

Ethical Guidance for a Pandemic

Whakapuāwaitia e tatou kia puāwai tātou





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Contents

- National Ethics Advisory Committee – Kāhui Matatika o te Motu5
 - Structure of the publication5
 - Acknowledgements5
- Foreword.....6
- Chapter 1: A fresh approach to pandemics7
 - Context7
 - Building resilient health and economic systems and communities7
- Chapter 2: Ethical principles for a pandemic12
 - Principles13
 - Interpreting and applying the principles17
 - Framework18
- Chapter 3: Readiness and reduction of risk19
 - Introduction.....19
 - Readiness.....20
 - Reduction of risk.....28
- Chapter 4: Response30
 - Interventions to improve a pandemic situation.....30
 - Communications and engagement37
 - Data, privacy, and digital technologies in a pandemic39
- Chapter 5: Recovery45
 - Vaccine development and use45
 - Reopening.....48
 - Ongoing impacts.....50
- Chapter 6: Disability51
 - Readiness and reduction of risk52
 - Response55
 - Recovery57
 - Conclusion58
- References59

National Ethics Advisory Committee – Kāhui Matatika o te Motu

The National Ethics Advisory Committee – Kāhui Matatika o te Motu (NEAC) is an independent advisor to the Minister of Health (the Minister). NEAC's statutory functions are to advise the Minister on ethical issues of national significance in respect of any health and disability matters and determine nationally consistent ethical standards across the health sector.

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Structure of the publication

We've arranged these guidelines into five chapters.

- Chapter 1 outlines a shared ethical approach to responding to a pandemic.
- Chapter 2 introduces a set of foundational ethical principles and a framework for decision-making in a pandemic.
- Chapters 3 to 5 provide insight into how these principles might operate before, during and after a pandemic. These chapters are structured using the four 'R's approach to align with Aotearoa New Zealand's wider response to pandemics.
- Chapter 6 explores what these ethical principles mean for New Zealanders with disabilities.

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NEAC acknowledge the support of the Māori Health Directorate at the Ministry of Health in the development of the subtitle. 'Whakapuāwaitia e tatou kia puāwai tātou' reflects that we are all growing and working together, to prepare for and to get through a pandemic.

The sign-language illustrations are from the *Online Dictionary of New Zealand Sign Language*.¹

The harakeke illustration was provided by Kate Mabin.

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Foreword

We know that Aotearoa New Zealand can get through a pandemic when faced with one. We know this because we have done it. The global experience with the COVID-19 pandemic has shaped our nation's understanding of both who we are and how pandemics can disrupt, harm and destroy. But we can get through together. We know the truth of the whakataukī 'He waka eke noa': A canoe that we are all in – with no exception.

The National Ethics Advisory Committee (NEAC) offers this update to our 2007 guidance publication *Getting through Together: Ethical values for a pandemic*.² Our hope is that this updated guidance will protect all New Zealanders. However, we know some communities are likely to be particularly vulnerable. For example, Māori experience health inequities,³ and these are compounded in a pandemic.⁴ Māori and other communities have a history of resilience, and in this updated guidance, we seek to support these strengths through a call for equity and by fostering community participation.

We have deliberately sought to amplify the call for a te ao Māori and strengths-based approach to pandemic planning. This builds on the previous 2007 edition, which addressed the ethical issues in a pandemic by identifying shared values and offering broad guidance.

The principles in this set of guidance give us a shared basis for decision-making. Many of us, in many different situations, will still have to make hard choices. There are new pandemics on our horizon, and the better prepared we are, the better we will cope. The Government can prepare by investing in our health system and by connecting more strongly with the social infrastructure that exists in our diverse communities. The Ministry of Health (the Ministry) is the lead agency for this whole-of-government action. But the Ministry cannot succeed alone. Businesses, iwi, community groups, households and individuals also must play a part, as we are all critical in the success of any pandemic response.

The development of the *Ethical Guidance for a Pandemic* was made possible by the generosity and knowledge of many contributors. We are particularly grateful to those who contributed their time and expertise to ensure that equity was held at the heart of this guidance, and for those who contributed their stories of getting through together.

Professor John McMillan

Chair, National Ethics Advisory Committee



Chapter 1: A fresh approach to pandemics

Tūngia te ururua kia tupu whakaritorito te tupu o te harakeke.
Clear the undergrowth so that the new shoots of the flax will grow.

This whakataukī reflects the opportunity that we have in Aotearoa New Zealand to create an approach to pandemics that supports new thinking and ways of operating in the health and wellbeing sector. It also reflects this publication's opportunity to stimulate debate and discussion about the ethical principles that should underpin our planning for, responding to and recovering from a pandemic.

Context

COVID-19

In early 2020, following the arrival of COVID-19 on our shores, Aotearoa New Zealand implemented a four-level national suppression strategy, focused on eliminating the virus.⁵ At the time, the full costs, justifications and benefits of such a strategy were not clear.⁶ However, it was widely understood that previous influenza pandemics had disproportionately and catastrophically impacted Māori,^{7, 8} and the 2019 measles outbreak in Sāmoa (understood to have originated in Aotearoa New Zealand), had highlighted the risks for our Pacific neighbours based on our strong connections with them.⁹ Therefore, while the strategy of elimination was understood to have substantial economic and social costs, the alternatives were believed to be more damaging.¹⁰

As the pandemic progressed, it became very clear that, while science has provided the evidence on which to base decisions, ethical principles were needed to establish how that evidence is applied,¹¹ for example:

- Individuals who have recovered from infection may have some degree of future immunity, but is it ethical to attribute forms of privilege to these individuals (for example, being able to undertake air travel) due to this immunity?
- Should some communities be prioritised when distributing vaccines and treatments during a pandemic?
- Is it ethical to mandate vaccines for incarcerated individuals?
- When is it ethical to restrict a citizen's freedom of movement?

The threat of future pandemics to Aotearoa New Zealand means that we should prepare and learn from the COVID-19 pandemic. This publication is designed to establish the ethical principles that will help prepare us for such conversations and decisions.

Building resilient health and economic systems and communities

Our communities are our greatest asset, with community resilience a critical component of Aotearoa New Zealand's ability to respond to a pandemic. As part of building resilience, NEAC have identified the following seven foundations for our country's pandemic response.

- Honouring Te Tiriti o Waitangi
- Developing a strong and well-functioning health system
- Building back better – getting ready for the future
- Adopting Te Whare Tapa Whā – a shared model of health and wellbeing



- Embedding mātauranga Māori
- Taking an intersectional approach
- Upholding human rights

Honouring Te Tiriti o Waitangi

The 2019 *Hauora* (Health) report from the Waitangi Tribunal recommended a series of principles be developed for the primary health care system in Aotearoa New Zealand.¹² The following five principles were identified as important in honouring Te Tiriti o Waitangi in the overarching health and disability system and remain critical in a pandemic.

- 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 health services.
- Equity
 - Equity requires the health and disability system to commit to achieving equitable health outcomes for Māori in a pandemic. In the process, clinicians, hospital administrators and public health policy makers should not lose focus on identifying, acknowledging, and addressing existing inequities experienced by Māori.
- Active protection
 - Active protection ensures, to the fullest practicable extent, that the health and disability system achieves equitable health outcomes for Māori.
- Options
 - Options means that the health and disability system is agile in adapting and responding to the pandemic resource needs of kaupapa Māori health and disability services to be able to serve Māori communities adequately.
- Partnership
 - Partnership means that the health and disability system leadership works alongside Māori leaders to enable a coordinated and united response to a pandemic or public health emergency, with Māori receiving adequate resources to govern, design, deliver, manage and monitor a response and the impacts of the pandemic or emergency on Māori communities.

Together, these five principles form a foundation for the national ethical principles proposed in these guidelines.

Developing a strong and well-functioning health system

Aotearoa New Zealand's health and disability system was stretched thin even before COVID-19. It struggles to cope with mental health issues and suicide, cancers, cardiovascular disease, diabetes, and poor oral health.¹³ There are staff shortages in primary health care as well as ongoing challenges in recruiting and retaining staff.^{14, 15, 16, 17} Many areas of health care are being compromised, including, access to general practitioner (GP) care, surgical services (with long waiting lists) and specialist outpatient clinics.^{18, 19, 20}

While we discuss this further in the **Readiness and reduction** chapter below, it is fundamental that our health system be transformed before the next pandemic. This transformation needs to acknowledge the social determinants of health (these are non-medical elements, such as housing quality and food security), support community approaches to wellbeing and ensure that primary health care and hospital services can meet demand.

Preparing a health system for a pandemic requires investment, and this investment needs to strike a balance between the country's current and future economic needs.

Building back better – getting ready for the future

To support preparedness and readiness for future pandemics, the Organisation for Economic Co-operation and Development (OECD) is promoting a series of economic policies it terms ‘building back better’. Based on the idea of the circular economy, such policy interventions focus on wellbeing and a more inclusive economy that aligns with long-term carbon emission reduction goals, factoring in resilience to climate impacts, slowing biodiversity loss and increasingly circular supply chains (a model which encourages companies and suppliers to recycle and re-use materials and products).^{21, 22}

Within the health care system specifically, COVID-19 introduced disruptions to global distribution and supply chains across the world.²³ From difficulties in sourcing personal protective equipment (PPE) to negotiating and securing access to COVID-19 vaccines, there is an opportunity to think more broadly about sustainable economic policies that will reduce the likelihood of future economic shocks and increase our resilience to them when they do occur.²⁴

NEAC sees considerable benefit in Aotearoa New Zealand using such an economic approach as a foundational element of increasing our country’s resilience in the face of repeated pandemics.

Adopting Te Whare Tapa Whā – a shared model of health and wellbeing

Within the context of health in Aotearoa New Zealand, there have been many models developed to address health and wellbeing. However, in developing these guidelines, we have chosen to use Te Whare Tapa Whā to explain health and wellbeing.

Te Whare Tapa Whā is a Māori model of health and wellbeing developed by Tā (Sir) Mason Durie in 1984.²⁵ While it was developed to articulate a Māori conception of health and health services, it is relevant to the health of all New Zealanders.²⁶ Te Whare Tapa Whā is a metaphor based on the four pillars of the whareniui or meeting house. Each of the four tapa (sides of the house) represent an element that is necessary to build health and wellbeing, with all elements working in harmony.



The pillars are as follows.

- Taha wairua addresses our capacity for faith and is about our spiritual life force. This encompasses who we are, where we have come from and where we are going. For some, this could be a religious faith or a spiritual connection to ancestors or the universe: the key component being that which gives each person meaning.²⁷ Taha wairua provides a sense of purpose and connectedness to self, communities, the environment, and potentially the significant or sacred.²⁸

- Taha hinengaro addresses our capacity to communicate, think and feel. The consequences of a pandemic can have far-reaching impacts on our mental health and emotional wellbeing.
- Taha tinana addresses our physical body and development. While physical health is the element most obviously disrupted during a pandemic, the physical dimension is just one aspect of health and wellbeing. A pandemic changes our behaviours at an individual and societal level, and our physical health cannot be separated from the other three elements (spirit, mind, and family).
- Taha whānau addresses our capacity to belong, care and share. This can be within families but can also be extended to our communities and wider networks.

The connection of the wharenuī with the whenua (land) forms the base of these four pillars. For Māori, whenua is a crucial part of identity, and connection to the land and to nature has been shown to improve mental and physical wellbeing.²⁹

Embedding mātauranga Māori

Te Whare Tapa Whā model of health is based on mātauranga Māori, or Māori knowledge – ‘the body of knowledge originating from Māori ancestors, including the Māori world view and perspectives, Māori creativity and cultural practices’.³⁰ 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 raro³¹) 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 (page 3).³²

Mātauranga Māori needs to be recognised as a foundation of any pandemic response. This not only reflects the importance of tangata whenua in Aotearoa New Zealand, and the importance of honouring Te Tiriti o Waitangi, but also acknowledges that a pandemic is likely to disproportionately effect Māori (particularly as Māori already face health inequities).³³

Therefore, if we are to navigate the next pandemic successfully, mātauranga Māori needs to be a foundational element in our approach.

Taking an intersectional approach

Preparing for, responding to, and recovering from a pandemic requires an intersectional approach. ‘Intersectional’ refers to the relationships of privilege and disadvantage that are revealed through systems of inequity, such as those relating to gender, age, class, ethnicity, disability, or sexual identity.³⁴ For example, a disabled European woman may experience discrimination due to her disability and gender, whilst simultaneously benefitting from white privilege.³⁵ A pandemic magnifies the presence of both multiple disadvantages and privileges of protection from vulnerability. The social, physical, and economic impacts for individuals in a pandemic depend on these intersectional relationships of inequity and privilege. Undertaking an intersectional approach to a pandemic requires understanding these intersections rather than responding to them in isolation.³⁶

Upholding human rights

Human rights are a foundational part of Aotearoa New Zealand’s legal and ethical foundation and must be considered in relation to our country’s resilience to another pandemic. In preparing for a pandemic, part of our readiness must be focused on ensuring Aotearoa New Zealand is in a position to uphold the rights of our citizens within a pandemic.

A human rights approach to a pandemic is concerned with process as well as outcome, including the right to participation and the importance of fair, reasoned, robust and transparent decision-making, alongside independent accountability when states exercise their discretionary powers.

Human rights draw upon international and national legislative state obligations that remain legally binding in times of emergency. Rights to life, health and wellbeing and health care without discrimination place obligations on our government to effectively respond to a pandemic. The right to the highest attainable standard of health is expressed in the 1966 **International Covenant on Economic, Social and Cultural Rights**. This covenant also established the steps nations should take to realise this right. It also forms part of a collection of legally-binding international human rights instruments (alongside the 1948 **Universal Declaration of Human Rights** and the 1966 **International Covenant on Civil and Political Rights**).

At a national level, Aotearoa New Zealand is legislatively bound to protect human rights through the Human Rights Act 1993, the New Zealand Bill of Rights Act 1990, the Privacy Act 2020 and has obligations under Te Tiriti o Waitangi.

Human rights documents, including the 2006 **Convention on the Rights of Persons with Disabilities**,³⁷ the 1989 **Convention on the Rights of the Child**,³⁸ the 1965 **International Convention on the Elimination of All Forms of Racial Discrimination**,³⁹ and the 1979 **Convention on the Elimination of All Forms of Discrimination against Women**⁴⁰ further enforce the importance of the principle of equity.

Intergenerational equity

Our consideration of human rights must also consider intergenerational equity, or the concept of fairness for a cross-section of different generations, including future generations.⁴¹ Actions taken in the present can affect the rights of later generations, and decision-makers should take these potential consequences into account when establishing our readiness for a pandemic – especially where there is a risk of potential harm.

A focus on Te Tiriti o Waitangi and equity aligns with a human rights-based approach to health in general as well as during a pandemic. The United Nations’ Committee on Economic, Social and Cultural Rights clarifies that states must guarantee that the right to the highest attainable standard of health will be exercised without discrimination.⁴² The right to equality and non-discrimination further supports an equitable approach to resource allocation. It also needs to be kept in mind that differential treatment is required where it can be justified rationally and objectively to restore the health rights of groups that have been rendered vulnerable via structural inequities within the health system.⁴³

Chapter 2: Ethical principles for a pandemic

This chapter sets out six ethical principles for Aotearoa New Zealand to apply during a pandemic.

Explicitly identifying principles offers a shared basis for decision-making. However, trying to describe each principle in isolation is difficult as the principles are interconnected and relate strongly to each other. In many situations, several different ethical principles will be important. Sometimes they will pull us in conflicting directions.

Different people may express the principles described in this statement in different ways. For example, equity and tika require honouring the mana of individuals, or manaakitanga and kotahitanga require respectful relationships.

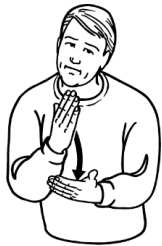
Ethical Guidance for a Pandemic should not be read as identifying any principles as being more important than others. Rather, all principles are important, and the appropriate emphasis to give each one depends on the context. While the same principles apply to pandemic planning as to pandemic response, the relative importance of each principle may shift. For instance, if a pandemic poses a great health risk to the population, health and wellbeing becomes particularly important.

Principles



Health and wellbeing

In its constitution, the World Health Organization (WHO) defines health as ‘a state of complete physical, mental and social wellbeing and not merely the absence of disease or infirmity’. In a pandemic, our response needs to be framed to emphasise our *collective* health and wellbeing.



Equity

Equity means we treat all people and groups fairly and with respect. In a pandemic, we must focus on the equity of outcomes as well as equity in processes. This does not mean treating everyone the same.



