

**neac**

National Ethics Advisory Committee

Kāhui Matatika o te Motu

# Finding Balance

## Ethical principles for epidemics and pandemics

NATIONAL ETHICS ADVISORY COMMITTEE | KĀHUI MATATIKA O TE MOTU





Citation: NEAC. 2025. *Finding Balance: Ethical principles for epidemics and pandemics*. National Ethics Advisory Committee (NEAC). Wellington: Ministry of Health.

Published in April 2025 for the National Ethics Advisory Committee by the Ministry of Health

PO Box 5013, Wellington 6140, Aotearoa New Zealand

ISBN 978-1-991324-27-6 (online)

HP 9119

This document is available at [neac.health.govt.nz](https://neac.health.govt.nz)



# Preface

## National Ethics Advisory Committee / Kāhui Matatika o te Motu

The National Ethics Advisory Committee | Kāhui Matatika o te Motu (NEAC) is empowered under the Pae Ora (Healthy Futures) Act 2022 as the independent advisor to the Minister of Health on ethical issues of national significance in respect of any health and disability matter (including research and services). The NEAC is required to determine nationally consistent ethical standards across the health sector and provide scrutiny for national health research and services.

The development of this publication spanned four years and required significant input from current and former members of the committee: Dr Lindsey Te Ata o Tū MacDonald, Julia Black, Maree Candish, Edmond Carrucan, Associate Professor Vanessa Jordan, Dr Tania Moerenhout, Nora Parore, Dr Hansa Patel, Dr Penny Haworth, Rochelle Style, Seini Taufua, Shannon Te Ahu Hanrahan, Dr Penny Haworth, Gordon Jackman, Dr Kahu McClintock, Professor John McMillan, Dr Wayne Miles, Associate Professor Neil Pickering, Liz Richards, Dr Cindy Towns, Dr Hope Tupara, Dr Dana Wensley and Dr Mary-Anne Woodnorth.

For information regarding NEAC membership visit the Committee members page on the NEAC website at: [neac.health.govt.nz/about-us/committee-members](https://neac.health.govt.nz/about-us/committee-members)

### Acknowledgements

We acknowledge and thank all those who contributed their time, insight, stories and submissions to the development of this document.

We acknowledge the contributions of current and former NEAC secretariat to the development of the publication.

We would like to thank all submitters who participated in the public consultation on earlier drafts of this document. More information on the consultation and a summary of the submissions can be found on the Ethical Guidance for a Pandemic: Whakapuāwaitia e tatou kia puāwai tatou page on the NEAC website at:

[neac.health.govt.nz/consultations/past-consultations/ethical-guidance-for-a-pandemic-whakapuawaitia-e-tatou-kia-puawai-tatou](https://neac.health.govt.nz/consultations/past-consultations/ethical-guidance-for-a-pandemic-whakapuawaitia-e-tatou-kia-puawai-tatou)

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# Foreword

Aotearoa New Zealand can get through an epidemic or pandemic. We of the National Ethics Advisory Committee (NEAC) observed our country do this during the recent experience with the COVID-19 pandemic. While we saw first-hand how a pandemic can disrupt and harm, we also observed how the pandemic brought to the forefront discussions about our nation's attitudes and values. The stories of how people in Aotearoa New Zealand lived these values during the pandemic demonstrate that, together, we can get through.

**Ki te kotahi te kākaho ka whati ki te kāpuia e kore e whati.**

**One strand of flax is easy to break,  
but many strands together will stand strong.**

This whakataukī and tongikura from Kīngi Tāwhiao acknowledges the strength in unity. In the context of Finding Balance: Ethical principles for epidemics and pandemics (Finding Balance), the whakataukī reflects the opportunity we have in Aotearoa New Zealand to create an approach to epidemics and pandemics that supports new ways of thinking and operating in the health and disability sector. It also reflects the opportunity to stimulate debate and discussion about the principles for epidemics and pandemics that should underpin how everyone can work together to plan for, respond to and recover from future epidemics and pandemics. We call these principles the Balance Principles.

Epidemics and pandemics have the potential to impact Aotearoa New Zealand's entire economy and may mobilise an all-of-government response. Often at a time of epidemic or pandemic incursion, complex decisions need to be made at speed. It is therefore critical to actively consider ethical issues before, during and after any response.

We hope the application of these Balance Principles will protect everyone in Aotearoa New Zealand. However, we know some communities are particularly vulnerable and health inequities are compounded in a pandemic (Wilson et al 2011).

Māori, Pacific peoples and community groups demonstrated resourcefulness and ingenuity in developing and designing solutions that worked for their communities and contributed to equitable health outcomes during the COVID-19 pandemic. There is a clear ethical case for decision makers to empower these communities to be involved in the design and delivery of a pandemic response, and we support these initiatives in this document. The Government can also prepare by investing in our health and disability system and tapping into the existing social infrastructure of Aotearoa New Zealand's diverse communities more effectively.

In this document, we have deliberately sought to amplify the call for a strengths-based, te ao Māori approach to Aotearoa New Zealand's epidemic and pandemic planning. Finding Balance builds on the 2007 edition, which addressed the ethical issues in a pandemic by identifying shared values and offering broad guidance.

While the Balance Principles listed in this document give Aotearoa New Zealand a shared basis for decision-making, they will not save New Zealanders from having to make hard choices, in many different situations, during an epidemic or a pandemic. And as we are likely to experience more epidemics or pandemics - the better we prepare now, the better we will get through in the future.

The development of Finding Balance was made possible by the generosity and knowledge of many contributors. We are grateful to the many people who contributed their time and expertise, made submissions, participated in focus groups and shared their stories of working together to get through the COVID-19 pandemic. The result is this document, which reflects the values and attitudes of people in Aotearoa New Zealand and holds equity for all at its very heart.

**National Ethics Advisory Committee**

# Executive summary

The frequency of epidemics and pandemics<sup>1,2</sup> is increasing. The NEAC has prepared *Finding Balance: Ethical principles for epidemics and pandemics (Finding Balance)* to guide the Minister of Health and key decision makers across the health and disability system to make ethical decisions during pandemics. The principles for pandemics described in *Finding Balance* (the Balance Principles) underpin how everyone can work together to plan for, respond to and recover from future pandemics. However, while they offer a shared basis for decision-making, they do not specify exact courses of action.

The Balance Principles (which are explained in full in chapter 2.1) are underpinned by the principles of human rights and equity, Te Tiriti o Waitangi | Treaty of Waitangi and the attitudes and values of people living in Aotearoa New Zealand. They can be summarised as the following.

- **Manaakitanga** – Responding in ways that are intentioned and respectful and demonstrate caring for others; establishing mutually beneficial communication and collaboration pathways.
- **Tika** – Responding in ways that are ‘right’ and ‘good’ for a particular situation by being open and transparent; cultivating trust between decision makers and the people impacted by their decisions.
- **Liberty** – Responding in ways that uphold human rights, including liberties and privacy.
- **Equity** – Responding in ways that eliminate or reduce unjust inequities in health outcomes for different groups of people and achieve healthy futures for all (pae ora).
- **Kotahitanga** – Responding in ways that strengthen social cohesion by empowering local government, leaders and communities (including iwi, hapū and other Māori groups) to be active participants in planning and responding to pandemics.

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<sup>1</sup> In this document, the term ‘pandemic’ refers to both epidemics and pandemics.

<sup>2</sup> While the focus of this document is on infectious large-scale disease outbreaks that require fast decision-making, many of the recommended approaches and decision-making tools will also apply to non-infectious epidemics, such as obesity and drug abuse, as well as to other types of large-scale emergency.

- **Promoting health and wellbeing** – Responding in ways that protect and uplift wellbeing as described by the Whare Tapa Whā health model: whānau health, mental health, physical health, and spiritual health. This model demands that, for a person’s holistic wellbeing to be optimal, all four areas need to be looked after, alongside the whenua the whare stands on. Healthy individuals and whānau turn into healthy communities and a healthy population (Ministry of Health 2017).

Decision makers will need to reflect on how the Balance Principles apply in each situation. This document provides suggestions on how to give effect to the Balance Principles in a variety of contexts (see 2.2: Applying the Balance Principles).

Decision makers have a responsibility, as outlined in the Pae Ora (Healthy Futures) Act 2022 (the Pae Ora Act), to ensure individuals and communities are involved in decision-making that impacts them. For example, this can involve engaging with many people within a community rather than just the designated representative. Co-designed, local government- and community-led responses can often result in more equitable, cost-effective responses that can be implemented faster. The time to connect with communities is before a pandemic occurs, as this will enable rapid stand-up of community-led responses during an event. Co-designing appropriate response plans now will ensure unbiased outcomes and mitigate risks inherent in rapid decision-making without adequate consultation (see 3: Promoting equity and tino rangatiratanga).

During a pandemic, there are known ethical issues to be considered for a range of populations. This includes the Pae Ora Act priority populations (Māori, Pacific Peoples, women, people in rural and remote areas, disabled people and people with poor mental health), those in higher-risk settings and occupations (for example, hospitals, residential services and correctional facilities) and other vulnerable groups (people over the age of 65 years, people experiencing homelessness, Rainbow community members, former refugees and recent migrants, and children in poverty). The needs of future populations should also be considered. These considerations must underpin planning to ensure tomorrow’s inequities are not increased because of a pandemic response. Co-designing pandemic plans with these population groups will ensure more equal outcomes for the whole population (see 3.2: Considerations for specific groups of people).

Decision makers should communicate with people and communities in ways that empower those people and communities to participate in and promote pandemic responses. A whole-of-society approach to build awareness about the impacts of misinformation and disinformation, along with ways of identifying and combating it, will strengthen Aotearoa New Zealand’s resilience to the mis/disinformation (see 4: Building trust and empowering communities through communication).

An effective pandemic response will require a range of responses, some of which, in the interest of protecting the collective's right to health, will limit individual or group liberties. To find the correct balance between individual and collective rights, responses should align with the Balance Principles, include mātauranga Māori and evidence-based science, and be proportional to the benefit they are trying to achieve or the risk they are trying to mitigate (see 5: Epidemic and pandemic responses).

Where there is minimal evidence underpinning a response, the response should be accompanied by a publicly transparent evidence-gathering programme. The rationale for the response (and full details about the known evidence base) should be openly communicated to the public and the response should be evaluated and amended as evidence builds (see 5: Epidemic and pandemic responses).

Decision makers must have regard for the significant positive impact of mātauranga Māori on people in Aotearoa New Zealand. Responses must avoid infringing on Māori rights under Te Tiriti o Waitangi (see 5: Epidemic and pandemic responses).

Vaccination programmes may be an appropriate part of a pandemic response strategy. However, a single implementation strategy alone will not ensure equitable uptake of vaccination programmes. Evidence shows that targeted solutions are required to achieve equitable vaccination uptake (Whitehead et al 2022). We advise decision makers to understand the importance of developing vaccination strategies that are specific and tailored to the Pae Ora Act priority populations, higher-risk settings and other vulnerable groups of people and communities. Collaborating with those affected can ensure the programmes meet the needs of intended audiences (see 5.2: Ethical considerations of responses to epidemics and pandemics).

Ethical considerations for digital contact tracing include ensuring equitable access to the benefits of contact tracing and reliable testing and the need for strict privacy control rules for collected data (especially if working with an overseas supplier) (see 5.2: Ethical considerations of responses to epidemics and pandemics).

Decision makers should acknowledge there may be substantial negative impacts from responses that are intended to eliminate or slow the spread of a pandemic, and some people will be affected much more than others. Equally, not responding may have substantial negative or unknown impacts on both existing and future populations and on populations in both well-resourced nations such as Aotearoa New Zealand and other nations that may be less able to mitigate harms. Movement-restricting responses, such as international border closures, requiring vaccine certificates or personal protective equipment (PPE), or limiting gathering sizes can have unintended negative consequences that must be balanced with the benefits from a possible elimination or slowed spread of the pathogen (see 5.2: Ethical considerations of responses to epidemics and pandemics).

Collecting quality data that is reportable by known equity indicators, such as ethnicity and disability, should be part of any pandemic response. High-quality data enables decision makers to identify injustices to different groups of people and develop targeted responses. All mātauranga Māori is classified as taonga, and this applies to the management of all data in Aotearoa New Zealand (Rauika Māngai 2020). As within other legal and ethical frameworks of data and records management, it is important to consider where and how data and other information are stored, accessed and used. This includes how and when information is provided for others to use, which may engage frameworks like the Health Information Privacy Code 2020, privacy rights and protection of vulnerable populations in deciding whether data can be released (Te Pou Matakana Limited and Whānau Tahī Limited v Attorney-General and Privacy Commissioner 2021). It must also be decided who should be the kaitiaki of cultural data (Rauika Māngai 2020; see also 6: Preparing for the next epidemic or pandemic).

The 'economics of readiness' require investment in the health system, digital responses and inclusions, and research (especially Māori research) of pandemic effects in the Aotearoa New Zealand context. Extreme climate events may impact the health system's ability to respond to a pandemic.

Aotearoa New Zealand should seek out opportunities to support global discussion, cooperation and agreements that will help minimise the negative effects of future pandemics. Pandemics do not respect national borders, and decision makers should be mindful of Aotearoa New Zealand's responsibility to act ethically towards people in other countries and our special relationships with Pacific Island nations. Helping another nation combat a pandemic quickly may be both the ethical thing to do and in Aotearoa New Zealand's best interest as cooperative approaches can reduce both the likelihood of future pandemics emerging and the risks associated with them (see 6: Preparing for the next epidemic or pandemic).

The NEAC vision is for Aotearoa New Zealand to get through a pandemic as a strong and united country, where everyone has had an equal chance to survive and thrive and New Zealanders can feel proud of the national response. We believe using the Balance Principles to guide decision making will enable Aotearoa New Zealand to achieve this vision.

# Summary of recommendations

## Promoting equity and tino rangatiratanga

1. Decision makers should establish and grow relationships **now** with Māori and other Pae Ora Act priority populations, those identified as being in high-risk settings and occupations and vulnerable communities and groups. *Manaakitanga, Kotahitanga, Equity*
2. Decision makers must have regard for the Crown's obligations to Māori under Te Tiriti o Waitangi. They must understand, recognise and give effect to the principles of Te Tiriti o Waitangi, especially when making decisions as part of a pandemic response. *Tika, Liberty*
3. Decision makers should ensure hospitals, health care systems and residential settings develop pandemic plans that adequately consider the needs of disabled people. *Manaakitanga, Equity*
4. Decision makers should ensure, as much as possible, that policies balance people's rights to visit and take part in social activities with minimising the risk of harm. In particular, decision makers should recognise the importance of a person having whānau with them at the end of their life, in all settings, including higher-risk settings. In settings such as hospitals and elder care facilities, receiving visitors is essential for residents' wellbeing and helps reduce social isolation. These needs must be balanced with minimising the risk of spreading infection, and facilities should support visits to occur in the safest possible way, using appropriate risk mitigation strategies. These policies should also be informed by and enable tikanga Māori. *Tika, Liberty, Promoting health and wellbeing*
5. Decision makers should take all practicable steps (alongside their legal obligations) to: reduce the occupational risks for essential workers (for example, providing them with early access to vaccinations, tests and PPE), ensure good working conditions to reduce the risk of burnout and ensure the workers and their whānau are protected from discrimination. *Manaakitanga, Tika*
6. Decision makers should consider how their response planning will impact people experiencing homelessness, particularly Māori. *Kotahitanga, Tika*
7. Analyses of pandemic response strategies should fully consider the long-term health impacts of both the disease and delayed health service delivery. *Manaakitanga, Tika, Promoting health and wellbeing*
8. There should be more investment in training the health workforce in post-infection diseases. *Promoting health and wellbeing*

9. The disability support system should be reviewed to provide the equivalent support to people with disabilities that have similar impacts on quality of life, regardless of whether the disability is caused by an accident or an infection. *Equity*

## Building trust and empowering communities

10. Decision makers should communicate with the public about the public's responsibilities in preparing for a pandemic. Decision makers should provide evidence-based guidance on what those measures should be. *Kotahitanga, Promoting health and wellbeing*
11. Decision makers should build trust with different communities and groups by communicating information that is evidence based, accurate, clear, timely and effective for the diverse communities across Aotearoa New Zealand. Decisions should be communicated with full transparency to the public. The various methods for providing official information (for example, via radio, television, online, images, etc) should be available in multiple formats (audio, large print, sign language, etc), following plain language guidelines and in accessible, disability-friendly colour scales. *Tika, Kotahitanga, Promoting health and wellbeing*
12. Decision makers should build trust in official sources of information by working in partnership with the Pae Ora Act priority populations, as well as those in higher-risk settings and occupations and other vulnerable groups of people or communities when developing and circulating information. Decision makers should ensure pandemic plans anticipate and enable partnering with local councils and community leaders and resources are readily available to support implementing solutions. *Kotahitanga, Equity, Promoting health and wellbeing*
13. Decision makers should proactively develop communications to alert the public to any false information and educate the public on how to identify accurate and false information. Decision makers should monitor communities at risk of influence from false information and work quickly to communicate to them in ways that both combat false information and provide effective access to quality information. *Kotahitanga, Promoting health and wellbeing*
14. Decision makers should develop a cross-agency, public-private and community solution to coordinate a national, regional and local approach to proactively combatting false information and rebuilding trust between communities and official information. *Tika, Kotahitanga*

## Epidemic and pandemic responses

15. Decision makers should ensure public health responses reflect the Balance Principles, are evidence based (inclusive of mātauranga Māori, lived experience and input from impacted communities) and are as unrestrictive as possible. *Manaakitanga, Tika, Liberty, Kotahitanga, Equity, Promoting health and wellbeing*
16. Decision makers should develop strategies to ensure those who cannot participate in responses are not additionally impacted by stigmatisation. *Kotahitanga, Equity*
17. Decision makers should consider the significant ethical and efficacy risks of herd immunity as the primary response, particularly for new diseases that can spread quickly and cause serious health consequences. There should be strong evidence that the benefits are likely to outweigh the risks, based on good knowledge of the characteristics of the disease, including its pandemic potential, before a response is chosen. *Kotahitanga, Tika, Promoting health and wellbeing*
18. Decision makers should ensure vaccination is voluntary wherever possible and appropriate. To protect the wellbeing and health of the community, decision makers should be careful to justify their decision whenever they require people or professions to have a vaccine. Decision makers should prioritise strategies focused on incentives and encouragement. *Manaakitanga, Tika, Liberty, Promoting health and wellbeing*
19. Decision makers should monitor for differences in vaccine use or uptake among different communities and groups of people and respond empathetically and thoughtfully to any concerns raised. If programmes to encourage vaccination are developed, these should be co-designed with the population groups they are intended for and the justification for the vaccination programme should be clearly communicated. *Tika, Kotahitanga*
20. To protect the public's right to informed consent, decision makers must be transparent with the public about privacy issues and about their level of confidence in or uncertainty about any digital or data-based method for testing or contact tracing. They must assure the public they have mitigation plans ready to be stood up in the event of any technical failures. *Manaakitanga, Tika, Liberty*

21. Decision makers should develop responses that limit gathering sizes and regional/local travel in a way that respects and, where possible, enables significant whānau events and social connection to take place. Manaakitanga should be shown in the development of these policies and alternatives suggested. The needs, wishes and human rights of people who are at the end of life and their whānau must be considered. These needs must be balanced against the risk of exposing others to infection. *Manaakitanga, Tika, Promoting health and wellbeing*
22. Decision makers should ensure whānau are supported to educate their children and rangatahi from home during restrictions. Whānau who have safety concerns about sending their children to school should be treated with flexibility and compassion and supported to educate from home. To balance the risks of staying home / missing education and the risks of returning, decision makers should support schools and other educational institutions to enable students' return as quickly and safely as possible. *Promoting health and wellbeing*
23. Decision makers should focus on strengths-based messaging that encourages the public to follow the public health measures in order to manaaki those who cannot follow the measures. *Manaakitanga, Kotahitanga*
24. Decision makers should collect high-quality data, reportable by known equity indicators, such as ethnicity and disability, and uphold people's right to privacy by establishing and following safeguards in the safe collection, use, management, governance, storage and destruction of data. Māori data sovereignty requires decision makers to work with Māori when making decisions about the primary collection, sharing, analysis and interpretation of Māori data. *Manaakitanga, Tika, Liberty, Equity*
25. Decision makers should develop clear and publicly transparent policies on who has a right to know medical history and how any infringement on people's right to privacy will be minimised as much as possible, taking into account relevant legislation. *Tika*

## Preparing for the next epidemic or pandemic

26. Decision makers should establish sustainable, routine resourcing to ensure the health system is more resilient and adequately prepared to respond to future emergencies. *Manaakitanga, Tika*
27. Decision makers should co-design supportive programmes that build digital literacy skills with the groups of people who need them and encourage digital solutions to improve health and wellbeing outcomes. *Kotahitanga, Equity, Promoting health and wellbeing*
28. Decision makers should invest in research to better understand the effects of epidemics and pandemics on communities and other groups and the connections between climate change, health and epidemics and pandemics for Aotearoa New Zealand. *Manaakitanga, Tika, Kotahitanga, Equity, Promoting health and wellbeing*
29. Decision makers should take steps to protect and promote Aotearoa New Zealand's biodiversity, prioritise climate-smart land-use planning and use data to better understand the effects of climate change and monitor environmental threats to public health. *Manaakitanga, Tika, Kotahitanga, Promoting health and wellbeing*
30. Decision makers should consider how to: reduce or minimise single-use plastics and implement sustainable medical waste management processes before and during a pandemic to minimise the environmental effects of a pandemic response. *Tika, Liberty, Promoting health and wellbeing*
31. Decision makers should support policies that encourage international cooperation and information sharing during global emergencies and pursue the development of international economic and environmental agreements that will reduce the impact of future pandemics on health and wellbeing. *Kotahitanga, Promoting health and wellbeing*

# 1 Introduction

In 2019, the NEAC had planned to update the 2007 report *Getting Through Together – Ethical values for a pandemic*. Although we began this work, the arrival of COVID-19 pandemic highlighted other pressing ethical issues, and we switched our focus to producing *Ethics and Equity: Resource Allocation and COVID-19 – An ethics framework to support decision-makers*, which was published in February 2021. Alongside this work, decision makers asked for our advice to address the evolving challenges of the different stages of the pandemic.

