandemic response. Indeed, pandemic science can be thought of as divisible into four interdependent and overlapping domains: prevention, preparedness, response, and recovery. Research is essential to the development, evaluation, and deployment of interventions in each of these four

domains. In each of these domains effective, valuable, trustworthy and trusted research will require the identification, analysis, and addressing of ethical questions.

In the context of pandemic prevention, for example, research will need to be undertaken to inform the effective uses of surveillance and the analyses of data deriving from surveillance strategies. These data are likely to include information of a range of different kinds: genomic, syndromic, social media, satellite and drone imagery, in addition to clinical records and other sources. Research on prevention is also needed to investigate the effects of climate change, environmental degradation, and farming practices on the emergence of infectious diseases with outbreak, epidemic, and pandemic potential.

With regard to pandemic ‘preparedness’ research will also be crucial. Examples of research may include research related to early-stage vaccine platform development, and research about the factors underpinning health system resilience, amongst other priorities. As with pandemic prevention, however, much of the research relating to pandemic preparedness is necessarily going to focus on surveillance and the collection, curation, sharing, and analysis of data. A wide range of ethical questions arise and need to be addressed in the context of pandemic preparedness research, and a ground-up case-based approach such as that used in this casebook would be an ideal way to do this. Some of these ethical questions will concern structural issues, such as those relating to global health inequities, in which case-based approaches will need to be complemented by capacity-strengthening resources of other kinds, as discussed above. However, contextually-rich cases about the implications of the different manifestations of global health injustice on the ground can play a key role in enhancing and informing discussions and debates about appropriate responses, and responsibilities, to address such inequities.

Finally, the ‘recovery’ phase of pandemics is also one in which medical, scientific, and social science research is both needed and will raise important ethical questions (British Academy 2021). Some of these will concern the ethical implications of the very decisions to declare emergencies ‘over’, including the implications such decisions have for the populations most directly affected by such emergencies, and for stakeholders’ perceptions of their responsibilities to ameliorate ongoing burdens and impacts (Wadman 2022). Additional ethical questions will arise in the context of responsibilities to conduct research into the complex and multi-faceted longer-term effects of emergencies, outbreaks, epidemics and pandemics on populations. Taken together these suggest that there is value in expanding the use of a case based approach to include the ethical issues in research beyond questions relating to response and to include those arising in research undertaken as part of epidemic and pandemic prevention, preparedness and recovery.

## 10.4 Final Thoughts

In this afterword, we have discussed the ways in which the cases presented in this casebook are inevitably a selection, and moreover a selection both informed by and constrained by the processes through which they were sought and developed, and by the pandemic period through which we have all lived. These complex real-world cases offer a window into some important aspects of the ethical landscapes that researchers, communities, health professionals, policy makers – and ethicists – have had to navigate during the COVID-19 pandemic. Despite the fact that this collection of cases cannot be comprehensive, we believe that they provide an important resource for promoting and facilitating reflection on the ethics of research conducted during health emergencies. We have discussed the breadth and scope of research required in the context of the pandemic, and welcome this resource being connected to additional cases and conceptual resources that enhance and expand the themes and topics covered.

## References

- British Academy. 2021. *Shaping the Covid decade: Addressing the long-term societal impacts of COVID-19*. London: British Academy. <https://www.thebritishacademy.ac.uk/documents/3239/Shaping-COVID-decade-addressing-long-term-societal-impacts-COVID-19.pdf>.
- Borges do Nascimento, I.J., A.B. Pizarro, J.M. Almeida, N. Azzopardi-Muscat, M.A. Gonçalves, M. Björklund, and D. Novillo-Ortiz. 2022. Infodemics and health misinformation: A systematic review of reviews. *Bulletin of the World Health Organization* 100(9): 544–561. <https://doi.org/10.2471/BLT.21.287654>.
- Elavarasan, R.M., R. Pugazhendhi, G.M. Shafiullah, et al. 2022. Impacts of COVID-19 on sustainable development goals and effective approaches to maneuver them in the post-pandemic environment. *Environmental Science and Pollution Research* 29: 33957–33987. <https://doi.org/10.1007/s11356-021-17793-9>.
- Miyah, Y., M. Benjelloun, S. Lairini, and A. Lahrichi. 2022. COVID-19 impact on public health, environment, human psychology, global Socioeconomy, and education. *Scientific World Journal*: 5578284. <https://doi.org/10.1155/2022/5578284>.
- Nuffield Council on Bioethics. 2020. *Research in global health emergencies: Ethical issues*. London: Nuffield Council on Bioethics. <https://www.nuffieldbioethics.org/topics/research-ethics/research-in-global-health-emergencies>.
- Osterrieder, A., G. Cuman, W. Pan-Ngum, et al. 2021. Economic and social impacts of COVID-19 and public health measures: Results from an anonymous online survey in Thailand, Malaysia, the UK, Italy and Slovenia. *BMJ Open* 11: e046863. <https://doi.org/10.1136/bmjopen-2020-046863>.
- Phuong, T.T., M. Duwal, D. Timoria, I.A. Sutrisni, S. Rijal, C. Bogh, A. Kekalih, D. Friska, A. Karkey, R.L. Hamers, S. Lewycka, M. Chambers, on behalf of the OUCRU COVID-19 Research Group, and J.I. Van Nuil (Submitted) Exploring layers of vulnerability during COVID-19: Qualitative research with 13 communities in Indonesia, Nepal, and Vietnam.
- Schneiders, M.L., B. Naemiratch, P.K. Cheah, G. Cuman, T. Poomchaichote, S. Ruangkajorn, et al. 2022. The impact of COVID-19 non-pharmaceutical interventions on the lived experiences of people living in Thailand, Malaysia, Italy and the United Kingdom: A cross-country qualitative study. *PLoS One* 17(1): e0262421. <https://doi.org/10.1371/journal.pone.0262421>.



- Swaminathan, S., B. Pécoul, H. Abdullah, C. Christou, G. Gray, C. Ijsselmuiden, M.P. Kieny, et al. 2022. Reboot biomedical R&D in the global public interest. *Nature* 7896: 207–210. <https://doi.org/10.1038/d41586-022-00324-y>.
- Wadman, M. 2022. When is a pandemic ‘over’?: World Health Organization prepares to confront thorny decision. *Science* 375(6585): 1077–1078. <https://doi.org/10.1126/science.adb1919>.

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