Kotahitanga

Kotahitanga is the process of developing unity, togetherness, solidarity and associated collective action.



Tūngia te ururua kia tupu whakaritorito te tupu o te harakeke.
Clear the undergrowth so that the new shoots of the flax will grow.

Tika
Tika refers to what is right and what is good for any particular situation. To understand what is right and good in context, there needs to be underlying relationships to enable awareness of the needs of particular communities and what is important to them.



Manaakitanga

Manaakitanga refers to caring for others, nurturing relationships and being careful in the way we treat others. Sharing, reciprocity and generosity are essential parts of a pandemic response, as we uphold the mana of all parties.



Liberty
Liberty refers to a state of freedom from oppressive restrictions imposed by authorities on one’s way of life, behaviour or political views. In a pandemic, our response needs to emphasise our collective rights.



Health and wellbeing

Te Whare Tapa Whā model of health and wellbeing encourages us to consider the following four concepts.

- Taha hinengaro (our capacity to communicate, think and feel)
- Taha whānau (our capacity to belong, care and share)
- Taha wairua (who we are, where we have come from and where we are going)
- Taha tinana (our physical body and development).



This approach to health and wellbeing is consistent with the WHO's definition of health and wellbeing – 'a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity'. It is also consistent with the 'capabilities approach', a philosophical framework that proposes that the freedom to attain wellbeing is of 'primary moral importance',⁴⁴ with wellbeing understood as what people could do or be (that is, their capabilities and functioning) rather than what they have.^{45, 46}

This principle focuses on collective wellbeing, or population health, as well as the health of specific individuals.

Discussions about public health⁴⁷ often emphasise precautionary thinking, which suggests that interventions may be taken (for example a lockdown) without complete evidence of the benefits of the intervention or the risk.⁴⁸ Lockdowns in a pandemic save lives. However, they also impose constraints on our liberty and livelihoods. In some instances, life-saving medical interventions such as surgery, cancer treatment and other vaccination programmes may not proceed in the strictest lockdown.⁴⁹ Additionally, the economic harm that may impact families during a lockdown can have ramifications for generations. For example, some students in Aotearoa New Zealand dropped out of education in COVID-19 level-four lockdown to take on jobs to support their families, with ongoing ramifications for their wellbeing and economic outlook.^{50, 51} Decision-makers need to operate with caution when using precautionary thinking in public health matters, particularly with regard to assessing the probability of particular possibilities and unexpected events.⁵²

Equity

Equity recognises that people have:

... differences in health that are not only avoidable but unfair and unjust. Equity recognises different people with different levels of advantage require different approaches and resources to get equitable health outcomes.⁵³



Equity does not mean treating everyone the same, because different individuals and different groups have different starting points. A one-size-fits-all approach to a pandemic exacerbates existing inequities.⁵⁴ This principle involves considering who benefits and who is burdened by our culture, economy, and health system.

The principle of equity is about ensuring people can access what they need and recognising that reducing barriers can make access fair. This is not the same as equality. It means directing more effort and resources to those in need, proportionate to their circumstances, to ensure that everyone has the same opportunities for health and wellbeing. As Aotearoa New Zealand's Human Rights Commission notes: sometimes treating people differently 'may be necessary to enable a particular group of people to achieve equality with others'.⁵⁵

This principle calls on us to eliminate inequities in health and wellbeing and to think about the populations who need support to achieve the same health outcomes as others.⁵⁶ There are many ways that equity should be considered during a pandemic, including language equity or ensuring the availability of translated pandemic information. The Crown also has specific obligations to achieving equitable outcomes for Māori under Te Tiriti o Waitangi.

While Aotearoa New Zealand’s health service is an entitlement for all New Zealanders, in a pandemic, resources need to be prioritised in a way that is fair to all New Zealanders.⁵⁷

Kotahitanga

In responding to a pandemic, we should commit to kotahitanga (or unity): a commitment to seeing this through together and to strengthening individuals and communities.



Kotahitanga means we need to be mindful of those who may be particularly vulnerable. For example, data from the United Kingdom’s national statistics office suggests that, in England, almost six out of every 10 people who died as a result of COVID-19 between January and November 2020 were disabled.⁵⁸

Additionally, because life in a pandemic can differ fundamentally from normal experience, there will be members of our community who struggle to respond and adapt to the changes required of us. They ‘may require emotional, psychological, and spiritual support’ to navigate this difficult period⁵⁹. All of us have a role, big or small, in responding to the needs of those who are suffering.

Kotahitanga does not undermine the principle of **equity**, just as building unity does not mean that there is a one-size-fits-all approach to a pandemic. Instead, it requires us to understand our context, and in Aotearoa New Zealand’s context of colonialism and unequal power, kotahitanga is a multi-generational task.⁶⁰ Nevertheless, we need to ensure that our health response in a pandemic does not propagate the systems that have led to inequity and poor health outcomes in the past, particularly for Māori and disabled communities.

The principle of kotahitanga encourages action at both a national and community-level. For example, in response to COVID-19, Ngāti Tūwharetoa organised food and sanitation supplies for distribution not just to Māori but to the entire community. Volunteers packed boxes or made contactless deliveries throughout the rohe (region).⁶¹ Meanwhile, Ngāti Kahungunu in the Hawke’s Bay organised the local manufacture of sanitisers and toilet paper so that they could be provided to those at risk or who could not obtain such materials.⁶² These collaborative approaches illustrate kotahitanga in action, at a community level.

Manaakitanga

Manaakitanga refers to caring for others, nurturing relationships and being careful in the way we treat others. Sharing, reciprocity and generosity are essential parts of a pandemic response as we seek to uphold the mana of all parties.



Manaakitanga relates to cultural and social responsibility and respect for people. For decision-makers, this principle requires an understanding of the appropriateness of privacy and confidentiality, preventing harmful effects, prioritising collective participation, and empowering partnerships. It requires a two-way flow of information.

In a pandemic, manaakitanga for individuals and communities implies improving or benefiting people’s health or broader wellbeing – however, the idea of what counts as a benefit may differ between individuals and communities.

Reciprocity is often a key feature of this principle, representing:

- helping one another
- acting on any special responsibilities we may have, such as those associated with a profession
- agreeing to provide or enable extra support for those who have extra responsibilities to care for others, for example, providing earlier vaccines or boosters to health professionals exposed to greater risk through their jobs.

The principle of manaakitanga includes ensuring that individuals are not discriminated against if they cannot follow pandemic guidance.⁶³ For example, the guidance from the Government on mask wearing during the COVID response in September 2021 said that ‘wearing a face covering may be unsuitable for some people due to a disability or health condition’.⁶⁴ Nevertheless, many New Zealanders were refused services, or shamed, for their inability to wear a mask.⁶⁵ The principle of manaakitanga aims to protect the social wellbeing of these individuals.

This principle acknowledges the relationship that exists between health professionals and the communities in which they live and work. Health professionals have a special status in society and particular responsibilities. NEAC’s guidance supports the lead taken by health professional organisations and the Health and Disability Commissioner to confirm that health professionals have special responsibilities to provide care in a pandemic, alongside the family responsibilities they may hold, at considerable personal sacrifice.

Tika

Tika refers to what is right and good for any particular situation.⁶⁶ To understand what is right and good in context, there needs to be relationships that enable understanding of communities and what is important to them.

For example, during the COVID-19 pandemic, those New Zealanders who could physically wear a mask, and did so, helped to keep others safe. For a small personal discomfort or inconvenience, the wearing of faces masks in public was shown to be a particularly effective method of preventing transmission.^{67, 68, 69, 70, 71, 72} It helped protect the vulnerable in our society.



In te ao Māori, ‘tika’ is often framed in relation to ‘pono’ and ‘aroha’.^{73, 74} Tika may be thought of as a central principle of ethical behaviour towards other people and the world. Pono means honesty and integrity. Aroha relates to the supreme power and the essence of humanity. All three words are closely intertwined aspects of traditional Māori understandings of the nature of reality, of being human and of right actions in the world, underpinned by other key Māori concepts such as mana and tapu.

In the context of *Ethical Guidance for a Pandemic* this principle embraces openness, reasonableness and tikanga Māori.

- Openness – that is, informing people about why, what, and how decisions will be made and what the next steps are, as well as being seen to be fair. It is hard for those affected by decisions to understand whether those decisions are appropriate if they cannot understand the criteria being used by leaders and those in authority to make the decisions.⁷⁵
- Reasonableness – that is, working with alternative options and ways of thinking, reflecting cultural diversity, using a fair process to make decisions and basing decisions on shared values and best evidence.
- Tikanga Māori – that is, a Māori concept incorporating practices and values from mātauranga Māori or Māori knowledge (and all that underpins it: language, whakapapa, technology, systems of law and social control, systems of property and value exchange, forms of expression, etc).^{76, 77, 78} It is important in a pandemic for tikanga Māori and mātauranga Māori to be reflected and used for the benefit of all New Zealanders.

Tika acknowledges that trust is the foundation upon which our relationships rest. This can be trust at an individual level, with organisations or in the government. The effectiveness of Aotearoa New Zealand’s response to a pandemic rests on the active cooperation of our people and an underlying foundation of tika.

Disinformation, or the purposeful dissemination of false information intended to mislead or harm, erodes trust within and between communities.⁷⁹ This challenges our ability to put this principle into action, and in this context, open government⁸⁰ is essential to establishing tika in context.

Liberty

Article 3 of the 1948 Universal Declaration of Human Rights (UDHR) establishes that everyone has the right to liberty,⁸¹ and the New Zealand Bill of Rights Act 1990 sets out the rights and fundamental freedoms of anyone subject to Aotearoa New Zealand law. As part of Aotearoa New Zealand's uncodified constitution, this Act establishes the liberty of thought, conscience, religion and beliefs and liberties, such as the freedom to peacefully assemble.



Aotearoa New Zealand's Government, Te Kāwanatanga o Aotearoa, is a representative democracy, with a long-standing and deeply held national commitment to liberal democracy.⁸² Liberal democratic states are likely to perceive their governing role as being responsible for reducing health risks to citizens, including promoting the health of groups that are unable to take full responsibility for themselves (such as children).⁸³

A core tension for liberal democracies in reducing health risks is striking the balance between an individual's rights and protecting the collective good. In this context the term 'collective good' means the collective health rights of everyone to the enjoyment of the highest attainable standard of mental and physical health without discrimination, i.e. the collective health rights of the overall population.^{84, 85, 86, 87, 88} Where the decisions of a liberal democratic government infringe on individual rights, any form of coercive measure must be ethically justified.⁸⁹ For New Zealanders, our liberal democracy means we don't consider just our individual right to liberty, but rather we take a collective understanding of our rights. For example, our individual right to liberty does not mean that others do not have a right to health and wellbeing. Our right to liberty should not mean we put others at risk.⁹⁰

However, this principle means that respecting a person's freedom translates to intervening for the shortest duration at the minimum level required to save lives. An important mechanism by which decision-makers can show respect is by seeking information and gaining an awareness of social licence settings from individuals and communities.

Interpreting and applying the principles

Ethical principles require reflection in order to determine what they mean in a given situation. Ethical principles can diverge in what they imply, and, in some cases, a public health decision might remain controversial, no matter how hard we try to reach an ethical decision. For those reasons, we need a framework that guides our interpretation and application of ethics in decision-making.

For example, in the context of a pandemic response, it may not be possible to achieve the principles of equity and health and wellbeing at the same time. A structured approach to how we should interpret and weigh principles is likely to be helpful. In allocating intensive care unit (ICU) beds, a clinician might decide to treat those with fewer comorbidities first, considering this to be the best way to save as many lives as possible. Yet this decision may undermine the principle of equity as we know that comorbidities are not distributed equally, proportionally being more common in indigenous populations, ethnic minorities, the disabled and older people.^{91, 92, 93, 94} There is no way of resolving that ethical tension where the decision-maker does not have to make decisions about the relative value of the principles as they apply. In such cases, it is important to follow a fair process that is accountable and open.

Framework

In some instances, ethical principles will be enough to help individuals and groups respond to a pandemic in an ethical manner. However, there are particularly difficult ethical situations that may need greater support or analysis, particularly in a pandemic relating to public health. Marckmann et al describe a framework for thinking through the ethics of public health.⁹⁵ They describe a set of objectives that those who are making ethically complex public health decisions should aim for.

Making ethically complex public health decisions

The following seven elements show the aims of ethically complex public health decisions. Public health focuses on groups of people rather than individuals and could involve decisions about a wide range of situations or services that impact the Te Whare Tapa Whā model of health.

- 1. Transparency**
Transparency means that those making significant decisions during a pandemic can demonstrate how they considered and applied ethical principles and evidence. This element relates strongly to the principle of **tika** and enables openness and reasonableness.
- 2. Consistency**
Consistency, or applying the same principles and criteria across different public health interventions, does not undermine the principle of **equity**. Instead, having identified that equity is a shared principle for Aotearoa New Zealand, consistency ensures that we do not put aside equity when it could be inconvenient, difficult, or politically inconvenient.
- 3. Justification**
Justification implies a good faith effort to show how the pandemic decision is one that follows from the evidence and principles. Justification is particularly important for contributing to the principles of **kotahitanga** and **liberty**.
- 4. Participation**
Participation is about helping those affected by public health interventions to participate in decision-making. Undoubtedly, this element would be difficult to implement in a pandemic, nevertheless, it links to **tika** and operating in an open manner, as well encouraging **manaakitanga** at a collective level.
- 5. Managing conflicts of interest**
Managing conflicts of interest for decision-makers and minimising harm allows the principle of **health and wellbeing** to flourish.
- 6. Openness for revision**
Being open to revising public health interventions in pandemics, following changes or new information is an important prerequisite to enabling the principles of health and wellbeing and tika.
- 7. Regulation**
Having a regulatory framework that guarantees the other six decision-making elements means that New Zealanders have a clear indication about how decisions will be made and their relationship to the six national ethical principles for a pandemic.

Chapter 3: Readiness and reduction of risk

Introduction

Pandemics

Pandemics are large-scale outbreaks of infectious diseases that can greatly increase morbidity and mortality over a wide geographic area and cause significant economic, social and political disruption.⁹⁶ They have physical impacts, but they also impact our mental, emotional and spiritual health. This aligns with Tā Mason Durie's *Te Whare Tapa Whā* model as each element in the model is interconnected.

Humanity has been confronted by deadly pandemics and large-scale epidemics throughout our history, and such pandemics are becoming more common.^{97, 98} Since 2000, globally there have been:

- a near pandemic from severe acute respiratory syndrome (SARS) (2002–2004)
- H1N1 pandemic from the A(H1N1)pdm09 virus (2009)
- Chikungunya (CHIKV) pandemic (2014)
- Zika pandemic (2015)
- a near Ebola pandemic in over five African countries (2014–2015)
- COVID-19 pandemic caused by the virus SARS-CoV-2 (2019–).

The COVID-19 pandemic has, in particular, fundamentally changed Aotearoa New Zealand. However, not all pandemics are or will be caused by viral microbes. Pandemics have also been caused by bacteria.⁹⁹ Some commentators have also suggested that fungal or man-made pathogens may be the cause of the next global pandemic.^{100, 101} This means that there is no one-size-fits-all health response and the ethical choices we need to make may not match the decisions we made in past pandemics.

National emergency approach

In Aotearoa New Zealand, a pandemic can be categorised as a national emergency.¹⁰²

Our approach to emergency management is known as the '4 Rs': Reduction, readiness, response and recovery. In a pandemic, these can be seen as occurring before, during, and after critical events.

- **Before:** Reduction and readiness – identifying and analysing risks; taking steps to eliminate if practicable, and, if not, reducing the magnitude; and developing systems and capabilities before a pandemic.
- **During:** Response – actions taken during a pandemic to save lives and help communities recover.
- **After:** Recovery – our coordinated efforts and processes to bring about the holistic regeneration of communities following a pandemic.

In national emergency planning 'reduction' and 'readiness' relate to pre-event activities to help protect New Zealanders. Because our national ability to respond to a pandemic is predicated on our health system, the body of this chapter concentrates on the state of our health and disability system.