In 2022, we returned to updating *Getting Through together* and published a draft version, *Ethical Guidance for a Pandemic*, for public consultation from July 2022 to November 2022. The NEAC secretariat analysed the consultation responses and published a summary report in June 2023. The responses highlighted areas for refinement and where respondents, particularly those from professional groups, wanted further guidance. We adjusted the document in response to create *Finding Balance: Ethical principles for epidemics and pandemics (Finding Balance)*.

*Finding Balance* provides ethical guidance on the known ethical considerations that arise during a pandemic. This guidance is based on the principles for epidemics and pandemics<sup>3</sup> that should underpin how everyone can work together to plan for, respond to and recover from future pandemics. We have named these the ‘Balance Principles’. The Balance Principles are designed to support decision-making and to be tailored to local environments. *Finding Balance* builds on our previous work around responding to pandemics and is focused on supporting decision makers in the intense and often fast-moving context of pandemics and helping Aotearoa New Zealand prepare for future pandemics.

## 1.1 Audience

This guidance has been primarily written for the Minister of Health and senior public health advisors responsible for making national level decisions in preparing and responding to pandemics.

Health and disability organisations, public health experts, health care administrators, iwi, hapū and other community leaders with authority to make decisions on behalf of their communities may also find this guidance useful.

Throughout this document, we refer to this audience as ‘decision makers’.

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<sup>3</sup> For the purpose of simplifying reading, in this document, the term ‘pandemic’ covers both epidemics and pandemics.

## 1.2 How to use this guidance

Pandemics stretch the capacities of health and social care systems and raise challenging ethical dilemmas. Finding Balance aims to support decision makers to balance competing ethical issues when preparing for, responding to and recovering from a pandemic and inform planning and management activities (Nuffield Council on Bioethics 2020).

Experiences from the COVID-19 pandemic informed the development of this document, in particular highlighting the speed at which decisions need to be made during the response phase, the importance of having structures already in place to bring a wide range of people into decision-making processes and the need for transparency in how decisions are made.

Finding Balance is composed of the Balance Principles and a framework for how to apply the Balance Principles. Recommendations and examples of how to integrate and give effect to the Balance Principles are provided throughout this document. For a full list of the recommendations, see Summary of Recommendations above.

This guidance is not the only ethical guidance that may inform decision-making for pandemics. Other examples of ethical frameworks decision makers may need to consider in Aotearoa New Zealand include:

- Māori tikanga, kawa and ritenga
- research ethics, including for Māori and Pacific peoples and other intersectional research ethics (see Hudson et al n.d.; Smith 2021 pp. 136 and 137)
- professional codes of conduct (such as those for medical, nursing and emergency care workers)
- clinical ethics
- state sector codes of conduct (such as for the public service, New Zealand Defence Force and Police)
- business and legal ethics
- animal welfare ethics (such as those relating to the culling of wildlife, production and companion animals and care of animals during travel restrictions)
- media and communications ethical standards
- digital ethical standards and data sovereignty expertise
- spiritual, cultural or religious values
- The Treasury's Living Standards Framework (The Treasury – Te Tai Ōhanga 2022) and corresponding He Ara Waiora (The Treasury – Te Tai Ōhanga 2023).

A glossary of terms used in this document is provided in Appendix 1: Glossary of terms.

## 1.3 Context of this guidance

When using this guidance, decision makers should be aware there are other resources that also provide context when dealing with the complexity of pandemics. The United Nations' Universal Declaration of Human Rights (United Nations n.d.), the Pae Ora (Healthy Futures) Act 2022 (the Pae Ora Act) (New Zealand Legislation n.d.) and Te Tiriti o Waitangi – Treaty of Waitangi (Ministry of Justice 2023) provide important context and a summary of how they may apply in a pandemic is provided below. There are also other documents that provide context in specific areas that may be useful, such as the strategies for the Pae Ora Act priority populations, Aotearoa New Zealand legislation and international treaties. A comprehensive list of potentially relevant documents is provided in Appendix 2: Related documents.

### 1.3.1 Upholding human rights in an epidemic or pandemic

Human rights are a foundational part of Aotearoa New Zealand's legal and ethical framework. Human rights draw upon the national and international legislative obligations provided in Appendix 2: Related documents. They remain legally binding in times of emergency, including during a pandemic.

A human rights-based approach to a pandemic requires that the human rights principles of universality, indivisibility, equality and non-discrimination, participation and accountability guide a nation's preparation and response (WHO Sexual and Reproductive Health and Research 2020). Decision makers must focus on upholding the rights of New Zealanders as much as practicable during a pandemic.

### 1.3.2 The Pae Ora (Healthy Futures) Act 2022

Achieving equitable health outcomes is one of the three purposes of the Pae Ora Act. The Act provides for the public funding and provision of services to achieve equitable health outcomes for everyone in Aotearoa New Zealand. Decision makers must be fully informed of inequities<sup>4</sup> that already exist in the health system, as these may be exacerbated during a pandemic.

Decision makers must be mindful that priority populations may change over time. As a population changes, epidemic and pandemic planning must also change to account for the changing and diverse cultural needs.

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<sup>4</sup> See Came et al. 2016 page 72.

### 1.3.3 Te Tiriti o Waitangi

The health and disability system is committed to fulfilling the special relationship between tangata whenua and the Crown under Te Tiriti o Waitangi. The principles of Te Tiriti o Waitangi, as articulated by courts and the Waitangi Tribunal, and the health sector principles outlined in section 7(a–e) of the Pae Ora Act informed the creation of the Balance Principles (Waitangi Tribunal 2019). An outline of how the principles of Te Tiriti o Waitangi might apply in the context of a pandemic response is summarised below, with guidance provided throughout this document.

#### Tino rangatiratanga

In the context of a pandemic, tino rangatiratanga means that Māori are key decision makers in the design, delivery, prioritisation and monitoring of Aotearoa New Zealand’s responses. Decision makers must recognise the right of iwi, hapū, whānau and other Māori communities to exercise their tino rangatiratanga and mana motuhake. This includes providing adequate resources to govern, design, deliver, manage and monitor the responses and the impacts on Māori.<sup>5</sup>

#### Partnership

Partnership means that decision makers ensure iwi, hapū, whānau and other Māori communities are active partners in preventing, managing and recovering from the impacts of a pandemic.

#### Equity

Equity requires decision makers to commit to achieving equitable health outcomes for Māori when planning for, managing or reviewing a pandemic response. Decision makers must also continue to identify, acknowledge and address existing inequities experienced by Māori.

#### Active protection

Active protection ensures, to the fullest practicable extent, that decision makers actively pursue equitable health outcomes for Māori when undertaking actions in pandemic planning, response or review.

#### Options

Options means that decision makers are agile in adapting Aotearoa New Zealand’s pandemic planning and responses to meet the needs of iwi, hapū, whānau, other Māori communities and kaupapa Māori health and disability services to ensure Māori have consistent access to quality services.

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<sup>5</sup> Came et al 2021 page 15 argue that “Within a fully Te Tiriti compliant public sector, collaboration would occur across Crown agencies to ensure all Māori have access to the prerequisites of health ... and no longer live in circumstances which put whānau at risk .... In addition, intergenerational trauma and the legacies of colonisation would be recognised as drivers of inequities ...”

## 2 Supporting decision makers

Pandemics require large-scale response and require decision makers to make difficult decisions in an often fast-paced, high-stakes environment while Aotearoa New Zealand's health care professionals, whānau and communities also grapple in real time with life-or-death decisions.

To help decision makers build the relationships and address pandemics, we have developed a set of principles – the Balance Principles. The Balance Principles and recommendations within this document provide an evidence-based roadmap for implementing an ethically informed pandemic response in the Aotearoa New Zealand context.

### 2.1 The Balance Principles

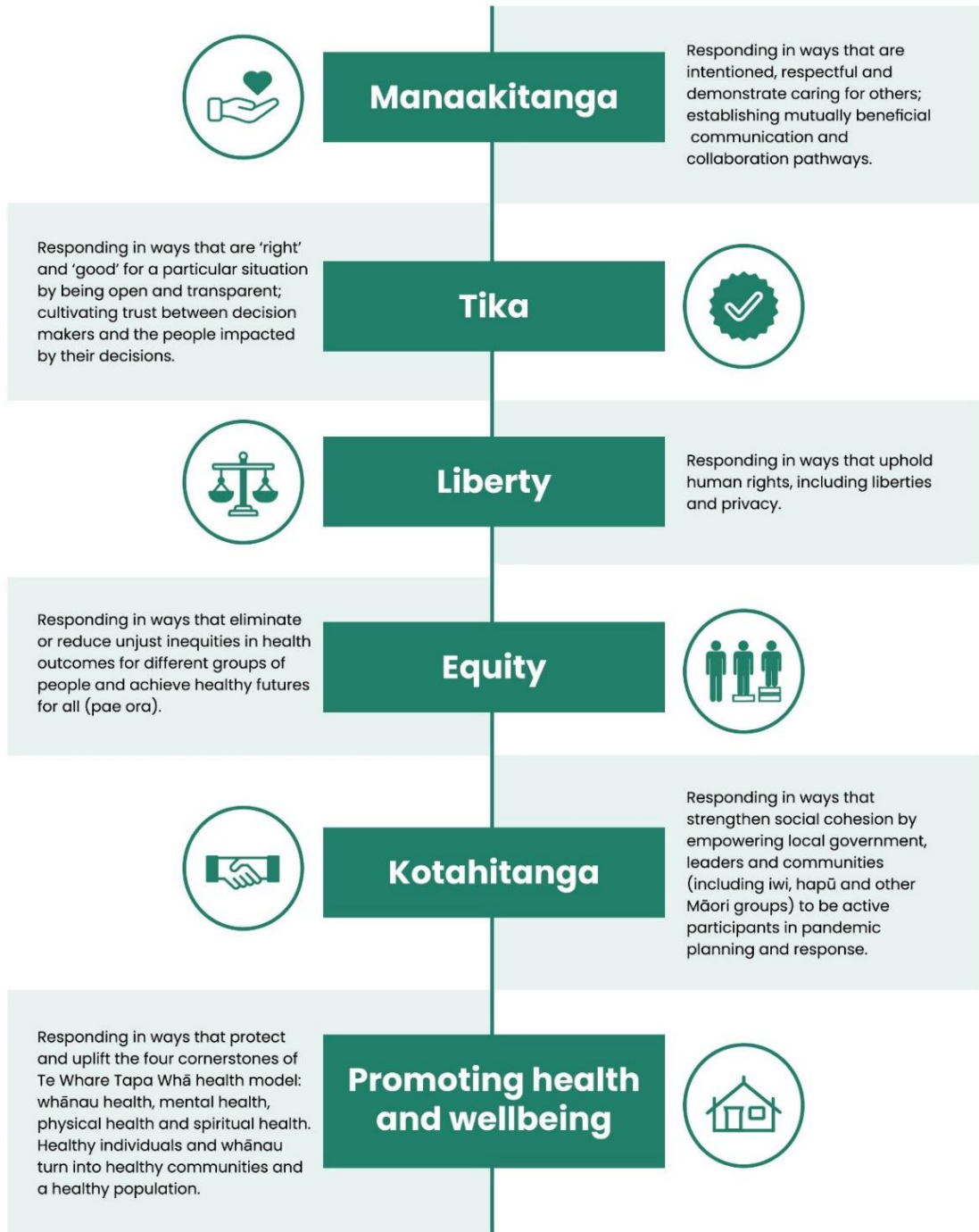
The Balance Principles are based on human rights, equity, Te Tiriti o Waitangi and the principles and values of New Zealanders. They also draw on the principles within *Te Ara Tika Guidelines for Māori Research Ethics* (Hudson et al n.d.). The Balance Principles reflect the whakataukī<sup>6</sup> shared by our chair in the foreword. Woven together, they offer a strong framework to guide the application of ethics in pandemic response decision-making. The relative importance of each principle will depend on context. We advise decision-makers provide a publicly available rationale for how they have applied the Balance Principles as part of a transparent and accountable process. For example, restrictions on the liberty of some people for a specified period may be warranted in order to attempt to eliminate a pathogen to protect the wellbeing of many.

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<sup>6</sup> Ki te kotahi te kākaho ka whati ki te kāpuia e kore e whati.  
One strand of flax is easy to break, but many strands together will stand strong.

# Finding Balance

## Ethical Principles for Epidemics and Pandemics



### 2.1.1 Manaakitanga

Manaakitanga refers to the process of caring for others, nurturing relationships and being intentional and respectful when engaging with others. Other words that provide insight into the meaning of manaakitanga include: sharing, reciprocity and generosity. Manaakitanga relates to cultural and social responsibility and respect for people.

Manaakitanga is an essential part of a pandemic response that maintains and uplifts the mana of others (Hart 2021; Yates 2023). During a pandemic, manaakitanga for individuals and communities can be interpreted as actions that improve or benefit people's health and wellbeing.

This principle acknowledges the relationships and information that flow throughout a pandemic response; between health professionals and the communities in which they live and work; between health professionals and decision makers and between decision makers and communities.

### 2.1.2 Tika

Tika refers to what is right and good, pono and aroha and may be thought of as a central principle of ethical behaviour towards other people and the world (Butler and Rangahau 2019; Stewart et al 2021).

To understand what is right and good in the context of a pandemic, decision makers should develop relationships with communities and understand what is important to them before they need to make their decisions. Tika acknowledges that trust resulting from past good actions is the foundation upon which relationships rest. This trust allows for the active cooperation of communities, working together to respond effectively to an emergency.

### 2.1.3 Liberty

Liberty reminds decision makers of their responsibilities to uphold human rights in the context of a pandemic. A core tension in reducing health risks is striking the balance between protecting an individual's rights and protecting the collective's right to health (Bodenheimer 2005; Childress et al 2002; Mann 1997; Radoilska 2009). Human rights laws recognise that pandemics may require limits to be placed on the exercise of human rights (United Nations 2020).

Decision makers should actively seek to understand the aspirations of Aotearoa New Zealand's communities when considering the ethical justification of measures that infringe an individual's or the collective's liberty (Childress et al 2002).

## 2.1.4 Equity

### Balance Principles in action: Equity

‘Equity is more than a word or an add-on at the end of a sentence supporting the value of ‘diversity’. It represents the absence of the systematic, entrenched, and pervasive inequities that we, our loved ones, and our communities, experience. For us, equity MEANS something. It is about who will be left on our paepae, in our homes, and in our communities.’ (King et al 2020)

Different communities will require different approaches and resources to achieve equitable health outcomes (Ministry of Health 2019a). A one-size-fits-all approach to a pandemic will worsen existing inequities (Te Hiringa Mahara 2022). The Crown also has specific obligations to achieving equitable outcomes for Māori under Te Tiriti o Waitangi. Equity calls on decision makers to both identify current inequities and design pandemic plans in collaboration with these priority populations that will eliminate inequities. This may require directing more effort and resources to those who need it, proportionate to their circumstances, to ensure everyone achieves the same health and wellbeing outcomes (Ministry of Health 2019a).

## 2.1.5 Kotahitanga

Committing to kotahitanga is committing to getting through the pandemic together whilst strengthening people and communities. Each person and whānau in Aotearoa New Zealand has a role in responding to a pandemic.

Kotahitanga also encompasses mindfulness of those who may be particularly vulnerable.<sup>7</sup> Decision makers need to be responsive to the different types of support people and communities require to navigate a pandemic (Mashaphu et al 2021).

## 2.1.6 Promoting health and wellbeing

### Balance Principles in action: Promoting health and wellbeing

‘Growing up I was always told that there were four sides to hauora, think of it as the walls of the whare. So there’s te taha tinana – the physical aspect, te taha hinengaro – the mental aspect, te taha wairua – the spiritual and emotional part of it, and then there’s te taha whānau. So, it is who you’re connected to and who you surround yourself with and how that impacts all of those other aspects. It is a very important thing and each [sic] one of those walls is just as important as the other. Everything has to be balanced to be okay.’ (Mero, 17: Ngāti Whātua, Ngā Puhī) (Calder-Dawe et al 2022)

<sup>7</sup> For example, data from the United Kingdom’s national statistics office suggests that, in England, almost 6 out of every 10 people who died as a result of COVID-19 between January and November 2020 were disabled (Office for National Statistics 2022).

This principle focuses on collective wellbeing, population health and the health of individuals and whānau in the context of a pandemic. Healthy individuals and whānau turn into a healthy population. Decision makers can use Te Whare Tapa Whā model of health and wellbeing to evaluate their pandemic preparedness and response. The four tapa of Te Whare Tapa Whā are:

- hinengaro (mental health)
- whānau (family health)
- wairua (spiritual health)
- tinana (physical health) (Durie 1985).

For a person's holistic wellbeing to be optimal, all four areas need to be looked after, alongside the whenua the whare stands on.

## 2.2 Applying the Balance Principles

The Balance Principles offer a shared basis for decision-making and alone do not suggest specific courses of action. Decision makers will still need to make complex decisions during a pandemic as part of ensuring public health and safety. They will need to reflect on how the Balance Principles apply in a specific context.

While the Balance Principles are interconnected and relate strongly to each other, there will be situations where they appear to stand in opposition to each other. For example, it may not be possible to achieve equity and promoting health and wellbeing at the same time. Decision makers must be prepared for and open to the objections to prioritising one Balance Principle over another.

Different people may express or interpret the Balance Principles in different ways, and there is often more than one justifiable decision, especially in times of national emergency. In some cases, despite careful ethical consideration, a decision may remain controversial to the public. In such cases, the Balance Principles will be valuable for showing how the decision can be justified by important and shared ethical commitments.

## 3 Promoting equity and tino rangatiratanga

### 3.1 Ethical case for proactive partnership with communities

During the COVID-19 pandemic, over 20 Aotearoa New Zealand Government agencies were routinely involved in policy development. Decision timeframes were often extremely short, with decisions on significant public health measures made in a matter of hours. However, pandemics cannot be managed effectively by centralised decision makers alone (Nuffield Council on Bioethics 2020).

Co-designed and local government- and community-led responses can often result in more equitable, effective and cost-effective responses that can be implemented faster (New Zealand Independent Monitoring Mechanism 2020). The Pae Ora Act creates a new approach to the health system and includes a Code of Expectations for Health Entities' Engagement with Consumers and Whānau (New Zealand Independent Monitoring Mechanism 2020). Decision makers have a responsibility, as outlined in the Pae Ora Act, to ensure people and communities are involved in decision-making that impacts them. For example, this can involve engaging with many people in a community rather than just with the designated representative.

