neac
National Ethics Advisory Committee
Kāhui Matatika o te Motu

getting through

TOGETHER

ETHICAL VALUES FOR A PANDEMIC

JULY 2007

Getting Through Together

ETHICAL VALUES FOR A PANDEMIC

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.

NEAC's statutory functions are to:

- advise the Minister of Health on ethical issues of national significance in respect of any health and disability matters (including research and services); and
- determine nationally consistent ethical standards across the health sector and provide scrutiny for national health research and health services.

NEAC works within the context of the New Zealand Public Health and Disability Act 2000 and the key strategy statements for the health sector.

The members of NEAC, appointed by the Minister, bring expertise in ethics, health and disability research, health service provision and leadership, public health, epidemiology, law, Māori health and consumer advocacy.

Committee membership

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Foreword

If a pandemic came, we would get through it. We know this because we have done it before. It would be difficult, but the better prepared we are, the better we would cope.

The first step is to plan. The Ministry of Health is the lead agency for this whole-of-government action. Businesses, community groups and households are also making their plans. As part of the public sector work, the National Ethics Advisory Committee – Kāhui Matatika o te Motu (NEAC) is addressing the ethical issues by identifying shared values and offering broad guidance.

If a bird flu or some other form of pandemic looks likely, we should do all we can to keep it out of New Zealand. Decisive action might be needed through quarantine or other restrictions at our borders. If that did not work, additional restrictive actions would be needed to stamp it out. Planning is being done for these vital public health actions. NEAC's guidance is that such actions to protect the public should also express respect and manaakitanga, by using the least restrictive measures possible where freedom must be restricted for public good.

Through good planning, with strong participation and support from communities, we should prepare to keep out or stamp out any pandemic. We should also prepare to manage a pandemic in case we do not succeed in keeping it out. Managing a pandemic would be frightening and difficult, but we know from experience that we can do it and would get through it together.

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 share with all citizens. Health professionals would play key roles, and society should reciprocate with special recognition and support.

If we were not able to keep out or quickly stamp out a pandemic, it is likely we would make overwhelming demands on our health services as we tried to manage the pandemic. NEAC's guidance offers criteria to help health professionals to make the best and fairest use of resources in situations of overwhelming demand. Not all of us would be able to get all the services or support we would need from health professionals. This means we would also need to care for ourselves and one another. NEAC's guidance is that, alongside prudent self-care, we all have responsibilities to our whānau and neighbours. In working out what neighbourliness and whānaungatanga require of us, we should ask ourselves, 'who is my neighbour?'.

When faced with difficulty, ordinary people do extraordinary things. If we make it clear in advance that we expect a lot of ourselves and from each other, this will help more of us to do extraordinary things. It will also equip more of us to give honest answers when future generations ask us, 'what did you do in the pandemic?'.

If a pandemic came, we would all be vulnerable, but some communities are likely to be particularly vulnerable. For example, Māori have been disproportionately affected by past pandemics, and we must ensure this does not happen again. Māori and other communities also have a history of resilience and have expertise concerning their own situation and needs. Pandemic planning should draw on and develop these strengths by fostering community participation at all stages.

A wider part of pandemic planning involves stating our values—the basic things that matter to us. NEAC has attempted to do this. The resulting summary statement of ethical values for a pandemic is brief (see section 1). It states widely shared values in common-sense ways. The values apply in many settings and at all pandemic phases from planning to recovery. The statement emphasises the values New Zealanders share about how to make decisions and what decisions to make. It states values recognised in Māori tikanga alongside other values. It also recognises that our values can pull us in more than one direction, and it challenges us to get through as far as we can in 'both/and' ways rather than 'either/or' ways. An earlier version of this summary statement of values is in the *New Zealand Influenza Pandemic Action Plan* (Ministry of Health, 2006).

Shared values give us a shared basis for decisions. Many of us, in many different situations, would still have to make hard choices. But, in general, if we base our choices on shared values and make our decisions with goodwill and reasonable judgement, we can expect society to support us. Identifying our shared values now also prepares us to act quickly and adapt well later, when there may be less time.

Informed by an outbreak of SARS (severe acute respiratory syndrome), the Canadian report *Stand on Guard for Thee* suggests that using ethical values to guide decision-making can enhance trust and solidarity within and between healthcare organisations and communities, and can strengthen the legitimacy of plans and levels of trust in those who may need to make difficult decisions for the common good (Joint Centre for Bioethics Pandemic Influenza Working Group, 2005).

Getting Through Together includes all of NEAC's work on pandemic ethics. It discusses the key ethical issues and states NEAC's guidance on these. This document also includes NEAC's summary statement of ethical values and puts these values to work in hypothetical cases: an urban community response to a pandemic and a hospital-based response. The community case is based on the response of New Zealanders to the 1918 pandemic. NEAC thanks historian Geoffrey Rice for his contribution to this.

Getting Through Together includes many improvements suggested by a wide range of organisations and individuals through a public consultation process. NEAC is grateful to all those who contributed. NEAC also benefited from an invitation to present its work as part of the World Health Organization's Global Consultation on Addressing Ethical Issues in Pandemic Planning. In keeping with the process values stated in its work, NEAC welcomes further feedback. When it has made further improvements, NEAC will seek to have the key parts of its work included in the next update of the *New Zealand Influenza Pandemic Action Plan*. ■

Andrew Moore
Chair
National Ethics Advisory Committee
Kāhui Matatika o te Motu

Feedback on *Getting Through Together*

Getting Through Together was informed by public consultation on a discussion document that included an earlier version of the summary statement of ethical values (National Ethics Advisory Committee, 2006b). Over six weeks, a wide variety of people and organisations involved in pandemic planning were invited to comment on the discussion document. The document was also made publicly available through NEAC's website and publicised through a media release. The people and organisations who made submissions are listed in Appendix B.

The feedback guided this document's development. Even so, it is likely that *Getting Through Together* could still be improved. Future work may be carried out in this area, so NEAC is interested in your comments on this document. In particular, NEAC is interested in whether you:

- used *Getting Through Together* in your planning work
- would like to see aspects of this work developed.

Send your comments to NEAC by post or email.

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Introduction and Purpose

An influenza pandemic would be likely to lead to high levels of illness and death, both in New Zealand and other countries. Pandemic planning aims to prevent a pandemic wherever possible, and to minimise the negative impacts of a pandemic when prevention is not possible. The World Health Organization has recommended that ethical issues be considered as part of pandemic planning.

The National Ethics Advisory Committee – Kāhui Matatika o te Motu (NEAC) has prepared *Getting Through Together: Ethical values for a pandemic*, which includes a summary statement of ethical values (see section 1). An earlier version of the summary statement is an appendix to the Ministry of Health's *New Zealand Influenza Pandemic Action Plan (NZIPAP)* (Ministry of Health, 2006).

Getting Through Together:

- considers ethical issues in a pandemic
- is informed by other work on ethics and decision-making (see Appendix C and the bibliography)
- identifies shared values on which to base the process and content of our decisions
- focuses on how to enable one another to act as best we can on the basis of shared values
- examines the challenges we may face in a pandemic using hypothetical cases (see section 2)
- offers guidance in some key areas of ethical decision-making in a pandemic
- aims to express Māori values alongside other values
- is written to reflect the New Zealand context.

> **Section 1** introduces the statement of ethical values and its purpose and then describes how this statement could be used.
>
> **Section 2** outlines two cases, one in an urban community and one in a hospital, to explore the challenges we may face when planning for, and responding to, a pandemic.
>
> **Section 3** describes why we think the shared values identified in the statement of ethical values are important.

Three appendices contain supporting information: NEAC guidance on ethical issues in pandemic planning and response (Appendix A); respondents to NEAC's discussion document (Appendix B); and background to this work (Appendix C).

The document ends with a bibliography. ◼

Summary Statement of Ethical Values for a Pandemic

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SUMMARY

1. Summary Statement of Ethical Values for a Pandemic

1.1 Introduction

This summary statement identifies widely shared ethical values for planning for, and responding to, a pandemic. These values can be applied in many situations. Some govern how to make decisions; others govern what decisions to make. Values recognised in Māori tikanga or kawa (right or appropriate ways of acting) are identified alongside other values.

The best way to act on our values depends on each situation. This may range from developing public policy for a future pandemic right to deciding how best to help a sick family member or neighbour.

With imagination, common sense and discussion, we can act on our values even when we have little time, and even when our values pull us in more than one direction. Good planning when we have time can help us to respond well later, when we may have little time and need to make quick decisions.

1.2 Ethical values to inform how we make decisions

The characteristics of good decision-making processes are summarised in Table 1.

Table 1: Ethical values to inform how we make decisions

Ethical value	Actions associated with the value
Inclusiveness	• including those who will be affected by the decision • including people from all cultures and communities • taking everyone's contribution seriously • striving for acceptance of an agreed decision-making process, even by those who might not agree with the particular decision made
Openness	• letting others know what decisions need to be made, how they will be made and on what basis they will be made • letting others know what decisions have been made and why • letting others know what will come next • being seen to be fair
Reasonableness	• working with alternative options and ways of thinking • working with and reflecting cultural diversity • using a fair process to make decisions • basing decisions on shared values and best evidence
Responsiveness	• being willing to make changes and be innovative • changing when relevant information or the context changes • enabling others to contribute whenever we (and they) can • enabling others to challenge our decisions and actions
Responsibleness	• acting on our responsibility to others for our decisions and actions • helping others to take responsibility for their decisions and actions

1.3   Ethical values to inform what decisions we make

Good decisions are based on the values summarised in Table 2.

Table 2: Ethical values to inform what decisions we make

Ethical value	Actions associated with the value
Minimising harm	• not harming others • protecting one another from harm • accepting restrictions on our freedom when needed to protect others
Respect/ manaakitanga	• recognising that every person matters and treating people accordingly • supporting others to make their own decisions whenever possible • supporting those best placed to make decisions for people who cannot make their own decisions • restricting freedom as little as possible, but as fairly as possible, if freedom must be restricted for the public good
Fairness	• ensuring everyone gets a fair go • prioritising fairly when there are not enough resources for all to get the services they need • supporting others to get what they are entitled to • minimising inequalities
Neighbourliness/ whānaungatanga	• helping and caring for our neighbours and friends • helping and caring for our family/whānau and relations • working together when there is a need to be met
Reciprocity	• helping one another • acting on any social standing or special responsibilities we may have, such as those associated with professionalism • agreeing to extra support for those who have extra responsibilities to care for others
Unity/ kotahitanga	• being committed to getting through the situation together • showing our commitment to strengthening individuals and communities

1.4   Role of the summary statement of ethical values

This summary statement of ethical values for a pandemic aims to identify widely shared ethical values. If it achieves this aim, we can focus on enabling one another to act on these shared values as best we can.

Some Māori values are recognised in this statement. Further Māori values, and other cultural and spiritual values, may not be expressed here.

The supporting discussion in this document examines these values and how they might apply in pandemic planning and response. The hypothetical cases (in section 2) illustrate the relevance of these values.

1.5 Using the statement of ethical values

1.5.1 Aim

In developing a summary statement of ethical values for a pandemic, NEAC aims to identify widely shared ethical values and provide tools to enable us all to act on these values.

The statement of ethical values needs to be:

- thought-provoking
- accessible to a wide range of people
- useful at all stages of pandemic planning
- useful in a wide range of situations.

In many situations, several different ethical values will be important. Sometimes these values will pull us in conflicting directions. Even when our values have informed our decision-making, we must still make the decisions. This statement of ethical values aims to help us to plan for, and respond to, a pandemic in a way that is as consistent as possible with each of these shared values.

1.5.2 The values

Many of the shared values in this statement already inform decision-making in health and many other contexts, even if this is not always made explicit. People make decisions in everyday life that are based on values such as these, though many people may regard this as common sense rather than a matter of ethical values. Explicitly identifying shared values helps to ensure that pandemic planning and response occurs with these values in mind. It also offers a shared basis for thought and decision.

Trying to describe and discuss values is complex. Different people may express the shared values in this statement in different ways. Some values may be interrelated and their meanings may overlap. For example, in this document 'trust' is discussed under both reciprocity and unity and is related to both.

This document does not identify any values as intrinsically more important than others. Rather, all values are important, and the appropriate emphasis to give each value depends on the context. While the same values apply to pandemic planning as to pandemic response, the relative importance of each value may shift. For instance, if a pandemic poses a great threat to the population, minimising harm becomes particularly important. Neighbourliness/whānaungatanga is another value that is important at all times, but particularly so during a pandemic.

1.5.3 Who this statement of ethical values is for

As a pandemic would have a large impact on the health sector, special consideration has been given in this statement to issues those in the health sector may face. NEAC also hopes that a wide range of people, including health professionals, planners, policy makers and members of the public and the business community, can use this statement of ethical values as they plan for, and think about, their potential response to a pandemic.

1.5.4   When to use this statement of values

Ideally, this statement of ethical values should be used in both planning for, and responding to, a pandemic. It might also be useful when we review how well our decision-making measured up to our values after a pandemic. In practice, this will mean understanding the relevant ethical values and processes in advance of a pandemic, and then referring to the statement during decision-making as needed.