Readiness

Aotearoa New Zealand has a publicly funded health and disability system that is under stress and has structural access barriers for some groups that mean it does not deliver equally for all our people.¹⁰³

Our health and disability system is faced with increasing demands as people live longer, our population ages and the global costs of medical technology and pharmaceutical advances rise. 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, compared with similar funding systems in countries such as Australia and the United Kingdom.¹⁰⁴

In 2018, the Government inquiry into mental health services identified that our mental health and addiction system is under pressure. Markers of this increased pressure include:

- limited or unavailable advice or support at times of crisis
- waiting times for young people (0–19 years old) that are longer than those for all other age groups and do not meet government targets or community expectations
- specialist services operating at capacity
- restrictive criteria being applied and health services being able to accept only the most distressed or unwell people.¹⁰⁵

As stated above, we are living longer, and our population is ageing. It is expected that, by 2034, older people (65 years and older) will make up 21 percent of our population.¹⁰⁶ This significant group of our society may be living with chronic anxiety, depression and dementia or may develop schizophrenia, psychosis or addictions late in life.¹⁰⁷ Recent trends in service-use data indicate that older people are less likely than people aged 25–64 years to use primary mental health care services and are especially unlikely to use psychologist services.¹⁰⁸ Older people may be overlooked in reporting about mental health services, in part, as a result of inconsistent service provision and a lack of national data.¹⁰⁹ Harms to vulnerable older people may be compounded by multiple intersecting factors, including a lack of protection for essential front-line workers’ mental and physical health and a lack of access to PPE and triage policies that prioritise younger patients.¹¹⁰ Multiple medical conditions can compromise older adults’ abilities to advocate for their needs or rights.¹¹¹ A pandemic, with reduced or limited access to family, friends or carers, can exacerbate this situation.^{112, 113, 114}

To be ready for the next pandemic, our health care system needs to be fit for purpose and connected to our diverse communities so that we respond immediately and readily reach all our people. This includes ensuring that the system and associated committees and providers have a diverse membership, including disabled people, women, Māori, Pacific peoples, migrants, former refugees, and LGBTQIA+ including takatāpui Māori to facilitate unbiased outcomes and increase trust in the decision-making process.

While the government has a key role to play, being ready also relies on individual, whānau and community involvement. During the COVID-19 lockdowns, commentators noticed that many of the most successful approaches drew on collaborative applications of tikanga Māori (for example, iwi checkpoints and care packages led by hapū and iwi).¹¹⁵

As a model that has all four elements working in harmony, each one requiring the other, Te Whare Tapa Whā can teach us how to foster readiness for the next pandemic. It highlights that such readiness is about not just the physical element of health but also the elements of mental health and social and spiritual connection.

Preparing our health and disability system

Over the next two decades, our population is projected to become more ethnically diverse. According to Stats NZ's median population projection, Māori will increase from 17.1 percent of the population on 30 June 2021 to 20.1 percent by 2041.¹¹⁶ Likewise, Pacific peoples are projected to increase from 8.6 percent of the population to 10.5 percent and Asian populations from 17.1 percent to 25.2 percent over the same time period.¹¹⁷ And in 2021 the Red Cross noted that New Zealand welcomed former refugees from 21 different countries.¹¹⁸ As our population changes so must our health care system to account for diverse cultural needs.

Alongside these changes in our population, the health care system itself is about to undergo the largest change in a generation, with the 2021 announcement of the health and disability system reforms.

Indigenous health

The 2019 *Hauora* report from the Waitangi Tribunal identified the need for fundamental changes in our health care system, with the Director-General of Health noting in his testimony:

This state of health for Māori is unacceptable and it is the core business of the New Zealand health and disability system to respond effectively ...¹¹⁹

In addition, the Final Report of the Health and Disability System Review in 2020 acknowledged the health and disability system “must create opportunities for Māori to exercise their rangatiratanga, mana motuhake, and whānau rangatiratanga”.¹²⁰

Progressing equality is a feature of the subsequently proposed reforms, and a key measure of the success of the reforms has been identified as being whether the reforms embed:

... te Tiriti principles throughout, where Māori have real authority to develop and implement policies which address their needs in ways which respect te Ao Māori, and a system where all New Zealanders, Māori, Pacific, European, Asian, disabled, rural or urban, understand how to access a system which is as much about keeping them well, as it is about treating them when they become sick.¹²¹

This is reflected in the **ethical principles** that this document has proposed for a pandemic. However, the health and disability system has a responsibility to contribute to meeting the Crown's obligations under Te Tiriti o Waitangi. Te Tiriti o Waitangi is a fundamental component of Aotearoa New Zealand's unwritten constitution, and in an emergency like a pandemic, it is even more important that the Crown upholds its obligations.¹²²

Supporting the Aotearoa New Zealand health and disability system to meet its obligations under Te Tiriti o Waitangi is necessary if we are to ensure iwi, hapū, whānau, and Māori communities are active partners in preventing, mitigating, and managing the impacts of a pandemic or public health emergency on those communities.¹²³

The need for equity

Alongside the importance of Te Tiriti o Waitangi, the focus on Māori health and equity is critical as Māori experience higher rates of infectious diseases than other New Zealanders.^{124, 125} For instance, the Māori infection rate for the 2009 H1N1 influenza pandemic were twice as high the rate for Pākehā.¹²⁶ Furthermore:

- Māori are more likely than non-Māori to access health services later and to experience serious disorders and/or co-existing medical conditions,¹²⁷ and individuals with underlying conditions are at increased risk of severe infection from disease and may therefore be more vulnerable in a pandemic

- one-quarter of New Zealanders live with one or more disabilities, and this is expected to increase¹²⁸ (Māori have significantly higher rates of disability, with 14 percent of Māori children living with disabilities compared with 11 percent of children nationally; 32 percent of young and working age Māori living with disabilities compared with 21 percent of young and working age people nationally, and 62 percent of older Māori (over the age of 65 years) living with disabilities compared with 59 percent of elderly people nationally)¹²⁹
- Aotearoa New Zealand’s mental health challenges and suicide rates remain high, with higher suicide rates remaining for males, Māori, and those in rural areas.¹³⁰

All these inequities mean that, in preparing for a pandemic, we must also address comorbidities and conditions such as hypertension, obesity, diabetes, cardiovascular and chronic respiratory diseases, and cancer. Comorbidities and conditions are preventable and can often occur as a result of systematic inequities within the health and disability system. This creates an even greater imperative for us to focus on equity as an integrated response to a pandemic and the relational impacts of the wider health system.^{131, 132}

While a pandemic response should aim to avoid exacerbating existing inequities, ongoing solutions to address historical injustices are still required. As stated in the Waitangi Tribunal’s *Hauora* report:

Under an equity-focused health system, the depth of, or imminent threat posed by, health inequity should heighten the urgency of action; the Crown’s Treaty obligations are heightened under similar conditions. The deeper the need, the more urgent and substantial the targeted response should be.¹³³

This is reiterated in the statement by Te Rōpū Whakakaupapa Urutā (Urutā), the national Māori pandemic group, that:

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 [Māori], our loved ones and our communities experience daily.¹³⁴

Aotearoa New Zealand must address the inequities that currently exist in the health and disability system for our diverse population. Our response to a pandemic relies on this health system. Pandemics and other public health emergencies often have the biggest impact on marginalised communities.¹³⁵ The next pandemic will therefore highlight and exacerbate existing inequities within the health system. For this reason, NEAC has prioritised its explanation of equity and its importance in regard to addressing pandemics.

Health investment

In 2019, the OECD estimated that 9.1 percent of our gross domestic product (GDP) is spent on health, slightly more than the OECD average.¹³⁶ Nevertheless, they also noted that in Aotearoa New Zealand’s health system:

- at least one-third of all cancer deaths could be avoided through primary and secondary health preventions
- obesity is estimated to be responsible for 4.4 percent of Aotearoa New Zealand’s total health expenditure, with Aotearoa New Zealand having the third highest rates of obesity in the world
- two of the highest rates of hospital admissions are for chronic obstructive pulmonary disease (COPD) and asthma, which may be partially driven by our high rates of these conditions, but that our primary health care system could provide better support for these conditions.¹³⁷

In the OECD, Aotearoa New Zealand has one of the lowest levels of ICU beds per capita, with close to 4 beds per 100,000 people (as at 2019).¹³⁸ In comparison, in the same year Australia had 9 and Belgium had 17 ICU beds per 100,000 people.¹³⁹

A 2018 report from the OECD on the employment, health and welfare systems in Aotearoa New Zealand identified that these systems were failing people who suffered mental illness.¹⁴⁰ The findings from the Government inquiry into mental health the same year identified that Aotearoa New Zealand's mental health services were overwhelmed and focused on crisis care rather than the wider population's increasing rates of depression, trauma, and substance abuse.¹⁴¹

The economics of readiness

The health and disability system reforms are an indication that Aotearoa New Zealand is willing to invest in improvements to our overarching approach to health and disability. However, ensuring our health and disability system can respond to the next pandemic is not without economic cost. Nevertheless, the cost of not preparing for the next pandemic is likely to be more expensive in the longer term than preparing ahead of time. For example, within the first year of the COVID-19 pandemic the Economic Counsellor and Director of the Research Department at the International Monetary Fund (IMF) estimated the global response cost at over USD11 trillion.¹⁴² By comparison, the Global Preparedness Monitoring Board suggests that investments in pandemic preparedness would be an additional USD5 per person per year – or about USD39 billion globally. At that level, it would take 500 years to spend globally as much in preparedness as the world lost in less than a year to COVID-19.¹⁴³

The noted success of Aotearoa New Zealand's international response to COVID-19 has often emphasised the fact that our leaders did not make a choice between protecting people and protecting the economy. Rather, by taking strong and effective public health action, they have minimised harm and encouraged productivity and security.^{144, 145}

Despite this international acclaim, Aotearoa New Zealand's Child Poverty Action Group (CPAG) has estimated that, in the year since the first COVID-19 outbreak, up to 18,000 more of our children could be living in poverty. CPAG has estimated that Māori and Pacific children around 2.5 to 3 times as likely as Pākehā children to have been pushed into poverty, and children of other ethnicities are also around two times more likely than Pākehā to have been pushed into poverty.¹⁴⁶ The continued rise in childhood poverty and economic inequity, particularly for Māori, indicates that Aotearoa New Zealand's investments would be better targeted ahead of the next pandemic rather than during.

Building back better

A central tenet of this economic approach is investment in a people-centered recovery that focuses on wellbeing, improves inclusiveness, and reduces inequality. It calls for governments, when developing policy, to place emphasis on elements that improve wellbeing, such as income, job quality, housing, and health.

Placing an emphasis on preventative investments across a range of sectors for all society will both improve resilience to and reduce the costs of future pandemics. Some key examples for building back better across sectors include:

- enhancing biodiversity while ensuring a resilient supply of food
- investing in low-carbon, resilient electricity systems
- encouraging energy efficient housing as part of compact, resilient, and sustainable cities
- improving resilience of supply chains while accelerating the shift towards circular economy principles.¹⁴⁷

Social determinants of health

NEAC's wide definition for ensuring that Aotearoa New Zealand's health and disability system is ready builds on the WHO's description of social determinants, that is:

... the circumstances in which people grow, live, work, and age, and the systems put in place to deal with illness. The conditions in which people live and die are, in turn, shaped by political, social, and economic forces.¹⁴⁸

The WHO proposes that the social determinants of health include socioeconomic position, early life, social exclusion, work, unemployment, social support, addiction, food and transportation.¹⁴⁹ Other social determinants of health include education,¹⁵⁰ housing and the environment¹⁵¹ and disability.¹⁵² Social inequalities and disadvantage have been identified as the main reasons for avoidable and unfair differences in health outcomes and life expectancy across groups in society.¹⁵³

Te Whare Tapa Whā, as a model of health, means that in preparing for a pandemic Aotearoa New Zealand must consider several factors outside the remit of traditional health concerns, including the following.

- Psycho-social stresses linked with being unemployed or underemployed and their link to physical and mental health and wellbeing.¹⁵⁴ Obtaining quality work helps to protect health through increased self-esteem and a positive sense of identity, while also providing the opportunity for social interaction and personal development.¹⁵⁵
- Access to appropriate, affordable, and secure housing, which can limit the physical and mental health risks of homelessness and overcrowding. There is evidence to suggest a direct link between poor-quality housing and poorer physical and mental health.¹⁵⁶ Young people, Māori, Pacific peoples, disabled people and the unemployed are at greater risk of living in poor-quality housing.¹⁵⁷
- Social connectedness or the degree to which individuals form close bonds with others has been linked with lower morbidity and increased life expectancy.¹⁵⁸ Social networks may provide benefits to mental and physical health by providing emotional or practical support.¹⁵⁹
- A strong sense of cultural identity has been shown to have a positive impact on mental health outcomes in Māori youth.¹⁶⁰ This is of particular importance in a pandemic where, due to travel restrictions, Māori may be unable to return home to their papa kāinga.

Therefore, when considering our readiness for a pandemic, our collective consideration should not be limited to physical health, but rather it should comprise a summation of how we have responded to the holistic needs of our communities before the next event.

Digital inclusion

Internet access, digital technologies and digital capabilities will be essential tools for getting through any pandemic. However, research has shown that 11 percent of New Zealanders do not currently have access to internet at home,¹⁶¹ and 20 percent do not have the digital skills needed to navigate the modern world.¹⁶²

Preparing for the next pandemic means bridging this digital divide so that a portion of the population is not left behind in our country's response to a pandemic. This could entail ensuring all New Zealanders have equitable access to internet, smart devices and digital skills and we innovate and invest in alternatives to app-based methods of contact tracing.

Community readiness

While the health and disability system is the major contributor to our pandemic readiness, there is a wider role for us all to play. A whole-of-society approach to pandemic readiness emphasises the significant roles played by individuals, whānau and communities in mitigating the effects of a pandemic.¹⁶³

Businesses

Businesses have a responsibility to develop capacities for mitigating the effects of a pandemic, including developing robust contingency and business continuity plans.^{164, 165} As part of ensuring readiness, it is crucial businesses explore alternative approaches that allow existing key business priorities to continue during any pandemic. The COVID-19 pandemic also highlighted the need for businesses to have free-flowing, trustworthy methods of communicating verified information to staff and customers.

The importance of businesses having pandemic management plans (for a range of scenarios, not just air-borne viruses) should be at the forefront of business security. The OECD have provided a responsible business conduct (RBC) approach to support companies as they build resilience and their longer-term value during a pandemic.¹⁶⁶

The **ethical principles** we have identified are applicable to the operation of businesses in a pandemic, as the *Harvard Business Review* noted in response to COVID-19: 'Be aware that consumers will remember how you reacted during the crisis'.¹⁶⁷ As individuals, we can act on these principles too when we interact with businesses: for example, by offering manaakitanga to small businesses by going out of our way (where financially possible) to buy local and support industries that may have to limit or change their operations in a pandemic. We can protect the health and wellbeing of businesses and their staff by engaging in such a way that we lower the risk of any transmission. We may also choose to show kotahitanga by using social media to show support for businesses that have undertaken ethical and meaningful actions in their communities.

Businesses also have important roles in supporting the overall **response** to a pandemic. While businesses such as supermarkets and in-home care services are clearly critical for maintaining health and wellbeing, medical and technology-based businesses also have a strong role to play. For example, they enable access to and training in digital technology or medical research to track and reduce the transmission or impact of a pandemic in Aotearoa New Zealand. Multi-disciplinary businesses or researchers may be highly effective at capturing complexities in social inequalities and human behaviour to enable a rapid response through early detection.

Aotearoa New Zealand businesses may also form part of an international web of local and international expertise and knowledge, available in the public health and animal, plant, and environmental health (such as climate change) domains of pandemic management.

Collectives

Communities

Community groups can be well placed to raise awareness, share accurate information, provide, or facilitate potentially needed services and liaise directly with the government during a pandemic. For this reason, it is important for community groups to know their strengths and potential roles ahead of the next pandemic. Understanding the limits of their role and what roles would be inappropriate for them to take on are also fundamentally important. The need for government to be aware of and support community-led readiness is particularly meaningful for marginalised communities, including lesbian, gay, bisexual, transgender, intersex, queer and/or 'questioning', or asexual (LGBTQIA+) individuals. For younger LGBTQIA+ individuals, being in Aotearoa New Zealand's COVID-19 lockdown often meant staying with family. But not all family situations are safe and supportive.¹⁶⁸ In a restricted, lockdown environment, family members may abuse, shame or add barriers to accessing community support networks that offer protective services and information.¹⁶⁹ LGBTQIA+ populations over all demographics have well-documented health disparities, often arising from inequitable

treatment and historical (and sometimes ongoing) marginalisation, discrimination and mistreatment.¹⁷⁰ The first comprehensive trans-led research project into the health and wellbeing of trans and non-binary people in Aotearoa New Zealand, *Counting Ourselves*, speaks to some of these health inequities.¹⁷¹

The Ministry of Justice's New Zealand Crime and Victims Survey from November 2020 indicated that LGBTQIA+ communities experience higher levels of crime (sexual crimes and violence) on average than other population groups.¹⁷² In particular, the survey found that 14 percent of bisexual people and 23 percent of lesbian and gay adults reported sexual or violence crimes to police, compared with the Aotearoa New Zealand average of 25 percent. Hence, from a health perspective, these communities remain a vulnerable group that needs to be specifically supported to be treated equitably.