Decision makers must also build capacity within their own organisations to enable community participation. Developing plans that provide resourcing for these groups to support their efforts as part of the national response will enable participation by communities who often have capacity and willingness to do so (Paipa et al 2022).

The time for decision makers and, especially, government to start developing and connecting with communities is before a pandemic occurs (WHO 2020b). This will enable rapid stand-up of community-led responses during the pandemic, which can significantly reduce and eliminate the risk of infection spreading.

Having a diverse membership in decision-making groups facilitates unbiased outcomes, increases trust in the decision-making process and builds relationships. It also mitigates risks inherent in rapid decision-making that does not include adequate consultation. Where decision makers are required to make decisions without appropriate consultation, they must prioritise quality communication with those affected, being open and transparent about why they made particular decisions, and provide an opportunity for affected parties to work with them in monitoring the impact of any response or decision. This will be essential to maintaining trust in decision makers and aligns with manaakitanga and tika (Nuffield Council on Bioethics 2020).

If people and communities do not understand or trust decision makers, the decision makers may struggle to operate effectively in a crisis without control measures, and the liberty of the people and communities will suffer.

### Recommendation 1

Decision makers should establish and grow relationships now with Māori and other Pae Ora Act priority populations, those identified as being in high-risk settings and occupations and vulnerable communities and groups. *Manaakitanga, Kotahitanga, Equity*

## 3.2 Considerations for specific groups of people

A pandemic can magnify inequities. Different approaches may be required for different groups of people to achieve equal health and wellbeing outcomes. This section discusses key ethical considerations for specific groups. It is divided into three parts: Pae Ora Act priority populations, higher-risk settings and other vulnerable groups of people or communities. Appendix 3: People and communities consideration tool provides a broader list of groups that decision makers may consider.

Decision makers should take an intersectional approach by considering how a person's various social and political identities combine to create different modes of discrimination and privilege, such as gender, age, class, ethnicity, disability or sexual identity (Maestriperi 2021). The compounding risk and disadvantage experienced and the needs of certain groups should each be specifically considered.

### 3.2.1 Pae Ora Act priority populations

The Pae Ora Act defines five health strategies for priority populations: Māori, Pacific peoples, disabled people, women and rural health. To align those strategies with Finding Balance, below we set out a series of ethical considerations for each priority population relating to pandemic responses.

## Māori – Tangata whenua

### Balance Principles in action: Kotahitanga

During the COVID-19 pandemic, Ngāti Tūwharetoa organised food and sanitation supplies for distribution for the entire community (non-Māori and Māori). Volunteers packed boxes or made contactless deliveries throughout the rohe.

Ngāti Kahungunu addressed shortages of sanitisers and toilet paper by organising the local manufacture of these items. They were then distributed to those at risk and/or who could not obtain them (Wilson 2020).

During the peak of the COVID-19 pandemic, iwi, hapū, whānau and other Māori communities demonstrated the effectiveness of a pandemic response grounded in tikanga Māori and mātauranga Māori, and research confirms that Māori-designed solutions can achieve better outcomes for Māori (Controller and Auditor General 2023; Wilson 2020). Such solutions draw on collaborative and driven applications of tikanga Māori that are centred around the whānau, making use of established networks and relationships and include iwi checkpoints, food and care parcels, and support tailored to the needs and abilities of different community members (Cram 2021; Te One and Clifford, 2021). Marae often became a community focal point during the pandemic and a hub for coordinating support and the response (Cram 2021).

Māori networks play a critical and highly effective role in ensuring official public health information reaches a significantly wider group of people than the Aotearoa New Zealand Government typically reaches (Te Hiringa Mahara 2023e). The success of these solutions was enabled during the COVID-19 pandemic by decision makers who recognised and supported tino rangatiratanga (Te Hiringa Mahara 2023e).

Extensive research, evidence and experience demonstrates Māori are disproportionately more likely to be negatively impacted by a pandemic (McLeod et al 2020; HQSC 2019; Wilson et al 2012). Additional intersectionalities include significantly higher rates of disability<sup>8</sup>, co-morbidities<sup>9</sup> and mental health conditions. Alongside Te Tiriti o Waitangi, applying the principle equity highlights decision makers' responsibility to ensure pandemic planning takes these intersectionalities into consideration for Māori.

Pandemic planning must always include Māori, recognise and support tino rangatiratanga and build true partnerships based on trust. Working with Māori will better ensure tikanga Māori and mātauranga Māori is not unnecessarily intruded on in a pandemic response, in line with the principle of tika.

<sup>8</sup> For example, 14% of Māori children are living with disabilities compared with 11% of children nationally; 32% of young and working-age Māori are living with disabilities compared with 21% of young and working-age people nationally. In people over the age of 65 years, the percentage living with disabilities is higher in Māori than non-Māori, despite a much bigger percentage of non-Māori living to 80 years and beyond (Hayman et al. 2012; Ministry of Health 2019b).

<sup>9</sup> For example, there are much higher incidences of hypertension, obesity, diabetes, cardiovascular and chronic respiratory diseases, and cancer in Māori populations (Hayman et al. 2012; Ministry of Health 2019b).

The unilateral exercise of extraordinary powers by the government can protect lives in an emergency, meeting the obligation of active protection, however, it can limit the Crown's ability to comply with the principles of tino rangatiratanga, partnership and options (Te Hiringa Mahara 2023e). A focus on individual liberties (as implied by the New Zealand Bill of Rights Act 1990) can align poorly with the collectivist foundation of te ao Māori. In an emergency, staff in a decision-making organisation will be struggling to do all that is required of them quickly. There may be a loss of focus on meeting Te Tiriti o Waitangi obligations at a time when the risk of increased inequities is greatest (Paipa et al 2022). It is therefore particularly important that there is partnership between the Crown and Māori in all emergency planning.

## Recommendation 2

Decision makers must have regard for the Crown's obligations to Māori under Te Tiriti o Waitangi. They must understand, recognise and give effect to the principles of Te Tiriti o Waitangi, especially when making decisions as part of a pandemic response. *Tika, Liberty*

### Pacific peoples

#### Balance Principles in action: Kotahitanga

During the COVID-19 pandemic, a Delta outbreak occurred among a Pacific church community in South Auckland. A local leader from the Cause Collective saw the negative media coverage and proactively got involved.

His proactive involvement resulted in effectively eliminating language barriers between the community and Ministry of Health officials, so the community knew what to do. They established a crisis management team that provided individualised support to each church member to enable them to isolate and coordinated with South Seas Healthcare, a local Pacific health provider, to assemble and deliver food packages to families who needed them (Paipa et al 2022).

Pacific communities are typically well connected with flexible and supportive networks that are often faith based. Families are particularly important for Pacific collective structures across households (Paipa et al 2022). Many Pacific community leaders and churches are well positioned to participate and support pandemic planning, both within Aotearoa New Zealand and further afield in the Pacific Islands. They have experience in ensuring public health information is shared and adapted to protect their communities, as was demonstrated during the COVID-19 pandemic. This included bespoke contact tracing support and rapid adoption of digital platforms for service delivery and community events (Ministry for Pacific Peoples 2022; Te Hiringa Mahara 2023c).

Planning with community leaders who understand the needs of their communities will be required. This will include working with families who have limited or no access to digital resources and capability, low or no employment income, a diverse Pacific family make-up, disconnection from cultural and spiritual support or limited community support. The successful management and elimination of a pandemic should be assessed by how well Pacific and other vulnerable communities survive during and beyond such crises (Nosa et al 2023).

## Women

Decision makers should be aware that epidemics, and allowing an epidemic disease to become endemic, may have a disproportionate impact on women. As a result, pandemic management, vaccines, and treatments will impact women, and especially pregnant women, differently. For example, the COVID-19 pandemic significantly increased maternal deaths in the United States in 2020 and 2021 (Litman et al 2022).

Women often hold multiple roles within a household, are likely to oversee the running of the household (for example, grocery shopping, cooking, cleaning) and are generally the main carer of children and other whānau (Coltrane 2000; Croda and Grossbard 2021). These responsibilities become increasingly complex during restrictive public health responses, such as at times when people are required to work from home.

In Aotearoa New Zealand, women make up 83% of the health care and social assistance workforce, which makes them at higher risk of exposure to a pandemic pathogen than men (Ministry of Health 2020a). Repeated infections and responsibilities for caring for sick family members and for children unable to attend school may reduce their ability to undertake paid work, and therefore to have financial stability and maintain careers, especially in single-parent families. Additionally, during the COVID-19 pandemic, women experienced the greatest loss of employment, largely because many worked part-time or in casual employment (Kamm 2023; VanBenschoten et al 2022).

Women are adversely impacted by gender issues, which are likely to be exacerbated in a pandemic. They are more likely to experience domestic abuse and death by homicide, and these rates increased globally and locally during the COVID-19 pandemic restrictions.<sup>10</sup> Women in Aotearoa New Zealand who had recently separated from an abusive partner also reported the abuse worsened during the pandemic movement restrictions.<sup>11</sup>

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<sup>10</sup> In New Zealand, under alert levels 4–2, the number of family violence reports to New Zealand Police increased by 127%–135% per day compared with the same period in 2019 (Te Hiringa Mahara 2023a).

<sup>11</sup> For example, with the isolation, fear, risk of illness and lack of clarity and consistency of information leading the abusive partner to escalate control, isolation and abuse of their ex/partners and children (Te Hiringa Mahara 2023a).

## People in rural and remote areas

Approximately 35% of Aotearoa New Zealand's population lives outside large urban areas, with 16% living in rural areas (Te Hiringa Mahara 2023d). These figures are higher for Māori (Te Hiringa Mahara 2023d).

People living in rural or remote areas are more likely to experience access barriers to health and wellbeing services, PPE and digital communication. Many people living in rural areas are essential workers and will have responsibilities for caring for animals, which could also be at risk of spreading or contracting the disease. Movement restricting measures may split parents from children who may attend boarding schools (Te Hiringa Mahara 2023d).

Ensuring equitable access to health and social services may require decision makers to proactively develop solutions around childcare, travel support and digital communication.

## Disabled people

According to Stats NZ, one in four New Zealanders have a physical, sensory, learning, mental health or other disability that they were born with or have developed/acquired through injury, illness or age (Stats NZ 2013). The wide diversity of disabilities mean that decision makers will need to actively obtain guidance and direction on meeting disability needs from people with lived experience of disability as service users or as whānau of a disabled person to guide any pandemic planning.

### Balance Principles in action: Kotahitanga

‘Whānau hauā members like Dayna and myself held Zoom hui with the vaccination staff and Māori providers to help them understand our communities. It is important to understand our experiences and what works best directly from us. We have held these Zoom hui multiple times a week since the start of October. We have discussed the differences between hearing impaired, Deaf and Deaf plus communities and how to best engage with these communities. We have also discussed mask alternatives, like plastic shield barriers, and how to uphold the mana of our Turi whānau.’ – Tauri Lyndon (Waitangi Tribunal 2021)

Disabled people as a group have worse health and wellbeing outcomes than the general population, and a pandemic is likely to increase this disparity. Māori experience disability at a higher rate than other population groups. The disabled population suffers higher rates of chronic medical conditions (for example, diabetes and cardiovascular disease), which may be associated with worse health outcomes, depending on the pandemic (EHINZ n.d.; Kamalakannan et al 2021). Disabled people are more likely to be exposed to transmission risk and less likely to be able to anticipate, cope with and recover from the effects of infection (Ministry of Health 2023).

This is due to multiple factors, including risks associated with living in residential care facilities, a lack of accessible information, the fact that disabled people often face greater health problems when infected and the unethical disadvantages in the rationing of lifesaving and critical care that may be experienced by disabled people (Kamalakaran et al 2021).

Further, impairments (for example, mobility, developmental, communication) can create barriers to protection against infection (for example, difficulty washing hands or physically distancing due to support needs) (Ministry of Health 2023).

Disabled people have the same rights as all other New Zealanders. The multiple intersectionalities that most disabled people experience puts them at greater risk of inequitable outcomes, particularly where a national-level health response fails to account for a more diverse set of needs or responses. Decision makers should therefore take extra care in addressing, reducing and eliminating these inequities as part of pandemic planning. For example, telemedicine options should include accessibility measures that are compatible with electronic devices (such as, remote audio-visual description services, captioning or third-party remote connection with a sign language interpreter). Decision makers should consider accessibility issues when commissioning and purchasing infection control supplies and software.

Plans to stand up alternative care settings as part of a pandemic response, like drive-through testing facilities or sensory environments that cater to neurodiverse population groups, must consider how to enable people with vision or developmental disabilities to navigate these settings when seeking care. Public health measures such as social distancing require additional considerations as to how the implementation will impact disabled people in the community. When considering naming certain professions as 'essential workers', decision makers should consider protecting disabled people's access to personal care assistants who enable liberty in their daily lives.

### Recommendation 3

Decision makers should ensure hospitals, health care systems and residential settings develop pandemic plans that adequately consider the needs of disabled people. *Manaakitanga, Equity*

#### Mental wellbeing

People experiencing poor mental wellbeing are likely to be more at risk during a pandemic due to a range of factors. They may experience increased stress or anxiety, and this may result in increased negative behavioural changes (for example, increased drug use or poor diet and exercise) (Pollak et al 2020).

Research conducted in Aotearoa New Zealand during and after the COVID-19 pandemic suggests that the lockdowns exacerbated mental distress for some people (Officer et al 2022). This research found that services were not always responsive, and people were not always able to

access telephone/videoconferencing services or informal community supports. Those with pre-existing mental health issues did better when they had ready access to primary health care or other services, especially if they already had a relationship with the health provider (Officer et al 2022).

Some people experiencing poor mental wellbeing may also experience a reduced ability or willingness to engage with official public health guidance or identify misinformation (Pollak et al 2020; Te Pou 2021). To address this issue, current research suggests that public health messaging about access to mental health and wellbeing services be made clear and consistent and that emergency services need to remain available during a pandemic. It is also advised that those experiencing poor mental wellbeing be given the choice to use telehealth services, but services need to recognise this may result in different outcomes for patients who are used to face-to-face consultations (Imlach et al 2020; Moreno et al 2020).

Whanāu and carers of those experiencing poor mental wellbeing can also be impacted as they may be sharing a house with people who are suffering from reduced access to mental wellbeing services and social services such as housing (Officer et al 2022). Restrictive measures can also limit opportunities for community and extended whānau support. Decision makers need to acknowledge that family connection means different things depending on cultural values and must consider how best to foster (extended) family unity while maintaining appropriate distancing measures (Officer et al 2022).

### 3.2.2 Higher-risk settings and occupations

During a pandemic, decision makers may identify occupations and settings where there is a higher risk of infection or transmission or a higher proportion of people at risk of severe disease compared with the general population. Decision makers are responsible for giving special consideration to people in these settings and occupations, as justified by the principle of *manaakitanga*.

#### Higher-risk settings

##### Balance Principles in action: Manaakitanga and Kotahitanga

‘I felt the fear. I knew there was a real risk to our Māori community based on the knowledge of our history. As a nurse, I knew I was going out into what could be a risky situation. I felt anxiety and fear for myself and my extended family. But I felt the weight of being a Māori nurse; that our Māori community and especially our rural Māori community was going to be hardest hit and that I was walking into something huge.’ [CW – research participant] (Davis et al 2021)

The Aotearoa New Zealand Government designated health care, aged residential care (ARC), residential disability care (RDC) and correctional facilities as higher-risk settings during the COVID-19 pandemic (Health New Zealand 2023). People within these settings are at higher risk for both transmission (due to proximity or difficulties instituting control measures such as physical distancing) and of severe illness from infection (due to such factors as medical complexity or age) (Health New Zealand 2024b, 2023). People within these facilities shared experiences of having significantly less control over their daily lives and/or significant reliance on staff for support.

Across each of these settings, decision makers have the complex task of balancing people's need to connect with their whānau and communities with limiting the risk of transmission for others, including staff. There was a decline in the quality of life and wellbeing of people living in these settings during the COVID-19 pandemic lockdowns, which was often attributed to the restrictions on visiting and activities (Jackways et al 2020; Te Hiringa Mahara 2023d). The psychosocial impact of visiting restrictions was particularly difficult in instances where people had an acute medical condition or were dying or where other important life events were occurring. It also adversely impacted whānau and whakapapa (Donnelly et al 2022), for example, restricting the development of grandparent/grandchild relationships.

In the COVID-19 pandemic, people in ARC, RDC, and correctional facilities retained their right to choose to be vaccinated. Decision makers had to balance a person's right to choose to be vaccinated with the rights of staff working within these facilities to a safe workplace.

Department of Corrections | Ara Poutama Aotearoa (Corrections) staff working in prisons were subject to the COVID-19 Public Health Response (Vaccinations) Order 2021 and were therefore required to be vaccinated to work in prisons. Corrections also took a proactive approach to encouraging people in prison to get vaccinated by providing information about vaccine safety, working with cultural leaders and making tikanga a central feature of vaccination clinics (Department of Corrections | Ara Poutama Aotearoa 2021). This approach aimed to balance *liberty* and *promoting health and wellbeing* for both staff and people in the facilities.

#### **Recommendation 4**

Decision makers should ensure, as much as possible, that policies balance people's rights to visiting and taking part in social activities with minimising the risk of harm. In particular, decision makers should recognise the importance of a person having whānau with them at the end of their life, in all settings, including higher-risk settings. In settings such as hospitals and elder care facilities, receiving visitors is essential for residents' wellbeing and helps reduce social isolation. These needs must be balanced with minimising the risk of spreading infection, and facilities should support visits to occur in the safest possible way, using appropriate risk mitigation strategies. These policies should also be informed by and enable tikanga Māori. *Tika, Liberty, Promoting health and wellbeing*

### **Additional ethical considerations for correctional facilities**

There are additional ethical considerations decision makers must be aware of when considering restrictions on a population that is already restricted in terms of rights and opportunities. In June 2020, a report by the New Zealand Ombudsman found that the relationship between staff and prisoners was reasonably positive and health and safety measures aimed at preventing the spread of the disease were generally of a high standard (Boshier 2020). However, the report also stated that some steps that had been taken to try to keep COVID-19 out of prisons came at the expense of some basic rights. For example, during the period when the most restrictive public health measures were in place to prevent transmission of COVID-19, some prisoners were not allowed to access at least one hour of fresh air daily or were not provided with activities to occupy their time (Boshier 2020). Due to the difficulty of implementing protective measures and staff illness and shortages, the use of solitary confinement and negative impacts on inmate wellbeing increased (Murray and Kras 2020). The impact on people of potential delays in legal proceedings should also be considered.

Corrections is part of a wider justice system. During a pandemic, decision makers may consider early release of low-risk prisoners.<sup>12</sup> These decisions will need to find a balance between the health and wellbeing of those imprisoned or working in prisons and their whānau against those of the wider community, who could be endangered if prisoners were released early or required to be admitted to hospital. These policies should be co-designed with prisoners, prison staff, whānau, local communities and clinical and public health professionals.

### **Higher-risk occupations**

Health and disability professionals have an ethical duty to provide care if a pandemic occurs, including when there is increased risk to themselves and their whānau (NEAC 2007). Such care must be conducted within the wider framework of health and safety legislation and obligations. Decision makers, therefore, have particular duties in terms of solidarity and manaakitanga towards health and disability workers, given the additional burdens these workers bear on the front line of care and the additional risks to which they are exposed (Nuffield Council on Bioethics 2020; Stephens and Breheny 2022). The effects of public health measures, such as the impact of quarantine, deteriorating work conditions, stigma and violence, and mental health issues, alongside increasing demands for services adds to their burden (WHO 2022a). These effects can be worsened when intersectionalities with ethnicity, status, gender, identity, disability and residency status come into play.

In addition to health and disability workers, there will be a much broader range of essential workers whose services are required during a pandemic to keep the economy operating. These essential workers often work longer hours or may be required to work away from home for

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<sup>12</sup> In the case of sentenced prisoners, the decision is made by the New Zealand Parole Board. The Courts make decisions for early release of remand prisoners.

periods of time. These workers may face difficulties beyond the risk of disease, including managing public dissatisfaction with the supply of goods or the imposition of restrictions. People required to kill animals, possibly including companion animals, are likely to face considerable opposition and stress.