Ethical issues may arise at all five stages of pandemic planning in New Zealand (see Table 3), and this statement aims to be useful during each stage. The statement may also be useful in analysing, from an ethical perspective, our and others' decisions.

Table 3: Five stages of pandemic planning

STAGE	DESCRIPTION	
1	Planning	'Plan for it'
2	Border management	'Keep it out'
3	Cluster control	'Stamp it out'
4	Pandemic management	'Manage it'
5	Recovery	'Recover from it'

Source: Ministry of Health, 2006.

1.5.5   Where to use the statement of values

Every sector of society would be affected in a pandemic, and many groups and organisations are currently carrying out their own planning for dealing with a pandemic. Health issues will be very important, and the statement of ethical values should be relevant to those in the health sector, but it aims to be useful at all levels of decision-making. It should also be relevant to those making decisions in other government sectors (national and local), at the corporate and business levels, and at a community level.

We all know people who will have a role in making decisions that may reduce the impact of a pandemic in New Zealand. For example, doctors are likely to be confronted with prioritising patients for even more limited medical resources; officials will have to decide whether to close our borders, schools and workplaces; and community support groups may be overwhelmed with requests for help or advice. How would all these people make decisions confidently and quickly to limit sickness and death and general disruption to daily life?

Individually, we are also likely to have to make difficult decisions, regarding our family, friends and neighbours. How would we check on our neighbours to see whether they are worried or sick? How important do we think it would be to give extra support to those whose profession, and whose special standing in society, requires them to put their own health at risk in order to help others? How prepared are we to distance ourselves from others if necessary?

The above questions do not have easy or 'one-size-fits-all' answers. NEAC's hope is that its work will be a resource for many people who might need to answer these questions for themselves in many different settings. In general, those who act with goodwill on shared values should have confidence in their judgement and can reasonably expect others to support them.

The best way to act on our values depends on the particular situation, so this statement of ethical values aims to be useful in a range of settings. Two hypothetical settings are described in section 2, and these aim to further illustrate and test the use of these values.
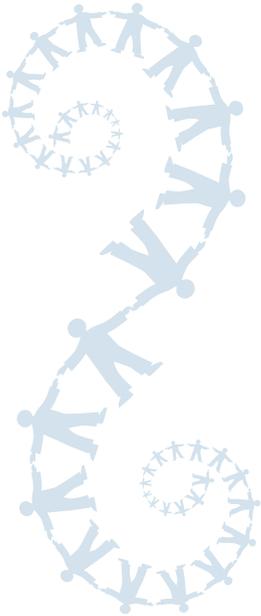
1.5.6   New Zealand Influenza Pandemic Action Plan

The NZIPAP summarises the key preparations being made in case a pandemic occurs (Ministry of Health, 2006). It discusses planning for each phase of a pandemic and for different pandemic scenarios. It describes actions that could be taken in a pandemic and the different agencies and sectors involved in pandemic planning.

An earlier version of the NEAC summary statement of ethical values was an appendix to the NZIPAP. Those involved in pandemic planning will already be aware of the NZIPAP, but others may find it useful to consult the NZIPAP to provide context to this document on ethical values for a pandemic, which is available at http://www.moh.govt.nz/pandemicinfluenza

1.5.7   Limitations of this statement of ethical values

While this document may not fully integrate a Māori world view, it does aim to identify Māori values that are important in pandemic planning. Some of these values are discussed in the document. Other Māori values are represented alongside non-Māori values, indicating the important features they have in common.

Other values are also not fully integrated into this statement, because, although they are very important to many people, they are not shared by us all. Spiritual values are one sort of example. Some people may see many of the shared values in this statement as being based on underlying spiritual values. Other cultural values may also be important to some groups. This statement aims to identify the most widely shared values, but it is important to acknowledge that other values may also be important for many people.

The summary statement identifies shared values to inform our decision-making. It is not an in-depth discussion of the importance of these values and does not identify strategies that may be followed when these values conflict. However, the supporting discussion (sections 2 and 3) discusses these matters, providing more detail of use to decision-makers. ■

Hypothetical Cases

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2. Hypothetical Cases

2.1   Introduction

The two hypothetical cases discussed below illustrate and test the use of the ethical values identified in this document. They are also intended to generate discussion about the issues that may arise in particular cases. The cases are hypothetical, so they could be quite different from the actual situation in a pandemic. The cases may also differ in some ways from actual pandemic planning being undertaken, although we have tried to minimise inconsistencies. The main aim is to identify shared values and raise issues for discussion that are important, whatever the details of any specific pandemic events might be.

The cases cover two important settings: an urban community (section 2.2) and a hospital (section 2.3). The ethical values are intended to be applicable across all the pandemic stages and settings, but the cases focus on the 'manage it' stage of a pandemic (stage 4). Many important decisions would have been made during stages 1–3 (planning, border management and cluster control), with the aim of avoiding the need to manage a pandemic. Even so, we should still think about how we would get through this most difficult situation.

2.2   Case one: using the statement of ethical values in an urban community setting

Case one shows how the statement of ethical values might be used in pandemic decision-making in an urban community setting. The case described here shows the variety of decisions a volunteer community care team might face and the ethical problems they might confront.

Parts of this scenario are based on the experiences of relief workers in the 1918 influenza pandemic, while others have been extrapolated from the possible situation in a future pandemic, taking account of social and technological changes since 1918.

NEAC considers that in situations of pandemic response, society would generally support people who acted on shared values with goodwill and reasonable judgement, including where this leads them to do things for the good of others that they would not usually need to do.

2.2.1   Description of the case one community setting

Imagine New Zealand is in the midst of a severe influenza pandemic. Infection control measures are in place, the borders have been closed and appropriate protective equipment has been issued to doctors, nurses and other staff in essential services such as ambulance, fire and police.

Absentee levels in workplaces are rising rapidly as large numbers of people fall ill and stay away from work. Shopping malls, schools and early childhood centres have been closed to reduce the spread of infection. Parents are staying home to look after their children, whether ill or not. Many businesses, offices and factories are closed or operating on reduced hours. Police resources are stretched because, along with their normal duties, they are also guarding banks, supermarkets and petrol stations against looters.

CASE ONE

Hospitals are overwhelmed with cases of severe pneumonia following influenza, and intensive care units (ICUs) have to prioritise cases. Hospital and ambulance switchboards are swamped with calls from people seeking assistance.

Community assessment centres, staffed by primary care practitioners, have been set up. Some centres are sending doctors and nurses to visit patients in their homes to assess whether they need further care, but the sudden rise in the number of cases and the level of illness among staff have stretched workloads to capacity, and doctors and nurses are collapsing from exhaustion.

An appeal has been made over radio and television stations for all able-bodied volunteers to come forward to help locate people who need assistance. As well as helping sick people, volunteers are needed to staff telephones, act as interpreters, keep records and dispense equipment. Equipment such as face masks, surgical gloves, antiseptic hand wash and paracetamol are being distributed to community care teams for the volunteers.

Authorities have defined the areas surrounding each centre and have issued photocopied maps showing their boundaries. Each leader subdivides their area into smaller blocks, depending on the number of volunteers available to make up teams, and assigns one team per block. Some streets and communities have made preparations in advance, such as by distributing lists of names and phone numbers, while other neighbourhoods have made few or no preparations.

Radio stations broadcast an 0800 number for people to call if they need help. Some householders' calls for medical services are addressed by volunteers visiting to assess the urgency of the case if no doctors or nurses are available for a home visit.

Volunteers with vehicles, especially station wagons or other vehicles able to carry a stretcher, are rostered for day and night ready-response to transport urgent cases to the public hospital or temporary community assessment centre.

The mounting death rate has overwhelmed undertakers and funeral directors. Arrangements have been made for collecting bodies. Stockpiled plastic body-bags are being used instead of coffins. Cool stores are being used as temporary morgues.

2.2.2   Detailed case one scenario

Volunteers have been ringing houses in an inner-city suburb. This scenario follows a team as it visits houses where phone contact could not be made, because no one in the household has answered the phone or the household has no phone.

The team might comprise four people. Ideally, its members would be trained for this role and would reflect the community in terms of gender and ethnicity. They would aim to make themselves identifiable as part of this team, perhaps by wearing reflective jackets. Useful equipment for the team might include:

- mobile phones, to contact the 0800 advice line and other relevant bodies
- digital thermometers
- personal protective equipment (for example, face masks and gloves)
- supplies of paracetamol, hand wash and so on
- a notebook for recording details of each visit.

Whether teams carry this equipment will depend on its availability. Items could be carried in backpacks.

CASE ONE

Rather than carrying heavy bottles of fluids, they might carry sachets of essential salts that can be mixed with water for dehydrated patients. Careful training on the proper use of personal protective equipment and other infection control measures would be essential.

At each house, the team leader introduces the team and explains they are offering immediate help and ongoing support. The leader asks for the householder's consent to note the name, age, sex and health status of all occupants, including disabilities, chronic health problems, and current medications. The leader assures the householder this information will remain confidential to the team and any doctor or nurse called to attend the household, unless further disclosure is necessary for the protection of public health and safety.

Each team records its decisions and who makes them.

FIRST HOUSE: Single parent with two preschool children. No influenza symptoms yet, but the mother is worried about her parents on the other side of town as they are not answering her phone calls. The team leader tells her about the 0800 advice line, and says the team does not have the resources to make enquiries for her.

SECOND HOUSE: Elderly couple, husband very ill, wife unable to cope after several sleepless nights. Team calls the 0800 advice line. No ambulance or doctor is available. Team members administer an inhaler to help the husband's breathing, give him fluids and paracetamol, then show the wife how to sponge her husband to reduce his fever. A doctor visits later that day with antibiotics. The husband survives and recovers.

THIRD HOUSE: No response to doorbell or knocking, but a dog can be heard barking inside the house.

FOURTH HOUSE: Husband, wife and teenage daughter. Both parents are ill, the daughter is coping well, administering fluids and paracetamol. She tells the team the neighbour in the previous house is an elderly man living alone. She has not seen lights or movement next door, but has been preoccupied looking after her parents.

The team seek police assistance to enter the third house, but no help is available. Two volunteers break in and control the starving dog. They find a male occupant dead in bed. No doctor is available to certify the death, so the team leaves the body where it is for the time being.

Police arrive later, identify the victim and call a funeral director to remove the body. They also secure the premises and attempt to contact the deceased's next of kin. A dog-ranger collects the dog.

FIFTH HOUSE: Family of recently arrived refugees who speak very little English and have no reserves of food or medical supplies. Two children have mild influenza. The wife is very ill, but her husband refuses to let her be examined in bed for religious reasons. The team leader calls the 0800 advice line to try to locate an interpreter. A female team member persuades the husband to let her administer fluids and paracetamol to his wife, who needs hospital treatment. The team leader tries to arrange for a doctor to visit. The wife later dies.

SIXTH HOUSE: Big family living in a small house. Four influenza cases are in two bedrooms. The family has no reserves of food or medical supplies. The parents and teenagers are feeling unwell and not coping. They are also concerned about a family member who is visiting Samoa, but they do not have contact details. Team members administer fluids and paracetamol and give instructions about nursing care, but are unsure how much the parents understand, despite their smiles and nods. The house has no telephone, so the family is advised to contact neighbours if those with influenza deteriorate. The parents indicate that they do not know any neighbours as they have only recently rented the house. The team leader agrees to ask the neighbours to help with food and medical supplies.

SEVENTH HOUSE: Professional couple, no children, no influenza. The couple refuse to open the door and talk with the team through the cat flap. They insist they are fine, with ample stocks of food, water, paracetamol and so on and intend to isolate themselves until the emergency blows over. The team leader asks if they could help the large family next door, but the couple refuse, saying they do not know them, do not want to catch influenza and it is not their problem.

Problem: How to encourage people to help their neighbours, while minimising personal risks?

The team leader tells the couple that a pandemic is everyone's problem and if the fit refuse to help the sick then people will die whose lives could have been saved. The leader writes the 0800 number on a card and puts it through the cat flap in case the couple later needs help. The team leader suggests they volunteer to drive their vehicle to assist with transport, but the couple do not reply.

EIGHTH HOUSE: Woman who uses a wheelchair, lives alone, and is fiercely independent. The woman refuses to open the door for fear of infection. She admits to being short of some food items. A team member persuades the woman to contact her neighbours, relatives or the 0800 advice line if she begins to feel unwell.

NINTH HOUSE: Family with three school-age children with influenza. The mother has just died and the husband is agitated and distraught. The team leader offers to call a funeral director to arrange for removal of the body, but the husband objects and insists the body remains where it is while he contacts relatives to arrange a tangi. The team leader agrees. The children are bewildered and hungry, but their temperatures are close to normal. Very little food is in the house. The team leader suggests contacting the local marae to ask if someone could come to help support the whānau. The husband agrees.

TENTH HOUSE: Male couple, both have influenza. They are fearful of going to hospital or being separated and are running low on their current medication. Their general practitioner is on the other side of town. Team members dispense fluids and paracetamol, give nursing advice and suggest the 0800 advice line, but the couple is reluctant to call it. One partner is running a high fever. The team leader, therefore, insists that a doctor or nurse visit them, and contacts the advice line.