To continue making progress towards LGBTQIA+ inclusion, Aotearoa New Zealand needs policies that foster a culture of equal treatment in health care, employment, and education and to better represent these populations in our national statistics.

Additionally, responding to a pandemic may have flow-on effects for women in domestic abuse environments. Domestic violence is a key component of the inequality experienced by women and their health and death by homicide.¹⁷³ In 2015, the United Nations referred to this violence as one of the most significant issues to be addressed in our time.¹⁷⁴ And when globally COVID-19 restrictions increased the rates of domestic violence globally, the United Nations Secretary-General called for governments to “make the prevention and redress of violence against women a key part” of national pandemic response plans.¹⁷⁵ However, the time for government to connect with and support the social infrastructure that exists in our communities is not during a pandemic but rather *before* a pandemic.^{176, 177, 178} In doing so, the government is better able to facilitate a community-led response that is resilient and leads to better health and wellbeing.¹⁷⁹ Future pandemics may affect different communities in different ways, for example over half of Māori, Pasifika, and Asians say incidents of racism in New Zealand increased following COVID-19.¹⁸⁰

Former-refugee and migrant communities

For the same reason, it is also vital that government connects with and supports former-refugee and migrant community groups *before* a pandemic. Even in the absence of a pandemic, the critical challenges people from former refugee and migrant backgrounds face as they build their lives in Aotearoa include inequality, social isolation, discrimination and even exploitation.¹⁸¹

Former-refugee and migrant groups living in Aotearoa New Zealand have reported the impacts of COVID-19 as including: financial difficulties and feelings of isolation, loneliness and anxiety due to financial status and separation from family and friends.¹⁸² Lack of information and language barriers could hinder former refugees and migrants from seeking and receiving COVID-19 related support.¹⁸³ A WHO advocacy brief on the subject (in which over 30,000 people from WHO member states were consulted) reported similar findings.¹⁸⁴

Readiness plans should attend to the decrease in connectedness that former-refugee and migrant communities (including international students and migrant workers) face during a pandemic. The plans should also foster positive relationships with appropriate social networks and community services. A call has been made for a ‘whole-of-society approach’¹⁸⁵ to address the challenges and build a better future for former-refugee and migrant communities. A whole-of-society-approach, in keeping with Te Whare Tapa Whā model of health, recognises the interdependency of systems and:

- creates a platform for different sectors to come together to discuss issues and opportunities to co-create action-based solutions with communities
- communicates community insights to Aotearoa New Zealand leaders, recognising the importance of engaging with policy makers to activate systems change
- cultivates relationships for accountability.

Iwi

Marae often become a community hub when a disaster strikes, including during pandemics.¹⁸⁶ For instance, Kōkiri Marae in Lower Hutt was one of many that provided food parcels and health and social services during COVID-19 responses in 2020.¹⁸⁷ The strengths of this approach have been supported in research from COVID-19, including finding that a Māori led and Māori designed approach is more effective.¹⁸⁸ The research focused on eight iwi around Taranaki and highlighted that:

... an indigenous-led response to a new infectious disease threat can provide a high level of protection for people who are normally considered to suffer poor health outcomes. Taranaki iwi and Māori health providers quickly rose to the challenge and provided comprehensive and holistic services for their people in a way that mainstream services, with their one-size-fits-all approach, were unable to ... this study reinforced the value of whakapapa and relationships as the most important parts of a successful COVID-19 response for Māori in Taranaki.¹⁸⁹

The research also found that the use of mātauranga tangata whenua or indigenous knowledge contributed to the resilience of iwi throughout the lockdown period.¹⁹⁰ The use of tikanga Māori and mātauranga Māori should be considered under the principle of tika in any pandemic response.

Taking a tikanga Māori and kaupapa Māori approach does not negatively impact non-Māori – the benefits are felt across the wider community.^{191, 192} For example, when Te Arawa Lakes Trust placed a rāhui on 14 Te Arawa lakes over Easter weekend in 2020, this ensured the safety and security of the wider community living around the lakes.¹⁹³ A rāhui is a form of tapu, restricting access to, or use of, an area or resource by the kaitiaki of the area.

The powerful role that iwi and hapū leaders have in communicating and providing information in response to mis- or dis-information shared about a pandemic and potential treatments or vaccines, is discussed further in the **Community groups and iwi** subsection under the **Communications, engagement and freedom of speech** section below.

Individuals and families

Ahead of a pandemic, there is a responsibility for individuals to take preparatory steps. For instance, ensuring they have access to food, water, and medicines in their emergency preparedness kit (a guide for what to include in an emergency kit can be found from the government's Get Ready website at <https://getthru.govt.nz>). Additionally, Te Puni Kōkiri has published a *Civil Defence Marae Emergency Preparedness Plan*,¹⁹⁴ which may be useful to others who can provide shelter and support in the next pandemic.

Because a pandemic may be transmitted from one person to another, the adoption of individual and household behaviours and measures as accepted cultural habits is likely to increase our readiness collectively as a country.¹⁹⁵ Such behaviours include covering coughs and sneezes, rigorous hand washing and staying home when feeling unwell.

The role that individuals play in communicating clear and accurate information is discussed further under **Individuals and families** in the section **Communications, engagement and freedom of speech** below.

Reduction of risk

Alongside ensuring that we are ready to face the next pandemic, there are steps that Aotearoa New Zealand can take to reduce the likelihood of a pandemic beginning here or overseas.

Environmental risks

The Intergovernmental Science-Policy Platform on Biodiversity and Ecosystem Services (IPBES), an organisation affiliated with the United Nations, has published a report on the links between pandemics and the environment. This report estimates that there are 1.7 million as yet ‘undiscovered’ viruses existing in birds and mammals, with at least 631,000 suspected as being able to infect humans.¹⁹⁶

The report outlines that the risk of pandemics is increasing rapidly, and that with at least five new diseases emerging every year in humans, there is a possibility of any one of these diseases meeting the conditions required to start a new pandemic.¹⁹⁷ Over 70 percent of emerging diseases (for example Zika or Ebola) and almost all pandemics (for example HIV/AIDS and influenza), have been caused by microbes usually found in animals but that can be transmitted to humans (scientifically known as zoonoses).^{198, 199} This means that human behaviour that changes how we engage and relate to animals has the largest impact on the risks of developing a new pandemic.²⁰⁰ In particular, it is estimated that 30 percent of emerging infectious diseases since 1960 have been due to land use changes, particularly deforestation for farming and urbanisation.²⁰¹ Land use changes have driven a loss in biodiversity and this loss can lead to increased risk of emerging diseases, where species who can adapt to human landscapes are also sometimes able to harbour zoonotic pathogens.²⁰²

In particular, most animals involved in zoonotic events are domestic (livestock, domesticated wildlife and pets), logically reflecting their contact rates with humans.²⁰³ Researchers note that eight variants of avian flu already exist that can infect and kill humans and are now regularly found in chicken factory farms globally, although not yet in Aotearoa New Zealand.²⁰⁴ In 2013, the Food and Agriculture Organization of the United Nations noted:

... a pathogen may turn into a hyper-virulent disease agent; in *monocultures* involving mass rearing of genetically identical animals that are selected for high feed conversion, an emerging hyper-virulent pathogen will rapidly spread within a flock or herd.²⁰⁵

In 2020, there were close to 25 million chickens in chicken farms in Aotearoa New Zealand.²⁰⁶ While conventional cages will be banned by 2022 (and the new colony cage environment provides 750 square centimetres per bird), nevertheless keeping animals penned in the same location triggers genetic changes in common bugs, for example, *Campylobacter*, which is fairly widespread in Aotearoa New Zealand’s poultry population.^{207, 208, 209}

Globally, there is an increasing demand for bovine milk and meat.²¹⁰ However, this demand encourages more intensive production (higher stocking rates of potentially genetically similar stock), meaning these animals have greater contact but also may lack the genetic diversity that would resist the spread of a potential disease (this is also known as the monoculture effect).^{211, 212}

This intensification of farming systems also results in increased fertiliser use and effluent (livestock waste). This can then foster potentially dangerous pathogens through the creation of nutrient-rich environments.²¹³ This may be of particular concern in Aotearoa New Zealand, with dairy cattle numbers increasing nationally from 3.4 million to 6.3 million between 1990 and 2019 (an increase of 82 percent).²¹⁴

Climate change has also been implicated in the emergence of new diseases.²¹⁵ For example, the tick-borne disease encephalitis (inflammation of the brain) causes around 2,500 cases a year in the European Union, with 95 percent of realised²¹⁶ infections requiring hospitalisation and an overall patient fatality ratio of 0.5 percent of patients.²¹⁷ Increasingly warm temperatures are increasing the risks of encephalitis by causing changes in the tick’s lifecycle.²¹⁸

Climate change may also cause pandemics in the future through its impact on behaviours – there may be new areas of contact between humans and animals, increased contact or otherwise disruptions of natural host/pathogen dynamics.²¹⁹ For example, fungi are now able to move out of the geographical zones they have previously remained within due to climate change and are learning new behaviours that allow them to move between species in new ways.²²⁰ In doing so, they are becoming more successful pathogens, with the possibility of threatening human health in new ways.²²¹

However, in Aotearoa New Zealand, human health considerations may not always be considered in land-use planning decisions.

NEAC would note that there is a strong opportunity to build the principle of health and wellbeing into the replacement legislation for the Resource Management Act 1991 (RMA). The three replacing Acts (due on or before 13 January 2024) are:

- the Natural and Built Environments Act (NBA) for land use and environmental regulation (as the primary replacement for the RMA)
- the Strategic Planning Act (SPA) to integrate with other legislation relevant to development
- the Climate Change Adaptation Act (CAA) to address issues associated with managed retreat and adaptation resulting from climate change.

These Acts are obvious opportunities to embed health considerations into our legislative framework around land use for health protection. As Aotearoa New Zealand makes choices around our collective response to conservation, climate change and biodiversity, there is an opportunity for our country to become a world-leader in integrating health considerations. There may also be a chance to avoid potential increased risk of pandemics.

Global cooperation

Given the global nature of the recent COVID-19 pandemic, with multiple epicentres and mutations, experts agree that a broader cooperative approach is needed to reduce the likelihood and risks of future pandemics.

As the G20 High Level Independent Panel on Financing the Global Commons for Pandemic Preparedness and Response (HLIP) outlined in July 2021:

The world does not lack the capacity to limit pandemic risks and to respond much more effectively than it has responded to COVID-19. We have the ideas, the scientific and technological resources, the corporate and civil society capabilities, and the finances needed.

Our collective task must be to better mobilize and deploy these resources to sharply reduce the risk of future pandemics, and the human and economic damage they bring. This will require whole-of-government and whole-of-society responsibilities, not only those of health authorities and medical scientists.²²²

This type of multi-country agreement could lead to an opportunity for Aotearoa New Zealand to contribute to mutually agreed goals or targets for the environment, focused on human health. The report from the IPBES promoted a similar approach alongside an opportunity for intergovernmental ‘health and trade’ partnerships designed to reduce risks of zoonotic diseases from the international trade of wildlife.

The World Economic Forum has called for the United Nations, WHO and international financing institutions to develop a mechanism to sustainably finance global health security. This would recognise preparedness as a ‘global common good’ outside the normal political and economic cycles.²²³

Chapter 4: Response

Aotearoa New Zealand can get through a pandemic when we work together. The COVID-19 pandemic of 2020/21 showed us that, as a nation, we can make personal, social and economic sacrifices for the good of others.

However, while this chapter on Aotearoa New Zealand's response to pandemics emphasises a national approach, this does not mean that every response should be the same across the country. There may be differences in how New Zealanders are asked to unite and respond based on a number of factors including, for example, age or region. As we understand more about the nature of any future pandemic (for example, mutations in a water-borne virus or infection rates in a fungi-based pathogen, etc), the national and regional approach to that pandemic will change. This may include taking a flexible, multi-level approach that can allow for the pandemic response to be tailored according to epidemiological evidence across varying contexts in real time.

This section is divided into an ethical review of:

- interventions to improve a pandemic situation
- communications and engagement during a pandemic
- data, privacy, and digital technologies in a pandemic.

Interventions to improve a pandemic situation

A range of interventions may be used to slow or stop the spread of a pandemic. These include personal hygiene measures, the use of PPE, social distancing, contact tracing, testing, lockdown, quarantine, and vaccinations.

Each of these interventions includes, to varying extents, a potential restriction upon individual rights, such as the freedom of movement or protest. Protecting such individual rights must be balanced against protecting collective rights, for example, the right to good health.

Justification for interventions

Interventions designed to slow or eliminate the spread of a pandemic should align with the national ethical principles. They must also reflect the following considerations.

1. When possible and appropriate, restrictions should be agreed rather than imposed. Measures that have been agreed to willingly are, all other things being equal, better ethically.
2. Restrictions should aim to minimise any limitation of human rights and carefully describe the justification for that limitation. Special attention may be needed for people who are subject to restrictions (for example, to their freedom of movement) to ensure their other rights are protected.
3. Reciprocal support may be appropriate for people who, in order to protect others, have restrictions imposed upon them.
4. Restrictive measures can be justified only when all the narrowly defined circumstances set out in human rights law, known as the Siracusa Principles (discussed below), are met.²²⁴

Siracusa Principles

The Siracusa Principles on the Limitation and Derogation of Provisions in the International Covenant on Civil and Political Rights (the Siracusa Principles) set out narrowly defined circumstances in international law where human rights may be restricted in the interests of public health. These principles, agreed by the United Nations Commission on Human Rights in 1984, provide a useful guide when restricting individual freedoms in the public interest during a pandemic. The Siracusa Principles can be summarised as follows.

- a) The restriction is provided for and carried out in accordance with the law.
- b) The restriction is in the interest of a legitimate objective of general interest.
- c) The restriction is strictly necessary in a democratic society to achieve the objective.
- d) There are no less intrusive and restrictive means available to reach the same objective.
- e) The restriction is not drafted or imposed arbitrarily, that is, in an unreasonable or otherwise discriminatory manner.
- f) The restriction is based on scientific evidence.
- g) The restriction is of limited duration.
- h) The restriction is respectful of human dignity.
- i) The restriction is subject to review.²²⁵

Although it is important that restrictions on human rights are in accordance with the law, adherence to this Siracusa principle is not necessarily enough to ensure that a human rights restriction is ethical. Therefore, these principles *must* be taken in conjunction with one another. Laws may need to be adapted, or we may need to have new laws passed in order to be able to ethically respond to a pandemic.

Government intervention

The Nuffield Council on Bioethics' intervention ladder (which NEAC has adapted below for relevance to a pandemic) highlights the general strategies, across increasing levels of coerciveness, available to decision-makers when intervening for public health.²²⁶ The ability of governments to use all elements of the ladder rests on social licence or the population's acceptance of the government's governance. The ladder provides guidance for how cooperation can be informed, encouraged, and enabled in order to achieve the intervention objective voluntarily where possible, without the need for mandatory restrictions on individual rights. This ladder is useful not just for government decision-makers but also for wider community decision-makers, such as doctors and business owners.

The intervention ladder

Do nothing

- Do not intervene, potentially monitor the situation

Provide information

- Inform and educate the public, for example, by starting a campaign to encourage people of the benefits and safety of vaccination.

Enable choice

- Enable individuals to change their behaviours, for example, by offering free vaccines and support to get the vaccine (for example, transport, tailored support to discuss any concerns).

Guide choice through changing default policy

- Change the default policy, for example, by providing vaccines as standard of care in routine medical appointments, with the option available to decline.

Guide choice through incentives

- Guide choice through fiscal or other incentives, for example, by giving out supermarket vouchers upon vaccination.

Guide choice through disincentives

- Guide choice through fiscal or other disincentives to influence people not to pursue certain activities, for example, by imposing fines on those who do not get vaccinated.

Restrict choice

- Regulate in such a way to restrict the options available to people, for example, by requiring proof of vaccination in order to partake in non-essential, commonplace activities such as going to a cafe or getting a haircut.

Eliminate choice

- Regulate in such a way as to entirely eliminate choice, for example, by requiring proof of vaccination in order to partake in essential activities such as going to the supermarket or accessing medical care.