Manaakitanga demands that decision makers should (alongside their legal obligations) ensure health and disability and other essential workers are nurtured, protected and able to continue their important contribution to managing and responding to a pandemic. These workers should be acknowledged and their contributions to the safety of people in Aotearoa New Zealand recognised, as justified by the principle of kotahitanga.

### Recommendation 5

Decision makers should take all practicable steps (alongside their legal obligations) to: reduce the occupational risks for essential workers (for example, providing them with early access to vaccination, tests and PPE), ensure good working conditions to reduce the risk of burnout and ensure the workers and their whānau are protected from discrimination. *Manaakitanga, Tika*

### 3.2.3 Other vulnerable communities or groups of people

There are other groups of people where ethical considerations for decision-making come into play in a pandemic. These considerations are discussed below in relation to people over 65 years old, children, people experiencing homelessness, as well as Rainbow, migrant and recent refugee communities. The continued rise in childhood poverty and economic inequity, particularly for Māori, makes an ethical case for Aotearoa New Zealand to address these inequities well ahead of the next pandemic to prevent further harm to children and young people.

#### People 65 years and older

##### **Balance Principles in action: Manaakitanga and Kotahitanga**

To reduce the risk of residents with dementia contracting COVID-19, the staff in one ARC facility decided to stay inside the facility for the duration of the most stringent movement restrictions.

This both effectively reduced risk of transmission and increased quantity and quality of interactions, with positive changes in residents' behaviour and mood as a result (Moir et al 2021).

By 2034, people 65 years and older will make up 21% of Aotearoa New Zealand's population (currently 16.9%) (Stats NZ 2022). The wide range of abilities and vulnerabilities of this cohort will require a range of approaches to ensure people 65 years and older are enabled to both contribute to the national response and have the supports they need to be as protected as possible. Among people 65 years and older, there are likely to be more people who are

vulnerable to the effects of a pandemic as the likelihood of comorbidities and health and wellbeing issues increases with age (Abey-Nesbit et al 2023). Harms to people 65 years and older may be compounded by multiple interacting factors, such as triage policies that prioritise younger patients and an increased reliance on others to provide services (Pollak et al 2020).

Abuse is an important intersectionality for people 65 years and older in Aotearoa New Zealand. As many as one in 10 older people experience some kind of elder abuse (Office for Seniors – Te Tari Kaumātua 2023). Although the reporting rates of abuse of people 65 years and older remained steady during the COVID-19 pandemic, some stakeholders working with people 65 years and older reported increases in abuse during lockdown periods (Office for Seniors – Te Tari Kaumātua 2021). Advocacy groups and the Ministry of Social Development highlight that much abuse of people 65 years and older is financial or emotional abuse, which can go unnoticed or unreported (Ministry of Social Development 2019).

When taking a balanced approach to responding to a pandemic, decision makers must conversely consider that, during the COVID-19 pandemic, many people aged 65 and over showed resilience and agency and made significant contributions to whānau and/or their community more broadly (Te Hiringa Mahara 2022). People 65 years and older developed their own solutions, worked hard to remain socially engaged, were aware of the needs of their communities and provided support where they were able to (Te Hiringa Mahara 2022). They also held leadership and frontline roles and represented a range of communities, including Māori, Pacific peoples, Chinese and Korean (Te Hiringa Mahara 2022).

### **People experiencing severe housing deprivation**

People experiencing homelessness are more vulnerable during a pandemic as there may be factors that make it difficult to follow public health measures, which could increase the risk of spreading the infection.<sup>13</sup> There are also added complexities in ensuring access to support services and public messaging, as people experiencing homelessness may be disengaged from the usual communication channels.

A diverse range of people experience homelessness in Aotearoa New Zealand, and decision makers must ensure that responses meet the breadth of need. In 2019, it was estimated 1 in every 100 New Zealanders experienced severe housing deprivation (2023).

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<sup>13</sup> The factors described in *Finding Balance* do not fully account for indigenous perspectives on homelessness, which often include aspects of connection and relationship. Lawson-Te Aho et al assert that 'New Zealand-based interventions that assume a Western definition of homelessness may continue a pattern of disconnection by failing to address these wider aspects of homelessness' and provide a principles framework for action in Aotearoa New Zealand (Lawson-Te Aho et al. 2019). For other examples of indigenous perspectives of homelessness, see Thistle (2017) and Memmott (2015).

While similar numbers of men and women are reported to experience severe housing deprivation in Aotearoa New Zealand, men are more likely to live without shelter or in boarding houses while women are more likely to be in severely crowded dwellings (Te Tūāpapa Kura Kāinga – Ministry of Housing and Urban Development n.d.). However, there is evidence that the prevalence of women experiencing homelessness is inadequately captured in Aotearoa New Zealand’s official statistics (Allen + Clarke 2023), and qualitative research suggests they are more likely to be couch-surfing or living in tents and cars and may not be accessing services dominated by men, who may also be violent.<sup>14</sup> Women experiencing homelessness in Aotearoa New Zealand are also more likely to have children than men (Fraser et al 2023). Women’s experience of homelessness is distinct from that of men, and decision makers should develop specific responses for everyone experiencing homelessness to ensure support meets their needs.

Severe housing deprivation disproportionately affects ethnic minorities in Aotearoa New Zealand. Māori and Pacific peoples’ severe housing deprivation prevalence rates are four and six times the New Zealand European rate, respectively (Te Tūāpapa Kura Kāinga – Ministry of Housing and Urban Development n.d.; Lawson-Te Aho et al 2019). Inequities in homelessness reflect a number of interlinked inequities that disproportionately affect Māori (Lawson-Te Aho et al 2019; Poata-Smith 2013) across many domains, including health (Harris et al 2006) and housing, which are anchored by the enduring impacts of colonisation and historical trauma (Lawson-Te Aho et al 2019). The distinct causes and experiences of homelessness for Māori, as well as decision makers’ responsibilities under Te Tiriti o Waitangi, require that any pandemic responses designed to support them are led by Māori/iwi, centred around whānau, holistic and integrated and founded on te ao Māori values. For further guidance, see Lawson-Te Aho et al 2019.

Young people also experience homelessness. A 2021 study of students in Auckland, Northland and Waikato schools found that 29% of youth aged between 12 and 18 years had experienced housing deprivation at least once during the past year (Clark et al 2021). Furthermore, research has also found that, due to the limited range of options available to them, youth in Aotearoa New Zealand are often rendered homeless to escape abuse and low quality of life in their family homes (Clark et al 2021; Groot et al 2017). Decision makers must be aware of the unique requirements of youth experiencing severe housing insecurity and make every effort to support young people throughout pandemics.

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<sup>14</sup> The undercounting of women’s homelessness has been well evidenced in other countries, including Canada (Yakubovich and Maki 2022) and the United Kingdom (Young and Horvath 2018). Further research is required to understand the prevalence and cause of this issue in Aotearoa New Zealand.

## Recommendation 6

Decision makers consider how their response planning will impact people experiencing homelessness, particularly Māori. *Kotahitanga, Tika*

### Rainbow communities

Members of the Rainbow community have well-documented health disparities, often arising from inequitable treatment and historical or ongoing marginalisation, discrimination and mistreatment (Ker et al 2022; Veale et al 2019).

During the COVID-19 pandemic, public health restrictions meant that young Rainbow community members often returned to live with whānau, however, not all whānau situations are safe and supportive (RNZ 2020). Living with unaccepting whānau, being unable to safely express who they are or being required to conceal their identity will negatively impact a person's health and wellbeing (Kneale and Bécares 2020). With movement-restricting measures in place, family members may abuse, shame or add barriers to accessing community support networks that offer protective services and information (Love and Vye 2020).

### Refugees and recent migrants

Aotearoa New Zealand accepts 1,500 refugees each year (New Zealand Immigration 2023) and, before the COVID-19 pandemic, received an average of 121,400 migrants per year (Stats NZ 2023). Aotearoa New Zealand paused accepting refugees between March 2020 and February 2021. Annual migration numbers dropped to a low of approximately 49,200 people in March 2021 before returning to 130,800 in 2022 (Stats NZ 2023).

The United Nation's High Commissioner for Refugees (UNHCR) estimated that at the peak of the COVID-19 pandemic, 168 countries fully or partially closed their borders, with close to 100 of those countries making no exception for individuals seeking asylum (initially this included Aotearoa New Zealand) (UNHCR n.d.). There has been criticism that this approach violated international laws and the rights of migrants and refugees (Chetail 2020; Libal et al 2021). Border closures significantly impacted the lives of millions of refugees who were unable to move because of the closures (Balakrishnan, 2021). Decision makers will need to balance the rights and safety of refugees with the rights and safety of people already in Aotearoa New Zealand during a pandemic.

Many of the access barriers that recent migrants and refugees face were exacerbated during the COVID-19 pandemic due to the refugees' limited: knowledge of available services, English language skills, access to interpreters and cultural support and their experiences of racism and discrimination (Kanengoni-Nyatara et al 2023; Te Hiringa Mahara 2023a). Asian communities in particular reported the need for culturally appropriate services and support to overcome linguistic barriers (Te Hiringa Mahara 2023b). Advocacy groups described the courage and effort it took migrants and refugees to ask for help from beyond their community only for such requests to be unsuccessful (Te Hiringa Mahara 2023a).

### Children living in poverty

Children<sup>15</sup> living in poverty is another equity issue that is exacerbated by the effects of a pandemic. For example, families living in crowded and poor-quality houses with little access to safe outside spaces may find it harder to keep their children healthy, give them good experiences and facilitate their learning during an epidemic.

Aotearoa New Zealand's Child Poverty Action Group (CPAG) estimated that, in the year following the first outbreak, up to 18,000 more children could be living in poverty (McAllister et al 2021). Māori and Pacific peoples' children were 2.5–3 times as likely as Pākehā children to have been pushed into poverty. Children of other ethnicities were approximately twice as likely as Pākehā children to have been pushed into poverty (McAllister et al 2021).

### 3.2.4 Considering future impacts of epidemics and pandemics

Pandemics are often discussed in terms of the number of cases or deaths and the nature of transmission during their progression, but there is less discussion about the impacts they have on the health of the surviving population. Experience with the COVID-19 pandemic shows that we can expect post-acute-infection health consequences, as well as economic impacts (Kvalsvig et al 2024). Therefore, allowing a disease to spread may impose considerable costs and hardship on future populations. However, we also know that restrictions can reduce people's access to timely health care and immunisation programmes and increase the number of people living in poverty, and these effects can have long term consequences, too.

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<sup>15</sup> The Child Poverty Reduction Act 2018 defines a child as a person who is aged under 18 years (0–17 years) (Stats NZ 2021).

## Impact of delayed health service delivery

Pandemics can also result in the disruption of health service delivery, which can have long-term consequences people's health. It is essential to consider both direct and indirect pandemic consequences for more comprehensive pandemic preparedness plans and for adaptive policies that consider a wide variety of direct and indirect pandemic-related risks. Decision makers should consider how delayed care contributes to post-pandemic population health so that public health and medical infrastructure can be better understood and pandemic responses adjusted to improve long-term health outcomes and reduce disparities.

## Post-acute infection consequences

Many infectious diseases have significant persisting post-acute infection consequences (Choutka et al 2022). Some of these consequences present soon after infection, such as the Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) type illnesses after Crimean Congo haemorrhagic fever (Ambikan et al 2023), SARS-CoV-1 infection (Li et al 2023), Ebola (Wohl et al 2022), Q-fever, dengue-fever and COVID-19 (Choutka et al 2022). Other health consequences have a delay before manifesting, such as human immunodeficiency virus infection and acquired immune deficiency syndrome (HIV AIDS) (WHO 2022c), cancers caused by the human papillomaviruses (National Institutes of Health National Cancer Institute 2023) and post-polio syndrome (Choutka et al 2022).

Research on past and current pandemics (such as the Black Death, the 1918 influenza pandemic and COVID-19) has shown pandemics can cause significant and long-lasting population health consequences (DeWitte and Wissler 2018; van Doren and Sattenspiel 2021; Kelmelis and DeWitte 2021; van Doren and Kelmelis 2023; Wissler 2021; Saglanmak et al 2011; Noymer and Garenne 2000; van Doren and Brown, 2023). The full consequences of COVID-19 are not fully understood, but personal and societal impacts arising from persisting symptoms, grouped under various terms, such as long COVID, post-COVID condition and post-acute sequelae of COVID-19 (PASC), are significant (Callard and Perego 2021; Choutka et al 2022). There is also increasing evidence suggesting that COVID-19 causes neuropathological changes that could develop into neurological disorders later in life (Kim et al 2023). In addition to consequences triggered by the infection itself, there can be long-term health consequences arising from disease treatments (Vasilevskis et al 2010) and vaccinations (Tondo et al 2022).

As with the acute effects of a disease, different risks of post-infection consequences borne by different groups will exacerbate existing inequities. For example, fetuses may suffer brain damage causing permanent cognitive impairment as was the case for the Zika virus (Jash and Sharma 2022), and women appear to have a higher risk of ME/CFS-type illnesses (Clayton 2015).

Each re-infection may also risk post-infection consequences, as appears to be the case with COVID-19 (Bowe et al 2022; Kuang et al 2023). People who are repeatedly infected, as healthcare workers, people living in large family groups, and unvaccinated children attending school are likely to be, will have an accumulating lifetime risk of post-infection consequences.

It will be very rare for a pandemic disease to result only in short-term health impacts. Many of the long-term consequences of infections majorly impact quality of life and productivity and do not yet have diagnostic tests or effective treatments. They have been understudied, and the health workforce is generally poorly informed about them (Choutka et al 2022).

Differences in how people disabled by an infection or a post-infection chronic illness are supported compared with people disabled by an accident creates and exacerbates inequities (Cameron 2023; Kia Piki Ake - Welfare Expert Advisory Group 2019). An essential worker may have difficulty proving that they have been disabled by an infection contracted at work, particularly when the disease has become widespread in the community (Fisher 2022). A family member who contracts a disease from an essential worker and then goes on to be disabled is no less deserving of support but would not meet a criterion of harm sustained while at work. Aside from the equity issues, inadequate support provided to people harmed by infections and a lack of effective treatments may impact on the willingness of essential workers to put themselves at risk during a pandemic.

### **Recommendation 7**

Analyses of pandemic response strategies should fully consider the long-term health impacts of both the disease and delayed health service delivery. *Manaakitanga, Tika, Promoting health and wellbeing*

### **Recommendation 8**

There should be more investment in training the health workforce in post-infection diseases. *Promoting health and wellbeing*

### **Recommendation 9**

The disability support system should be reviewed to provide the equivalent support to people with disabilities that have similar impacts on quality of life, regardless of whether the disability is caused by an accident or an infection. *Equity*

## 4 Building trust and empowering communities through communication

Trust between communities and decision makers increases the likelihood of compliance with public health measures during a pandemic (Nuffield Council on Bioethics 2020). Quality communication can grow trust between communities and decision makers as well as trust in the public health measures themselves. Knowing where to find information can give people a sense of agency and purpose through making them active participants (WHO 2022c). High-quality communication enables kotahitanga to flourish in a pandemic as people adopt certain behaviours and measures as accepted cultural habits.

### Recommendation 10

Decision makers should communicate with the public about the public's responsibilities in preparing for a pandemic. Decision makers should provide evidence-based guidance on what those measures should be. *Kotahitanga, Promoting health and wellbeing.*

Quality communication means all aspects of information provided to the public are trustworthy and evidence-based, accurate, clear, consistent and provided in a timely manner (Nuffield Council on Bioethics 2020) (WHO 2022c). Quality communication also requires the information to be effective and engage a diverse range of people and communities across Aotearoa New Zealand (WHO 2022c). Sometimes it isn't possible to communicate perfectly. For example, it may not be possible to cite good evidence for a decision, a message may need to change or it may not be possible to consult or give people much notice of a requirement. In such cases, honesty and a willingness to be open to feedback and to review the decision will be helpful.

Transparency on decisions that impact the public can help the public understand the criteria and rationale for decisions and will likely result in increased compliance with public safety measures (Drew and Nyerges 2004).

Campaigns designed to engender cooperation and collective action should not be used to mislead or conceal potential risks associated with cooperation. Value-laden information must be provided alongside data and scientific evidence. For example, television and online advertisements may encourage people to get vaccinated on the basis of collective responsibility as well as scientific evidence.

Effective access to information across all audiences has the potential to empower communities and reduce pre-existing inequities (Ministry of Social Development 2021). Accounting for these differences in audiences may require decision makers to ensure each audience has access to the internet and appropriate digital technologies and to consider cultural, language and disability diversities. Information should be provided in a way that reaches vulnerable groups and works for them, for example, consolidating information for disabled people (Tan et al 2023). Other examples of providing effective access to information include:

- making online webpages more user friendly and available in different formats, including audio dictations
- distributing information across a variety of sources, including televised press conferences, online and in-person hui, billboards, radio, advertisements, emergency mobile alerts, pamphlets and newspapers
- sharing information through open conversations and providing opportunities for public debate and discussion
- translating information in the different languages used in Aotearoa New Zealand, especially te reo Māori<sup>16</sup> and New Zealand Sign Language
- engaging with community leaders who can share and discuss information within their communities from a trusted position.

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<sup>16</sup> As New Zealand Sign Language (NZSL) accessibility and recognition progresses alongside the Māori language renaissance, Māori Deaf people who identify with NZSL and the Deaf culture are connecting more frequently with te ao Māori (McKee et al. 2007). As a result, Māori Deaf individuals now seek a deeper connection to their Māori identity (AKO Ltd 1995; Smiler 2004; Smiler and McKee 2007). This aspiration is also formalised in the NZSL Strategy 2018–2023 within the use/access language priority1 (New Zealand Sign Language Board 2019; Simchowitz 2023).

## Recommendation 11

### Balance Principles in action: Kotahitanga and Promoting health and wellbeing

During the COVID-19 pandemic, Ministry of Health officials noted that the success of the government's 'Super Saturday' vaccination drive in October 2021 with Māori was largely due to the trusted communication from Māori leaders encouraging youth participation and peer communication between youth. Officials remarked on the success of this approach over previous, government-led communications.

'What we needed to do was have rangatahi talk to rangatahi about coming out, because they came out in the thousands!' – Super Saturday volunteer (Ministry of Health 2021)

Decision makers should build trust with different communities and groups by communicating information that is evidence based, accurate, clear, timely and effective for the diverse communities across Aotearoa New Zealand. Decisions should be communicated with full transparency to the public. The various methods for providing official information (for example, via radio, television, online, images, etc) should be available in multiple formats (audio, large print, sign language, etc), following plain language guidelines and in disability-friendly colour scales. *Tika, Kotahitanga, Promoting health and wellbeing*

Community leaders play a vital role in disseminating public health information (Paipa et al 2022). Decision makers should proactively include community leaders to help develop and deliver communication strategies during a pandemic. Empowering communities in developing communication and strategies during COVID-19 highlighted the positive impact of these groups, including iwi, hapū and Pacific leaders, both in communicating the official messages and increasing uptake of public health measures (Paipa et al 2022).

## Recommendation 12

Decision makers should build trust in official sources of information by working in partnership with the Pae Ora Act priority populations, as well as those in higher-risk settings and occupations and other vulnerable groups of people or communities when developing and circulating information. Decision makers should ensure pandemic plans anticipate and enable partnering with local councils and community leaders and resources are readily available to support implementing solutions. *Kotahitanga, Equity, Promoting health and wellbeing*

## 4.1 Combatting misinformation and disinformation

Misinformation and disinformation can contribute to the mistrust some people may have of government, experts and institutional structures. False information is a direct threat to a successful public health response. During the COVID-19 pandemic, false information led to widespread concerns about the side effects, medical safety and long-term effects of the vaccine. Ensuring whānau and communities have the tools to identify trust-worthy sources of information will empower them to identify false information. During the COVID-19 pandemic, iwi and hapū leaders played a powerful role in communicating and providing information in response to misinformation or disinformation, and this potential exists for other communities (Te Hiringa Mahara 2023b).