ELEVENTH AND TWELFTH HOUSES: Four cases of influenza between the two houses. These two families, already good friends, have prepared well, with good stocks of emergency supplies. They keep in close touch by phone each day. They ask the team if they should isolate their influenza cases in one house and visit them there, with the remaining healthy individuals living in the other house, to avoid further cross-infection. The team leader agrees. Team members take temperatures of the family members and find one man running a high fever with signs of distress and having difficulty breathing. The team leader believes he needs hospital care, but no ambulance is available.

The family of the seriously ill man consult and decide to nurse him themselves, fearing the journey to hospital may prove fatal. A doctor calls that evening and gives the man an antibiotic injection. With careful nursing, this patient survives.

THIRTEENTH HOUSE: Distraught mother with two small children and delirious and violent husband. The husband has a high fever, but is refusing assistance and no longer recognises his wife or children. The team leader requests urgent police assistance to restrain the husband, who has to be strapped to the bed. The wife calls her husband's rugby club friend, who comes to sit with him that night, while she catches up on sleep. A doctor visits that evening and administers antibiotics and a sedative but thinks the man is beyond aid. He dies the next day. The friend calls the 0800 advice line to ask what to do.

FOURTEENTH HOUSE: Student flat. Usually five occupants, but no one is sure where the fifth flatmate is, perhaps staying with his girlfriend, but the flatmates do not have her number. Two people in the flat appear to have mild influenza symptoms. One is an international student, recently arrived in New Zealand and very anxious, as he has found it hard to understand all the advice in the media. The team leader contacts the 0800 advice line to request that someone call later who can talk with him in his own language. The other sick student is convinced she does not have influenza, but the team leader emphasises it is still important to take all precautions as though it were influenza. One of the healthy flatmates is refusing any contact with the two sick students because she is worried about getting sick herself. Team members give all occupants advice on protective measures, including hand hygiene, cough and sneeze hygiene, and social distancing, and encourage them to help each other.

FIFTEENTH HOUSE: Retired couple trying to cope with their divorced daughter who has caught influenza while visiting from Australia. The daughter is anxious about her teenage sons in Brisbane, as they are not responding to phone calls. The team leader returns to the previous house to ask whether someone could make email enquiries on the daughter's behalf.

SIXTEENTH HOUSE: Two sick parents with three small children, unable to cope. Team members offer to prepare food for the children, but parents insist the team must leave before they eat, as their religion prevents them from sharing food with people not of their faith. The team leader agrees but suggests the parents contact other members of their church to arrange care for the children.

SEVENTEENTH HOUSE: Family, but no influenza cases. The father, a teacher, is working as a volunteer. They have good stocks of food, medicine, and so on. The mother is coping well.

EIGHTEENTH HOUSE: Family of four with two influenza cases. The people with influenza seem to be over the worst, and are convalescing comfortably and coping well, but are too busy to check on neighbours.

NINETEENTH HOUSE: No reply to doorbell or knocking, but the door is not locked. The team enters and notices a terrible smell. A woman is found dead in bed and an infant in a cot is comatose and dehydrated, with a soiled nappy. One team member goes back to the seventeenth house to ask whether they could care for the infant while other arrangements are made.

The people in the seventeenth house refuse to care for the child, but provide a contact phone number for the infant's father, who lives in another city. The father is called, but does not reply. The team leader calls the advice line for urgent assistance, but there is no reply.

Problem: If no ambulance is available, who takes the infant to hospital?

TWENTIETH HOUSE: No reply to doorbell or knocking and no signs of life. Team decides to check with neighbours rather than breaking in to check on potential occupants.

TWENTY-FIRST HOUSE: Family with no influenza cases, but is anxious and fearful. They say the neighbours at the previous house have gone to their bach at the beach to isolate themselves for the duration of the pandemic.

By this time, the team members are exhausted and need a hot meal. They return to their centre to find that the centre co-ordinator has collapsed from exhaustion and the deputy co-ordinator is now in charge. All comment on the shortage of volunteers. There is a message for one team member that her husband is ill and her children want her to return home at once.

2.2.3 Discussion of case one

Case one is just one scenario of what might happen in a pandemic, but is towards the severe end of the range of possibilities. The actual situation might be less severe or even more severe. Through good planning and response at earlier phases, we aim to prevent such a situation from arising. Still, it is important to think about how we would get through even the most difficult situation that could confront us.

If a pandemic occurred in New Zealand, the situation might be significantly different from the one described above. Even so, identifying in advance shared values to inform pandemic decisions, regardless of the situation, may make a useful contribution to pandemic planning and response. This case aims to illustrate how the ethical values identified in this document could be important in a pandemic scenario and to generate discussion.

Many of the ethical values are relevant to the events in this scenario. For example, the team showed *respect /manaakitanga* by allowing people in households to make their own decisions and by respecting their privacy whenever possible; those who were most vulnerable, such as those with pre-existing medical conditions, were offered additional support when possible. In all cases, *minimising harm* was an important aim of the team. *Fairness* would have been important when deciding the criteria for who should be visited by a doctor. The efforts made by this volunteer team, and by those community members who were helping each other, expressed the values of *neighbourliness/whānaungatanga* and *unity /kotahitanga*.

The team also faced ethical challenges. Some households had chosen to act in ways that were unlikely to minimise harm to themselves or others. How could the team best minimise the risk to these households, while still trying to respect the choices that people had made? There were also challenges associated with trying to promote neighbourliness/whānaungatanga and unity/kotahitanga within the community, while showing understanding and respect for those people who were reluctant to help others. Some of these issues are discussed further in section 3.

Some households were more prepared for a pandemic than others. Having an emergency kit is one thing households can do to be prepared. This sort of 'self-care' would be a very important contribution to enabling communities to get through a pandemic. It could also help to reduce the demands for help from emergency services, which would be stretched in a pandemic.

Many services might be available in only limited ways in a pandemic. It is possible, for example, that there might not be enough resources available to answer all the calls for help described in case one. This means households, neighbourhoods and communities can make a particularly valuable contribution by being prepared. How well we would get through a pandemic may depend partly on how prepared we are to help ourselves, and partly on how prepared we are to help others.

We would also need to balance the social distancing that might be needed for self-care with the social contact that might be needed for caring for our families, friends and neighbours.

2.3   Case two: using the statement of ethical values in a hospital setting

Case two shows how the statement of ethical values might be used in pandemic decision-making in a hospital setting.

2.3.1   Description of the case two hospital setting

Imagine New Zealand is in the midst of a severe influenza pandemic. Infection control measures are in place, the borders have been closed and appropriate protective equipment has been issued to doctors, nurses and other staff in essential services such as ambulance, fire and police. Despite measures to contain and control the pandemic, large numbers of people are becoming ill.

Some people are sick enough to be considered for treatment in an ICU, but ICU beds are scarce, with too few beds for all the pandemic and non-pandemic patients who might benefit. Prioritisation decisions need to be made quickly, but they still need to be made well. This case considers the questions that might be raised during this decision-making process and how this statement of ethical values relates to how decisions could be made. Examples of relevant values are in *italicised text*.

2.3.2   Prioritising pandemic patients who need intensive care unit beds

Case two involves a patient with influenza who has severe breathing problems. Access to ventilation in an ICU may help. However, many other patients need similar care and there are not enough ICU beds. Ventilation may help some patients temporarily as time or other treatments allow some recovery of their lungs. However, some patients will not recover sufficiently despite ventilation and some frail patients may be harmed by ventilation. Even when demand is not overwhelming, access to ICU treatment will not always be agreed, because it may not benefit the patient or it may harm the patient.

The questions that follow are framed to be asked about each patient to determine patient priority for services during a pandemic. The pandemic planning team, in this hypothetical case, selected these questions as a fair means of prioritising patients. The consulted stakeholders supported the use of these questions, and the questions were published before the pandemic (*openness, inclusiveness, reasonableness, fairness*).

These questions are summarised in Table 4 on page 22.

If the answer to a question is 'no', the patient does not receive ICU treatment. If the answer to a question is 'yes', further questions are asked to determine whether the patient will receive ICU treatment.

CASE TWO

Would this patient meet the clinical criteria for ICU treatment during normal times (that is, when there is not overwhelming demand for the resource)?

NO — this patient is not offered ICU treatment. Stop here.

If the answer is 'no', the patient is not offered ICU treatment. Possible reasons for denying this patient ICU treatment at this point include: the patient is not sick enough to need the treatment, has a terminal illness and will not benefit from the treatment, or has other conditions such as asthma and ventilation may harm them.

If access to the ICU is denied in response to question 1, the reasons for this are communicated to the patient openly, clearly and sensitively (*openness*). When appropriate, cultural support services and interpreters are provided to assist in this communication, to ensure the patient and their family understand and have an opportunity to have their concerns heard and addressed (*responsiveness, inclusiveness*). If everyone is aware that access to the ICU is not in the patient's best interests and the denial of access is not because of the limited resource, energies can be refocused towards more useful interventions. Good communication is a sign of respect for patients (*respect/manaakitanga*).

YES — this patient is considered for ICU treatment.

If this patient meets the criteria for access to ICU treatment during normal times, but others also warrant access and there are too few ICU beds, go to question 2.

QUESTION **2** **Is ICU treatment the most beneficial form of treatment for this patient?**

NO — this patient is not offered ICU treatment. Alternative treatment is offered. Stop here.

Some patients can be managed adequately outside the ICU with increased nursing and medical attention and access to non-invasive ventilation. However, the ability to provide increased levels of care outside the ICU is limited because of decreased staffing levels because of the pandemic. Non-invasive ventilation for influenza patients is provided as an alternative to ICU care. This is an innovative approach to providing care and its effectiveness is monitored, with feedback from health professionals on patient outcomes and staff experiences (*responsiveness*). Results are communicated to other hospitals and the Ministry of Health, with the potential for communication internationally if results are particularly striking. It was identified during pandemic planning that it would be important to foster a spirit of co-operation between different hospitals and different countries at this time and to share information that could be mutually beneficial (*unity/kotahitanga*).

At this stage, it has been identified that some patients competing for ICU treatment are likely to benefit just as much from an alternative service, so competition for ICU treatment is reduced. However, there are still too many patients for the ICU to accommodate.

YES — this patient is considered for ICU treatment. Go to question 3.

QUESTION 3   **Does this patient require ICU treatment immediately (that is, it is not possible for this patient's treatment to be safely deferred)?**

NO — this patient is not offered ICU treatment. ICU treatment deferred. Stop here.

During pandemic planning, the decision had been made that, when possible during a pandemic, major surgery would be deferred when patients were likely to need to be admitted to the ICU after surgery. This is possible in stable cases where patients would not be significantly disadvantaged by having their cases deferred for several months. Indeed, for some of these patients, it would be preferable to have their surgery performed when a pandemic was not occurring, because of its effects on staffing levels and other difficulties maintaining the usual quality of care.

These decisions were made in advance by hospital management in consultation with clinicians. During the pandemic, decisions for each individual patient are made by clinicians involved in their care, with continued liaison with hospital management. Processes are put in place to accept and address patient and family complaints, where patients feel they could be disadvantaged by having their surgery deferred, and in some cases rules are adjusted on the basis of this feedback (*responsiveness*). It is often difficult and stressful for the staff involved to communicate these decisions to patients and their families. A support team was developed to help staff to cope with the demands of a pandemic, and this team facilitates discussions of staff experiences and provides staff feedback to management as appropriate (*responsiveness, reciprocity, unity/kotahitanga*).

As a consequence of deferring the care of some patients, demand for ICU treatment is reduced.

YES — this patient is considered for ICU treatment. Go to question 4.

The patients who have severe breathing difficulties from influenza and who do not meet the criteria for the non-invasive ventilation alternative cannot have their treatment deferred. There are still too many patients for the ICU to accommodate.

QUESTION 4   **Could ICU capacity be expanded to treat this patient, with only minimal disadvantage to others?**

NO — this patient is not offered ICU treatment. The hospital is unable to treat additional patients in the ICU. Stop here.

The hospital might have chosen not to redistribute resources from other services on the grounds that the process of choosing the services from which resources would be taken might cause too much disruption and conflict and have an adverse effect on unity within the organisation (*unity/kotahitanga*). The hospital might have chosen instead to investigate other avenues for procuring additional ICU resources.

This patient will have to be turned away from the ICU, unless a patient already in the unit is assessed as having lower priority and is transferred elsewhere.

YES — this patient is considered for ICU treatment. The hospital may be able to treat additional patients in the ICU. Go to question 5.

CASE TWO

During pandemic planning, a decision was made to invest in expanding ICU capacity in anticipation of the increased demands during a pandemic. Investments were made in further equipment, and staff training was increased in critical areas. This investment required redistribution from some other health services. Decisions to redistribute hospital resources were made carefully and attempts were made to ensure that there was greater value from increasing ICU capacity than from any alternative use of these resources (*reasonableness*). Discussions were held with the pandemic planning team, the ICU team and staff from the services that would lose resources to explain the justification for the redistribution and address concerns. It was considered that this process would help to promote trust and unity within the organisation (*unity/kotahitanga*).