Justification for restricting choice

The intervention ladder shows that the non-voluntary versus voluntary nature of interventions is often not clear cut. For example, an intervention may be presented as 'voluntary' where in fact, due to the severity of disincentives or restrictions, it could more accurately be described as 'de-facto non-voluntary'.

All else being equal, voluntary measures are preferable to non-voluntary interventions. Non-voluntary interventions threaten individual rights, and they can also undermine public trust and cooperation, which are crucial in getting through a pandemic. Allowing groups and individuals to maintain choice and control from the beginning of a pandemic may encourage cooperation throughout.

However, voluntary measures are not always preferable over non-voluntary measures, when factoring in the nuanced context of a pandemic. Some examples to illustrate this are provided below.

1. Non-voluntary interventions have the advantage of ensuring that the intervention is widely utilised, thereby better ensuring that the benefits of the intervention are obtained. For example, if a rest home encouraged visitors not to visit their elderly relatives during a pandemic (to prevent the pandemic from spreading within the home), a single individual who chooses to not cooperate could undermine the cooperation of the majority. The cooperating majority would have made considerable sacrifice to ensure the safety of friends and loved ones but would also have to bear the burden of the uncooperative individual's behaviour. This behaviour would undermine the ethical principles of **health and wellbeing** and **manaakitanga**.

2. Non-voluntary interventions, such as mandatory mask wearing or using contact tracing apps, may also be preferable if they prevent the need for more restrictive interventions, such as lockdown, later. Such minor restrictions ultimately help promote the ethical principle of **liberty**.
3. Most importantly, strong interventions can protect those who are most at risk of being disproportionately affected by the pandemic due to pre-existing inequities. This promotes the ethical principle of **equity**.

Tika, health and wellbeing, and **kotahitanga** should also be kept in mind when being asked to comply with government interventions or restrictions in a pandemic. Although restrictions may involve some level of personal sacrifice, what is good and right for the health and wellbeing of the collective must not be overlooked in personal decision-making.

Manaakitanga is an appropriate response for those people who, in order to protect others, are subject to restrictive measures. For example, social distancing, lockdown, and quarantine measures can have strong negative impacts on mental health by elevating levels of stress, loneliness, boredom or fear.²²⁷ However, these impacts can be reduced by keeping interventions as short as possible, providing adequate supplies and ensuring that quality information is clearly communicated regularly.²²⁸

The justification for interventions is likely to depend on factors such as base levels of social licence and the context of the pandemic. A disease with high morbidity and mortality rates may better justify the use of compulsory interventions than a disease with low morbidity and mortality rates. Taking these factors into consideration requires a careful weighting of values, restrictions, and levels of coerciveness. Whatever balance is arrived at must be transparent and clearly explainable to the groups and individuals that the decision affects. Special care must be taken to prevent rights from being unduly restricted.

Restriction of rights in a pandemic

Article 29 of the **Universal Declaration of Human Rights** states that:

1. Everyone has duties to the community in which alone the free and full development of [their] personality is possible.
2. In the exercise of [their] rights and freedoms, everyone shall be subject only to such limitations as are determined by law solely for the purpose of securing due recognition and respect for the rights and freedoms of others and of meeting the just requirements of morality, public order, and the general welfare in a democratic society.²²⁹

This means that in a pandemic, some rights will need to be restricted in order to protect and promote other rights. For example, the right to refuse to undergo any medical treatment may be limited in order to protect the health and wellbeing of the community. However, the justifications for an intervention, given at the start of this chapter, must be met. Special attention may be needed for people who are subject to restrictions to ensure their other rights are protected.

Local government

During a pandemic response and recovery, local-level efforts are often most critical. Local government decisions are at the forefront of slowing the spread and impact of a pandemic. Local councils play a critical role in ensuring the safety and wellbeing of local communities throughout Aotearoa New Zealand. It is therefore important that central government links in, and works together, with local government. This is particularly important to enable people to continue to access essential services such as drinking and wastewater, public transport and crematoriums and cemeteries.

Community support

Any government intervention in a pandemic needs to involve the community and community-based systems and processes that already exist. For example, in mid-2021 medical professionals in Aotearoa New Zealand expressed concern that the bureaucracy of creating a new approach to COVID-19 vaccination fundamentally delayed this life-saving intervention. Only 143 of 500 vaccination-capable pharmacies and approximately 300 of 1,000 GP practices were providing vaccination services by late August 2021.²³⁰

A community infrastructure-based approach to health and wellbeing has been proven to be cost effective, both in Aotearoa New Zealand and overseas. In the United States, research suggests that investing USD10 per person per year in community-based health programmes (for example, to increase physical activity or prevent smoking) could save the country more than USD16 billion annually within five years.²³¹ While in Aotearoa New Zealand, a 2021 report found that since 2003, Māori health care has been underfunded by up to NZD531 million.²³² This report also suggested that an NZD1 billion a year of extra investment in Māori health care would annually save the country NZD5 billion in health-related costs.

Effects of interventions

Interventions deployed in an emergency may have unforeseen or unintended consequences and may remain with us for a long time.²³³

Many short-term emergency measures will become a fixture of life. That is the nature of emergencies. They fast-forward historical processes. Decisions that in normal times could take years of deliberation are passed in a matter of hours. Immature and even dangerous technologies are pressed into service, because the risks of doing nothing are bigger.²³⁴

It is therefore important to strike a balance between the need to roll out interventions to stop the spread of disease in a timely manner with the need for equity and foresight for the unintended future consequences of these measures.

When choosing between alternatives, we should ask ourselves not only how to overcome the immediate threat, but also what kind of world we will inhabit once the storm passes.²³⁵

This context of uncertainty surrounding efficacy and outcomes of interventions highlights the need for transparency in design and implementation, monitoring (by an independent agency or research body, with the results published)²³⁶ and clear mechanisms for accountability. Findings from the monitoring process should be made publicly available.

It is also important that development of public health interventions not be left to specialists alone. The design and monitoring processes should involve input from individuals, community groups and iwi.

And lastly, to ensure health and wellbeing, these interventions should be treated as *experimental* solutions, with the ability to redesign or withdraw them from the public arena.

Immigration and border settings

In 2020, before COVID-19, over 1,000 people were expected to arrive in Aotearoa New Zealand annually as refugees.²³⁷

Refugees arriving in Aotearoa New Zealand

Refugees arrive in Aotearoa New Zealand in three ways:

- through the United Nations Refugee Agency (UNHCR) resettlement programme
- as ‘convention’ refugees (who have fled from their own country because they fear persecution or harm)
- as family members of former refugees who are already living in Aotearoa New Zealand.²³⁸

When refugees arrive in Aotearoa New Zealand, they stay at the Mangere Refugee Resettlement Centre for six weeks. During this time, they are provided with support to learn English, improve their health, progress their education and find work, and become permanent residents of Aotearoa New Zealand.

Border controls were introduced in Aotearoa New Zealand’s 2020 COVID response to protect public health. However, these controls had a large impact on both New Zealanders, our neighbours, and our mutual economies. In some instances, New Zealanders were unable to return, migrants were separated from their families and there were supply chain issues and skills shortages due to the limits on migration.^{239, 240}

Following the announcement of Aotearoa New Zealand’s border closure in March 2020, no refugees entered the country until February 2021. The UNHCR estimated that, at the peak of COVID-19, 168 countries fully or partially closed their borders, with close to 100 of those countries making no exception for individuals seeking asylum (including initially Aotearoa New Zealand).²⁴¹ There has been criticism that this approach to border closures in relation to COVID-19 violated international laws and the rights of migrants and refugees.^{242, 243}

It is clear that border closures have negatively impacted the lives of the 26.4 million refugees identified by the UNHCR during 2020 and the COVID-19 pandemic. However, it is also clear that the global border closures undertaken in response to COVID-19 are not the only approach to balancing citizen safety with the needs of refugees. For example, Portugal automatically provided full residency rights to migrants and asylum-seekers at the start of the COVID-19 pandemic.²⁴⁴ And the success of refugee resettlement in Aotearoa New Zealand while border controls were in place in 2021 suggests that it is possible to retain border safety during a pandemic while offering *manaakitanga* and *kotahitanga* to refugees. For, as the director of the WHO explained, in a pandemic, ‘no one is safe until everyone is safe’.²⁴⁵

Interventions and incarcerated populations

Ensuring the safety of our incarcerated population is also an important consideration. During the COVID-19 pandemic, internationally prisons were major sources of outbreaks due to factors such as overcrowding, difficulty implementing social distancing procedures and poor access to quality health care.²⁴⁶ Due to the difficulty of ensuring physical distancing and appropriate PPE use, the use of solitary confinement increased, resulting in higher rates of social isolation within prisons, and negative impacts on inmate wellbeing.²⁴⁷ In the United States, it was found that those in incarceration had a five-times greater likelihood of infection and three-times greater likelihood of death from COVID-19.²⁴⁸ Given the strong vulnerabilities of this population in a pandemic, prioritising interventions (like a vaccine) for them has been identified as best practice.^{249, 250, 251}

While COVID-19 had detrimental effects on those imprisoned and working in the prisons, the impact did not stop at prison gates, with families of inmates reporting negative psychosocial effects due to lack of communication and contact.²⁵²

Evidence suggests that where safe, decarceration has had a positive impact on both reducing COVID-19 spread and improving health equity.²⁵³ Decarceration involves releasing inmates, be it on early or compassionate release or pre-trial detentions and reducing the number of new arrests. This helps to reduce prison populations and allows inmates to access communities and community resources, as well as reuniting families; thus, reducing social isolation throughout lockdowns and stay-at-home orders. Where decarceration has occurred for different reasons, no notable increase in violent crime has been found as a result in both Russia and the United States.^{254, 255} However, further research is required to confirm if such an approach would work in

Aotearoa New Zealand and in a pandemic (particularly with regard to domestic violence). This is discussed further under **Chapter 6: Disability** below.

Further evidence is necessary to assess whether decarceration is a viable policy solution to mitigate the risks of a pandemic and improve health and healthy equity outcomes, especially for marginalised groups.

Treatment and elective surgeries

In response to a pandemic, wider elements of safety may need to be considered. For example, in the level 4 COVID-19 response, many elective surgeries were cancelled or postponed in order to preserve resources and PPE, free up space in hospitals and prevent the possible spread of infection. Throughout the ‘first wave’ of COVID-19 and lockdowns in March and April 2020, elective surgery incidence was down globally and wait times were increased compared with in previous years.^{256, 257, 258}

As part of a wider response to a pandemic, specialist appointments may also be deferred, potentially resulting in delayed diagnosis, investigation, and management of a huge number of disabling, painful and potentially life-threatening conditions, such as cancers, vascular disease, heart disease, dementia, inflammatory and neurodegenerative conditions, amongst numerous others. The inability to access specialist services and their associated multidisciplinary teams would also have an impact on recovery and rehabilitation as well as the ability for families to continue to manage the illnesses of their loved ones in their own homes. The delay or deferral of screening services could cause downstream morbidity and reductions in life expectancy for these patients.

In Aotearoa New Zealand during the national lockdown in March and April 2020, there was a significant drop in cancer diagnoses.²⁵⁹ Although this returned to previous levels over subsequent months, there are ongoing impacts, for example, existing inequalities around access to health care services for Māori with lung cancer were exacerbated by the disruptions caused by COVID-19.²⁶⁰

It is also clear that pandemics have ramifications for other significant communicable diseases. For example, globally the number of deaths from tuberculosis rose in 2020 for the first time in more than a decade, according to the WHO.²⁶¹ Approximately 1.5 million people died globally from tuberculosis in 2020, a slight increase from the number of deaths in 2019, when 1.4 million people died.²⁶² This increase was largely driven by fewer people getting tested and treated for the disease due to the focus on COVID-19.²⁶³

In Aotearoa New Zealand, district health boards (DHBs) were directed to reduce their emphasis on the measles vaccination campaign, despite the COVID-19 lockdowns already contributing to a delay in vaccinating children for measles and other diseases.^{264, 265, 266} In this country, the immunisation levels for measles dropped below the 95 percent herd-immunity point that prevents outbreaks.²⁶⁷ There were some community-based steps to rectify this deficit, for example, in September 2021, MidCentral DHB’s primary health organisation Think Hauora organised drop-in clinics and Saturday morning appointments in Palmerston North to make it easier to catch up on measles vaccinations.²⁶⁸ Nonetheless, Associate Professor Helen Petousis-Harris, from the Department of General Practice and Primary Health Care in the Faculty of Medical and Health Sciences at The University of Auckland and a former advisor to the WHO on vaccinations, suggested that ‘New Zealand is facing a measles epidemic in the making’.²⁶⁹

Alongside physical impacts there are psychological impacts for both those waiting for surgeries and first specialist appointments and their carers and families. Many of those waiting for their surgeries reported higher levels of stress, anxiety and/or depression the longer they waited for surgery.²⁷⁰

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.²⁷¹ These patients reported a need for acknowledgement of their situation and greater communication regarding wait times.

Communications and engagement

Access to high-quality information is crucial for getting through a pandemic. High-quality information needs to be accurate, clear, consistent, effective, timely, engaging, and trustworthy. In a pandemic, this ensures that everyone knows what to do and where they can find more information and support. Not only does quality communication inform, but it also encourages people to engage with key public health measures. It can help to build transparency, trust, and cooperation and, in doing so, facilitate a coordinated national response. It can also reduce panic and give people confidence about how to respond in a time of great uncertainty. Without high-quality information, it is difficult for **kotahitanga** to flourish in a pandemic.

Access to high-quality information is therefore of high significance in a pandemic. Key information may fail to effectively reach communities and individuals due to differing needs across audiences, including:

- access to internet and appropriate digital technologies
- cultural and language diversities
- disabilities.

Lack of effective access to information across all audiences has the potential to compound pre-existing inequities. Accounting for these differences in audiences may mean:

- 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, hui, billboards, radio, advertisements, emergency mobile alerts, pamphlets, and newspapers
- sharing information through open conversations
- translating information across the different languages used in Aotearoa New Zealand, especially te reo Māori and New Zealand Sign Language (NZSL)
- engaging with community leaders who can share and discuss information within their communities from a trusted position.

The **data, privacy, and digital technologies in a pandemic** section below discusses more about the digital divide.

Chapter 6: Disability discusses inclusive ways of communication for disabled people.

Not only does a lack of access to high-quality information further entrench inequities, it can also mean that people come to rely on misinformation or disinformation instead. Misinformation is information that is false but not created with the intention of causing harm, while disinformation is information that is false and deliberately created to harm a person, social group, organisation, or country.

Misinformation and disinformation have played a part in wider societal themes centred around mistrust of government, experts and institutional structures and have led to concerns about side effects, medical safety and long-term effects of the vaccine. False information is a direct threat to a successful public health response that must be addressed proactively to ensure that everyone has access to reliable information and is able to discern between reliable and unreliable information.

This requires strategies to counter false information, while also upholding the right to freedom of speech in Aotearoa New Zealand, as a vital component of a robust democracy. Countering false information requires a whole-of-society approach to build awareness about false information and strengthen resilience to it. This means government, civil society, technology-focused companies, media, academia, community figures and the public all have a role to play in developing and preserving public safety, from education to communication. This includes preparing the public to understand that false information will be widely circulated and providing advice on how to identify accurate information. The most effective responses have focused on rapidly intervening to fill an information gap or providing a response to false narratives, without naming or repeating the false information.

Government

In a pandemic, the government should provide a unified voice, offering factual information and practical guidance for the population, as well as positive reinforcement of collective actions to be taken in responding to the pandemic. In COVID-19, this took the form of key messaging, such as:

- ‘unite against COVID-19’
- ‘wash your hands, wear a face mask’
- ‘team of five million’
- ‘stay home, save lives’
- ‘protect yourself and others from COVID-19’
- ‘Super Shot Saturday’.

The government can build trust in official sources of information by working in partnership with iwi organisations and channelling information through localised, tailored, community focused pathways that build on existing trust foundations.

Such campaigns, designed to engender cooperation and collective action, are ethically justifiable insofar as they are not used to mislead or conceal potential risks associated with cooperation. Communications ought to be both informative and encouraging. Sources of further information, including current data and scientific evidence, ought to be provided alongside value-laden information. For example, TV advertisements may encourage people to get vaccinated on the basis of collective responsibility as well as scientific evidence.

Media

The media also have a role to play in preventing the spread of false information. This entails providing accurate, timely reports of relevant information, as well as questioning the government’s response in order to keep the government to account.