### Recommendation 13

Decision makers should proactively develop communications to alert the public to any false information and educate the public on how to identify accurate and false information. Decision makers should monitor communities at risk of influence from false information and work quickly to communicate to them in ways that both combat false information and provide effective access to quality information. *Kotahitanga, Promoting health and wellbeing*

People working in communications and media also have a responsibility to prevent the spread of misinformation and disinformation. While the public's right to hold the Government to account must be upheld, the media (including social media platforms) needs to have regard for the fragile balance with trust and cooperation, which are crucial in getting through a public health emergency. Trust can be maintained through fact checking or flagging false information or analysing data to reveal sources that can be used to inform counterstrategies. Decision makers should work with media to develop and implement strategies to reduce the spread of misinformation and disinformation on media platforms and channels and enable counterstrategies to the spread of false information through information sharing.

### Recommendation 14

Decision makers should develop a cross-agency, public-private and community solution to coordinate a national, regional and local approach to proactively combatting false information and rebuilding trust between communities and official information. *Tika, Kotahitanga*

# 5 Epidemic and pandemic responses

## 5.1 Liberty, evidence and proportionality

Effective management of a pandemic will require a range of responses. In an effort to protect the public's collective right to health and wellbeing, those responses might infringe on or limit individual liberties, such as freedom of movement or to protest. It is important to recognise that inaction is also a response and has consequences of its own (Bazzi et al 2021) (see Appendix 5: Scale for response intrusiveness). To help find the correct balance within the context of a pandemic, responses designed to manage the spread of a disease should support the Balance Principles recommendations and be evidence based and proportionate.<sup>17</sup>

### 5.1.1 Liberty

Liberty is one of the rights listed in the New Zealand Bill of Rights Act 1990. Decision makers implementing a public health measure, particularly a mandatory one, must consider whether liberty is limited by that measure and, if it is, whether that limitation is justified.<sup>18</sup> Appendix 4: Response justification tool provides a framework to help decision makers determine whether a public health response's infringement on liberty is justified. Individual rights are not absolute and must be balanced against the rights of others and the interests of society, including protecting public health (Andrew Borrowdale v Director-General of Health and Attorney-General 2020).

Putting all other factors aside, public health responses that have been voluntarily agreed to are ethically better and the degree of intrusion or coercion from any response used should be minimised as much as possible (Nuffield Council on Bioethics 2020) (liberty and tika).

<sup>17</sup> Responses designed to reduce the spread of disease include avoiding becoming a host for a virus to mutate in and avoiding depleting health resources and overcrowding hospitals (Kamm 2023).

<sup>18</sup> Although the COVID-19 Public Health Response Act 2020 enabled Orders that would implement mandatory public health measures, to make an Order, the Minister had to (among other things) be satisfied that the Order did not limit, or was a justified limit, on the rights and freedoms outlined in the New Zealand Bill of Rights Act 1990.

### 5.1.2 Evidenced-based responses

Policy decisions intended to promote wellbeing and minimise harm should have a reasonable likelihood of helping the proposed measure achieve its intended outcome, be feasible to implement and be backed by evidence (International Bioethics Committee and World Commission on the Ethics of Scientific Knowledge and Technology 2020). Decision makers have an ethical duty to make decisions based on the best available evidence known at the time. This is not limited to mainstream academic resources, science and knowledge but must include mātauranga Māori, the values and aspirations of New Zealanders and their communities, as well as learnings from the wider international landscape. Iwi, hapū, whānau, other Māori communities and Māori health service providers have access to powerful evidence, insights and data to transform and advance Māori health and wellbeing (Ministry of Health 2020b).

To balance infringements on liberties, responses should be underpinned by evidence, with input from the communities and people they impact. Robust evidence that the response will effectively achieve the desired outcome is important to demonstrate the response is proportionate. The more intrusive the response, the stronger the justification and the clearer the evidence required (Nuffield Council on Bioethics 2020). To better ensure effectiveness, the decision makers should establish interdisciplinary dialogues among public officials and technical experts, from both Aotearoa New Zealand and overseas, as well as health professionals and community groups, particularly Māori, when developing and implementing public health responses (International Bioethics Committee and World Commission on the Ethics of Scientific Knowledge and Technology 2020).

An additional layer of ethical complexity may come into play when responses are implemented with significantly less insight into their risks and benefits or minimal scientific evidence, especially when applied to many different groups of people at once (Flood et al 2020). Decision makers will need to balance the ethical risks of not responding against the impact a response may have on equity. They must also consider the potential unintended consequences of any measures they take.<sup>19</sup> Decision makers can manage this ethical dilemma by giving the public transparency in the design and implementation, monitoring and sharing the results of responses.

Responses with a minimal evidence base should be accompanied by a publicly transparent evidence-gathering programme so the policies can be evaluated and revised as scientific evidence builds (Nuffield Council on Bioethics 2020). Decision makers should practice open communication regarding the rationale for responses, including full transparency on the known evidence base (Nuffield Council on Bioethics 2020).

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<sup>19</sup> There is evidence to suggest that Aotearoa New Zealand should have closed its border sooner (The Independent Panel The Independent Panel for Pandemic Preparedness and Response 2021).

### 5.1.3 Proportionate responses

Public health responses should respond proportionately to immediate threats whilst protecting human rights and liberty under the rule of law (United Nations 2020). Responses must also be proportionate to the benefit they are trying to achieve or the risk they are trying to mitigate. Decision makers have a responsibility to determine whether a less-restrictive measure could achieve the same intended outcome. Appendix 5: Scale for response intrusiveness and Appendix 6: Response proportionality tool will support decision makers in determining what level of intrusion may be ethically justifiable.

Robust evidence will ideally contribute to determining whether a response is proportional and ethically justifiable (Nuffield Council on Bioethics 2020). Determining what is considered an ethically proportional response will also depend on the current social context. Decision makers will need to consider the immediate and future impacts on people of both infection and response (such as physical, mental, spiritual, whānau, social health and economic disruption) and the different impacts on different people and communities, including people outside Aotearoa New Zealand. Appendix 7: Balance Principles justification tool provides a checklist to test whether responses are or were justified by the Balance Principles.

Decision makers should take steps to ensure responses do not increase the risk of discrimination, especially those prohibited under Aotearoa New Zealand legislation and our obligations to international treaties (see Appendix 2: Related documents). People who are not able to comply with responses should be protected from discrimination and should be offered alternatives to keep them as safe as possible.

### 5.1.4 Mātauranga Māori

Mātauranga Māori is specifically referenced and protected by both Te Tiriti o Waitangi and the Pae Ora Act. How mātauranga Māori is included, protected and enabled throughout a pandemic is a key consideration of a quality response in Aotearoa New Zealand.

A strong sense of cultural identity has a positive impact on mental health outcomes in Māori youth (Williams et al 2018). Pandemic restrictions may limit the rights of Māori to practice tikanga Māori, such as not legally being able to access their papa kāinga amidst travel restrictions. Finding the balance in relation to te ao Māori beliefs, concepts, practices and realities is best achieved by empowering Māori to develop their own solutions. For example, the use of mātauranga Māori contributed to the resilience of iwi when movement restrictions were in place (Williams et al 2018). Protecting and enabling (wherever possible) tikanga Māori and mātauranga Māori is justified by the principle of tika.

### Recommendation 15

Decision makers should ensure public health responses reflect the Balance Principles, are evidence based (inclusive of mātauranga Māori, lived experience and input from impacted communities) and are as unrestrictive as possible. *Manaakitanga, Tika, Liberty, Kotahitanga, Equity, Promoting health and wellbeing*

### Recommendation 16

Decision makers should develop strategies to ensure those who cannot participate in responses are not additionally impacted by stigmatisation. *Kotahitanga, Equity*

## 5.2 Ethical considerations of responses to epidemics and pandemics

This chapter discusses known ethical considerations of pandemic responses. The information draws heavily on responses developed during the COVID-19 pandemic and the known ethical issues that arose as a result of their implementation. It should also be noted that taking no action is also a response and has consequences (see Appendix 5: Scale for response intrusiveness).

### 5.2.1 Herd immunity as a primary strategy

Decision makers may consider seeking herd immunity, also known as community immunity, as part of a pandemic response strategy. Herd immunity is when the proportion of individuals with immunity is large enough to prevent the disease from spreading in a population (Fine et al 2011). One approach to developing herd immunity is to allow the disease to spread in the population without using tools such as quarantine, or lockdowns. This approach has drawn criticism from the World Health Organisation who noted that, in the first year of the COVID-19 pandemic, attempting to reach herd immunity simply by exposing a population to the disease was “scientifically problematic and unethical” and that “Allowing a dangerous virus that we don’t fully understand to run free is simply unethical (WHO 2020b).

Vaccinations may significantly reduce the harm of pursuing such a strategy, by allowing most people to gain immunity without getting the disease. However, developing an effective and sufficiently long-lasting vaccine takes time, during which the disease may spread rapidly, overwhelming health systems (Health and Social Care 2021).

Non-human host reservoirs, incomplete or short-duration immunity that allows for re-infection and transmission, a lack of a vaccine that provides long-lasting protection, insufficient uptake of vaccination, a quickly mutating pathogen, and the rapid transit people of people around the world can make achieving herd immunity impossible (Morens et al 2022). If herd immunity is not achieved then the harm of pursuing a herd immunity strategy, including the considerable ethical

consequences such as higher death rates and health care costs in perpetuity, may greatly outweigh short term economic benefits.

The impact on the global community of a herd immunity approach must also be considered. A country with an outbreak or epidemic that follows a primary herd immunity strategy may increase the risk of the disease becoming a pandemic, affecting countries that may have less capacity to manage the health care and governance consequences.

### Recommendation 17

Decision makers should consider the significant ethical and efficacy risks of herd immunity as a primary response, particularly for new diseases that can spread quickly and cause serious health consequences. There should be strong evidence that the benefits are likely to outweigh the risks, based on good knowledge of the characteristics of the disease, including its pandemic potential, before a response is chosen. *Kotahitanga, Tika, Promoting health and wellbeing*

### 5.2.2 Vaccines

Vaccines can eliminate pandemics, manage ‘flare-ups’ and act as an insurance policy against future outbreaks (Ferrerri 2021; Chumakov et al 2021; O’Shea et al 2021; Beazley 2020). They can enable freedom of movement while keeping the risk to individuals at a manageable level (Weinstock 2020). Access barriers, such as a cost, travel time or the need to take time of work will reduce uptake, potentially resulting in inequitable outcomes and inadequate population coverage.

Requiring individuals or groups to be vaccinated will need to be approached with care, and it is likely that the right to refuse medical treatment will need to be considered alongside the harm reduction potential of the required vaccination.<sup>20</sup> A judicial review of the requirement for certain groups of employees (for example, border workers and health and medical practitioners) to be vaccinated in the COVID-19 pandemic noted this balance and, in most cases, upheld the requirement for vaccination (NZDSOS Inc and NZTSOS v Minister for COVID-19 Response, Director-General of Health and The Attorney-General 2021; Four Midwives v Minister for COVID-19 Response 2021; K, B, L, N & Ors v Minister of COVID-19 Response & Ors 2021). Changing circumstances will affect the balance. Decisions should be reviewed regularly as vaccinations may become more or less effective at reducing harm. Attempts to guide choice through public shaming and unjustified restrictions are contrary to the Balance Principles of manaakitanga and kotahitanga, are unethical and may only create further disunity.

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<sup>20</sup> Section 11 New Zealand Bill of Rights Act 1990.

## Recommendation 18

Decision makers should ensure vaccination is voluntary wherever possible and appropriate. To protect the wellbeing and health of the community, decision makers should be careful to justify their decision whenever they require people or professions to have a vaccine. Decision makers should prioritise strategies focused on incentives and encouragement. *Manaakitanga, Tika, Liberty, Promoting health and wellbeing*

The Balance Principle of equity implies that populations that include people who are more likely to be vulnerable should be given priority access. Populations with a higher proportion of vulnerable people may change depending on the nature of the pandemic. During the COVID-19 pandemic, priority access was given to essential workers, people over 65 years and people with illnesses or other pre-existing health inequities caused by social determinants of health. Unfortunately, this did not consider intersectionalities for different groups of people and resulted in increasing inequities, particularly for Māori (Megget 2022; Whitehead et al 2022).

A single strategy alone will not ensure equitable uptake of vaccination programmes. Evidence shows targeted solutions are required to achieve equitable vaccination uptake (Whitehead et al 2022). We advise decision makers to understand the importance of developing vaccination strategies that are specific and tailored to the Pae Ora Act priority populations, higher-risk settings and other vulnerable groups of people or communities. Collaborating with those affected can ensure these strategies work for and meet the needs of intended audiences.

### Vaccine uptake hesitancy

Vaccine hesitancy may occur when the public has a choice in vaccination. Decision makers should be aware that different groups of people may be vaccine hesitant during the next pandemic.

Current research demonstrates that vaccine hesitancy also occurs against a colonial backdrop of inequities in global health research, social-cultural complexities, poor community involvement and public distrust (Ochola 2023). These factors undermine the confidence that is crucial for sustaining collective immunity in vaccine programs (Ochola 2023). Addressing components of vaccine hesitancy should involve relying not on coercive public policies but on consistent ethical strategies that go beyond current health care ethics and embrace the Balance Principles.

## Recommendation 19

Decision makers should monitor for differences in vaccine use or uptake among different communities and groups of people and respond empathetically and thoughtfully to any concerns raised. If programmes to encourage vaccination are developed, these should be co-designed with the population groups they are intended for and the justification for the vaccination programme should be clearly communicated. *Tika, Kotahitanga*

### **People who cannot get a vaccine**

There will be people who are unable to receive a vaccine for a variety of reasons, including that it is not safe for them to do so or due to access issues. This may result in negative wellbeing in those unable to get a vaccine due to feeling excluded, vulnerable or stigmatised. Decision makers should be mindful of this and take measures to reduce negative impacts on these people (Baylis and Kofler 2020; Brown et al 2021; Jecker 2022).

### **Medicines to reduce the severity of illness**

Depending on the nature of the pandemic, it may be possible to develop treatments that reduce the severity of the illness for some people. Where properly implemented, treatments such as antivirals can reduce viral loads, limit transmission and help manage severe infections, thereby reducing morbidity and mortality until effective vaccines are available. As with vaccines, as justified by the Balance Principle of equity, populations that include people who are more likely to be vulnerable should be given priority access. Populations with a higher proportion of vulnerable people may change depending on the nature of the pandemic. Decision makers should enable increased access to medications through primary health care services and pharmacies to ensure access is equitable.

### **Privacy and vaccination**

A person's vaccination status is personal information and falls under the protections laid out in the Privacy Act 2020. However, there are many instances in which an individual's right to privacy must be balanced with the right of other individuals to good health. The Health Information Privacy Code 2020 states that health agencies can disclose information where necessary to deal with a serious threat to anyone's health or safety, as may be the case during pandemics.<sup>21</sup> To balance the infringement on an individual's right to privacy, the New Zealand Government has a duty to protect the privacy of the information received from the wider public. This may be achieved by deidentifying the data, although in some cases the balancing may mean disclosure is the only way to achieve the level of protection required (Te Pou Matakana Limited and Whānau Tahī Limited v Attorney-General and Privacy Commissioner 2021). This is justified by the Balance Principle manaakitanga and can also be implemented for information on positive test results or other indicators of infection.

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<sup>21</sup> For more information, see the Health Information Privacy Code 2020 webpage on the Privacy Commissioner website at: [www.privacy.org.nz/privacy-act-2020/codes-of-practice/hipc2020/](http://www.privacy.org.nz/privacy-act-2020/codes-of-practice/hipc2020/)

### 5.2.3 Testing and contact tracing

The use of at-home testing kits can greatly improve the speed with which people can find out that they are infected and take action to take care of themselves and prevent transmissions. However, these kits can produce significant amounts of plastic and hazardous waste and pollution. (WHO Water Sanitation Hygiene and Health Unit 2022; Wise 2022). Decision makers should consider the environmental implications of the widespread use of at-home testing kits and establish and promote ways to sustainably dispose of used kits. This is justified by the Balance Principle promoting health and wellbeing.

Contact tracing is an evidence-based response that interrupted chains of transmission within Aotearoa New Zealand during the COVID-19 pandemic (Verrall 2020). Contact tracing minimised the need for other more intrusive or restrictive responses (such as lockdown or quarantine) (Parker et al 2020; Weinstock 2020). Ready access to reliable testing and the development of a data-based contact tracing solution increased the effectiveness of this response in Aotearoa New Zealand (Dubov and Shoptawb 2020).

Contact tracing may be paper-based and/or digital. However, not everyone will be able to use contact tracing measures if there is a reliance on the use of digital technology. Paper-based contact methods may be slower, less hygienic and bear a greater risk to privacy (as identifying details can be easily seen) than digital methods.

During the COVID-19 pandemic, wearables were successfully implemented in countries such as Singapore (Government of Singapore 2024). Although the Aotearoa New Zealand Government explored the use of wearables as a possible solution to address inequitable smartphone access and privacy rights, it was not implemented. The use and efficacy of wearables for contract tracing may still be considered as part of a future pandemic response.

#### **Balance Principles in action: Manaakitanga, Kotahitanga and Promoting health and wellbeing**

When providers in one community were first beginning to test for COVID-19, the Māori nursing leadership team were asked to support a Māori health provider in a rural area, which had only a few nursing staff and kaimahi. One of the Māori nurse leaders had connections with the local hapū, so she brokered the relationship with the provider to support the COVID-19 response in that community. A study participant highlighted the importance of existing relationships to enable a swift response: 'As a Māori wāhine, she had the whakapapa and relationships. She was seen to be a safe pair of hands who had the trust of the community and was able to break down the barriers and negotiate with [the provider]' (Davis et al 2021)

All testing and contract tracing methods have the potential to further entrench inequities during a pandemic. Decision makers should weigh up the advantages and disadvantages of the methods available to ensure the response is equitable for all New Zealanders.

## Recommendation 20

To protect the public's right to informed consent, decision makers must be transparent with the public about privacy issues and about their level of confidence in or uncertainty about any digital or data-based method for testing or contact tracing. They must assure the public they have mitigation plans ready to be stood up in the event of any technical failures. *Manaakitanga, Tika, Liberty*

### Data use, privacy and contact tracing

Digital technology solutions can be useful in a pandemic response, but caution should be taken given their invasive nature (Hart et al 2020; Pagliari 2020; Raskar et al 2020). Mass surveillance of people may expose private personal details, impinge on personal privacy and potentially limit individual freedoms. It should also be noted that privacy is not a universal concept, and individual societies should determine its limits and, by extension, the reasonable use of digital public health technologies (Gasser et al 2020). As Aotearoa New Zealand is often dependent on international private-sector companies for data storage and management, the risks associated with this storage and management must also be managed (see also 5.3: Data quality and privacy during an epidemic or pandemic).

Decision makers can manaaki peoples' data by ensuring that contracts include limits on what personal and aggregated data can be accessed for and plans for destruction are in place. Data should not be used or retained for research, product development or marketing unless there is prior informed consent or, in the case of research, an appropriate waiver from a research ethics committee.

Privacy risk can be balanced by: following the recommendations made through the Balance Principle of liberty and from evidence-based and public health responses, defining limits on data collection and being transparent on how the technology works, who has access and how the data is governed.<sup>22</sup>

### 5.2.4 Movement-restriction responses

Restricting movement, for example, by applying isolation, quarantine and travel restrictions or placing restrictions on how many people may gather, is an evidence-based public health response used to respond to a pandemic. Restricting movement can include instituting lockdowns (where people are required to stay at home) or limiting where people can move based on vaccination status or PPE use. Responses that restrict movement can have positive effects, such as increasing time with whānau and significantly reducing the spread of disease.

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<sup>22</sup> For guidance, see the webpage Privacy and COVID-19 – Matatapu me te KOWHEORI-19 on the Privacy Commissioner website at: [www.privacy.org.nz/resources-2/privacy-and-covid-19/](http://www.privacy.org.nz/resources-2/privacy-and-covid-19/)

However, there can also be negative effects, such as being separated from whānau and constraints on liberty and livelihood. These negative effects can cause significant long-term harm for whānau and for spiritual, physical and mental health and wellbeing. Decision makers must give special consideration to people experiencing severe housing deprivation whenever movement-restriction measures are introduced, as was demonstrated during the COVID-19 pandemic, when the Aotearoa New Zealand Government secured housing for people experiencing homelessness so they could meet the movement restrictions (Beehive.govt.nz 2022a).