However, after fully implementing near-equivalent alternative care for some, deferring care for others and maximising the capacity of the ICU resource, there are still more patients needing to access the resource than the resource can accommodate.

QUESTION 5 Is it impossible to mitigate the negative effects for this patient of missing out on ICU treatment?

NO — it is instead possible to mitigate these negative effects enough, so this patient is not offered ICU treatment. Other care may be provided instead. Stop here.

For some patients, the disadvantage of being cared for on a ward rather than in ICU can be mitigated by providing increased levels of care; for example, by providing intensive nursing care, increased monitoring of vital signs and physiotherapy.

YES — it is impossible to mitigate these negative effects, so this patient is considered for ICU treatment.

Some patients would benefit significantly more from ICU treatment than ward care. The extent to which negative effects could be mitigated is taken into account when prioritising patients for ICU treatment. Go to question 6.

After considering alternative care, deferring care, expanding the ICU resource and mitigating the disadvantage of missing out on ICU care, there are still not enough ICU beds for the patients who need them.

QUESTION 6 Can this patient be ranked highly enough based on benefit from ICU treatment?

NO — this patient is not offered ICU treatment. Other care may be provided instead. Stop here.

YES — this patient is considered for ICU treatment. Patients with a comparatively high 'net benefit' may be offered ICU treatment. Go to question 7.

Ranking according to net benefit (including considering the benefit of ICU treatment, the harm of missing out, and the potential to mitigate the harm should the patient miss out) helps to determine many patients' access. If the competing patients can be ranked according to benefit, those whose 'net benefit' ranks higher should access the resource before those whose 'net benefit' ranks lower.

Senior clinicians work together to make ranking decisions, and take into account the views of patients and their families (*inclusiveness, reasonableness*). National guidance

also helps clinicians to prioritise. In a few cases, patients prefer not to receive life support in the ICU, and the autonomy of these patients is respected, while ensuring that such decisions were well informed (*respect/manaakitanga*).

In prioritising patients, the decisions that are made and who made them are clearly documented (*responsibleness*). This is considered important for accountability and defensibility.

These decision-making processes (the questions asked above, among other things) were agreed in advance and publicised in hospital newsletters and on the hospital website as part of broader communication about hospital pandemic planning (*openness*). As it was felt that these decisions could lead to a significant amount of disagreement and controversy, a wide range of stakeholders was consulted to discuss decision-making processes and values (*inclusiveness, responsibleness*). Other hospitals were consulted in order to learn from their experiences and to help to make decisions as consistent as possible across different units. Decisions about which patients would receive the limited number of ICU beds included consideration of how much patients would benefit from ICU treatment. It was also agreed in advance that factors, such as gender, ethnicity and disability, were not acceptable criteria by which to prioritise patients (*fairness*).

One of the people who is ill enough to warrant consideration for ICU treatment at this time is a hospital charge nurse. Nursing staff are in short supply at the hospital, and charge nurses are in particularly high demand. Patient care is likely to be affected if shortages become severe. When developing prioritisation criteria during the pandemic planning phase, consultation indicated that stakeholders and the public supported including whether someone was a healthcare worker as one criterion in the prioritisation decisions, both in order to maximise the availability of essential staff and as a means of supporting staff who accepted increased risks in the course of caring for others (*minimising harm, reciprocity*). The hospital also contacts the charge nurse's family to ensure the family is adequately supported and to express appreciation of the risk the charge nurse took on while providing valuable care to those with influenza (*reciprocity*). Because of a combination of an expectation that she would benefit significantly from ICU care and that she is a charge nurse who was infected while caring for others, the charge nurse is allocated an ICU bed.

The value of integrity is also worth considering here. Stakeholders could have expressed concerns that giving preference to staff might constitute a conflict of interest, and the hospital might then have decided to give less weight to reciprocity. Also, proportionality may have needed consideration: a staff member with only a small chance of benefit might not warrant priority over a non-staff member with a much higher chance of benefit.

QUESTION 7 **Can this patient be ranked highly enough based on order of presentation?**

NO — this patient is not offered ICU treatment. Other care may be provided instead. Stop here.

YES — this patient is considered for ICU treatment. Patients who present first have priority over patients who present later, if further prioritisation is needed even after questions 1–6 have been answered. If further prioritisation is needed, go to question 8.

CASE TWO

The clinicians cannot differentiate all patients on the basis of net benefit. Many of the uncertainties associated with determining prognosis in acutely unwell patients have left the clinicians with no clear way of putting some patients ahead of others. This possibility was predicted during pandemic planning, and the hospital's criteria stated that should a choice be necessary between patients who seemed equally able to benefit, those who presented first would have priority over those who presented later.

QUESTION 8 Can this patient be ranked highly enough based on random selection?

NO — this patient is not offered ICU treatment. Other care may be provided instead. Stop here.

YES — this patient is offered ICU treatment. Patients identified by random selection have priority over those who are not identified, if further prioritisation is needed even after questions 1–7 have been answered.

If prioritisation on the basis of order of presentation is not enough to decide which patients receive ICU treatment, the hospital decided the fairest way to allocate ICU treatment would be by random selection.

Table 4: NEAC questions for health service prioritisation in situations of overwhelming demand

1. Would this patient meet the clinical criteria for this treatment during normal times (that is, when there is not overwhelming demand for the resource)?
2. Is this treatment the most beneficial form of treatment for this patient?
3. Does this patient require this treatment immediately (that is, it is not possible for this patient's treatment to be safely deferred)?
4. Could capacity to deliver this service be expanded to treat this patient, with only minimal disadvantage to others?
5. Is it impossible to mitigate the negative effects for this patient of missing out on this treatment?
6. Can this patient be ranked highly enough based on benefit from this treatment?
7. Can this patient be ranked highly enough based on order of presentation?
8. Can this patient be ranked highly enough based on random selection?

Table 4 is generalised from the ICU case two. Source: NEAC's questions draw on Ardagh, 2006.

2.3.3   Summary of case two

Case two is one example of how the values and processes identified in the statement of ethical values might be used in planning for, and responding to, a pandemic in New Zealand. It also identifies potential prioritisation questions. The decisions made by the hospital in this case are not necessarily ideal or decisions that would always be appropriate in other hospitals or other settings. However, many of the processes this hospital followed when making decisions, and the values on which its decisions were based, may be relevant in other similar situations. The case also illustrates how challenging decision-making could be in the conditions of severe resource constraint faced during a pandemic. ■

Discussion of Values

3

3. Discussion of Values

3.1   Ethical values to inform how we make decisions

The ethical values for the decision-making process form the first part of the statement of ethical values and are summarised in Table 1. These values came from thinking about the situations people have faced in past, and might face in future, pandemics and outbreaks.

3.1.1   Why ethical values are important in how decisions are made

Good decision-making processes confer legitimacy on the decisions made. This matters in all cases, but it is especially valuable when not all agree with the decisions.

It is important pandemic planning decisions are consistent with ethical values and that they are seen to be consistent. A good decision-making process fosters trust and goodwill towards institutions such as hospitals, leading to greater acceptance and satisfaction and fewer complaints (Bell, 2004).

It has been suggested that 'due process requirements are inherently important because fair hearings affirm the dignity of the person' (Gostin, 2004: 571). Good decision-making processes may be necessary in order to show respect for people and ensure procedural fairness. As such, they may also reflect the value of tika, in the sense of acting in a way that is just and proper.

When ethical issues are considered, people hold a wide range of views and a lack of consensus is common on which values and principles are the most important ones on which to base a decision. This is a further reason why acceptable, fair processes need to be developed (Daniels and Sabin, 2002). Following good processes may help to resolve issues when people disagree. It may also help to ensure that decisions include comprehensive consideration of relevant issues. Finally, as noted above, a good decision-making process secures legitimacy for the decision, even when disagreement persists over the decision made.

The five characteristics of good decision-making processes are (from Table 1):

- inclusiveness (see section 3.1.3)
- openness (see section 3.1.4)
- reasonableness (see section 3.1.5)
- responsiveness (see section 3.1.6)
- responsibleness (see section 3.1.7).

3.1.2   Dealing with practical considerations

Practical constraints may also be important in pandemic decision-making. For example, during a pandemic it is particularly important that decisions are timely. Clear and firm leadership is also needed, and the roles and authorities of different decision-makers need to be clear.

Given these needs, it is unfeasible or inappropriate to carry out extensive consultation for every decision during the pandemic response. This limits the extent to which processes are inclusive. However, when it is not possible to be highly
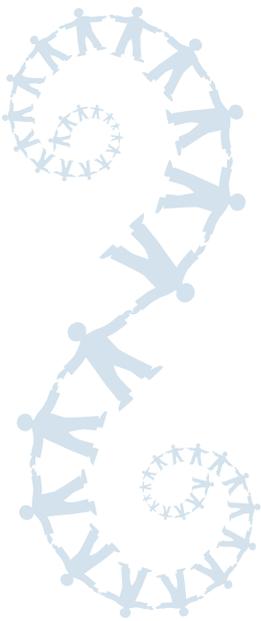
inclusive, it becomes particularly important to be responsive to new information that may not have been considered during initial decision-making. Clear, open and transparent decision-making is also particularly important during the pandemic response. In general, decision-making should also be reasonable and responsible. The difficulty of achieving inclusive decision-making during a pandemic also makes it particularly important to be inclusive during pandemic planning.

In short, practical constraints, as well as ethical considerations, inform decision-making. A report by the National Health Committee (2005) also identifies other important considerations in decision-making for health interventions. One major challenge in a pandemic would be balancing the decision-making values identified in this document with practical constraints such as the need for timeliness. Following good decision-making processes during pandemic planning can help to ensure these values are reflected in the pandemic response whenever possible. Those processes that are limited because of time constraints may still be addressed in part through responsiveness after decisions have been made.

3.1.3   Inclusiveness

Inclusive decision-making means:

- including those who will be affected by the decision
- including people from all cultures and communities
- taking everyone's contribution seriously
- striving for acceptance of an agreed decision-making process, even by those who might not agree with the particular decision made.

Why inclusive decision-making is important

If a pandemic occurs, we need to take account of differences in the importance and relevance of different values to different people. One approach is to try to establish a decision-making process that everyone can agree on, before focusing on the decision to be made. Including a wide range of people in decision-making processes and giving everyone's views fair consideration is a good way to ensure decisions are based on shared values.

An inclusive decision-making process may:

- bring to bear in decision-making a range of imagination and expertise that is difficult to achieve if processes are not inclusive
- help participants to feel engaged in, and understand, the process
- provide an opportunity to work through and refine the rationale behind proposed decisions
- make decisions seem fair to those who have had an opportunity to participate and also to those others who feel their interests were represented by those who did participate.

We also need to acknowledge the time constraints in decision-making during a pandemic. It is likely some decisions would need to be made very quickly. This may limit the extent to which decision-making can be inclusive. For instance, during a pandemic, it would be impractical and inadvisable to conduct an extensive consultation process for a government decision about whether to close schools.

However, while inclusiveness in decision-making may be restricted for urgent decisions, decision-making can still be open, reasonable and responsive. Being responsive enables the effects of rapidly made decisions to be critically assessed, further information to be collected, feedback to be given and acknowledged, and potential improvements to decisions to be retrospectively identified and implemented.

Inclusive decision-making processes also involve recognising Māori as tāngata whenua, the indigenous people of New Zealand. Māori should be involved in all aspects of pandemic planning processes to ensure their needs will be met. Issues relating to Māori cultural and ethical values should be addressed in discussion and partnership with the group or groups of Māori concerned, including, as appropriate, whānau, hapū or iwi.

Finally, those involved in pandemic planning should understand, respect and make due allowance for the diversity of affected populations. This wider point is expressed also in the Code of Health and Disability Services Consumers' Rights (the Code). (The Code has been created under the Health and Disability Commissioner (Code of Health and Disability Services Consumers' Rights) Regulations 1996.) Right 1(3) of the Code states that: 'Every consumer has the right to be provided with services that take into account the needs, values, and beliefs of different cultural, religious, social, and ethnic groups, including the needs, values, and beliefs of Māori'.

3.1.4 Openness

Open decision-making means:

- letting others know what decisions need to be made, how they will be made and on what basis they will be made
- letting others know what decisions have been made and why
- letting others know what will come next
- being seen to be fair.

Why open decision-making is important

Decision-making processes that are open and transparent may help to show that decision-making has been done well. Where the reasons for decisions are not apparent, trust in decision-makers may be undermined. Informing people of the reasons on which decisions are based may also promote compliance with difficult measures such as quarantine and restricted social interaction. Informing the public of what is being done to protect against a pandemic and the reasons for this is also consistent with the value of respect/manaakitanga. Related points are expressed in the Code, under which people have a right to be fully informed and communicated with effectively in healthcare decisions.

Openness is also related to truthfulness. These values are reflected in many professional codes; for example, the New Zealand Nurses Organisation's Code of Ethics (New Zealand Nurses Organisation, 2001). Openness is also related to the value of pono, meaning truth or integrity.