In doing so, the media needs to respect the fragile balance of trust and cooperation that is crucial in getting through a pandemic, avoiding undermining a united front for the sake of being controversial. Social media companies can help to counter the dissemination of false information by enabling features on their platforms that flag information that is known to be false and directing users to reliable sources of information. This enables members of the public to fact-check before forming their own independent opinions. Social media companies can also utilise data analytics to reveal where sources of false information are being derived from, which can inform counterstrategies.

Community groups and iwi

Communication during COVID-19 lockdowns showcased the importance of community groups and iwi in communicating the right message. Sometimes, what’s convincing is not the facts and figures behind the information but who is saying it (the ‘medium is the message’).²⁷² Respected figures in our communities play a vital role in providing clear and truthful information and need to be incorporated into the government’s approach to communicating during a pandemic.²⁷³

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 between Māori leaders encouraging participation of youth and peer communication between youth. Officials reflected 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, cause they came out in their thousands [to be vaccinated on Super Saturday] ...²⁷⁴

Individuals and families

Members of the public also have a responsibility to fact-check the information they receive and share. This may include investigating the reliability of the source, doing further research to verify unjustified claims, and reporting false information. Individuals can also have a powerful say in educating their whānau and communities.²⁷⁵

In a pandemic, ensuring access to high-quality information is truly everybody's responsibility. Without this type of information, Aotearoa New Zealand will struggle to unify and save lives.

Data, privacy, and digital technologies in a pandemic

Medical and location data (via health records and contact tracing) is likely to be drawn upon as part of any pandemic response. The collection, sharing, access, storage and use of such data in a pandemic raises important ethical concerns, particularly as the right to privacy comes into tension with the right to health.

Privacy

The right to privacy in Aotearoa New Zealand is established in the Privacy Act 2020 and the Health Information Privacy Code 2020. It is further protected in international law under the 1948 Universal Declaration of Human Rights and the 1966 International Covenant on Civil and Political Rights. Protecting privacy is important for society and individuals because personal information is a taonga (a treasure).²⁷⁶ This means that data should not be shared with those who do not have consent to access that data.

One of the harms of a data privacy breach is that individuals, communities, or groups of people may face stigma, discrimination, or persecution if findings from the data are not communicated sensitively. Even where individual privacy is upheld, identifying a location where an outbreak has occurred could stigmatise a group of people who are blamed for being sources of infection.^{277, 278, 279} It is important to note that the advancement of artificial intelligence (AI) and machine learning techniques poses a risk to both individual and collective privacy from supposedly anonymised data being re-identified, and aggregated datasets being linked.²⁸⁰

Data security, protection and oversight can be achieved and the risk to privacy minimised through various safeguards around the collection, use, management, governance, storage, and destruction of data. Tools to manage these risks are provided by Stats NZ. For example, **Ngā Tikanga Paihere framework** (www.data.govt.nz/toolkit/data-ethics/nga-tikanga-paihere/), which draws on 10 tikanga to help establish appropriate goals, boundaries and principles to guide and inform strong data practices. The Government Chief Data Steward and the Privacy Commissioner have also jointly developed **six key principles** to support safe and effective use of data and analytics, including algorithmic decision-making, in Aotearoa New Zealand. This and the Ministry of Social Development's **Privacy Human Rights and Ethics (PHRaE) Framework** (www.msd.govt.nz/about-msd-and-our-work/work-programmes/initiatives/phrae/index.html) are examples of tools that can be used to encourage safe and responsible data practices during a pandemic.

Access to medical data

The COVID-19 outbreak exacerbated and highlighted (anecdotally) the pre-existing issue of health care professionals' lack of universal access to patient medical data within Aotearoa New Zealand's health care system – for example, when patients needed to be seen by someone other than their regular clinician or managed isolation and quarantine (MIQ) nurses were unable to access a patient's medical record and notes to see, for example, if they had any comorbidities or underlying respiratory illnesses. Although patient privacy must be protected, this right should not unnecessarily interfere with the patient's right to adequate health care in an emergency.

Part of a pandemic response plan may therefore include ensuring that health care professionals have emergency access, through a centralised database, to the medical data of the patients that they are treating. This occurred in the COVID-19 pandemic with the integration of the secure electronic patient-file-sharing platform HealthOne into South Island MIQ facilities. HealthOne 'collects and holds a summary record for every patient in the South Island, including information such as prescribed and dispensed medications, allergies, and alerts, adverse reactions, and observations'.²⁸¹ The integration of this server into MIQ facilities enabled clinicians to provide better, safer care to unwell guests.²⁸²

Collection, access, storage and use of data in a centralised database in a pandemic must meet the privacy requirements set out in the **Health Information Privacy Code 2020** (HIPC) and the **Privacy Act 2020**. A new data system implemented mid-pandemic, granting emergency access to data, should be reviewed post-pandemic to ensure that access to this data is still justifiable.

Ethical access to data in a pandemic also raises the question of whether health care professionals have the right to be informed if a patient in their care has either tested positive for the virus or received a vaccine. In this instance, it is the health care professional's right to health that conflicts with the patient's right to privacy. Knowledge of vaccination or positive test status can help inform health care professionals' practices regarding use of PPE, especially in situations where there is limited supply of PPE. It is also important for protecting the health and wellbeing of other patients within the health care professional's care.

Furthermore, if someone returns a positive test result for a pandemic disease, the principle of health and wellbeing justifies that this data be shared with the government to aid in the government's response plan. The government has a duty to protect the privacy of this data, for instance, by not publicly sharing the information in an identifiable form. The right to privacy surrounding a positive test result or vaccination status is especially important considering the risk of stigma that this information bears.

Digital inclusion

Pandemic responses that rely on digital technology can exacerbate inequities due to the digital divide in Aotearoa New Zealand. Research has shown that Māori and Pacific peoples, older adults, people on low incomes, disabled people, people with lower levels of education and people living in rural areas and social housing are less likely to have access to the internet and digital technologies and the skills required to effectively use them.^{283, 284, 285}

In a pandemic, access to the internet and digital capabilities and technologies is crucial for many aspects of the response, potentially including:

- staying informed
- engaging in pandemic responses, such as contact tracing
- accessing government services
- ordering groceries
- receiving medical care

- working, running a business, or receiving education from home
- booking treatment or a vaccine
- maintaining social and community interactions whilst in lockdown.

As noted in **Chapter 3: Readiness and reduction**, preparing for a pandemic must therefore include reducing the digital divide.

Responding to the digital divide in a pandemic could include providing internet connection and devices to those who cannot afford them and digital skills support to the newly connected.

Spaces such as public libraries could leave their free Wi-Fi services available, while encouraging social distancing and hygiene measures to allow library visitors to use the internet.²⁸⁶

Additionally, meaningful alternatives to digital services should also be provided in a way that upholds the dignity of New Zealanders. This might include ensuring that physical access to supermarkets and in-person medical consultations are maintained and newspapers are still delivered.

Appropriate privacy and health safety measures should be taken to reduce the risk for those who rely on in-person rather than digital services.

More information about responding to the digital divide is provided under the **Communications, engagement and freedom of speech during a pandemic** section above.

Contact tracing

Contact tracing is a key data-based tool in a pandemic for interrupting chains of transmission within the community.²⁸⁷ This is done through the collection, storage and access of location or proximity data. Backward contact tracing refers to tracking an outbreak back to the original source of infection.^{288, 289}

Digital contact tracing tends to take the form of downloadable apps that track the user's activity, for instance, physical locations they have recently visited. In the COVID-19 pandemic, Aotearoa New Zealand's digital response incorporated a contact tracing application (the NZ COVID Tracer app) that people could download on a device to track their movements as a 'digital diary' by scanning QR codes or manually logging places they visit.^{290, 291} The NZ COVID Tracer app uses a strategy of alerting people when they have visited the same place around the same time as a person who tested positive for COVID-19.²⁹² A later modification of the app added optional Bluetooth functionality, allowing notification to occur from contact in a space without a QR code. It is important that there is ongoing review and improvement of contact tracing as the technology continues to evolve.

Choosing between a centralised or decentralised approach to contact tracing

Digital contact tracing can follow a centralised or decentralised model. In the centralised model, data is sent from the user's phone to a central database, where contacts are matched, for instance, by a government health agency. The government agency can then identify individuals and request they self-isolate or quarantine. In a decentralised approach, contacts are matched on the user's phone.²⁹³ This protects users' anonymity from a centralised agency. It has been suggested that a decentralised approach better protects user privacy, whilst a centralised approach may increase the utility, effectiveness, and efficiency of the contact tracing app.^{294, 295, 296, 297, 298}

This is partly because a central authority could use contact tracing data for purposes beyond contact tracing. For example, the data could also be used for research, such as creating social graphs that reveal how people interact with each other. This could help epidemiologists to understand how the disease spreads and the impact of various interventions.

However, this data should not be used for purposes beyond protecting public health in a pandemic, such as for enforcement or sharing with the private sector for marketing. Singapore's government sparked an outcry during the COVID-19 pandemic when it passed laws allowing its police to access data from its TraceTogether mobile app to help them track serious crimes like murder, rape, and drug trafficking after having previously assured its population that data would only be used for contact tracing purposes.²⁹⁹ To maintain social licence, data should not be used for purposes beyond what it was specifically consented for upon the point of collection. Data should be deleted post-pandemic unless specific consent for retention and future use has been obtained. This could include an opt-in consent. An 'opt-in' model of consent in this scenario means that users could choose whether their data is retained by government. A centralised app may also be more effective in a pandemic to the extent that users are more likely to respond to stay-at-home orders and other public health measures from a centralised authority than from a notification on their phone.

Decentralised apps also contain inherent privacy limitations.³⁰⁰ Ultimately, the degree of privacy afforded will depend on the unique configuration of the app. Again, privacy concerns will need to be weighed against protecting public health. Both centralised and decentralised approaches to contact tracing will require additional prevention measures to minimise the risk of a privacy or security breach.

Amidst privacy concerns in a pandemic, New Zealand academics have suggested that ethical contact tracing:

- provides adequate evidence of benefit
- has proportional benefits in relation to the risks
- ensures security and confidentiality of data
- is subject to independent monitoring
- limits data use to contact tracing
- is transparent on how the app works, who has access to data and how data use is governed
- provides equitable access to benefits of contact tracing.³⁰¹

Alternatives to app-based contact tracing

Due to the digital divide, not all people will be able to use contact tracing measures if such measures rely on the person having access to a smartphone. Not only is this an equity issue, as discussed above, but it also risks undermining the efficacy of a contact tracing intervention. This is because if there is not enough uptake, there will be insufficient data to track the spread of the disease.³⁰² Paper-based contact tracing and contact tracing wearables are two alternatives.

Paper-based contact tracing entails people physically signing in, using hard-copy paper forms, at the entrances to buildings. This method is slower, inherently less hygienic and bears a greater privacy risk (as identifying details can be easily accessed by building staff and potentially by other members of the public). This places a greater burden on individuals who do not have access to a smartphone and can therefore be seen as further entrenching inequities during a pandemic.

During the initial stages of the COVID-19 outbreak, Singapore introduced portable contact tracing wearable tokens (wearables), with the same functionality as a contact tracing app, to address this issue. This relied upon the centralised model and was freely distributed amongst the Singaporean population. The wearables were made available via the post or in vending machines at malls and community centres and contained a battery life of 4–6 months.³⁰³ It has been argued that wearables offer the same or possibly less threat to privacy compared with centralised contact tracing apps. Furthermore, they can increase uptake of contact tracing among those who do not have access to a smartphone, reducing inequities and increasing the effectiveness of contact tracing as an intervention.³⁰⁴ As with contact tracing apps, the efficacy of wearables will ultimately depend on the unique configuration and functionality of the device used.

Māori data

Māori data sovereignty must be protected and enhanced during a pandemic. Māori control of Māori data is the primary goal for Māori data sovereignty, improving iwi access to data for governance decision-making and ensuring iwi involvement in governance of data.³⁰⁵

Ensuring Māori have access to high-quality ethnicity data is crucial in enabling Māori to make and enact sovereign decisions.³⁰⁶ High-quality ethnicity data can provide evidence of ethnicity-based health inequities and can be used to inform and improve the pandemic response and health system in general. NEAC acknowledges that Māori are still likely falling between the cracks of data collection in our healthcare system and therefore may not be represented in the data that we have – for example, for those that do not have access to a GP or do not consent to their data being shared.

This necessitates Māori involvement in decisions about the primary collection, sharing, analysis and interpretation of Māori data. Further information and guidance about the treatment of data relating to Māori, including definitions, can be found in NEAC's **National Ethical Standards 2019** (www.neac.health.govt.nz/national-ethical-standards/) and **Ngā Tikanga Paihere** (www.data.govt.nz/toolkit/data-ethics/nga-tikanga-paihere/). The Health Information Standards Organisation (HISO) requirements for health providers and their industry partners regarding personal records and data is available from the **Approved standards** webpage on the Ministry of Health website (www.health.govt.nz/our-work/digital-health/digital-health-sector-architecture-standards-and-governance/health-information-standards-0/approved-standards).

On 30 October 2019, Stats NZ signed a Mana Ōrite Relationship Agreement with the Data Iwi Leaders Group (Data ILG) of the National Iwi Chairs Forum.³⁰⁷ The purpose of this agreement is to encourage Stats NZ and the Data ILG to work together to realise data's potential in making a sustainable, positive difference to outcomes for iwi, hapū and whānau. This may provide an approach for others to use to ensure Māori data is used safely and effectively.

Further considerations

Data collection is not a panacea

Data collection and use in a pandemic must be viewed as one tool amongst many to combat the spread of a disease. Contact tracing can minimise the need for other more intrusive or restrictive interventions, such as testing, lockdown or quarantine.^{308, 309} However, in order for this benefit to be realised, effective contact tracing requires there to be adequate supplies of tests for anyone who thinks they have been infected by the contagion.³¹⁰ Lack of quick, reliable testing will render the collection of data redundant. It is therefore important that the benefits of contact tracing not be oversold or viewed in isolation from other pandemic interventions. Even with adequate testing and high user uptake, there is a risk that a data- or digital-based intervention will fail for technical reasons. This is especially concerning in the pandemic context as the efficacy of digital apps may not have been extensively trialled before deployment. If there is low confidence or uncertainty that a data-based intervention will achieve its proposed benefit, this must be clearly communicated so that informed consent is not undermined. To mitigate the risk of ineffective data collection and use, data-based interventions ought to be based on scientific evidence and must be subject to review, as discussed under the section **Interventions to improve a pandemic situation** above.

The importance of consent

The practice of obtaining informed, voluntary consent enables individuals to maintain a degree of freedom and control over their data. Consent is informed when there is transparency about the associated risks and benefits of data sharing.^{311, 312} Consent is voluntary when a real option to give or decline consent is available. This includes the decisions to carry a smartphone or tracking device, collect data and share data if necessary.³¹³ While focused on informed consent in health research the **Informed consent section** of the National Ethical Standards 2019 (www.neac.health.govt.nz/national-ethical-standards/part-two/7-informed-consent/) provides guidance on how to ensure that consent is clearly and ethically obtained.

An important element of consent is to ensure the principle of **tika** can be enacted through openness and reasonableness. This approach requires that language barriers and lack of comprehension be accounted for.³¹⁴ The section **Communications, engagement and freedom of speech** above includes more information about equitable communication.

The intervention ladder in the section **Interventions to improve a pandemic situation** above provides further discussion on how cooperation in a pandemic can be achieved voluntarily rather than through coercion.

Role of private-sector technology companies

Private-sector companies may also be involved in data collection, surveillance and use in a pandemic, for instance, in the development and implementation of a contact tracing app. Whilst the use of these private sector technologies may be justified in a time of crisis and, in particular, where there is limited social licence for governments to collect such data, there are large risks associated with this approach.

A risk of using private-sector companies, in particular, international firms such as Alphabet (Google), Amazon, Apple, Meta (Facebook) and Microsoft, is the inherent loss of data sovereignty. Data may be stored overseas and may breach Māori data protocols. Handing over Aotearoa New Zealand data to global data corporations in a crisis context carries inherent risk and compromise, especially when, historically, these companies have failed to protect individual and collective privacy.³¹⁵ This risk is exacerbated in the context of increasingly powerful AI and algorithms with the ability to re-identify and extract patterns from supposedly anonymised, aggregated datasets.

There is also risk surrounding how private companies will use and store data about the Aotearoa New Zealand population. Governments have a responsibility to protect citizen privacy in a pandemic by ensuring that private contracts include limits on the purposes for which private companies may access personal or aggregated population data. Namely, access should be specifically limited to protecting public health in the pandemic, with a plan for destruction once the data is no longer required to protect public health. Data should not be used or retained for research, product development or marketing by private companies.