### **Closing international borders**

During the COVID-19 pandemic, Aotearoa New Zealand's border restrictions included closures, arrival requirements and isolation measures. The process implemented was judged insufficient to ensure Aotearoa New Zealand citizen rights under the New Zealand Bill of Rights Act 1990, as it did not prioritise Aotearoa New Zealand citizen entry over non-New Zealand citizens (Grounded Kiwis Group Incorporated v Minister of Health, Minister for COVID-19 Response, Chief Executive for the Ministry of Business, Innovation and Employment 2022).

There were additional ethical issues with closing the border, including supply chain issues and skills shortages due to migration limits.<sup>23</sup> Fair rules and systems need to be developed for selecting and allocating opportunities to cross the border.

### **Using certificates of immunity or vaccination**

The ethical use of immunity or vaccine certificates will depend on whether there is sufficient evidence available that vaccines are an effective means of preventing transmission (including asymptomatic transmission) of the infection (Jecker 2022; Brown et al 2021). There is now an opportunity to explore this further given different jurisdictional approaches to vaccine certificates during the COVID-19 pandemic.

### **Vaccine certificates**

Vaccine certificates can incentivise vaccine uptake or be used as a pathway to ease restrictions, return access to public spaces and reopen the border and the economy (Jecker 2022). Decision makers must be cautious in requiring a vaccine certificate to access essential goods and services (for example, health care, food and shelter) as this may restrict choice to the extent that vaccines may no longer be reasonably considered 'voluntary'.

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<sup>23</sup> Additional discussion and recommendations relating to recent migrants and refugees is provided under 3.2.3 Other vulnerable communities or groups of people: Refugees and recent migrants.

A balanced solution may be to use vaccine certificates to access non-essential goods and services, such as restaurants, entertainment and travel (Jecker 2022). Consultation can help identify appropriate exemptions, such as masked use of public transport in an emergency or to access essential services. This approach would be supported by health and safety legislation that requires employers to take steps to protect workers from workplace hazards, which includes an infectious disease (Health and Safety at Work Act 2015).

### **Immunity certificates**

During the COVID-19 pandemic, immunity certificates proved less likely to achieve fair and reliable outcomes. There was also the possibility that immunity certificates could create a perverse incentive for individuals to seek out infection in order to obtain a certificate (Brown et al 2021).

### **Significant whānau occasions and social gatherings**

Significant whānau events and gatherings, such as those held at marae, weddings, funerals, tangihanga and faith-based services, may be subject to restrictions during a pandemic to reduce transmission. These restrictions may increase psychological stress on whānau. The sense of social connectedness that such gatherings provide is linked to lower morbidity and increased life expectancy, and social networks may benefit mental and physical health by providing emotional or practical support (Seppala 2014; Australian Institute of Health and Welfare 2014). A balanced solution would be to develop restrictions on gatherings in a way that respects and, where possible, enables important events and gatherings to take place, thereby maintaining social connection. Manaakitanga should be shown in the development of these policies and alternatives suggested.

Death and tangihanga were particularly difficult for whānau during the COVID-19 pandemic. Dedicated measures based on the Balance Principles of manaakitanga, tika and liberty should inform pandemic policies relating to death and dying.

## **Recommendation 21**

Decision makers should develop responses that limit gathering sizes and regional/local travel in a way that respects and, where possible, enables significant whānau events and social connection to take place. Manaakitanga should be shown in the development of these policies and alternatives suggested. The needs, wishes and human rights of people who are at the end of life and their whānau must be considered. These needs must be balanced with the risk of exposing others to infection. *Manaakitanga, Tika, Promoting health and wellbeing*

## Education

The right to education is particularly significant for children and rangatahi in Aotearoa New Zealand (Fredman 2021). Closures of schools and higher education facilities during a pandemic can seriously disrupt education and increase inequities (Kamm 2023). During the strictest movement restrictions, some Aotearoa New Zealand students dropped out of education to take on jobs to support their families, which had ramifications for their wellbeing and long-term economic outlook (Franks 2021).

School closures can also have flow-on effects for parents and caregivers, who may be required to support their children's continued education from home and/or provide childcare. This may be in addition to the parents working, or at the expense of working, which can add additional economic hardship (Brown et al 2020). For some whānau, school closures will have a negative impact on children's nutrition as they rely on free or discounted school meals (France-Pressé 2020).

## Recommendation 22

Decision makers should ensure whānau are supported to educate their children and rangatahi from home during restrictions. Whānau who have safety concerns about sending their children to school should be treated with flexibility and compassion and supported to educate from home. To balance the risks of staying home / missing education and the risks of returning, decision makers should support schools and other educational institutions to enable students' return as quickly and safely as possible. *Promoting health and wellbeing*

## Employees and employers

Employers have a responsibility to develop capacities for mitigating the effects of a pandemic, including developing robust contingency and business continuity plans (Staples 2006; WHO 2009),<sup>24</sup> along with a duty to act in the public interest during emergencies, demonstrating their corporate social responsibilities. Employers should consider how to protect essential workers in higher-risk settings who have limited options to work from home. This might entail remuneration and ongoing compensation for the additional risk taken by these employees.

During movement restricting measures, employers and employees will need to adapt work in a way that complies with public health measures. However, not everyone will be able to do this, and there will be employers who will need to shut their businesses and employees who will lose their jobs due to a pandemic. Being under- or unemployed can harm physical and mental health and wellbeing (Lee et al 2021). Obtaining work helps to protect health by increasing self-esteem, generating a positive sense of identity and providing the opportunity for social interaction and personal development (WHO 2008). Retraining programmes may be required for those in industries negatively impacted in the long term.

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<sup>24</sup> The OECD have provided a responsible business conduct (RBC) approach to support companies as they build resilience and their longer-term value during an pandemic (OECD n.d.).

When returning to work, people's fear of becoming infected may cause stress and anxiety (Shaw et al 2020). This may be compounded by the general mental and physical health impacts of the pandemic. Employers should account for these effects and show compassion and flexibility in enabling people to work safely from home and adopt new work habits, such as reduced or flexible working hours and a socially distanced workspace (Employment New Zealand 2023). Extending sick leave entitlements will help people stay home when they or one of their whānau is unwell and allow people to care for unwell whānau.

The Balance Principles *manaakitanga* and *kotahitanga* demand that decision makers develop mechanisms that help whānau support local or small businesses in their community where possible and showcase such support on social media and/or other public forums.

### **Requiring personal protective equipment**

Requiring people to wear PPE is an evidence-backed response that can be used as a tool to slow the spread of a disease during a pandemic (Eikenberry et al 2020). The Aotearoa New Zealand Government implemented mask wearing as part of the COVID-19 response (New Zealand Parliamentary Counsel Office 2022) and offered guidance and exemptions to those who were unable to wear a mask (Health New Zealand 2024a; Beehive.govt.nz 2022b).

The significant increase in global use of single-use PPE resulted in massive amounts of plastic waste and pollution. Releasing microplastics (MPs) and microfibers (MFs) from discarded PPE is a threat to environmental sustainability, with MPs/MFs found in water, deep-sea sediments, air and soil (Khan et al 2023; Wise 2022; WHO 2022e). Decision makers should consider the environmental implications of single-use PPE and consider procuring more sustainable options or developing pathways for sustainable disposal. This is justified by the Balance Principle promoting health and wellbeing.

## **Recommendation 23**

Decision makers should focus on strengths-based messaging that encourages the public to follow public health measures in order to *manaaki* those who cannot follow these measures.

*Manaakitanga, Kotahitanga*

### **5.2.5 Responses that impact hospital treatment and priority**

During the strictest movement restrictions in a pandemic, there may be instances where life-saving medical interventions (such as surgery, cancer treatment or other vaccination programmes) cannot proceed (Flood et al 2020). In Aotearoa New Zealand and abroad, elective surgeries were cancelled or postponed to preserve resources, such as PPE (Imlach et al 2022; RACS 2020). Such measures have significant ethical implications as delayed diagnoses can result in significant, long-term harms, deaths and missed opportunities for improved quality and

duration of life.<sup>25</sup> The impact of these harms is inequitable, as some populations (such as Māori) experience higher rates of certain cancers, and the late diagnosis of these conditions exacerbates inequitable health outcomes (Gurney et al 2022). There may also be added complexities for whānau who are being supported through illness or rehabilitation at home.

Alongside physical impacts, there are psychological impacts for both those waiting for delayed treatment and their whānau and/or carers. Many of those waiting for surgery reported that their levels of stress anxiety and/or depression increased the longer they waited for surgery (Silver et al 2022). This predominantly affected women, younger people, new immigrants and those of low socioeconomic status, as these groups generally rely on public health services that already have long wait times (Silver et al 2022). These patients reported a need for acknowledgement of their situation and greater communication regarding wait times (Sauro et al 2023).

Pandemics can also have ramifications for other communicable diseases both locally and globally.<sup>26</sup> In refocusing on the COVID-19 response, health organisations reduced the emphasis on measles vaccination campaigns, with infection compounded as a result of movement restrictions contributing to a delay in vaccinating children for measles and other diseases (Chi et al 2020; Hoffman and Maclean 2020).

The Balance Principles of manaakitanga, tika and promoting health and wellbeing require decision makers to consider how to keep hospital services and lifesaving medical interventions running as much as, and as well as, possible and develop tailored and compassionate communications for whānau experiencing delays to lifesaving medical interventions during a pandemic.

Health professionals may use the Balance Principles to help determine intensive care unit (ICU) bed allocation, though this may not always result in a clear answer. For example, kotahitanga means that a clinician might decide to treat those with fewer comorbidities first in an effort to save as many lives as possible. However, this may conflict with equity as comorbidities are not distributed equally and are more common in indigenous populations, ethnic minorities and disabled or older people (Stokes et al 2018; Daw 2017; Australian Institute of Health and Welfare 2014; Bonham and Uhlenhuth 2014). The Balance Principles can help responsible authorities and professional associations develop guidance that is tailored to their members professions and outlines their ethical responsibilities during a pandemic. We have published guidance on resource allocation, and our framework *Ethics and Equity: Resource allocation and COVID-19* is available to support decision making (NEAC 2021a).

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<sup>25</sup> In Aotearoa New Zealand during the national lockdown in March and April 2020, there was a significant drop in cancer diagnoses (Gurney et al. 2022, pp. 23–43).

<sup>26</sup> In 2020, the number of deaths from tuberculosis globally rose for the first time in more than a decade (from 1.4 million in 2019 to 1.5 million). This increase was largely driven by fewer people getting tested and treated for the disease due to the focus on COVID-19 (Chaisson et al. 2022).

## 5.3 Data quality and privacy during an epidemic or pandemic

### 5.3.1 Quality data

Data can empower decision makers to make informed decisions about how to manage the public's resources effectively, efficiently and equitably. The collection, monitoring, analysis and reporting of quality data supports people's safety through both informing a targeted response and enabling the continued quality improvement of systems and processes. These capabilities are particularly valuable in the context of a pandemic, where resources may be constrained and inequities likely to worsen.

Collecting and analysing quality data that documents intersections (such as ethnicity, disability status and sexual/family violence history) alongside treatment decisions enables the development of equitable health care strategies. For example, currently there is little Aotearoa New Zealand-based data available about disease, recovery and mortality rates from COVID-19 for disabled people (Whaikaha — Ministry of Disabled People 2023). Decision makers must follow official guidance on gathering high-quality ethnicity data (Health New Zealand 2017).

### 5.3.2 Privacy and consent

The correct handling of data is an example of the Balance Principle *tika as*, in most circumstances, only those with the correct consent and authorisation should have access to the data. It is important that personal and health data is collected and stored securely and used in a way that ensures privacy rights are protected and only breached when there is a justifiable need to do so. Additionally, Māori data, as a living taonga, or something that is precious, should be handled according to the appropriate tikanga (Stats NZ 2020b). This applies to the management of all data in Aotearoa New Zealand (Rauika Māngai 2020) and is subject to the rights articulated in Te Tiriti o Waitangi and the United Nation's Declaration on the Rights of Indigenous Peoples (Te Mana Raraunga – Māori Data Sovereignty Network n.d.).

Handling people's data appropriately builds trust and is an example of *manaakitanga*. Any consideration of personal or health data used should begin with the legislative requirements. In the case of health data, this will include such frameworks as the Privacy Act 2020, Health Information Privacy Code 2020 and the HISO 10064:2017 Health Information Governance Guidelines. Decision makers must also determine who should be the *kaitiaki* of cultural data (Rauika Māngai 2020). The Balance Principles can help guide decisions that may arise around the use of data, particularly in the fast-moving circumstances that can occur when emergency measures are required. For example, data collected by digital tools can impinge upon privacy rights, however, health emergency legislation may allow for this, or it might be justified in order to protect public health (Gasser et al 2020).

The practice of obtaining voluntary and informed consent enables individuals to maintain a degree of freedom and control over their data. An approach guided by the Balance Principle of tika requires that language, disability and other barriers be eliminated from any process of gathering consent (Dubov and Shoptawb 2020; Health and Disability Commissioner 1996). We have published guidance on informed consent<sup>27</sup> and tools are available to support quality data collection and management (ACTaccelerator 2021; Hale et al 2023).

Individuals, communities or other groups of people could face stigma, discrimination or persecution if there were a data breach and findings from the data were not communicated sensitively. Any data breach should be reported to the Privacy Commissioner (Privacy Commissioner - Te Mana Mātāpono Matatapu 2020), however, taking time to consider tika throughout the lifecycle of the data can help mitigate the risk of a breach, as the Privacy Commissioner advised in relation to data collecting during the COVID-19 pandemic.

### Recommendation 24

Decision makers should collect high quality data, reportable by known equity indicators, such as ethnicity and disability, and uphold people’s right to privacy by establishing and following safeguards in the safe collection, use, management, governance, storage and destruction of data. Māori data sovereignty requires decision makers to work with Māori when making decisions about the primary collection, sharing, analysis and interpretation of Māori data.

*Manaakitanga, Tika, Liberty, Equity*

### 5.3.3 Access to medical data

#### Principles in action: Tika, Liberty, Promoting health and wellbeing

During the COVID-19 pandemic, HealthOne, a secure electronic patient-file-sharing platform, was integrated into South Island managed isolation and quarantine (MIQ) facilities.

HealthOne ‘collects and holds a summary record for every patient in the South Island, including information such as prescribed and dispensed medications and allergies and alerts, adverse reactions and observations’.

This enabled clinicians to provide better, safer and targeted care to anyone unwell while in MIQ facilities (McBeth 2021).

It is likely a person or their whānau will be unable to see the person’s regular health professional during a pandemic. If the health professional they do see does not have access to the person’s medical history, the risk of an adverse event increases. This issue is exacerbated during a pandemic.

<sup>27</sup> While focused on informed consent in health research, the Informed consent section of the National Ethical Standards 2019 (NEAC 2021b) provides guidance on how to ensure that consent is clearly and ethically obtained.

Aotearoa New Zealand's experience with the COVID-19 pandemic highlighted and exacerbated the issues caused by health professionals' inability to access people's medical data across the health system. Having systems in place that enable a person's medical data to go with them is essential to ensuring quality and safe services. However, decision makers must be thoughtful about how the sharing of information interacts with privacy rights and the right to health (Childress et al 2002).

Decision makers may need to carefully balance requests from organisations to access data against individual privacy rights. For example, the Ministry of Health was required to review the withholding of data about unvaccinated individuals, requested by a health provider, as it prevented the targeting of unvaccinated individuals in an at-risk community (Te Pou Matakana Limited and Whānau Tahī Limited v Attorney-General and Privacy Commissioner 2021).

### **Recommendation 25**

Decision makers should develop clear and publicly transparent policies on who has a right to know medical history and how any infringement on people's right to privacy will be minimised as much as possible, taking into account relevant legislation. *Tika*

## 6 Preparing for the next epidemic or pandemic: The economics of readiness

Decision makers should be thoughtful of intergenerational equity or the concept of fairness for a cross-section of different generations, including future generations (Weiss 2014). Actions taken in the present can affect the rights of future generations both negatively and positively. Decision makers must take these potential consequences and opportunities into account when investing in readiness for a pandemic.

In a pandemic, the whole economy is potentially impacted by public health responses. We see considerable benefit in including an economic approach in efforts to increase Aotearoa New Zealand's resilience for future pandemics – ensuring the health and disability system can respond to the next pandemic will require investment.

### 6.1 Investing in the health system

Aotearoa New Zealand's health and disability system is faced with increasing demands as people live longer, the population ages and the global costs of medical technology and pharmaceutical advances rise.<sup>28</sup> The rapid spread of infection can quickly overwhelm essential services, such as hospitals and testing capacities.

We believe that long-term underinvestment has made Aotearoa New Zealand's health system vulnerable to regional and national emergencies. Without adequate investment for pandemic preparedness, ethical support and guidance can only go so far in assisting with decision-making.

Investment is particularly essential as it will provide funding to work with communities, especially priority populations, in advance to understand what response would work for them and what their requirements might be. It will also help decision makers learn how to best preserve the key aspects of liberty that are important to those populations.

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<sup>28</sup> For instance, an independent report commissioned by Medicines New Zealand shows that, in the years 2011–2018, Aotearoa New Zealand's health system significantly reduced access to medicines across a wide range of health conditions, such as cancer, rare diseases and mental health conditions, compared with similar funding systems in countries such as Australia and the United Kingdom (IQVIA 2020).

## Recommendation 26

Decision makers should establish sustainable, routine resourcing to ensure the health system is more resilient and adequately prepared to respond to future emergencies. *Manaakitanga, Tika*

## 6.2 Investing in digital responses and inclusion

There are people in Aotearoa New Zealand who do not have access to the internet at home and who do not have the digital skills to navigate online. In 2023, a total of 11% of the population did not have access to internet at home, and 20% do not have the necessary digital skills (BNZ 2021). These people were predominately Māori and Pacific, older, on low incomes, disabled, with lower levels of education and/or are living in rural areas or social housing (PSA 2021). Our country's experience of the COVID-19 pandemic demonstrated the important role access to the internet and digital capabilities and technologies play in a pandemic.<sup>29</sup> Preparing for a pandemic should include plans for reducing digital inequities. While this will require investment, the benefits of providing communities with the means and knowledge to take care of themselves and their whānau will yield significant, compounding returns to society as a whole.

Digital technologies also present opportunities to reduce inequities. For example, a kaupapa Māori study investigated Māori experiences of Telehealth during the 2020 COVID-19 lockdown. The findings indicated that Telehealth is a viable long-term option and significantly reduces health care access barriers for Māori (Wikaire et al 2022).

## Recommendation 27

Decision makers should co-design supportive programmes that build digital literacy skills with the groups of people who need them and encourage digital solutions to improve health and wellbeing outcomes. *Kotahitanga, Equity, Promoting health and wellbeing*

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<sup>29</sup> These crucial activities conducted via the internet or through other digital capabilities included contact tracing and keeping people informed and engaged with the responses, accessing government services, ordering groceries, booking and receiving medical care, working, receiving education and maintaining social and community interactions during restrictions.

## 6.3 Investing in research

Embedding research at the centre of a pandemic response will help the world prepare for future public health emergencies (WHO 2022d, 2022b). Decision makers have an opportunity to invest in research that builds scientific, kaupapa Māori and mātauranga Māori evidence bases relating to pandemics effects and prevention in Aotearoa New Zealand. This investment will have significant positive domestic and international impact, especially on topics concerning indigenous knowledge and experience.

We have identified the following areas of research that should be supported by public investment. The final two topics are discussed in detail in section 6.4 Investing in the environment below.

- Placing communities and whānau at the centre of health emergency readiness and response in Aotearoa New Zealand
- Public health and social measures and their impact on different communities in Aotearoa New Zealand
- Mātauranga Māori and epidemics and pandemics
- Methods for effective management of the excessive amount of information in digital environments
- Infection prevention and control in Aotearoa New Zealand
- Ethics of conducting research during epidemics and pandemics in Aotearoa New Zealand
- Climate change effects on epidemics and pandemics in Aotearoa New Zealand
- Epidemics and pandemics effects on plastic waste in Aotearoa New Zealand.

### Recommendation 28

Decision makers invest in research to better understand the effects of epidemics and pandemics on communities and groups and the connection between climate change, health and epidemics and pandemics for Aotearoa New Zealand. *Manaakitanga, Tika, Kotahitanga, Equity, Promoting health and wellbeing*

## 6.4 Investing in the environment

The impact of climate change is already being felt in Aotearoa New Zealand and is escalating both the risk of pandemics occurring and the severity of their effects. Severe climate events will also influence Aotearoa New Zealand's health system resilience in terms of infrastructure and service access (Ministry for the Environment 2022b).