3.1.5   Reasonableness

Reasonable decision-making means:

- working with alternative options and ways of thinking
- working with and reflecting cultural diversity
- using a fair process to make decisions
- basing decisions on shared values and best evidence.

Why reasonable decision-making is important

For decision-making to be perceived as reasonable, it is important the rationale behind decisions is made clear. Explicit reasons for decisions help to avoid perceptions that decisions have been based only on the decision-makers' own understandings and values. Those with differing views may well challenge decisions, and making reasons explicit may provide assurance that each decision has a valid basis.

Reasonable decision-making includes making decisions that take into account and are consistent with shared values (see section 3.2) and are effective at minimising the harm from a pandemic. At times there may be tensions between minimising harm and other shared values such as respect/manaakitanga. For example, having harsh penalties for a lack of compliance with quarantine requirements might increase compliance but might not be acceptable to the public. Such possible conflicts are discussed further in section 3.2.3.

A problem often has a range of potential solutions. A decision may be seen as reasonable if the alternative courses of action that were considered are also identified and reasons are given for the course of action chosen.

Inclusive processes also help to make decisions more reasonable by including professionals or others with relevant expertise in an area. Reasons on which decisions are based should also reflect New Zealand's cultural diversity, and include provision for the divergent needs of different communities. It is also important to remember diversity within communities; for example, the existence of diverse Māori understandings and situations. Different Māori communities, whānau, hapū and iwi may all respond differently in a pandemic; such diversity will also occur within many other communities.

3.1.6   Responsiveness

Responsive decision-making means:

- being willing to make changes and be innovative
- changing when relevant information or the context changes
- enabling others to contribute whenever we (and they) can
- enabling others to challenge our decisions and actions.

Why responsive decision-making is important

Even with the best decision-making processes, the information available and the context in which we first make a decision are likely to change. Therefore, it is important to be aware of such changes and new information, to elicit feedback on decisions and to evaluate the outcome of decisions as fully as possible. Even decisions made through the best processes may later need to be revisited. For

instance, during the severe acute respiratory syndrome (SARS) outbreak, some hospitals implemented absolute bans on visitors to suspected SARS patients, but concerns were later expressed that this rule should have been revisited in the light of subsequent information (Ovadia et al, 2005). Evaluation and monitoring of the outcomes of decisions help to identify both positive and negative impacts. This may inform future decisions and enable an appropriate response to be made to concerns about previous decisions.

Since rapid decision-making may not fully cover all the ethical processes for decision-making suggested in this document, it is particularly important to respond to feedback on decisions after they have been made. For instance, some groups may not have been included in the decision-making processes, making it particularly likely that they will express concerns after decisions have been made. Being responsive may help to address these concerns.

Restrictive rules may also lead to some people feeling they have been unfairly treated or disadvantaged. In such situations, it is important to provide mechanisms for addressing these people's concerns. This is reflected in the Code, which states that patients have the right to complain. It has also been suggested that, if a clinician believes an exception to a restrictive rule is justified for a patient, the clinician should advocate on the patient's behalf on this point (Lo and Katz, 2005).

Responsiveness can also mean making policies and decisions that are sufficiently flexible to cater for a diverse range of needs. For instance, if communication in a pandemic is to reach those who are most in need of information, a range of culturally appropriate communication strategies may be required.

3.1.7   Responsibleness
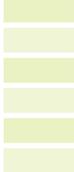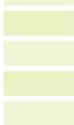
Responsible decision-making means:
- acting on our responsibility to others for our decisions and actions
- helping others to take responsibility for their decisions and actions.

Why responsible decision-making is important

It is important to have mechanisms in place to ensure decisions are being made well. This enables problems in decision-making to be addressed. We can assess whether good decision-making is occurring by using explicit, transparent and defensible processes, and having clear lines of accountability. In this context, accountability means being able to provide an account of whether responsible decision-making is occurring.

Decision-making may occur at multiple levels, which means efforts are necessary to co-ordinate the decisions appropriately and resolve conflicts that arise. It is also important to monitor whether decisions are being properly implemented; for example, monitoring whether quarantine orders are being adhered to. Therefore, responsible decision-making also involves being aware of others' decisions, and how this affects the outcome of decisions that have been made.

When decision-makers act responsibly and are seen to be responsible other people are more likely to trust them. Those others may also be more likely to act responsibly themselves. In contrast, if people think decision-makers are acting from

self-interest, trust diminishes. Decision-makers have a special responsibility to make decisions in the best interests of those they represent.

Expectations are important influences on our actions. When we expect ourselves and others to act responsibly, we find it easier to act accordingly. For instance, when decisions are made in a responsible way, and reflect an expectation that we will act responsibly in a pandemic, this will influence our expectations and help more of us to act more responsibly. It might even enable us to achieve things we could not otherwise have achieved.

3.2   Ethical values to inform what decisions we make

The ethical values informing what decisions to make that are outlined below form the second part of the statement of ethical values and are summarised in Table 2.

3.2.1   Why ethical values are important to what decisions are made

Pandemic planning involves making a wide range of advance decisions about pandemics. At the same time, many decisions cannot be made until the nature of a pandemic is known. It is impracticable to assess all the ethical implications of each decision in turn, or to attempt to predict the ethical implications of all possible future decisions. It is more practical, and more flexible, to identify the ethical values that might inform such decisions. This also enables advance discussion and debate to ensure these values are widely shared among all those who may be affected. This may then help to lead to decisions that are consistent with these shared values. An awareness of these ethical values may also help decision-makers to identify and appropriately manage conflicts between different values.

The values on which good decisions are made are (from Table 2):

- minimising harm (see section 3.2.2)
- respect/manaakitanga (see section 3.2.3)
- fairness (see section 3.2.4)
- neighbourliness/whānaungatanga (see section 3.2.5)
- reciprocity (see section 3.2.6)
- unity/kotahitanga (see section 3.2.7).

3.2.2   Minimising harm

Minimising harm means:

- not harming others
- protecting one another from harm
- accepting restrictions on our freedom when needed to protect others.

Why minimising harm is important

During a pandemic, it is desirable for society to continue to function as normally as possible. In many ways, protecting the public is the primary goal of pandemic planning and response. This involves reducing the amount of illness and death caused by the pandemic. It also involves taking into account broader pandemic

management strategies that are not directly related to health. Although minimising harm is an important value at all times, it has even greater importance during a pandemic, since the risks to the population are much higher.

Strategies to minimise harm in a pandemic may have different effects on different communities and population groups within New Zealand. Consideration should be given to the possible impacts on different communities, and care should be taken to ensure these strategies do not further disadvantage vulnerable populations or increase health inequalities.

Some strategies for pandemic management carry risks to the public. For instance, it has been suggested that while mass vaccination is an accepted component of pandemic planning, evidence about the predicted risk–benefit ratio is lacking (Kotalik, 2005). It is important to consider the potential harm arising from pandemic control strategies.

Another example would be the use of quarantine during the border management pandemic phase (stage 2). For instance, if four people have pandemic strain influenza among passengers on an arriving plane, consideration might be given to quarantining all passengers, since other passengers might have been infected during the flight. Not only would this involve restricting those passengers' freedom, but those passengers who were not infected could be put at a higher risk of infection, depending on the quarantine procedures used. Thus, in some cases, quarantine might increase the risk of harm to some individuals, and this should be considered when deciding how quarantine measures should be used.

Minimising harm is also relevant when communicating the risk of a future pandemic to the public. As a pandemic may or may not arrive in the near future, the public need to be aware of the risks of a pandemic, and what they can do about it. It is also important not to overemphasise the risk, which could lead to anxiety and a subsequent lack of urgency if a pandemic does not arrive immediately.

Clinicians aim to put a patient's needs first. However, in a public health emergency, a clinician's role may shift. Their responsibility to the common good may override the interests of an individual patient in some circumstances. Clinicians may have no discretion over compulsory measures such as disease notification, and this should be communicated to patients (Lo and Katz, 2005).

Minimising harm in a pandemic requires action from different people. Those involved in pandemic planning have a role to play, since good pandemic planning could limit harm if a pandemic occurred. Healthcare workers have special responsibilities in a pandemic, since many people would be sick and in need of care. The proper functioning of the health system during a pandemic would depend greatly on healthcare workers accepting these responsibilities. But all community members may have an important role to play in minimising harm in a pandemic. As so many people would become sick in a pandemic, it is likely that much care would need to be provided by people other than healthcare workers, including family, friends and neighbours. Measures that enable all these people to maintain this 'helping behaviour' must be an important part of pandemic planning and are an important way to minimise harm from any pandemic.
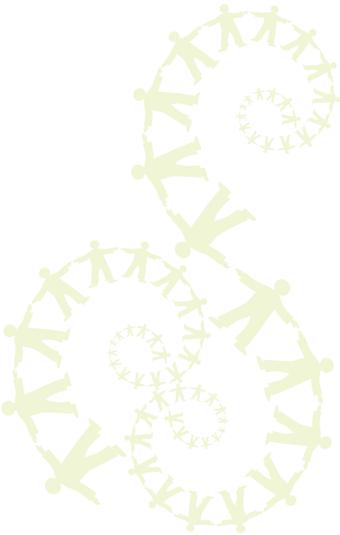
Minimising harm can require difficult decisions. Imagine a situation in which outbreaks of influenza have occurred in New Zealand. At this stage of cluster control (stage 3), several options are open to authorities. Local medical officers of health may need to decide whether public gatherings should be restricted, a power available to them under the Health Act 1956. School closures could be necessary. But closing schools will affect parents and reduce the number of staff available for functions such as tracing contacts and providing healthcare services. The Siracusa Principles provide guidance on when restrictive measures are justified in such a situation (see section 3.2.3). Medical officers of health may require support when making these important decisions and applying these powers, which are not part of their usual everyday practice.

3.2.3 Respect/manaakitanga

Respect/manaakitanga means:

- recognising that every person matters and treating people accordingly
- supporting others to make their own decisions whenever possible
- supporting those best placed to make decisions for people who cannot make their own decisions
- restricting freedom as little as possible, but as fairly as possible, if freedom must be restricted for the public good.

Why respect/manaakitanga is important and how we can foster it

Respect for people requires that those who are capable of thinking about and acting on their personal goals should be treated with respect for their capacity for autonomy or self-determination (CIOMS, 2002). Respect also involves protecting people with impaired or diminished autonomy and respecting privacy. These three aspects of respect are discussed below.

Manaakitanga has been described as 'nurturing relationships, looking after people, and being very careful about how others are treated' (Mead, 2003: 29). Treating people in this way is consistent with respect for their mana, personal authority or dignity.

Restrictive measures and respecting people's autonomy

One important way to protect the public from influenza is by limiting the spread of disease. Influenza is spread from person to person, so limiting social interaction and individual travel may help to contain the disease. This could mean quite drastic measures, such as closing schools, quarantining people or requiring people with influenza to undergo compulsory treatment. These measures limit people's freedom. Taking away people's choice of whether to undergo treatment also restricts their freedom. This means a potential conflict exists between respecting individual freedom and protecting the public by taking restrictive measures.

The ninth household in the urban community case (see section 2.2) illustrates how the value of respect/manaakitanga has the potential to conflict with minimising harm.

Ninth house: Family with three school-age children with influenza. The mother has just died and the husband is agitated and distraught. The team leader offers to call a funeral director to arrange for removal of the body, but the husband objects and insists the body remains where it is while he contacts relatives to arrange a tangi. The team leader agrees. The children are bewildered and hungry, but their temperatures are close to normal. Very little food is in the house. The team leader suggests contacting the local marae to ask if someone could come to help support the whānau. The husband agrees.

The father in this household wished to arrange a tangi. Although social distancing is an important infection control measure, no attempt was made to ban tangi in this case. Instead, a communications strategy was put in place advising how best to minimise the risk for events such as hui and tangi. In this case, the freedom to choose to attend a tangi was preserved, despite the risks. As well as respect/manaakitanga, this demonstrated understanding and compassion, or aroha, for those people who wished to accept some risk in order to attend a tangi for someone important to them. The needs of grieving whānau would be an important consideration in a pandemic. Therefore, cultural and health-related concerns would need to be addressed in a way that allows people to make informed choices whenever possible.

The whānau may also have wanted a kaumatua to attend to lift the tapu from the house following the mother's death. Tapu is a value that may be of particular importance in a pandemic, and whānau may consider it important to respect Māori protocols in these situations.

The restriction of individual freedom to protect public health is not a situation that is specific to influenza pandemics. For instance, New Zealanders with tuberculosis may be required to comply with restrictive measures that aim to prevent the disease from spreading to others (Tuberculosis Act 1948). Nevertheless, additional restrictive measures may be necessary in an influenza pandemic, and it is necessary to plan for these.

Restrictive measures should not be inappropriate or excessive. It has been suggested that the use of restrictive measures should follow principles of effectiveness, necessity, proportionality and fairness (Gostin, 2003). The Siracusa Principles also provide guidance in international human rights law on important considerations when freedom is to be restricted.

Human rights law

The Siracusa Principles set out the narrowly defined circumstances in international law in which human rights may be restricted in the interests of public health. These principles may provide a useful guide when restricting individual freedoms in the public interest during a pandemic. The Siracusa Principles have been summarised as follows (World Health Organization, 2002a).