Another concern is the creation of an overdependency on private companies that are already powerful in other domains. By outsourcing the development of contact tracing apps to private tech companies, the government risks allowing the private sector to take over the function of public sector actors in the provision of public services.³¹⁶

Awareness of the short- and long-term risks involved, resulting in a cautious approach and strong regulation, must remain at the forefront of public decision-making and debate.

Chapter 5: Recovery

Recovery is about charting a path forward, while unravelling what was put in place during a pandemic response, in a safe manner. Aotearoa New Zealand's domestic recovery may be impeded or enhanced by the international landscape of recovery and other geopolitical events.

While Aotearoa New Zealand is an island nation, with the ability to oversee border controls, we nevertheless are not a metaphorical island. Our health, economic and social recovery is likely to depend on the recovery of other countries.

There is also the likelihood of 'reactivity' or the need to return from recovery to response as we experience mutations or reinfections coming through our borders once more. It is critically important to reassess the ethical position of our response and interventions to pandemics against scientific and community-based insights rather than, by default, returning to the same interventions to combat returning contagions.

Vaccine development and use

Justification for use

Vaccine-development is a likely approach to enabling the recovery from future pandemics.^{317, 318, 319} As well as protecting individual health, vaccines can be used to eliminate pandemics, manage 'flare-ups' and act as an insurance policy against future outbreaks.³²⁰ In some pandemics, vaccines are likely to be the critical enabler: allowing us to emerge from confinement, regain our right to freedom of movement and engage in economic, cultural and social activity, while keeping the risk to individual lives at a manageable level.³²¹

Vaccinations may achieve recovery through the establishment of 'herd immunity'. Herd immunity refers to a degree of protection afforded to non-vaccinated individuals caused by a large proportion of vaccinated (or otherwise immune) individuals disrupting the disease's chain of transmission.³²² If enough of the eligible population volunteers to receive the vaccine, some degree of herd immunity can be established. However, this approach is pandemic dependent. For example, Israel's experience of COVID-19 suggests that even highly vaccinated populations can remain at risk from mutations. Israel had one of the world's highest levels of COVID-19 vaccination – with over 78 percent of those age 12 years or older fully vaccinated. Despite this, in August 2021, Israel experienced one of the world's highest infection rates, with nearly 650 new cases daily per million people.³²³ More than half of these cases involved fully vaccinated people, underscoring the transmissibility of the Delta variant or mutation of COVID-19 and raising concerns about the effectiveness of vaccination to facilitate recovery.

Before the infection rates start to decline, usually 50 percent to 90 percent of a population needs immunity.³²⁴ However, as Israel's experience shows, there is no 'magic number' for achieving herd immunity across all cases. Different pandemics will respond differently. Rather, herd immunity ought to be viewed as a spectrum in which the more people are vaccinated, the greater the community as a whole is protected.³²⁵

The roll-out of a vaccine in a pandemic must be justified against the considerations laid out in the 'framework' and in the section **Interventions to improve a pandemic situation** above.

If these justifications are met, the principle of **kotahitanga** encourages all those who are eligible to receive the vaccine in order to protect those who cannot safely receive the vaccine themselves. For example, there may be age-related restrictions placed on a vaccine while trials are undertaken. This may have ongoing impacts for those excluded, including feelings of vulnerability and exclusion.

Equity

In the interest of equity, priority access to vaccines should be afforded to those most vulnerable to the pandemic, for example, essential workers, older people, and people with illnesses or other pre-existing health inequities caused by the social determinants of health. Vaccinations and the medical appointments required to receive those vaccinations should be free of charge and should not require lengthy or costly travel or the need to take leave from work.

In the COVID-19 pandemic, lower initial vaccination uptake rates amongst the Māori population revealed inequitable access to vaccines for Māori communities, compared with Pākehā communities. This was due to long travelling distances to reach a vaccination clinic in rural areas with high Māori populations,³²⁶ as well as age restrictions that limited initial prioritisation of vaccines to people aged 65 years and older. This was in spite of the fact that the Māori population is, on average, younger than the Pākehā population^{327, 328} and is prone to disease at a younger age.^{329, 330, 331}

Levels of coerciveness

Where possible and appropriate, vaccination should be voluntary rather than non-voluntary. However, the justifications for restricting choice, discussed in the section **Interventions to improve a pandemic situation** above, would apply. There are a variety of strategies from across the intervention ladder to encourage and incentivise vaccination. At the least coercive end of the ladder, this may involve education campaigns to reassure the population of the safety and necessity of receiving the vaccine and ensuring that it is free and easy to access. Further down the ladder are incentives and disincentives, as well as restrictions on choice.

The introduction of vaccine certificates is a means through which vaccines may be incentivised and will likely be a necessary mechanism for easing restrictions, returning to public spaces, and reopening the border and the economy.

Vaccine certificates

Vaccine certificates (or passes) provide evidence that an individual has received a vaccination. In the reopening phase of a pandemic, the government or private businesses may require such certification as a condition for domestic and international travel, access to workspaces and schools and public spaces, and attending events.³³² However, vaccine certificates raise a variety of ethical risks. These are outlined further in the sections below.

Efficacy

As per the criteria for justifying an intervention given in the section **Interventions to improve a pandemic situation** above, vaccine certificates must be based on scientific evidence that supports that they will be effective at achieving their stated outcome. To discuss efficacy requires a distinction to be made between vaccine certificates and immunity certificates.

Immunity certificates provide evidence of immunity acquired through infection of the disease (likely to be determined by serological testing) or providing evidence of a positive and then negative test.^{333, 334, 335} However, this assumes that someone who has had the disease has developed antibodies and is therefore immune from getting ill again.^{336, 337} Yet, variability in each individual's immune response to a pandemic means that contracting and then recovering from a disease does not always guarantee immunity to a reoccurrence.³³⁸ Furthermore, there is a risk that testing may not always produce accurate results as tests can produce false positives or false negatives.^{339, 340} Immunity certificates may also create a perverse incentive for individuals to seek out infection in order to obtain a certificate.³⁴¹

Following COVID-19, discussion was more focused on the use of vaccine certificates, as these provide evidence of vaccination and may be easier to implement than immunity certificates.³⁴² Again, however, they might not guarantee immunity or the prevention of transmission.³⁴³

The efficacy of immunity or vaccine certificates will likely depend on our confidence that these are an effective means of preventing transmission (including asymptomatic transmission) of the pandemic.^{344, 345, 346} The effectiveness of vaccines must be continually monitored and used to review the justification of a vaccine certificate strategy. Successful implementation will also depend on the feasibility of other factors, such as the development and distribution of an appropriate vaccine and digital tools that reliably track who has, and has not, received the vaccine.

Supplementary effects

If a vaccine certificate is required to access essential goods and services, such as access to health care, food, and shelter, this could be seen as restricting choice to the extent that vaccines cannot reasonably be considered 'voluntary'. To determine whether this is ethical, the justifications for restricting choice, discussed in the section **Interventions to improve a pandemic situation** above, should be considered. A middle ground might entail the use of vaccine certificates for access to non-essential goods and services, such as restaurants, entertainment, and travel,³⁴⁷ noting that businesses have a duty to safeguard their customers and employees.³⁴⁸

Equity

The implementation of vaccine certificates must also consider the potential implications upon equity.^{349, 350} This entails equitable access to vaccines (discussed above) and the digital technology underpinning the certificate, so that the rights and freedoms afforded to those with a certificate are not inequitably distributed on an arbitrary basis, such as by wealth or location. The digital platforms that host the certificate need to be accessible for everyone, free of charge, or secure paper-based versions must be made available.

The Human Rights Act 1993 prohibits discrimination on the basis of physical illness. However, despite all care taken to ensure ease and practicality of access, some people might not be able to safely receive the vaccine due to underlying health reasons such as age, illness, or a compromised immune system. These exceptions risk creating a two-tier system based on health status, whereby those with a vaccine certificate are afforded greater rights and freedoms than those who cannot receive the vaccine.³⁵¹ This risk could be mitigated by developing a 'flexible passport'³⁵² that allows for a health-based exemption. However, vaccine certificates and health-based exemptions should only be rolled out once everyone who can receive the vaccine has had the opportunity to do so, in order to maintain **kotahitanga** and prevent a two-tiered system from developing.³⁵³

Furthermore, care must be afforded to ensure that marginalised groups that are prone to systemic discrimination are not subject to extra scrutiny when a vaccine certificate is required, especially when monitoring and enforcement may involve the police.^{354, 355, 356}

Responding to vaccine hesitancy, which is most common in Aotearoa New Zealand amongst young people and those with lower educational attainment,³⁵⁷ should involve taking efforts to educate, include and build trust. Attempting to guide choice through public shaming and unjustified restrictions on the rights and freedoms of those without a vaccine certificate may only create further disunity and does not support **manaakitanga**.

Data privacy

Another ethical consideration for vaccine certificates is the privacy of health information. A person's vaccination status is personal information and falls under the protections laid out in the Privacy Act 2020. Please see the section **Data, privacy, and digital technologies in a pandemic** above for more information on how to address this risk.

Global cooperation

In response to COVID-19, there was strong global cooperation around the development of a vaccine:

Even though the conventional vaccine development pipeline usually takes more than a decade, the escalating daily death rates due to COVID-19 infections have resulted in the development of fast-track strategies to bring in the vaccine under a year's time. Governments, companies, and universities have networked to pool resources and have come up with a number of vaccine candidates.³⁵⁸

However, the lack of international cooperation in vaccine distribution led to increased global disparities and inequities.³⁵⁹

The WHO, alongside Gavi, the Vaccine Alliance, and the Coalition for Epidemic Preparedness Innovations (CEPI), developed a global initiative called COVID-19 Vaccines Global Access (COVAX) to help encourage equitable access to tests and vaccines for low-to-middle-income countries.³⁶⁰ While COVAX began distributing vaccines in February 2021, by early April 2021, of the over 700 million COVID-19 vaccines administered worldwide, only 0.2 percent had gone to low-income countries.^{361, 362} COVAX was undermined by competition from governments who had greater resources and purchased directly from suppliers.³⁶³

Consequently, global COVID-19 vaccine supply was left to competition among countries based on their ability to pay rather than public health needs in what can be termed 'survival of the wealthiest'.³⁶⁴

These economic inequalities will have long lasting effects for countries both directly and indirectly affected. For example, slow vaccination rates could lead to a vaccine immune mutation.^{365, 366}

Aotearoa New Zealand will need to do its part to ensure that access to vaccines is 'fair and equitable' (as the central principle of the WHO-supported COVAX scheme).³⁶⁷ The World Economic Forum suggests that each country should initially receive an allocation of doses large enough to cover at least 2 percent of their population.³⁶⁸

Reopening

Upon entering the recovery stage of a pandemic and when restrictive measures such as a lockdown begin to lift, consideration must be given as to how to 'return to normal' in light of the ongoing impacts of the pandemic.

This might include addressing the ongoing mental and physical health harms of a pandemic, enabling a safe transition back to work and school and collectively redefining what the 'new normal' might look like.

Mental health

The effects of a pandemic and the actions taken to respond to that pandemic are likely to entail immense trauma for individuals, whānau and communities, in the form of death, grief, social isolation, job and income loss, ongoing physical illness and disability, stress and anxiety and confinement (in potentially harmful environments). To avoid a 'second wave' of mental health crises, we will need a proactive public health response to address these traumas.

Return to work and education

For those who have lost their jobs due to a pandemic, financial support ought to be provided for those who need it in the short term and job training programmes for negatively impacted industries in the long term. For those returning to work, fear of infection may be a cause of stress and anxiety, especially for those who are in high-exposure jobs or are particularly vulnerable. This will be compounded with the mental and physical health impacts of the pandemic. Employers will need to account for these effects, showing compassion and providing flexibility in enabling their employees to work safely from home and adopt new work habits, such as reduced or flexible working hours and a socially distanced workspace.³⁶⁹ Employment policies will need to pay special attention to protecting essential workers who may be more exposed to the disease in their line of work, with limited options to work from home. This might entail remuneration and ongoing compensation for the additional risk taken by these workers.

People returning to work must be provided with the resources required to do so safely. The risk (and its associated anxiety) of returning to work and other public spaces can be minimised through measures such as providing adequate PPE, testing and vaccinations.

Students and staff at all levels of education will face similar challenges. Educational leaders will need to consider how to ensure safe numbers of participants are in specific locations and social distancing is able to be implemented, along with other safety measures, such as the allocation and wearing of masks.

Children returning to school after a period of lockdown will entail many of the same considerations. For example, families should be supported if they wish to continue educating their children from home due to ongoing anxieties about the safety of returning to school. However, keeping children out of schools may include adverse consequences, especially for vulnerable and marginalised communities. Such consequences might include disruptions to learning and growth, poor nutrition where families rely on free or discounted meals at schools, social isolation, and challenges for parents of balancing work, childcare, and education.³⁷⁰

The government should support schools and educational institutions to enable students to return to study as quickly and as safely as possible in order to strike an effective balance between the risks of staying at home versus those of returning to the learning institution. Furthermore, children and families returning to school should be treated with flexibility and compassion. The same should apply to those adults in work-related or other higher education who may be unable to return to the physical learning environment for various reasons (for example, due to the existence of individual or family health inequities).

Redefining the 'new normal'

Whilst decisions on how to respond to a pandemic are made rapidly in an emergency context, the path forward must involve ongoing engagement with communities and iwi to collectively redefine what the 'new normal' should look like. Guided by and emerging out of this engagement, resources need to be developed that are innovative and recognise and respond to the varying needs of a range of population groups. This can help us build resilience for future pandemic outbreaks and use the lessons and opportunities for positive change that are present on the other side of every crisis.



Ongoing impacts

While in the recovery phase it is highly likely that, for some individuals and communities, the effects and impacts will linger. For example, in July 2021, more than 183 million confirmed cases of COVID-19 had been recorded worldwide, with indications that many individuals were suffering from 'long COVID'. Long COVID is a term that covers a range of symptoms that remain after the clearance of the acute COVID-19 infection.³⁷¹

While it is not yet clear how many New Zealanders have been and will be impacted by long COVID, the United Kingdom Office for National Statistics (ONS) has analysed the rate of long COVID symptoms in the United Kingdom. Their estimates suggest that, over a five-week period, the prevalence of any symptom among survey respondents who tested positive for COVID-19 was 22.1 percent, and the 12-week prevalence was 9.9 percent.³⁷² These estimates were established from data sampled between April and December 2020, before many of the variants dominated COVID-19 infections. While there are likely to be discrepancies between variants, there is a possibility that close to 10 percent of an infected population could experience longer-term effects from COVID-19.

At the time of writing, it was unclear what is the maximum duration of long COVID, but it is possible that some individuals meet the definition of having a disability through their experience with the pandemic. In Aotearoa New Zealand, disability is defined as any self-perceived limitation in activity resulting from a long-term condition or health problem lasting or expected to last six months or more and not eliminated by an assistive device.³⁷³ The ONS found that, after five weeks, 11.9 percent of COVID-19 patients continued to experience fatigue, 4.6 percent continued to experience breathlessness, and cardiovascular abnormalities remain an ongoing concern.^{374, 375}

These figures are worrying as long COVID may require long-term investment in support and treatment. Further studies are required to expand our understanding of long COVID,³⁷⁶ nevertheless it is possible that Aotearoa New Zealand will need to include consideration of disability through the lasting impacts of pandemics.

Further information about disability during a pandemic response is provided in the next chapter.



Chapter 6: Disability

Disabled people are a group that have unique needs in a pandemic. For this reason, NEAC have chosen to provide a chapter solely focused on the ethical considerations of and for disabled people in a pandemic.

This publication acknowledges that a pandemic can affect an individual's autonomy and their ability to access important resources. However, a pandemic should not exacerbate inequities faced by disabled people. Because disabled people are of equal value and have the same rights as all other New Zealanders, we urgently need to develop and implement measures to address the challenges this group faces before, during and after a pandemic and ensure they received equitable access to appropriate treatments in the future.

This chapter is informed by the life experiences of disabled people and communities throughout the COVID-19 pandemic. During consultation with the public in 2020, NEAC heard time and again from the public that pandemics can exacerbate existing inequities and different approaches are required to achieve equity.

Responses to any pandemic must not neglect disabled people. The responses must follow legal standards, principles of distributive justice and societal norms of protecting vulnerable populations (which are core commitments of public health) to ensure that inequities are not exacerbated. They should also provide a pathway for improvements to ensure equitable access to appropriate treatments.³⁷⁷ This is at the heart of the **principles** guiding Aotearoa New Zealand's response to a pandemic.