Emphasising preventative policies and investments across a range of sectors for all society will improve resilience to, and reduce the costs of, future pandemics. The Aotearoa New Zealand Government should place emphasis on developing policy that improves the focus on wellbeing and developing a more inclusive economy. Policy should also align with long-term carbon emission reduction goals, factor in resilience to climate impacts, slow biodiversity loss and support the circular economy and sustainable supply chains (OECD 2020).

### 6.4.1 Biodiversity

Changing how humans interact with animals and the environment can have a significant impact on reducing the risk of a new pandemic developing (Piret and Boivin 2021). Over 70% of emerging diseases and almost all pandemics have been caused by microbes found in animals (wild, livestock and domesticated) and then transmitted to humans (Bernstein et al 2022; Shaheen 2022).

#### **Balance Principles in action: Manaakitanga and Promoting health and wellbeing**

In the last three decades, 30 new human pathogens have been detected, and 75% of these have originated in animals.

Bird flu, swine flu and Middle East respiratory syndrome all originated from farmed animals – chickens, pigs and camels respectively.

Monitoring farmed animals and involving animal experts in that surveillance will ensure that any pathogen transmissible by animals, will be detected sooner and people working in this sector will be better prepared to rapidly respond. This will likely reduce adverse effects of the virus on both people working in this sector and the animals.

The scenario is further complicated by increased economic demand for animal products, resulting in farming intensification and high stocking rates of potentially genetically similar animals (Bartlett et al 2022). Such monocultures increase the risk of a pathogen spreading rapidly within a flock or herd (Bartlett et al 2022). Intensification may also trigger genetic changes in common bugs, as is the case with *Campylobacter* in Aotearoa New Zealand's poultry population (Anderson et al 2012). Protecting the genetic diversity of animals will help prevent

the monoculture effect and the increased risk of rapid disease spread (Gibson 2022). Intensive farming also results in increased fertiliser use and effluence, and this nutrient-rich environment can grow potentially dangerous pathogens (Espinosa et al 2020).

It is further estimated that 30% of emerging infectious diseases since 1960 have been due to land use changes and loss of biodiversity, particularly deforestation for farming and urbanisation. Loss of biodiversity may force species to move into human landscapes and bring pathogens that can be transmitted to humans (Guégan et al 2020).

### 6.4.2 Climate change

Increasing temperatures impact the emergence of new diseases and causes animal populations to migrate in search of better environments, increasing the risk of pathogens spreading (Baker et al 2022). Increasing temperatures are also making environmental conditions more favourable to certain disease vectors across the world, such as encephalitis in Europe (Semenza and Suk, 2018); dengue fever in France (Head 2022) and the chikungunya virus in Italy in 2017 (Rezza 2018) and Paraguay in 2023 (Giovanetti et al 2023). Climate change has also enabled fungi to move outside their former geographical zones, and they are becoming more successful pathogens by developing new ways to move between species (Casadevall 2020).

Extreme climate events and natural disasters, such as floods, are also driving a rise in pandemics. In certain climates, the aftermath of flooding can be associated with a significantly increased spread of infectious or waterborne diseases, such as the cholera epidemic in Pakistan in 2022 (Ahmed and Ebrahim, 2022). These strains may then go on to spread to other countries, with devastating impact. The cholera strain that emerged in Pakistan was associated with the deadliest cholera epidemic in the history of Malawi, Africa, in 2023 (CDC 2023b).

Climate change in Aotearoa New Zealand is expected to lead to an increase in the frequency and intensity of extreme rainfall, which is the most common trigger for flooding in this country (Ministry for the Environment 2010). Combined with a warmer climate, this could increase the risk of spreading waterborne diseases.

People who live in places with poor air quality are more at risk of death and severe disease from respiratory illnesses, such as COVID-19 (Hernandez Carballo et al 2022). While Aotearoa New Zealand has relatively good air quality, human-caused air pollution leads to 3,300 deaths, 13,100 hospitalisations and over 13,200 cases of asthma in children each year (Kuschel et al 2022). Sixty percent of these cases are due to air pollution from vehicles (Kuschel et al 2022).

More extreme fire events are expected to occur in Aotearoa New Zealand as a result of climate change, due to increased heat and wind and lower humidity (Ministry for the Environment 2022b). Fire events have a significant harmful effect on air quality and can contribute to excess deaths for any respiratory illness, as was the case during the COVID-19 pandemic in California, the United States (Zhou et al 2021). Wildfires also risk reducing biodiversity and pushing other species into areas of human population, which increases the risk of spreading pathogens.

### 6.4.3 Waste

#### **Balance Principles in action: Kotahitanga and Promoting health and wellbeing**

Decision makers should seek out and identify opportunities to incorporate these recommendations into other established work programmes.

Examples of this include the Ministry of Health and the Ministry for the Environment proactively collaborating to develop sustainable medical waste pathways for plastic or seeking out established community groups or advocacy bodies to start building relationships to understand what is important to them and incorporate this into epidemic and pandemic planning (Ministry for the Environment 2023a and b).

The flow of plastic litter and pollution into the marine environment is a growing global problem with significant environmental, health, social and economic impacts (Ministry for the Environment 2020). Exposure to plastics can harm human health, affecting fertility and hormonal, metabolic and neurological activity (Flaws et al 2020). The open burning of plastics contributes to air pollution (Flaws et al 2020). More than 800 marine and coastal species have been negatively affected by the 11 million tonnes of plastic waste that flows into oceans annually (this is predicted to triple by 2040) (The Pew Charitable Trust and SystemIQ 2021). The United Nations is developing a legally binding agreement to combat plastic pollution by 2024, which Aotearoa New Zealand is currently party to (Ministry for the Environment 2023b).

The global scale of additional medical waste resulting from the COVID-19 pandemic (such as single-use PPE, testing kits and vaccine packaging) exposed issues with waste management processes. One hundred and forty million test kits have the potential to generate 2,600 tonnes of, mostly plastic, non-infectious waste and 731,000 litres of chemical waste. Eight billion doses of administered vaccine produces 144,000 tonnes of additional waste (WHO 2022a).

Aotearoa New Zealand's waste strategy commits our country to developing a low-emissions, low-waste circular economy by 2050, and the Ministry for the Environment recently consulted on ways to reduce the impact of plastics (Ministry for the Environment 2020, 2023a). In light of the evidence around plastic and its harmful effects on humans and the natural environment, there is an opportunity for decision makers to proactively plan what a low-waste, circular economy might look like for the health sector, particularly in the event of a pandemic. This may include promoting and investing in more environmentally sustainable PPE and identifying sustainable waste practices.

### Recommendation 29

Decision makers should take steps to protect and promote Aotearoa New Zealand's biodiversity, prioritise climate-smart land-use planning and use data to better understand the effects of climate change and monitor environmental threats to public health. *Manaakitanga, Tika, Kotahitanga, Promoting health and wellbeing*

### Recommendation 30

Decision makers should consider how to: reduce or minimise single-use-plastic and implement sustainable medical waste management processes before and during a pandemic to minimise the environmental effects of a pandemic response. *Tika, Liberty, Promoting health and wellbeing*

## 6.5 Investing in global cooperation

During a pandemic, international solidarity is important to understand the nature of the risk and to develop international mitigation strategies.<sup>30</sup> During the COVID-19 pandemic, countries shared information and research about the virus and the development of a vaccine, which took one-tenth of the usual timeframes to develop (Uttarilli et al 2021). Conversely, the lack of global cooperation in vaccine distribution led to an increase in inequities (Javed and Chattu 2020).<sup>31</sup>

In the health sector alone, the COVID-19 pandemic caused disruptions to global supply chains and workforce skill demands, including sourcing PPE and hiring health professionals (Sharma et al 2020). Lower-income countries were significantly disadvantaged as they could not compete for these resources (OECD 2021). These economic inequities will have long-lasting effects for many countries.

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<sup>30</sup> There may be similar coordination during epidemics, however, depending on the nature of the disease, this is less likely. Therefore, this section focuses on pandemics.

<sup>31</sup> Although programmes were stood up to encourage equitable access, these were ultimately undermined by competition from governments who chose to purchase directly from suppliers. (Wouters et al. 2021).

Experts agree that a broader cooperative approach will reduce both the likelihood of future pandemics emerging and the risks associated with them (Javed and Chattu 2020). The world has the civil, corporate and financial capacity to limit pandemic risk and respond much more effectively than it did for the COVID-19 pandemic (Shanmugaratnam et al 2021). This form of global agreement could lead to mutually agreed goals relating to health and the environment, such as biodiversity retention or trade partnerships designed to reduce risks of zoonotic diseases.

### **Recommendation 31**

Decision makers should support policies that encourage international cooperation and information sharing during global emergencies and pursue the development of international economic and environmental agreements that will reduce the impact of future pandemics on health and wellbeing. *Kotahitanga, Promoting health and wellbeing*

# Appendix 1:

## Glossary of terms

<b>Aroha</b>	To love, feel concern for, feel compassion for and/or empathise with; be caring, compassionate, kindly, sympathetic, benevolent; demonstrate sympathy, charity (Te Aka Māori Dictionary, <a href="https://maoridictionary.co.nz/">https://maoridictionary.co.nz/</a> ) 'Aroha is a supreme power and the essence of humanity' (Stewart et al 2021, p 16).
<b>Circular economy</b>	An economy based on the following three principles: <ol style="list-style-type: none"> <li>1. Design out waste and pollution;</li> <li>2. Keep products and materials in use;</li> <li>3. Regenerate natural systems</li> </ol> (Ministry for the Environment 2022a).
<b>Co-design</b>	Involving the equal partnership of people who work within the health and disability system (health care and support workers), people who have lived experience of using that system (including whānau or carers) and the 'designers' of the new health and disability system (such as disability support organisations or similar organisations, government agencies or private organisations). Co-design involves working together, using shared decision-making, to design a new system or service with the collective aim of improving service delivery through making full use of each other's knowledge, resources and contributions to improve efficiency and create better outcomes for people.
<b>Contact tracing</b>	A key aspect of pandemic management is the collection, storage and access of location information or proximity data. Digital contact tracing can take the form of downloadable apps that track the user's activity, for instance, physical locations they have recently visited. Contact tracing may also be conducted via paper-based solutions, using hard-copy paper forms filled in at the entrances to buildings.
<b>COVID-19</b>	A disease caused by the coronavirus SARS-CoV-2.
<b>Decision maker</b>	The term used in reference to the audience for this document. This includes the Minister of Health and senior public health advisors responsible for making decisions at the national level in preparing and responding to epidemics and pandemics. The term also encompasses people working within health and disability organisations, public health experts, health care administrators, iwi and community leaders with authority to make decisions on behalf of their communities.

<b>Disinformation</b>	Information that is false and deliberately created to harm a person, social group, organisation or country; or the purposeful dissemination of false information intended to mislead or harm, eroding trust within and between communities (Edelman 2021).
<b>Encephalitis</b>	Inflammation of the brain. There are several causes, including viral infection, autoimmune inflammation, bacterial infection, insect bites, etc. When inflammation is caused by an infection in the brain, it's known as infectious encephalitis (Mayo Clinic, <a href="http://www.mayoclinic.org">www.mayoclinic.org</a> ).
<b>Epidemic</b>	The occurrence of more cases of disease than expected in a given area or among a specific group of people over a particular period of time (U.S. Centers for Disease Control and Prevention, <a href="http://www.cdc.gov">www.cdc.gov</a> ).
<b>Essential workers</b>	<p>During the COVID-19 pandemic the Aotearoa New Zealand Government designated the following professions as providing critical services that are necessary to meet basic human needs and safety. (Note: Depending on the nature of the epidemic or pandemic, the professions that are designated as 'essential' may change).</p> <ul style="list-style-type: none"> <li>● Health and disability workers, community workers and any people who come in contact with these workers (for example, whānau, family members, patients, etc)</li> <li>● Carers</li> <li>● Social services staff</li> <li>● Teachers and workers in educational settings</li> <li>● Supermarket workers</li> <li>● Hospitality workers</li> <li>● Interpreters</li> <li>● Drivers</li> <li>● Telecommunications workers</li> <li>● Farmers</li> <li>● Emergency service workers (for example, fire, ambulance and police)</li> <li>● Justice and Corrections workers and military personnel</li> <li>● Border workers (such as Customs officers and airport/airline staff)</li> <li>● Courier and postal services</li> <li>● Those working in the transport sector (air, land and sea)</li> <li>● Food production, harvesting, manufacturing and distribution workers</li> <li>● Workers in the construction sector.</li> </ul>

<b>Hapū</b>	Kinship group, clan, tribe, subtribe – section of a large kinship group and the primary political unit in traditional Māori society. Hapū consists of a number of whānau sharing descent from a common ancestor, usually being named after the ancestor but sometimes from an important event in the group’s history. A number of related hapū usually shared adjacent territories, forming a looser tribal federation (iwi) (Te Aka Māori Dictionary, <a href="http://www.maoridictionary.co.nz">www.maoridictionary.co.nz</a> ).
<b>Herd immunity (also known as community immunity or population immunity)</b>	The indirect protection from an infectious disease that happens when a population is immune either through vaccination or immunity developed through previous infection (WHO 2020a).
<b>Homelessness</b>	Defined by the Aotearoa New Zealand Government as ‘a living situation where people with no other options to acquire safe and secure housing are without shelter, in temporary accommodation, sharing accommodation with a household, or living in uninhabitable housing’ (Stats NZ 2014, p 5). Amore (2016) extended this definition to include multiple dimensions of habitability.
<b>Immunity certificate</b>	Provides evidence of resistance acquired through infection of the disease.
<b>Informed consent</b>	When the relevant information that a reasonable person would need to make an educated choice about the risks and benefits is provided in a way that the person can understand (NEAC 2019).
<b>Intersectionality</b>	The complex, cumulative way in which the effects of multiple forms of discrimination (such as racism, sexism and classism) combine, overlap or converge, especially in the experiences of marginalised individuals or groups (Merriam-Webster dictionary, <a href="http://www.merriam-webster.com">www.merriam-webster.com</a> ).
<b>Iwi</b>	Extended kinship group, tribe, nation, people, nationality, race – often refers to a large group of people descended from a common ancestor and associated with a distinct territory (Te Aka Māori Dictionary, <a href="http://www.maoridictionary.co.nz">www.maoridictionary.co.nz</a> ).
<b>Kaimahi</b>	Worker, employee, clerk, staff (Te Aka Māori Dictionary, <a href="http://www.maoridictionary.co.nz">www.maoridictionary.co.nz</a> ).
<b>Kaitiaki</b>	Custodian, guardian, caregiver or trustee (Te Aka Māori Dictionary, <a href="http://www.maoridictionary.co.nz">www.maoridictionary.co.nz</a> ).
<b>Kaupapa Māori</b>	Māori approach, topic, customary practice, institution, agenda, principles and ideology – a philosophical doctrine, incorporating the knowledge, skills, attitudes and values of Māori society (Te Aka Māori Dictionary, <a href="http://www.maoridictionary.co.nz">www.maoridictionary.co.nz</a> ).

<b>Kawa</b>	Marae protocol – customs of the marae and wharehau (meeting house), particularly those related to formal activities such as pōhiri (welcome ceremony), speeches and mihimihi (speech/greeting) (Te Aka Māori Dictionary, <a href="http://www.maoridictionary.co.nz">www.maoridictionary.co.nz</a> ).
<b>Long COVID</b>	<p>A patient-created term broadly defined as signs, symptoms and conditions that continue or develop after initial SARS-CoV-2 infection. The signs, symptoms and conditions are present four weeks or more after the initial phase of infection, may be multisystemic and may worsen over time or reappear in a relapse situation, with the possibility of severe and life-threatening events even months or years after infection. Long COVID is not one condition. It represents many potentially overlapping conditions, likely with different biological causes and different sets of risk factors and outcomes.</p> <p>‘Post-COVID-19 conditions’ is equivalent to the lay term long COVID and is used to describe the new, returning or ongoing health problems people can experience four or more weeks after initial infection with the SARS-CoV-2 virus, the virus that causes COVID-19.</p> <p>‘Post-acute sequelae of SARS CoV-2 infection’ is a term used in the scientific and medical communities that refers to ongoing, relapsing or new symptoms or other health effects occurring after the acute phase of SARS-CoV-2 infection. This definition will be revised in an iterative manner based on existing and new data, medical literature and feedback from the scientific community (CDC 2023a).</p>
<b>Mana</b>	Prestige, authority, control, power, status (Te Aka Māori Dictionary, <a href="http://www.maoridictionary.co.nz">www.maoridictionary.co.nz</a> ).
<b>Mana motuhake</b>	Separate identity, autonomy, self-government, self-determination, independence, sovereignty, authority – power through self-determination and control over one's own destiny (Te Aka Māori Dictionary, <a href="http://www.maoridictionary.co.nz">www.maoridictionary.co.nz</a> ).
<b>Manaaki</b>	To support, take care of, give hospitality to, protect, look out for – show respect/generosity and care for others (Te Aka Māori Dictionary, <a href="http://www.maoridictionary.co.nz">www.maoridictionary.co.nz</a> ).
<b>Māori data</b>	Facts and figures produced by Māori or that are about Māori and the environments Māori have relationships with (Te Mana Raraunga – Māori Data Sovereignty Network n.d.).
<b>Māori data sovereignty</b>	Māori control of Māori data is the primary goal for Māori data sovereignty, improving iwi access to data for governance and decision-making and ensuring iwi involvement in governance of data (Te Mana Raraunga – Māori Data Sovereignty Network n.d.).

<b>Marae</b>	Courtyard – the open area in front of the whareniui (meeting house), where formal greetings and discussions take place. Often also includes the complex of buildings around the marae (Te Aka Māori Dictionary, <a href="http://www.maoridictionary.co.nz">www.maoridictionary.co.nz</a> ).
<b>Mātauranga Māori</b>	<p>Māori knowledge – the body of knowledge originating from Māori ancestors, including the Māori world view and perspectives, creativity and cultural practices.</p> <p>The Museum of New Zealand Te Papa Tongarewa have included the following interpretation in their mātauranga Māori strategy. ‘Mātauranga Māori is a dynamic and evolving system of knowledge (te kauwae runga and te kauwae raro) used by tangata whenua ... to interpret and explain the world in which they live. It is framed by the whakapapa (genealogy) of all things and whanaungatanga (kinship connections) between them’ (Johnstone 2006, p 2).</p>
<b>ME/CFS</b>	Myalgic encephalomyelitis / chronic fatigue syndrome, a debilitating syndrome with symptoms that include post-exertional malaise, physical and mental fatigue, and muscle pain. In many cases, ME/CFS arises after an infection. It is also known as post-infection fatigue syndrome (ANZMES n.d.).
<b>Migrant</b>	A person who moves of their own free will either within Aotearoa New Zealand or between Aotearoa New Zealand and another country, especially for work or for better living conditions.
<b>Misinformation</b>	Information that is false but not created with the intention of causing harm.
<b>Pākehā</b>	New Zealander of European descent – probably originally applied to English-speaking Europeans living in Aotearoa New Zealand.
<b>Pandemic</b>	<p>Like an epidemic but even more widespread over several countries or continents. Most of the diseases posing the greatest risks to humans are contagious, meaning that they are caused by an infectious agent and can be spread from person to person (U.S. Centers for Disease Control and Prevention, <a href="http://www.cdc.gov">www.cdc.gov</a>).</p> <p>In this publication, we have used the term pandemic to cover ‘epidemic’ as well as ‘pandemic’.</p>
<b>Papa kāinga</b>	Original home, home base, village, communal Māori land (Te Aka Māori Dictionary, <a href="http://www.maoridictionary.co.nz">www.maoridictionary.co.nz</a> ).
<b>Pathogen</b>	A microorganism, such as a bacterium, that parasitises an animal (or plant) or a human and produces a disease (Oxford Reference, <a href="http://www.oxfordreference.com">www.oxfordreference.com</a> ).
<b>Pono</b>	Be true, valid, honest, genuine, sincere (Te Aka Māori Dictionary, <a href="http://www.maoridictionary.co.nz">www.maoridictionary.co.nz</a> ).