> Only as a last resort can human rights be interfered with to achieve a public health goal. Such interference can only be justified when all of the narrowly defined circumstances set out in human rights law, known as the Siracusa Principles, are met.
>
> - The restriction is provided for and carried out in accordance with the law.
> - The restriction is in the interest of a legitimate objective of general interest.
> - The restriction is strictly necessary in a democratic society to achieve the objective.
> - There are no less intrusive and restrictive means available to reach the same objective.
> - The restriction is not drafted or imposed arbitrarily, that is, in an unreasonable or otherwise discriminatory manner.

Using the least restrictive measures possible

When restrictive measures are required, the least restrictive measures possible should be used. This idea is also reflected in the Siracusa Principles. People subjected to restrictive measures such as quarantine may be deprived of their freedom of movement, but they should not be deprived of other rights. Quarantine measures can be implemented in ways that are respectful, supportive and fair, and cater for divergent needs. Supportive measures may help to alleviate the negative effects of such restrictions. For instance, ensuring that those affected have good access to a safe means of communication with family and friends (for example, by telephone or email) could be a useful way to provide support. Identifying ways to mitigate the impacts of restrictive measures on patients may help clinicians to meet their responsibilities to act in their patients' interests (Lo and Katz, 2005).

The importance of access to support is also reflected in the Code. Right 8 of the Code states that 'every consumer has the right to have one or more support persons of his or her choice present, except where safety may be compromised or another consumer's rights may be unreasonably infringed'. While some measures such as quarantine may restrict the ability of support people to visit for safety reasons, providing access to a means of communication may help preserve support as much as possible.

Informed consent

A further way to respect individual autonomy is to ensure people are adequately informed. In research, informed consent helps to protect the individual's freedom of choice and respects the individual's autonomy (CIOMS, 2002). Although some pandemic measures such as quarantine may be compulsory, so not require consent, ensuring affected individuals are well informed can protect their autonomy to some extent.
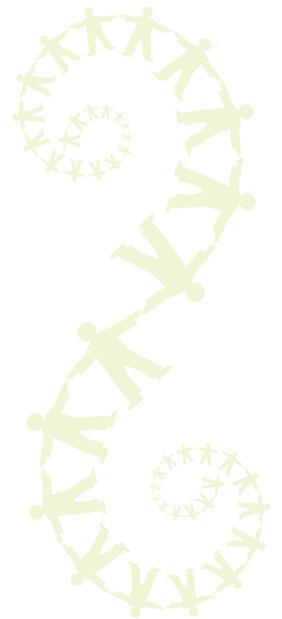
Even when freedom is restricted by infection control measures, clinicians could continue to act in patients' best interests to the greatest extent possible. Addressing a patient's needs and concerns may help patients to cope in such a situation (Lo and Katz, 2005), and is consistent with respect/manaakitanga.

Good decision-making processes

Whether restrictive measures are perceived to be fair and reasonable may depend on how such measures are implemented. Open and transparent decision-making, with good communication of the nature of restrictions and the rationale for their use, may promote acceptance of, and compliance with, these measures, while maintaining trust and goodwill towards decision-makers.

Due process is also important when people are subject to restrictive measures. In such cases, due process may assist in preventing or correcting errors in the application of restrictive measures, and may be an intrinsic component of fairness even when such measures are justified (Gostin, 2003). There have been calls to better provide for due process in proposed legislation that aims to ensure proper legal authority for restrictive measures in the event of a pandemic in New Zealand (Gray, 2006).

Encouraging voluntary measures

Encouraging and enabling people to behave in ways that limit the harm from a pandemic may reduce the need for more coercive measures that restrict individual freedoms. In some cases, voluntary measures may be both more desirable and more feasible. For example, the success of a mass vaccination programme would depend more on public education than on coercion, since enforcing compulsory mass vaccination might well be impossible (Gray et al, 2006).

Proportionality

As suggested by the Siracusa Principles, in some situations the restriction of human rights is justified in the interests of public health. However, such restrictions should be in proportion to the size of the threat to public health. For instance, if the risk to the public is small, highly restrictive measures might be inappropriate. But if a pandemic appeared to pose a large threat to the population, we should accept proportionally more restrictive measures to minimise the risk.

Proportionality is possible because many infection control measures are not all-or-nothing concepts. Quarantine, for example, can vary along several different dimensions.

- Who is being quarantined? For instance, does quarantine apply to only those who are known to be highly infectious or does it include people who are merely suspected of exposure?

- What sort of quarantine is used? During the SARS outbreak, quarantine measures varied between 'work quarantine', where healthcare workers were required to travel directly between work and home without stopping at other destinations, and the quarantine of an entire housing complex (Ries, 2004).

- Is quarantine voluntary or mandatory? For instance, during the SARS outbreak, Canada relied primarily on voluntary compliance (Ries, 2004).

- What is the penalty for non-compliance? While Canada relied mainly on voluntary compliance, it has been reported that the citizens of China faced penalties of imprisonment or execution for breach of quarantine (Mitka, 2003).

In emergency situations, the most effective response may require authorities to err on the side of restrictiveness, with a subsequent scaling down of restrictiveness as it becomes possible. The converse—the scaling up restrictiveness—may be a less effective approach to infection control. Nevertheless, proportionality remains an important consideration in both the initial response and the scaling down process.

Further legal and ethical implications

The Health Act 1956 already provides the legal authority for some restrictive measures, such as quarantine or compulsory examination. Some legislative provisions may need to be reviewed and updated to ensure they adequately provide for the reasonable measures needed for pandemic control. This would also be in line with the Siracusa Principles, which require that measures used to protect the public be consistent with the law. It is also important that any necessary amendments to legislation be made in a transparent manner.

The New Zealand Bill of Rights Act 1990 affirms the freedoms of association and peaceful assembly. However, if limiting social gatherings were necessary to reduce the spread of infection, because no less restrictive means were available, it might be acceptable to use such restrictions. But, imposing different levels of restrictions on people's activities could not be justified by mere difference of ethnicity, as this would be discriminatory. The Human Rights Act 1993 sets out specifically prohibited grounds of discrimination.

Right 1(1) of the Code states that 'every consumer has the right to be treated with respect'. Thus, the importance of respect/manaakitanga is also reflected in New Zealand legislation. The application of some of the other rights provided for in the Code—the rights to effective communication and to be fully informed—was also illustrated in the hospital-based case in section 2.3.

NEAC guidance on restrictive measures and respect/manaakitanga

- When possible and appropriate, restrictions should be voluntary rather than compulsory. Measures that promote voluntary compliance will reduce the need for compulsory restrictions.

- Restrictive measures should restrict only those rights that it is necessary to restrict. 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.

- Reciprocal support may be appropriate for those people who, in order to protect others, are subject to restrictive measures.

- Restrictive measures can be justified only when all the narrowly defined circumstances set out in human rights law, known as the Siracusa Principles, are met:

  - the restriction is provided for and carried out in accordance with the law

  - the restriction is in the interest of a legitimate objective of general interest

  - the restriction is strictly necessary in a democratic society to achieve the objective

  - there are no less intrusive and restrictive means available to reach the same objective

  - the restriction is not drafted or imposed arbitrarily, that is, in an unreasonable or otherwise discriminatory manner.

  (The Siracusa Principles are summarised in World Health Organization, 2002a)

Protection of people with impaired or diminished autonomy

Respect/manaakitanga also includes the protection of people with impaired or diminished autonomy. This requires that people who are dependent on others or are members of vulnerable populations are protected from harm (CIOMS, 2002).

Vulnerable people have been defined as (CIOMS, 2002: Guideline 13): those who are relatively (or absolutely) incapable of protecting their own interests. More formally, they may have insufficient power, intelligence, education, resources, strength, or other needed attributes to protect their own interests.

Societal factors such as relative disadvantage or disablement may also create vulnerability for some people. For instance, people who depend on additional support would be vulnerable to the removal of that support in a pandemic. This may include some people with disability, some older people and children, and people in residential care. People with chronic illnesses may be vulnerable if they have limited mobility, require extra care and support, or are taking medications to maintain their health. People with difficulty accessing medical care, including some older people, are also vulnerable. Other vulnerable populations may include people with psychiatric or behavioural disorders, refugees and prisoners.

Pregnant women and fetuses may require special consideration. For example, protective measures such as antiviral medication and vaccines may be less safe for these groups. Breastfeeding mothers and children may also warrant special consideration.

The Bellagio Statement of Principles, which resulted from a meeting of an international group of experts in public health, medicine, bioethics, public policy and other disciplines, noted that 'socially and economically disadvantaged groups and individuals are almost always the worst affected by epidemics' (Amon et al, 2006: 1). Such vulnerable populations may be recognised by having poorer population health status. For example, in common with many other indigenous populations, Māori have poorer health status than does the overall population (Bramley et al, 2004). This indicates that, from a health perspective, Māori are a vulnerable population, and that working with Māori for the protection of Māori in the event of a pandemic requires particular attention. In New Zealand, other populations with relatively poor health status, who may thus be vulnerable, include Pacific peoples and low-income populations.

Other disadvantaged groups may also be vulnerable. For example, policies and services are often constructed with able-bodied people in mind, potentially disadvantaging those with disability. During a pandemic, people with disability would be vulnerable to being further disadvantaged by policies and interventions, unless particular consideration was given to avoiding such an outcome. Vulnerable populations may need particular support during a pandemic, and it is useful to anticipate these needs in pandemic planning. If pandemic planning caters only for people who are not vulnerable, then vulnerable populations are likely to be further disadvantaged. The best outcomes may occur when pandemic planning is mindful of the different needs of different communities.

Privacy

Individuals' privacy may not be protected in a pandemic. Examples of privacy issues arose during the SARS outbreak. For instance, if it were recognised retrospectively that passengers on a train had been exposed to a person who was infectious, it might be justified to inform the passengers of this, so they could be vigilant about symptoms and seek treatment early if they became unwell. However, informing these passengers might not require the infectious individual to be named. The principle of proportionality requires that the least intrusive means possible is used (Singer et al, 2003).

As a further example, a person who carried SARS from China to Canada was named, with the family's consent, as it was felt this would provide a public health benefit. However, linking SARS with someone who had travelled from China subsequently led to people avoiding Chinese businesses (Singer et al, 2003). When releasing personal information, it may be necessary to consider the effects not only on that individual but also on communities, as well as any potential unintended consequences such as discrimination.

In New Zealand, the Health Information Privacy Code 1994 sets out conditions under which health information may be disclosed, including:

(d) ... the disclosure of the information is necessary to prevent or lessen a serious and imminent threat to:
(i)   public health or public safety; or
(ii) the life or health of the individual concerned or another individual.

Thus, the disclosure of health information is legally permitted in some pandemic situations. However, in keeping with the principle of proportionality, disclosure without consent should be limited as far as possible.

3.2.4   Fairness

Fairness means:

- ensuring everyone gets a fair go
- prioritising fairly when there are not enough resources for all to get the services they need
- supporting others to get what they are entitled to
- minimising inequalities.

Why fairness is important

This section discusses several different aspects of fairness that are important in pandemic planning, with particular emphasis on Māori and the prioritisation of resources in pandemic planning and response.

Fairness in pandemic planning and response

Certain groups are at higher risk during a pandemic, such as those identified as vulnerable populations (see section 3.2.3) and people such as healthcare workers who would be at higher risk of infection because of contact with infected patients. As these populations are at higher risk than the rest of the population, fair treatment requires that they receive additional protective measures.

Reducing inequalities is a goal of the New Zealand Health Strategy (Minister of Health, 2000). Groups disadvantaged by health inequalities, including Māori, Pacific peoples and low-income populations, are at risk of being further disadvantaged in a pandemic. Equity considerations mean pandemic planning should strive to ensure any pandemic does not further increase health inequalities.

Fairness may also require equitable communication. Groups for whom communication in English is difficult might also be at higher risk during a pandemic. Special attention may need to be paid to communicating in a variety of languages.

Using fair processes may also contribute to ethically sound decision-making. If fair processes are used, even if people do not agree with the decisions reached, they may feel they have been fairly treated if their views have been heard. Inclusive processes may help to avoid situations where certain groups feel unfairly treated due to their exclusion from the decision-making process. Even when good decisions are made, people may feel unjustly treated if they believe the decision-making processes used were inappropriate.

As pandemics spread from one country to another, they may provide fertile ground for stigmatisation and discrimination. Many healthcare workers from SARS-affected hospitals felt stigmatised because of their occupation (Nickell et al, 2004). Stigmatisation also occurred for people from countries that people from other countries associated with SARS outbreaks (Singer et al, 2003). The risk that discrimination and stigmatisation might occur should be kept in mind when communicating pandemic information to the public, and steps should be taken to minimise the risk of these problems occurring.

Māori

During the 1918 influenza pandemic, Māori had mortality rates five to seven times higher than those of non-Māori (Pool, 1973; Rice, 1983). Lack of immunity has been suggested as one possible, but incomplete, explanation for this difference. Other reasons could have included inequalities in socioeconomic status and access to health care as well as increased medical co-morbidity. These factors still affect Māori populations today. The history of the 1918 pandemic has been passed down within whānau, informing people's expectations and fears about future pandemics.