While this chapter can be read in conjunction with the whole document, it can also be read as a standalone chapter. It takes into account existing obligations and expectations, including but not limited to: NEAC's framework on **Ethics and Equity: Resource allocation and COVID-19**,³⁷⁸ the **Health and Disability System Review – Final report – Pūrongo Whakamutunga**,³⁷⁹ Te Tiriti o Waitangi, the Convention on the Rights of Persons with Disabilities (CRPD) and ensuring disabled people are involved in decision-making that impacts them.³⁸⁰

NEAC's framework on resource allocation addresses equity in COVID-19 resource allocation and prioritisation. As a high-level guidance document for the health and disability sector, it is designed to help health workers and policy makers consider ethics when deciding how to allocate resources. The framework sets out ethical and Te Tiriti o Waitangi principles that medical staff, service planners and policy makers should consider when responding to pandemics. It adds an equity lens to decision-making and assesses how equity sits alongside other ethical principles and Te Tiriti o Waitangi.

Equity as a concept recognises that different people have different levels of advantage and so require different approaches and resources to attain equitable health outcomes. In a resource allocation setting, this means that health workers and policy makers should consider how resources can be allocated to mitigate the adverse consequences of pandemic response measures while avoiding or minimising growth in inequity from those measures.

Terminology

Disability

Many words and terms can be used to identify disability. This document upholds the definition of disability in article 1 of the CRPD that 'those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others ...'.³⁸¹

For the purposes of this document, the definition includes all disabilities and the commonalities between them, acknowledging the wide diversity of disability need, such as physical, sensory, intellectual, mental, health (but not always disability), communication, age-related and common challenges that are often invisible and hence not recognised by or included in public health policies or that are overlooked as needing support or continuation of care in pandemic responses.

Some people prefer using the term ‘disabled people’ as a source of pride, identity and recognition that disabling barriers exist within society and not within individuals. For others, the term ‘people with disabilities’ carries the same meaning and is seen as being important for recognising the person before their disability.³⁸² The CRPD uses the term ‘persons with disabilities’. ‘Tāngata whaikaha’ may be used to refer to disabled Māori.³⁸³

The current consensus in Aotearoa New Zealand, based on the advice of the Disability Strategy Revision Reference Group, is to use the term ‘disabled people’.³⁸⁴ We have used this terminology throughout our report. We acknowledge that members of the disabled community may prefer to be referred to differently, and we stress that, in our use of ‘disabled people’, we seek to recognise the person before considering their impairment.

Vulnerability

There is a risk to physical and mental wellbeing as vulnerable individuals become even more vulnerable in times of a pandemic or crisis. However, vulnerability may vary over time; people may be considered vulnerable at some stages in their lives but not in others. Vulnerability is situational and contextual – it is the combination of factors that determines risk.

Public health measures such as lockdowns, social distancing, isolation, and quarantine can have a disproportionate impact on the health and wellbeing of vulnerable people.

Disability in a pandemic should be considered through an intersectional lens, in which inequities corresponding to, for example, gender, age, class, ethnicity, incarceration or visa status are considered in relation to the inequities present for disabled people. These factors may amplify the degree of vulnerability or protection disabled people will experience within a pandemic.

Readiness and reduction of risk

Globally, compared with the general public, disabled people generally have poorer health outcomes, lower education achievements, fewer economic opportunities and higher rates of poverty generally.³⁸⁵ This has a marked impact on how we can ensure Aotearoa New Zealand is ready for a pandemic (see **Chapter 3: Readiness and reduction** for more information on the **social determinants of health**).

Preparing our health care system

Pandemics stretch the capacities of health care systems and raise challenging ethical dilemmas. The rapid spread of infection can overwhelm testing and care capacities. As health care professionals, families, and society grapple in real time with life-or-death decisions regarding equitable access to testing, shortages in PPE, rationing of medical goods and clinicians’ distress, the need for comprehensive emergency plans and guidelines is more critical than ever.



Long-term underinvestment in the health sector has made the health system vulnerable to regional and national emergencies, and NEAC recognise that without adequate investment going forward for pandemic preparedness, support and guidance can only go so far to assist in ethical decision-making. Efforts should be made to increase the resilience of health systems and better resource them in business-as-usual times so that they are adequately prepared for future emergencies. This is in line with the recommendation from the independent monitoring mechanism of the CRPD that the government develop and promote schemes that proactively support increasing resilience for disabled individuals and their families, disability support groups and communities to mitigate the risks and impacts of emergencies such as pandemics.³⁸⁶

It is also important to acknowledge the pressure points in any disability response, such as vaccine hesitancy, communication issues and workforce shortages.

Systemic barriers that have persisted for decades (for example, inaccessibility of facilities and equipment) cannot be instantly reversed. However, adopting measures to facilitate engagement and care for disabled people is essential. Such measures could include the following ideas.

- Informed consent processes should take place, as much as possible, through direct conversations with disabled people and their family members.
- The already expanded use of telemedicine options to facilitate communication among clinicians, patients, caregivers, and family members should include disability-friendly accessibility measures that are compatible with computers and mobile devices (for example, remote audiovisual description services for blind and low-vision individuals, captioning or third-party remote connection with a sign language interpreter for deaf and hard-of-hearing people).
- Alternative care settings like drive-through testing facilities should also provide services to help blind and low-vision individuals and people with developmental disabilities to navigate their way through so they can seek care and be tested as necessary. Where safely possible, home-based testing can also reduce the barriers to accessing such services.
- Disabled people may require an extended period of ventilator use for recovery or bed allocation in an established care setting, where accessible equipment is more likely to be available.
- Medical professionals should receive training around how to care for people with disabilities to ensure this group receive equal access to effective health care services.
- Plain language forms inquiring about the needs of a patient with disabilities on their admission to a health care facility and coordinated efforts with community-based organisations can be instrumental in finding practical solutions and better addressing the needs of patients and providers with disabilities.
- Well-coordinated robust disability supports need to be established that can continue during times of disruption and scarcity. This includes ensuring there is a viable disability support workforce during events that could reduce the number of people able to work and access to essential disability support.

Access to PPE was a major issue for disabled people during the level 4 COVID-19 lockdown in 2020.³⁸⁷ It is essential that individuals continue to have access to care and that adequate PPE for health and community workers is available in a time of shortage so that they do not inadvertently infect others.

Measures such as social distancing require additional considerations to implement within the disability community. Those who cannot avoid touch, including those who rely on personal care assistants for whom physical distancing is difficult, struggle to practise self-isolation.

See the section **Interventions to improve a pandemic situation** above for more information.

Community readiness

With stay-at-home and social distancing orders invoked because of the pandemic, some disabled people's access to personal care assistants who provide direct support in their daily lives can also be restricted. We know that there are a significant number of disabled people who do not access funded support. Instead, family and friends support them, which can lead to gaps in essential support when alert levels change. In late 2020, the New Zealand Disability Support Network (NZDSN) estimated that 15,000 disabled people did not have access to supports that they were eligible for.³⁸⁸ It is important to note that the situation of these people can rapidly change during emergencies, and they may need a range of support services at different times to ensure their financial and physical wellbeing.

There is a responsibility to include disabled people in the planning, integration, and implementation of emergency programmes, where consolidated and consistent guidelines are lacking. As hospitals, health care systems and residential settings for disabled people move to develop responses to a pandemic, it is critical they understand the key issues likely to impact on their patients' care. These include access to adequate communication and medical information, non-discrimination, reasonable accommodation and rationing of medical goods.

Disabled people are also vulnerable to abusive treatment in all areas of their health³⁸⁹ and they may become more isolated.³⁹⁰ This may be exacerbated during an emergency as peoples' earning ability, social contact and daily support is affected. More information about domestic violence can be found in **Chapter 3: Readiness and reduction** above.

Inclusion

The United States Centers for Disease Control and Prevention reports that, overall, 'adults with disabilities are 3 times more likely to have heart disease, stroke, diabetes, or cancer than adults without disabilities'.³⁹¹

To prevent discrimination, we should avoid decisions that use disability alone as a proxy determinant of clinical prognosis in life-saving treatment or allocation. The health and disability system should have clear, unbiased processes to assess patients individually, ensuring that allocation decisions are based solely on objective medical evidence for likelihood of survival and risk of serious/unwanted complications rather than on perceived quality of life associated with an individual's disability. Patients should be involved in this decision-making process and in discussing the risks involved.

Aotearoa New Zealand's approach to pandemic preparedness needs to represent our population. Furthermore, regular contact with disabled people has been shown to reduce biases and increase the prognosis and quality of life of patients with disabilities. This is critical if we are to uphold the principles of unity and equity. Given the high stakes for disabled people in pandemic allocation and rationing decisions, representatives of organisations of disabled people or disability rights experts should be consulted in the decision-making processes as we prepare for a pandemic.

Under the wider principle of *tika*, the incorporation of disabled people into advisory bodies could help advance the consideration of people with disabilities, rare disorders, chronic illnesses, and unique needs associated with certain conditions.

Facility/care readiness

The unique vulnerability of disabled people in group homes and residential facilities, psychiatric institutions, nursing homes, and prisons should also be considered. The limited and inconsistent guidelines in such facilities regarding visitations, facilitation of communication and decisions, staff screening, entry back into shared-care facilities after a hospital visit, PPE and readiness to respond appropriately to a pandemic or crisis is a result of systemic issues that need to be addressed.

Future preparedness efforts must focus on increased funding to residential facilities and the development of policies to mitigate risks for staff and residents. These include ensuring residents have appropriate access to testing, planning for ways to separate infected or at-risk patients from other residents, providing PPE for direct-care staff, and improving training and support to ensure the safe and high-quality implementation of emergency procedures.

Data collection

Currently, there is little data available about disease, recovery, and mortality rates from COVID-19 for disabled people. However, we know that, in 2013, 29 percent of disabled people surveyed rated their health fair or poor (as opposed to good, very good or excellent) compared with only 4 percent of non-disabled people. Disabled people were far less likely to say they had very good or excellent health – only 10 percent said their health was excellent compared with 33 percent of non-disabled people.³⁹²

Collecting and analysing local and national data that includes documented underlying conditions and disability status and aggregated data from treatment decisions will enable the development of equitable strategies for health care allocation in future health crises.

More information can be found in the section **Data, privacy and digital technologies in a pandemic** above.

Health workers with disabilities

Quite often people forget that disabled people are not always patients: they may also be providers. There are many doctors and nurses with disabilities who are working at the frontline in this COVID-19 pandemic. The principle of *manaakitanga* should be freely offered to support these workers. This may mean considering how a pandemic changes or shapes accessibility issues, understanding, and acknowledging these workers' achievements and contribution and making sure they are not 'invisible' in our collective stories or reflections on the pandemic.

Response

Any response must recognise the fundamental role of legislation and regulation in supporting disabled people and communities during pandemics/emergencies. These include, but are not limited to, the Human Rights Act 1993, Privacy Act 2020, Code of Health and Disability Services Consumers' Rights, as well as statutory bodies such as the Ombudsman, the Health and Disability Commission and the Human Rights Commission in investigating and monitoring government pandemic responses.

Access to communication and medical information

Communicating the risks, measures of prevention and treatment options before, during and after a crisis are key to slowing down a pandemic and improving health outcomes. Disabled people should not be kept under-informed about the pandemic and its ramifications. Important advice must be made available in plain language; multiple, accessible formats (such as audio and large print) and in multiple languages.

For example, information conveyed through charts and graphs is inaccessible for blind and low-vision individuals and may be incomprehensible for people with intellectual disability (and others) if not provided in plain language. Similarly, news briefings conducted without captioning or qualified sign language interpreters precludes deaf and hard-of-hearing individuals from being well informed.

Identifying and distributing short and long-term remedies

Treatment and vaccination options need to be transparent, reasonable, and believable to gain the population's trust. Fair allocation is also necessary. Distributive justice and the societal value of protecting vulnerable populations requires that, after protecting front-line health care service providers, those who are most vulnerable come next. Although disability status alone would not qualify, it is important to note that the disability population suffer higher rates of chronic medical conditions (for example, diabetes and cardiovascular disease), which are associated with worse outcomes from COVID-19.

The continuation of vaccination roll-outs are key for both the response and recovery phases of a public health emergency. It is important that information is provided in a way that reaches vulnerable groups and works for them, for example, consolidating information specifically for disabled people and those who have underlying health conditions or those with low tolerance to stimulation or crowds; supporting decision-making; providing a list of accessible vaccination centres, transport, and information in alternative formats.³⁹³

In the context of COVID-19, disabled people are at greater clinical risk of COVID-19 harm and impacts, being more exposed to transmission risk, more sensitive to COVID-19 infection if they have secondary health conditions and less able to anticipate, cope with and recover from the effects of infection. Further, impairments (for example, mobility, intellectual, communication) can create barriers to protection against COVID-19 risk and exposure (for example, handwashing, difficulty in physical distancing without support needs).

Rationing

Rationing requires difficult decisions about the allocation of scarce resources under conditions of extreme time pressure and limited data.

A key consideration is how equality and non-discrimination on the basis of disability are to be interpreted in rationing decisions. There is a risk that medical professionals may unwittingly rate the quality of life of disabled people, and such biases can have a negative impact on medical decisions.

Rationing based on prognosis for survival, a reasonable criterion in a pandemic, and the potential for subjective quality-of-life judgments may similarly enter rationing decisions and result in discriminatory outcomes. It is unethical to use stereotypes or misconceptions about an individual's disability to ration care – a patient's 'worth' should not be based on the presence or absence of disabilities. Choices by establishments around considering an individual for life-saving treatment ought to be founded on an individualised evaluation of the patient, using the best available clinical evidence, rather than on quality-adjusted life years that can fundamentally underestimate the value of a person's existence with a disability.

Further information can be found in NEAC's publication *Ethics and Equity: Resource allocation and COVID-19*. This resource addresses equity in resource allocation and prioritisation. The framework offers high-level guidance for the health and disability sector and aims to help health workers and policy makers consider ethics when deciding how to allocate resources. It can be found on the NEAC website at <https://neac.health.govt.nz/publications-and-resources/neac-publications/ethics-and-equity-resource-allocation-and-covid-19>.

Continuity of care

Any response to COVID-19 also needs to uphold Te Tiriti o Waitangi. For example, it should work alongside public health teams to ensure the annual influenza programme will help increase flu vaccinations for Māori and extend financial security to Māori and disability health providers to ensure they can maintain their services and provide continuity of care for the community both during and after a pandemic.³⁹⁴

Recovery

Future emergency preparedness

Marginalised groups, such as disabled people, must be included in the design of future emergency preparedness and implementation efforts. When developing approaches for future preparedness, it is important to take account of learnings from other emergencies, such as the COVID-19 pandemic. For example, the certain exacerbation of pre-existing resource allocation inequities in terms of housing, hospital beds and other resources that are already seen as scarce in non-pandemic situations.

Living with long-term disabilities or the effects of a pandemic

Those who suffer detrimental effects to aspects of their health and wellbeing as a result of an emergency may need long-term recovery support. For example, the political intervention of temporarily solving inequities in times of crisis (for instance, finding housing for the homeless so they could meet the requirements of the alert level 4 lockdown) improved overall health and wellbeing outcomes. However, caution needs to be taken in regard to discontinuing supports such as temporary housing during the recovery period of a crisis as this can contribute to further inequities.

Some individuals may also suffer long-term or lifelong health effects from infection during a pandemic that may impact their wellbeing and ability to participate in work and activities they enjoy. For example, people can develop respiratory issues, long COVID or historical effects from public health crises such as polio. Care should be taken to ensure that individuals adversely affected in the long term are not directly or indirectly discriminated against or excluded because of the impacts on them, and efforts should be made to increase the resilience of individuals suffering long-term effects to ensure that no one is neglected.

Use of data

Data collection during a pandemic can inform improvements of national and local responses to future pandemics. It is important that data collected for the emergency and response phases of a pandemic is kept safe and only used ethically and in a de-identified format where consent was not given for other uses of that data.

Conclusion

It is important that the ethical principles for a pandemic are relevant to and belong to everyone, including the disabled people in our communities.

Our shared principles give us a shared basis for decisions. Many of us, in many different situations, will still have to make hard choices. But, in general, if we base our choices on agreed principles and make our decisions with good will and reasonable judgement, we can expect to get through a pandemic, together. As Dr Tedros Adhanom Ghebreyesus, Director-General of the WHO said, 'no one is safe until everyone is safe', or as the whakataukī states 'He waka eke noa' – in the next pandemic, we truly will be all in it together.³⁹⁵



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