<b>PPE</b>	Personal protective equipment. What is considered useful or effective PPE in the case of dealing with a disease will change depending on the method of disease transmission (that is, air borne versus contact via surfaces or droplets).
<b>Priority populations</b>	Groups of most concern. Priority populations may change over time. At the time of writing this guidance, priority populations include groups recognised in the required strategies listed in section 10(b) of the Pae Ora (Healthy Futures) Act 2022, including Māori, Pacific peoples, rural, disabled people and women. The term also encompasses other population groups that are vulnerable in a pandemic, including: migrants, members of the Rainbow community, children, mental health service consumers and older people.
<b>Rainbow community</b>	An umbrella term that covers takatāpui, lesbian, gay, bisexual, transgender, intersex, queer and/or 'questioning', or asexual (LGBTQIA+) individuals.
<b>Rangatahi</b>	Younger generation, youth (Te Aka Māori Dictionary, <a href="http://www.maoridictionary.co.nz">www.maoridictionary.co.nz</a> ).
<b>Refugee</b>	A person who has come to Aotearoa New Zealand because of a well-founded fear of being persecuted in their country of nationality or habitual residence because of race, religion, nationality, membership with a particular social group or political opinion and who is unable, or because of that fear, unwilling to return to that country.
<b>Responsible authorities</b>	Body corporates legislated by the Health Practitioners Competence Assurance Act 2003 who ensure all health practitioners registered with them are fully competent in the practice of their profession.
<b>Ritenga</b>	Likeness, custom, customary practice, habit, practice, resemblance, implication – the normal way of doing things (Te Aka Māori Dictionary, <a href="http://www.maoridictionary.co.nz">www.maoridictionary.co.nz</a> ).
<b>Rohe</b>	Boundary, district, region, territory, area, border (of land) (Te Aka Māori Dictionary, <a href="http://www.maoridictionary.co.nz">www.maoridictionary.co.nz</a> ).
<b>Severe housing deprivation</b>	Synonymous with homelessness. It refers to people living in severely inadequate housing due to a lack of access to minimally adequate housing. This means not being able to access a private dwelling to rent or own that has all basic amenities. Housing that lacks at least two of the three core dimensions of housing adequacy – habitability, security of tenure, and privacy and control – is deemed severely inadequate. (Te Tūāpapa Kura Kāinga – Ministry of Housing and Urban Development n.d.).
<b>Tangata whenua</b>	Local or indigenous people – born of the whenua (land).

<b>Tangihanga</b>	Weeping, crying, funeral, rites for the dead, obsequies – one of the most important institutions in Māori society, with strong cultural imperatives and protocols. Most tangihanga are held on marae. The deceased’s body is brought onto the marae by their whānau and lies in state in an open coffin for about three days in a wharemate (house of mourning, place at the meeting house specifically where a body is laid down). During that time, groups of visitors come onto the marae to farewell the deceased with speeches and songs ( Te Aka Māori Dictionary, <a href="http://www.maoridictionary.co.nz">www.maoridictionary.co.nz</a> ).
<b>Taonga</b>	Treasure, anything prized – anything considered to be of value, including socially or culturally valuable objects, resources, phenomenon, ideas and techniques (Te Aka Māori Dictionary, <a href="http://www.maoridictionary.co.nz">www.maoridictionary.co.nz</a> ).
<b>Tikanga</b>	Correct procedure, custom, habit, lore, method, manner, rule, way, code, meaning, plan, practice, convention, protocol – the customary system of values and practices that have developed over time and are deeply embedded in the social context (Te Aka Māori Dictionary, <a href="http://www.maoridictionary.co.nz">www.maoridictionary.co.nz</a> ).
<b>Tino rangatiratanga</b>	Self-determination, sovereignty, autonomy, self-government, domination, rule, control, power (Te Aka Māori Dictionary, <a href="http://www.maoridictionary.co.nz">www.maoridictionary.co.nz</a> ).
<b>Vaccine certificates (or passes)</b>	Documents or digital resources that provide evidence that a person has received a vaccination.
<b>Wāhine</b>	Woman, female, lady, wife (Te Aka Māori Dictionary, <a href="http://www.maoridictionary.co.nz">www.maoridictionary.co.nz</a> ).
<b>Wearables</b>	Portable, contact tracing wearable devices.
<b>Whakapapa</b>	Genealogy, genealogical table, lineage, descent (Te Aka Māori Dictionary, <a href="http://www.maoridictionary.co.nz">www.maoridictionary.co.nz</a> ).
<b>Whānau</b>	The family or family group of people (Māori and non-Māori) who are important to a person. This includes a person’s extended family, their partners, friends, guardians or other representatives as chosen by the person (Standards New Zealand 2021).
<b>Whare</b>	House, building.
<b>Whenua</b>	Land (Te Aka Māori Dictionary, <a href="http://www.maoridictionary.co.nz">www.maoridictionary.co.nz</a> ).

## Appendix 2: Related documents

This guidance should be read alongside the following related legislation and key documents.

### Publications to be read alongside this document

- HDSR. 2020. Health and Disability System Review – Final Report – Pūrongo Whakamutunga. Wellington: Health and Disability System Review (HDSR). URL: [www.health.govt.nz/publication/health-and-disability-system-review-final-report](http://www.health.govt.nz/publication/health-and-disability-system-review-final-report) (accessed 21 June 2024).
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## Aotearoa New Zealand legislation

The following legislation and regulatory obligations provide the legal framework of rights, duties and ethical obligations that must be regarded when making policy decisions during a pandemic.

- Code of Expectations for Health Entities' Engagement with Consumers and Whānau
- Epidemic Preparedness Act 2006 (and any issued Epidemic Notice(s))
- Health Act 1956
- Health and Disability Commissioner Act 1994
- Health and Disability Commissioner (Code of Health and Disability Services Consumers' Rights) Regulations 1996
- Health Practitioners Competence Assurance Act 2003
- Health Information Privacy Code 2020
- Human Rights Act 1993
- New Zealand Bill of Rights Act 1990
- Pae Ora (Healthy Futures) Act 2022
- Privacy Act 2020
- Protection of Personal and Property Rights Act 1988
- Treaty of Waitangi Act 1975.

## International obligations

Aotearoa New Zealand is a party to the following United Nations treaties and World Health Organization (WHO) regulations and is obliged to implement the provisions of each.

- Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (1984)
- Convention on the Elimination of All Forms of Discrimination against Women (1979)
- International Covenant on Civil and Political Rights (1966)
- International Covenant on Economic, Social and Cultural Rights (1966)
- International Convention on the Elimination of All Forms of Racial Discrimination (1965)
- Convention on the Rights of the Child (1989)
- United Nations Convention on the Rights of Persons with Disabilities (2006)
- UN Declaration on the Rights of Indigenous Peoples (2007)
- International Health Regulations (WHO 2005).

# Appendix 3: People and communities consideration tool

Decision makers will need to consider the following groups of people to understand the full ethical implications of a pandemic response. This list is based on lessons learned from Aotearoa New Zealand’s COVID-19 pandemic experience. It is possible there will be other groups of people decision makers should consider that are not on this list.<sup>32</sup> This list has been provided in a checklist format so it can be copied and used in preparing for future pandemics.

**As part of epidemic or pandemic planning, have decision makers considered the impacts on:**

Pae Ora Act priority populations		
<input type="checkbox"/> Māori communities, iwi, hapū and whānau	<input type="checkbox"/> People living in rural or remote areas	<input type="checkbox"/> People experiencing poor mental health or addiction
<input type="checkbox"/> Women	<input type="checkbox"/> Pacific peoples	<input type="checkbox"/> Disabled people
People in higher-risk settings or higher-risk occupations		
<input type="checkbox"/> Health care workers	<input type="checkbox"/> Essential workers	<input type="checkbox"/> People in corrections facilities
<input type="checkbox"/> People in emergency and shared accommodation	<input type="checkbox"/> People in residential mental health facilities	<input type="checkbox"/> People in residential education facilities
<input type="checkbox"/> People in aged care residential facilities	<input type="checkbox"/> People in residential addiction facilities	<input type="checkbox"/> People experiencing overcrowded housing
<input type="checkbox"/> People in residential disability facilities	<input type="checkbox"/> People in refugee centres	

<sup>32</sup> Decision makers may find the following checklist published by the Office of the United Nations High Commissioner for Human Rights valuable: [www.ohchr.org/sites/default/files/Documents/Events/COVID-19/Checklist\\_HR-Based\\_Approach\\_Socio-Economic\\_Country\\_Responses\\_COVID-19.pdf](http://www.ohchr.org/sites/default/files/Documents/Events/COVID-19/Checklist_HR-Based_Approach_Socio-Economic_Country_Responses_COVID-19.pdf)

**As part of epidemic or pandemic planning, have decision makers considered the impacts on:**

<b>Other vulnerable communities or groups of people</b>		
<input type="checkbox"/> People aged 65 years and older	<input type="checkbox"/> People experiencing homelessness	<input type="checkbox"/> Members of the Rainbow community
<input type="checkbox"/> Refugees	<input type="checkbox"/> Recent migrants	<input type="checkbox"/> Children living in poverty
<input type="checkbox"/> People experiencing violence	<input type="checkbox"/> People experiencing poverty	<input type="checkbox"/> Under-immunised populations
<input type="checkbox"/> People with very high health needs or chronic conditions	<input type="checkbox"/> People requiring planned or emergency lifesaving interventions	<input type="checkbox"/> Sex workers and escorts
<b>Other communities</b>		
<input type="checkbox"/> Regions experiencing more movement restrictions than others	<input type="checkbox"/> People inadvertently unable to leave Aotearoa New Zealand	<input type="checkbox"/> Whānau who are inadvertently physically separated
<input type="checkbox"/> Asylum seekers	<input type="checkbox"/> Migrant workers	<input type="checkbox"/> Tourists
<input type="checkbox"/> People working in the cash/informal economy	<input type="checkbox"/> Different ethnic groups with strong cultural identities	<input type="checkbox"/> Sports groups
<input type="checkbox"/> Community groups	<input type="checkbox"/> Spiritual or religious groups	<input type="checkbox"/> People without digital access
<input type="checkbox"/> People participating in research about the epidemic or pandemic (researchers and clinical trial participants)		
<b>General population</b>		
<input type="checkbox"/> Individuals	<input type="checkbox"/> Whānau	<input type="checkbox"/> Tamariki/children
<input type="checkbox"/> Rangatahi/youth	<input type="checkbox"/> Employed people	<input type="checkbox"/> People enrolled in education

## Appendix 4: Response justification tool

### Determining the justification for public health measures that interfere with human rights

The Siracusa Principles on the Limitation and Derogation Provisions in the International Covenant on Civil and Political Rights (the Siracusa Principles) set out the narrowly defined circumstances in international law in which human rights may be restricted in the interests of public health (American Association for the International Commission of Jurists 1985). These principles may provide a useful guide when restricting individual freedoms in the public interest during a pandemic.

Only as a last resort can human rights be limited or restricted to achieve a public health goal. Such interference can only be justified when all the narrowly defined circumstances set out in human rights law, known as the Siracusa Principles, are met. The Siracusa Principles have been summarised and turned into a list of questions to support decision makers (American Association for the International Commission of Jurists 1985).

The questions are as follows.

- Is the limiting measure or restriction provided for and **able to be carried out in accordance with the law**?
- Is the limiting measure or restriction in the interest of a **legitimate objective** of general interest?
- Is the limiting measure or restriction strictly necessary in a democratic society to achieve the objective of the public health response or measure?
- Is there a **less intrusive and restrictive** means available to reach the same objective of the public health response or measure?
- Is the restriction **not arbitrarily drafted or imposed**, that is, in an unreasonable or otherwise discriminatory manner?
- Is the limiting measure or restriction intended to be in place for a **limited time**?
- Will the limiting measure or restriction be able to be **subject to review**, with the public able to hold those implementing the measure or restriction to account?

## Appendix 5: Scale for response intrusiveness

Determining adequate justification and proportionality when implementing restrictive responses during a pandemic will be heavily reliant on the current context, including the nature of the pandemic and the public's acceptance and trust in decision makers' governance.

The Nuffield Council on Bioethics' Ladder for Public Health Interventions (Nuffield Council on Bioethics 2007) (see below) presents health response options for decision makers during pandemics. The options increase in intrusiveness, from 'Do nothing' at the bottom to 'Remove choice altogether' at the top. The ladder provides guidance on how public cooperation can be informed, encouraged and enabled rather than forced.

### Remove choice altogether

Mandate responses for all. This might include compulsory wearing of masks in enclosed public places, stay-at-home orders and visiting bans for care homes.

### Restrict choice

Mandate responses in certain circumstances so that people have a choice of either complying with the requirement or not taking part in a particular activity. This might include requiring proof of vaccination or a negative test for certain activities, such as international travel or going to public spaces. In practice, measures that aim to restrict choice might constitute removing choice altogether.



## **Present safer behaviours as a social default**

Provide clear and persuasive public health messaging that goes beyond neutral information provision. The aim is to create social norms and values in acting to protect others. This might include public health messaging that strongly encourages people to continue to wear face masks voluntarily to protect others or clear public guidance on self-isolation after confirmation of infection.

## **Make it easier for people to adopt safer behaviours**

Remove disincentives for people to adopt behaviours that are known to help protect others. This could include mitigating financial factors that make it hard for people to remain at home when they know they are infectious; providing access to testing to enable people to make choices to protect others or ensuring that vaccination is readily available, with a particular focus on reaching out to communities where there is a lack of confidence in vaccines.

## **Provide information**

Empower people by making sure that they have access to the information they need so that they can manage their own risk and minimise any risk they might pose to others. This could include ensuring that the latest public health advice about how to protect oneself and others is readily available in appropriate languages and formats or publishing information about prevalence by local area to inform personal decision-making.

## **Monitor actively**

Use robust surveillance and research programmes to ensure that policy makers are alerted to significant changes in prevalence or the emergence of new variants of concern. It might include monitoring the impact of the disease and any related measures on different sectors such as hospitals, social care, education and parts of the economy or monitoring the impact on diverse parts of the population, with a particular focus on the Pae Ora Act priority populations, those in higher-risk settings and occupations and other vulnerable communities and groups of people. This provides the evidence necessary to inform other policy choices.

## **Do nothing**

This is still an active choice, rather than a default option.

Source: Adapted from the Ladder for Public Health Interventions (Nuffield Council on Bioethics 2007)

# Appendix 6:

## Response proportionality tool

### **Determining appropriate proportionality of measures that interfere with human rights**

In determining the proportionality of the measure, decision makers should use the following questions to determine whether the proportionality is ethically appropriate (Paul Rodney Hansen v The Queen 2007).

- Does the limiting measure or restriction serve a purpose sufficiently important to justify limitation of the right or freedom?
  - Is the limiting measure or restriction rationally connected with its purpose?
  - Does the limiting measure impair the right or freedom no more than is reasonably necessary for sufficient achievement of its purpose?
  - Is the limiting measure or restriction in due proportion to the importance of the objective?
-

# Appendix 7:

## Balance Principles justification tool

The following checklist will help decision makers determine whether public health responses are supported by the Balance Principles. Four questions are provided for each Balance Principle to give decision makers an idea of the types of thinking that should justify a response. The checklist ends with an additional section for response evaluation and review (NEAC 2021a).

This tool may easily be adapted to review previously implemented responses by changing the tense of the questions from the future tense to the past tense ('will' to 'has').

This tool should be used after the response justification tool has confirmed the response is justified and the response proportionality tool has determined the measure is appropriate and proportional.

Questions	Select	Outline the steps that will be taken to address or mitigate the issue
<b>Manaakitanga</b>		
Will the response benefit or improve people’s health and wellbeing?	<input type="checkbox"/> Yes <input type="checkbox"/> No	
Are there people who will be particularly impacted by this response that should be given extra support?	<input type="checkbox"/> Yes <input type="checkbox"/> No	
Will the people who will be impacted by the response be offered an opportunity to have a two-way conversation about the response?	<input type="checkbox"/> Yes <input type="checkbox"/> No	
Will the response be implemented in a respectful, empathetic and intentioned way, with people’s dignity maintained?	<input type="checkbox"/> Yes <input type="checkbox"/> No	

Questions	Select	Outline the steps that will be taken to address or mitigate the issue
<b>Tika</b>		
Is the response the 'right' and 'correct' thing to do, as will be generally perceived by Aotearoa New Zealand's core values?	<input type="checkbox"/> Yes <input type="checkbox"/> No	
Will the response be implemented in a transparent and open way that will cultivate trust with the people it impacts?	<input type="checkbox"/> Yes <input type="checkbox"/> No	
Does the response reflect what is important to the people it will impact?	<input type="checkbox"/> Yes <input type="checkbox"/> No	
Do the parameters of the response enable tikanga Māori and mātauranga Māori?	<input type="checkbox"/> Yes <input type="checkbox"/> No	
<b>Equity</b>		
Have the unique needs of the Pae Ora Act priority populations, those within higher-risk settings and occupations and other vulnerable groups of people and communities in relation to the response been identified to ensure the response will result in equitable health outcomes for everyone in Aotearoa New Zealand?	<input type="checkbox"/> Yes <input type="checkbox"/> No	
Has extra support been provided to the groups of people who need it?	<input type="checkbox"/> Yes <input type="checkbox"/> No	
Are there mechanisms in place to monitor the effects of the response on different groups of people and assess and rapidly implement changes if inequities are identified?	<input type="checkbox"/> Yes <input type="checkbox"/> No	
Will people with different socioeconomic or cultural backgrounds be able to benefit from the response equitably?	<input type="checkbox"/> Yes <input type="checkbox"/> No	

Questions	Select	Outline the steps that will be taken to address or mitigate the issue
<b>Liberty</b> (Note: Most questions pertaining to liberty are also in the response justification and proportionality tools)		
Have the rights people are entitled to across all relevant legislation and international treaties been assessed in relation to the intended response to ensure the measure is as least restrictive as possible across all entitled human rights?	<input type="checkbox"/> Yes <input type="checkbox"/> No	
Are the immediate infringements on liberty understood and transparently communicated to the people who will be impacted?	<input type="checkbox"/> Yes <input type="checkbox"/> No	
Are the flow-on infringements understood and able to be mitigated?	<input type="checkbox"/> Yes <input type="checkbox"/> No	
Can the response be willingly agreed to?	<input type="checkbox"/> Yes <input type="checkbox"/> No	
<b>Kotahitanga</b>		
Are community leaders and groups or local governments able to be supported to be champions and leads for the response?	<input type="checkbox"/> Yes <input type="checkbox"/> No	
Does the public have the information they need to understand their roles and responsibilities in relation to the response?	<input type="checkbox"/> Yes <input type="checkbox"/> No	
Is the response co-designed with the people it is intended for?	<input type="checkbox"/> Yes <input type="checkbox"/> No	
Will the response inspire unity?	<input type="checkbox"/> Yes <input type="checkbox"/> No	

Questions	Select	Outline the steps that will be taken to address or mitigate the issue
<b>Promoting health and wellbeing</b>		
Are the risks introduced by the response understood and mitigated against?	<input type="checkbox"/> Yes <input type="checkbox"/> No	
Does the response consider and address the four walls of Te Whare Tapa Whā: whānau health, physical health, spiritual health and mental health?	<input type="checkbox"/> Yes <input type="checkbox"/> No	
Have the social and economic impacts (education, employment, housing, food) of the response been identified and addressed?	<input type="checkbox"/> Yes <input type="checkbox"/> No	
Have the impacts of the response on the environment been considered and addressed?	<input type="checkbox"/> Yes <input type="checkbox"/> No	
<b>Evaluation of the measure</b>		
What are the lessons learnt from implementing the response?	<input type="checkbox"/> Yes <input type="checkbox"/> No	
Were the results of the response consistent with the intention?	<input type="checkbox"/> Yes <input type="checkbox"/> No	
Were there any unintended consequences?	<input type="checkbox"/> Yes <input type="checkbox"/> No	
Did implementing the response create or exacerbate inequalities?	<input type="checkbox"/> Yes <input type="checkbox"/> No	
Should the response be reviewed and amended?	<input type="checkbox"/> Yes <input type="checkbox"/> No	
Can it be reviewed in conversation or consultation with those impacted by the response?	<input type="checkbox"/> Yes <input type="checkbox"/> No	

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