In common with many other indigenous populations, Māori have poorer health status than the non-indigenous population (Bramley et al, 2004). Reducing such inequalities in health status is one goal of the New Zealand Health Strategy (Minister of Health, 2000) and He Korowai Oranga: Māori Health Strategy (Minister of Health and Associate Minister of Health, 2002) The existence of these health inequalities is also an indication that, from a health perspective, Māori are a vulnerable population. This suggests that the protection of the Māori population in a pandemic will require particular attention.

Other New Zealand population groups and communities may also be vulnerable in a pandemic and require special attention to ensure health inequalities do not increase.

The importance of a health gain for Māori is stated in the New Zealand Public Health and Disability Act 2000, section 4: 'with a view to improving health outcomes for Māori, Part 3 provides for mechanisms to enable Māori to contribute to decision-making on, and to participate in the delivery of, health and disability services'.

Accordingly, pandemic decision-making processes should involve Māori at all stages and levels of pandemic planning and response. In addition, Māori involvement is essential to ensure Māori are not disproportionately affected by a pandemic and that the best whānau outcomes are achieved should a pandemic occur.

Prioritisation

Prioritisation is already a major consideration in the health sector, as well as in other sectors of government. Resources are finite, and it is important resources are used in the best way possible. This means prioritisation is not an issue that is specific to pandemics. However, during a pandemic, the need for prioritisation would be likely to be particularly acute. Demand for health services would increase, particularly for services directly related to influenza. At the same time, the supply of health services would be likely to decrease. For instance, if a large proportion of the population was unwell with influenza, the supply of healthcare workers, and other workers, would decrease.

It has been suggested that scarcity should not be taken for granted, and that it is important to consider fully what resources would be required to avoid scarcity. Since scarcity could mean loss of life, any decision to accept a certain level of scarcity should be explicit and clearly balance costs and benefits (Kotalik, 2005).

Scarcity may occur in specific pandemic treatments (for example, antiviral therapy and vaccines), general treatments for those with pandemic influenza (for example, ventilators and antibiotics) and treatments for those who need health care but do not have pandemic influenza. Resources would need to be prioritised not only for people with influenza but also for people with illnesses unrelated to the pandemic.

Planning ahead

Pandemic planning can assist in limiting the need for prioritisation. For instance, resources such as antiviral medication can be set aside in advance of a pandemic, so supply is higher than it would otherwise have been. Plans can be put in place in advance to obtain other important supplies, such as vaccines, as quickly as possible during a pandemic. Measures to control or slow the spread of a pandemic may help to spread the load on health services over a longer period and reduce the number of workers who are absent from work simultaneously because of illness in the health sector and other sectors. Considerations such as these are raised in the NZIPAP (Ministry of Health, 2006).

Prioritising fairly

Even with the best possible planning, prioritisation would be necessary during a pandemic. This would mean some people would not receive the health care they need or would like. It is important such prioritisation is done in the fairest way possible.

For instance, stocks of antiviral medication are limited. Decisions must be made about when it is appropriate to use these stocks as prophylaxis (that is, as measures to prevent people becoming sick) and when they should be used for treating people who are already sick. Using stocks as prophylaxis may prevent disease in some people but would result in stocks being used up more quickly than if they were not used for such measures. If stocks are too low to offer treatment to everyone, decisions must be made about who will be offered treatment first and who may not be offered treatment at all.

Decisions may be made according to criteria that are implicit (criteria known only to those making the decision) or explicit (criteria that are known to those making the decision and others). Explicit criteria are generally preferable. Explicit criteria make it easier to know whether criteria are reasonable and resources are being distributed fairly, and whether criteria are being adhered to. The use of explicit criteria promotes transparency and may enable those who might be affected by the criteria's use to give feedback on, and challenge, the criteria. In a pandemic, it is also necessary that prioritisation decisions are timely, so explicit criteria should be developed in advance of decisions needing to be made. A hypothetical example of this is shown in the hospital-based case in section 2.3.

Prioritisation criteria often include considerations of need and the potential benefit. However, debate continues about whether some measures of 'benefit' carry the potential to discriminate against groups such as people with disability and older people. These potential problems should be kept in mind when developing prioritisation criteria.

Criteria must be revisable in the light of new information. For example, if new information suggests antiviral treatment is effective only at a certain stage of illness and existing criteria did not reflect this, the criteria should be revised accordingly. Efforts should also be made to ensure prioritisation decisions do not further disadvantage population groups that suffer from health inequalities.

Support and guidance for people implementing prioritisation decisions

Healthcare workers generally consider their first duty to be to their patients. However, in an environment of severe resource limitations (such as a pandemic), healthcare workers must also consider other patients' needs. This creates conflicts for healthcare workers. The Medical Council of New Zealand (2005: 1) provides guidance to doctors on this matter.

Doctors have a responsibility to the community at large to foster the proper use of resources and must balance their duty of care to each patient with their duty of care to the population.

Prioritisation decisions must be made well, but also implemented well. It is likely to be necessary to provide appropriate support for people implementing prioritisation measures and monitor the situation to ensure decisions are being properly implemented (Lo and Katz, 2005).

3.2.5 Neighbourliness/whānaungatanga

Neighbourliness/whānaungatanga means:
- helping and caring for our neighbours and friends
- helping and caring for our family/whānau and relations
- working together when there is a need to be met.

Why neighbourliness/whānaungatanga is important

Encouraging people to act in a neighbourly way towards each other during a pandemic is perhaps one of the most effective tools we have to manage the effects of a pandemic. Hospitals and doctors would be likely to be overwhelmed quickly
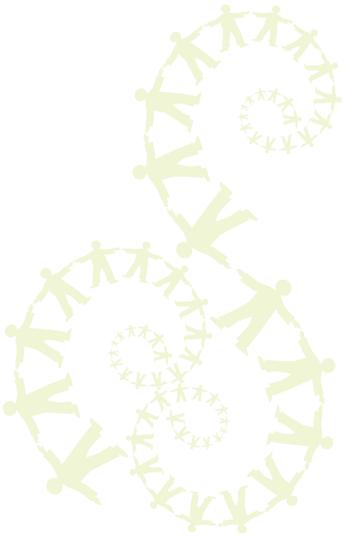
in a pandemic, which would make the way we act in our homes and communities even more important than usual. A major lesson from the 1918 pandemic was that neighbourhood and community cohesion and support in times of crisis can be vital (Rice, 2005).

According to the value of whānaungatanga, individuals may expect support from both near and distant relatives, and the collective group may also expect the support and help of its members. Whānaungatanga may also include relationships with people who are not relatives (Mead, 2003).

Helping and caring for our family/whānau, friends and neighbours could be as simple as ensuring that people affected by the pandemic have good access to a safe means of communication such as telephones. How many of us know our neighbours' names and phone numbers? How many of our neighbours do we know well enough to count as a network of potential help for one another, if that were needed?

Who our neighbours are

As shown in the urban community case in section 2.2, the relationships that are important for neighbourliness/whānaungatanga include those with people living next door, but they also extend a lot further. Friends, family or flatmates, the wider whānau and marae, and those living further away with whom we have relationships may be the recipients or providers of neighbourliness/whānaungatanga.

At another level, it is important that similar processes also operate between cities, regions and countries. The responsibilities of countries and governments towards each other, and the responsibilities of international organisations such as the World Health Organization have been explored in more depth elsewhere (Joint Centre for Bioethics Pandemic Influenza Working Group, 2005; World Health Organization, 2006).

We can all be 'carers'

An effective pandemic response would require healthcare workers to be available to help people who are sick. Many other community members are also involved in providing care, such as people who care for a person with a disability or an older person. People may also be involved in caring for children or other family members. We would need many different carers, in addition to healthcare workers, for society to continue to function in a pandemic.

In a pandemic, many people who are sick would need to be cared for by people other than healthcare workers. This would see family members and, potentially, neighbours and other members of the community taking on an important role. Care in a pandemic would come from a variety of sources, and the amount of care that sick people would receive could depend greatly on the neighbourly behaviour of others. There are simple kinds of care any of us could give, such as making sure a sick person has enough to drink. What would happen in a pandemic if we were very ill but no one was willing to give us fluids?

The best outcome from a pandemic would be likely if well community members helped members who were sick, especially if there were shortages of medical care. This means approaches that support and enable such 'helping behaviour' are important ways to ensure the best outcome from any pandemic. For instance, people who accepted extra responsibilities (and, potentially, extra risks) by helping

other community members would need to be supported. Such support could include ensuring that people are aware of how to help their neighbours safely or acknowledging the great importance of such neighbourly behaviour.

Conflicts may occur between neighbourliness/whānaungatanga and other values. For instance, in the urban community case in section 2.2 a potential conflict with the value of autonomy was illustrated. The members of the seventh household appeared self-sufficient, but were reluctant to help others for fear of becoming infected. In such cases, understanding, compassion and aroha are appropriate, as it is quite understandable for community members to be afraid of becoming infected in a pandemic and to concentrate only on what seems best for themselves and their 'nearest and dearest'. On the other hand, our expectations regarding neighbourly behaviour may help us to behave in neighbourly ways. Also, if everyone refused to help others because of a fear of infection, it seems likely everyone would be worse off. This potential conflict can be minimised by promoting the importance to the whole community of neighbourly behaviour during a pandemic, and providing information on infection control measures to enable community members to help others while still protecting themselves from infection. Many New Zealanders will want to act in neighbourly ways, and need to know how to do so without contributing to the spread of infection.

A degree of self-sufficiency, including obtaining emergency supplies in advance, may also be good for households, and therefore the community. Reducing the need for our reliance on help from others may make an important contribution, given the degree to which community resources would be stretched in a pandemic. It is important we provide as well as we can for ourselves and our families. It is also important we help one another. In the 1918 pandemic, the willingness of New Zealanders to help one another was a very important factor in getting through together. This might well be the case in any future pandemic.

NEAC guidance on neighbourliness/whānaungatanga

- We all have obligations of neighbourliness/whānaungatanga to others.
- The extent of our neighbourliness/whānaungatanga could make an important difference to how well we get through a pandemic together.
- Pandemic planning should consider how best to foster self-care and neighbourliness/whānaungatanga.
- Communities may wish to consider how best to foster self-care and neighbourliness/whānaungatanga. One question to address might be 'who is my neighbour?'.

3.2.6 Reciprocity

Reciprocity means:

- helping one another
- acting on any social standing, or any special responsibilities we may have, such as those associated with professionalism
- agreeing to extra support for those who have extra responsibilities to care for others.

Why reciprocity is important

People helping one another is an expression of reciprocity and would be crucial to minimising harm from a major pandemic. Reciprocity is also the basis for providing additional support for those who accept extra responsibilities during a pandemic. This may apply to those who put themselves at high risk during a pandemic (such as healthcare workers and others caring for and helping others) and those who are affected by restrictive measures designed to limit the pandemic.

For example, during the border management or cluster control pandemic phases (stages 2 and 3), people could be quarantined, voluntarily or compulsorily. This would be done for the good of others, not for the person's good. Such people are required to bear an extra burden in the interests of others. Reciprocity can be expressed by ensuring people who are quarantined are given extra support and well looked after, in keeping with the extra burden they carry for protecting others.

Trust

People may be more likely to help one another when there is an atmosphere of trust. Trust may also invite reciprocal trust, in processes called 'virtuous spirals' (O'Neill, 2002). This makes reciprocity an important part of trusting and helping one another.

Increased burdens and responsibilities for healthcare workers

Imagine the case of nurse A. She has two small children and works in the emergency department at the local hospital. What problems might she face in a pandemic?

Patients unwell with suspected influenza arrive at the hospital at which nurse A works. Hospital staff need to assess these patients and provide care to them, which may put those staff at greater risk of infection. If nurse A cares for these patients and becomes infected she might pass the infection to her children or she could die and leave them motherless. Alternatively, if her children become sick from another source she may need to stay home to care for them. But the patients at the hospital also need nurses to care for them. Nurse A has many responsibilities. She also has a claim on others for recognition and reciprocal support.

During a pandemic, large numbers of people would become ill. Many of these people would require medical treatment and the demand for healthcare workers would increase. However, treating patients with influenza will pose a risk to healthcare workers. During the SARS outbreak, some staff refused to work because of the risk they perceived to themselves and their families. A risk existed, and healthcare workers were among those who died during the SARS outbreak (Singer et al, 2003). However, if healthcare workers refuse to work, staff shortages are made worse. The healthcare system would not function in a pandemic if staff refused to go to work.

Although the discussion here focuses particularly on healthcare workers, other workers would also be at risk. Hospitals and other health services need many other staff to be able to work, including administrators, orderlies and cleaners. Interpreters may also be in high demand during a pandemic. The increased risk of infection applies not only to healthcare workers, but also to many other workers. As discussed elsewhere in this document, the increased risk also applies throughout the community, to those who combine self-care with neighbourly actions toward others.
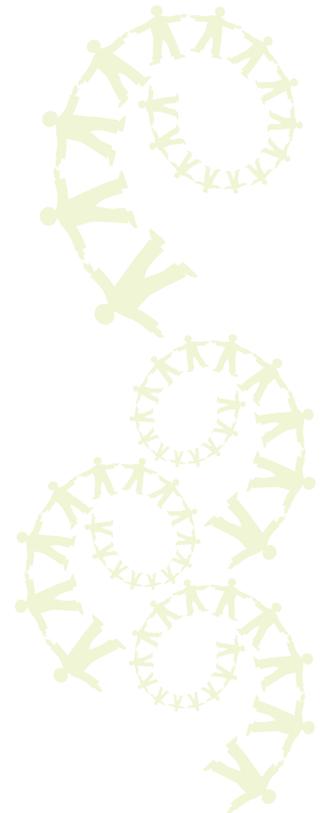
A conflict may exist between healthcare workers' desire to care for patients (and patients' need for this care) and healthcare workers' understandable desire to protect themselves and their families from harm, potentially by choosing not to work with infectious patients. One important way to manage this conflict is to provide extra support to healthcare and other workers to help to minimise the risks.

Providing reciprocal support for healthcare workers

Reciprocity, in the case of healthcare workers, can mean providing additional support to acknowledge the extra responsibilities these workers take on. This may be an important way to manage the conflict experienced by healthcare workers providing care despite the increased risk to themselves. Support could involve reducing the extra risk healthcare workers face and providing additional support for healthcare workers.

Additional support could include publicly acknowledging and demonstrating appreciation of workers' willingness to face additional risk, helping workers to cope with stressful situations and offering support to workers' families affected by illness (Singer et al, 2003). Other measures include taking all reasonable precautions to prevent illness among healthcare workers and their families. In countries like the United States, reducing or eliminating malpractice threats for those working in high-risk emergency situations is another form of additional support (Huber and Wynia, 2004). The New Zealand environment is much less litigious. In New Zealand, discussion of 'provider compliance' in the Code requires 'reasonable actions in the circumstances' and it has been suggested it is unlikely that 'discipline would be invoked to judge medical practice during a pandemic' (Paterson, 2005: 15). Nevertheless, the Code would still apply during a pandemic. Good training on pandemic patient care, the use of personal protective equipment and the potential risks for transmission may also help to protect and support healthcare workers (Loutfy et al, 2004). Clear planning for such support may help demonstrate to healthcare workers that their contribution is valued, and it may also foster a willingness to accept additional responsibilities.

An example of additional support was seen in the hospital-based case in section 2.3, where a nurse was given a higher priority for treatment because she was infected while caring for others. This is one form of reciprocal support that could be considered for healthcare workers.

Adverse effects on health workers may extend beyond the risk of infection. During the Canadian SARS outbreak, hospital staff felt stigmatised because of their role, so avoided public spaces and interaction with family and friends (Nickell et al, 2004). Measures to support hospital staff and others affected by a pandemic should also consider such indirect adverse effects.

Employer responsibilities

Employers are responsible for providing safe working conditions. While healthcare workers may be at risk when treating patients with infectious diseases, this risk may be lowered if patients are treated in appropriate facilities, using appropriate equipment (such as personal protective equipment), and staff are well trained in how to minimise their risk of infection (Loutfy et al, 2004).
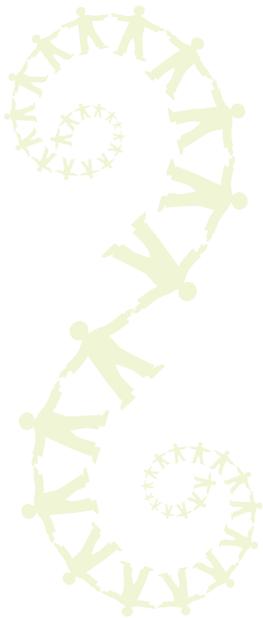
The principle of reciprocity is also important here, whereby those who are put at greater risk of infection warrant extra support.

Opinion polls in New Zealand have suggested strong public support for the idea that frontline health workers should receive priority access to antiviral medication. This suggests reciprocity is a shared public value (Public draws line at flu doses for politicians, 2006).

Employers' responsibilities are also reflected in the Health and Safety in Employment Act 1992, section 6(a) and (b), which states:

> Every employer shall take all practicable steps to ensure the safety of employees while at work; and in particular shall take all practicable steps to—
>
> (a) Provide and maintain for employees a safe working environment; and
> (b) Provide and maintain for employees while they are at work facilities for their safety and health.

We would all face risks in a pandemic. Employers will also get ill and have families, friends and neighbours to care for. They too will face challenges in doing all that would be asked of them.

Extra responsibilities of healthcare workers

We expect healthcare workers to act professionally, and many have their own professional codes. Professionalism includes practising skills of special value and maintaining relationships of trust with clients. Professionals also have a special status within society (Freidson, 1994), though this status may change over time. This means professionals face special expectations and responsibilities compared with the rest of the population.

Health professionals have special abilities to provide care that others do not have. Related to this is a public expectation that they will provide care in an emergency (Ruderman et al, 2006). The World Medical Association's (1987) Statement on Aids notes 'physicians have a long and honored tradition of tending to patients afflicted with infectious diseases with compassion and courage'.

It has been suggested that because health workers freely choose their professions, they have assumed the associated risks (Ruderman et al, 2006). However, the level of risk health professionals expect in the course of their work may vary widely, depending on their specialisation (such as the risks faced by infectious diseases specialists compared with dermatologists) and place of work (such as in developing countries compared with developed countries) (Sokol, 2006).

It has also been suggested the level of risk health professionals should assume depends on the degree of risk to themselves and the likely benefit to patients (Sokol, 2006). For example, it seems unreasonable to expect healthcare workers to put themselves at great risk when little benefit to patients is likely. Furthermore, alongside their professional responsibilities, healthcare workers also have personal responsibilities, including to their families (Sokol, 2006). They would also need to consider these other responsibilities in a pandemic.

The extent to which healthcare workers ought to accept additional risks in the course of caring for patients has been contested. Some argue that 'our profession exists to care for the sick despite any element of risk' (Ovadia et al, 2005: 78), while others suggest there are limits on the risks healthcare workers should be expected to bear in the course of their duties. It has been suggested that, as a starting point, there should be 'a minimal standard that calls for treating patients in the face of a moderate degree of unavoidable risk', and that any further duties should be the subject of professional and public dialogue (Huber and Wynia, 2004: W9).

At the very least, it seems reasonable that healthcare workers should accept some degree of risk, when this risk cannot be prevented through reasonable measures. One source of guidance on this is provided by professional codes.

Professional codes

Some health professionals, including doctors, have a duty to help others set out in their professional codes. The Medical Council of New Zealand (2006: 1) provides guidance to doctors on this point.

A doctor is at risk of being professionally or criminally responsible if he or she fails to render prompt and appropriate medical care to any person (whether the patient is a current patient or not), in a medical emergency. A doctor who chooses not to attend must have good reason and be able to defend this position at a later time.

The Council also recognises that in some situations doctors cannot, may not or should not attend a medical emergency, for example 'if attending the emergency places the personal safety of the doctor at risk' (Medical Council of New Zealand, 2006: 1).

The New Zealand Medical Association's Code of Ethics (2002: 3) lists as a principle that doctors should '[c]onsider the health and well-being of the patient to be [their] first priority'. But it also recognises (at p 6) that '[d]octors have both a right and a responsibility to maintain their own health and well-being at a standard that ensures that they are fit to practise'.

This means uncertainty exists, even in medical codes of ethics and practice, about the extent of risk that should be accepted in the provision of care. NEAC is also aware of, and supports further work by, the Medical Council of New Zealand and New Zealand Medical Association Ethics Committee on these matters.

While some professions have their professional duty to help set down in professional codes, others have no such code, but their contributions would still be needed in a pandemic. This means professional duties cannot be relied on to ensure people help others, whether in the context of patients or the wider community. It would also be wrong to assume that healthcare workers provide care only because their professional codes require them to. Thus, it is important to consider what else can be done to enable 'helping behaviour', by healthcare workers and other community members.

NEAC endorses the lead taken by health professional organisations to confirm that members of their professions have special responsibilities to provide care in a pandemic, alongside the family responsibilities that all citizens have. The Health and Disability Commissioner has also endorsed this view. Given the important role of health professionals in any pandemic, NEAC considers that society should reciprocate with special recognition and support.

NEAC guidance on health professionals' responsibilities

- NEAC supports the lead of health professional organisations that are providing guidance to their members on their responsibilities in a pandemic.

- Health professionals have obligations to provide care if a pandemic occurs, including when there is increased risk to themselves and their families.

- Community expectations of health professionals should be reasonable. For instance, we should not expect health professionals to provide care when personal risks outweigh patient benefits. Planning should aim to create conditions that enable health professionals to care for their patients and themselves.

- Extra support is appropriate for health professionals and other workers in recognition of their extra responsibilities. This includes facilitating their voluntary participation in pandemic response, minimising risk and, whenever possible, avoiding situations of unreasonable risk to health professionals. It also includes personal and public recognition of their contributions.

3.2.7   Unity/kotahitanga

Unity/kotahitanga means:

- being committed to getting through the situation together
- showing our commitment to strengthening individuals and communities.

Why unity/kotahitanga is important

During a pandemic, factors such as a scarcity of resources, overloaded health systems and an atmosphere of anxiety and fear could have a divisive effect. Unity between community members, patients, healthcare workers, organisations, different levels of government, and governments in different countries could be affected. Unity is also related to solidarity. 'Kotahitanga' may be interpreted as working together and taking a holistic approach (Ministry of Health, 2003).

Unity/kotahitanga may be particularly important during a pandemic. Healthcare workers may be more willing to provide care despite a degree of personal risk if they have a good relationship with, and feel valued and supported by, the institution to which they belong. People who are at home and unwell may need help from neighbours and other community members. Public compliance with restrictive measures may be influenced by the degree of goodwill towards policy-makers and healthcare workers. Internationally, surveillance and reporting standards in one country may have large impacts on other countries, reinforcing the benefits of co-operation and reciprocal assistance. The success with which a pandemic is managed may depend on the degree to which people, organisations and countries help each other and assume shared responsibility. It is important to maintain commitment to managing our way through any pandemic together.

Trust is an important component of, and contributor to, unity/kotahitanga. Trust may be strained during a pandemic, but it will be needed between community members, patients, doctors, different organisations and different countries. It has been suggested that efforts should be made in advance to foster trust, through

appropriate communication and planning processes (Kotalik, 2005). For instance, good communication and transparency in decision-making may enhance public trust in decision-makers. When members of the public trust decision-makers, they are more likely to accept difficult decisions, such as restrictive measures.

Public trust in those who are making decisions or are in positions of power or responsibility, may be fostered when people in these positions display integrity in their commitments and actions. Related concepts include good governance and stewardship (Joint Centre for Bioethics Pandemic Influenza Working Group, 2005). Integrity in these circumstances may be interpreted as honest and thoughtful conduct and being accountable for one's activities. Acting with integrity may also include minimising and disclosing potential conflicts of interest and intending to act in the public's best interests.

Including a wide range of people in decision-making is also an important way to promote unity between the public and authorities. For instance, inclusive decision-making may help to improve public understanding of restrictive measures and lead to increased compliance with such measures. Compliance with quarantine, for instance, could be improved if people understand the risk of infection to other people.

Relationships between clinicians and patients

Unity/kotahitanga and good relationships are also important between clinicians and patients during a pandemic. Relationships may be strained in situations, such as where clinicians have to inform patients that, due to prioritisation or infection control measures, the patient's wishes cannot be met. However, it is important to strive to maintain the clinician–patient relationship. Unity may be supported by maintaining common ground with patients. For instance, even if patients would rather not be subject to quarantine measures, they would probably agree it is important to recognise the risk others would face if they did not comply with such measures (Lo and Katz, 2005).

When restrictive public health measures such as quarantine or prioritisation measures are implemented, clinicians could be faced with a conflict between their duty to the patient and the need to protect the public's interests. Several strategies have been suggested to help clinicians deal with these conflicts. These include acknowledging and normalising patient concerns in such a situation, remembering the responsibility to the wider public, and acting in the patient's best interests to the greatest extent possible within the limits of restrictive public health measures (Lo and Katz, 2005). Strategies such as these may help maintain the clinician–patient relationship while protecting the public interest.

Communication and clinicians

Within healthcare organisations, decisions at all levels will have significant impacts on healthcare workers. This makes good governance and stewardship important in maintaining unity/kotahitanga and solidarity within these organisations. In addition to good decision-making, it is also important that the experiences of those who implement decisions are heard and taken into account in ongoing decision-making. Even when there is general agreement with the decisions and a shared

understanding of the rationale for the decisions, it remains important that the experience of those who implement decisions is heard (Bell et al, 2004). This shared understanding is another potential benefit of good communication and emphasises that communication is a two-way process. This point applies to decisions at all levels within healthcare organisations, whether by management, clinicians or other parties. Healthcare workers, in turn, may be able to use their listening skills to help patients to secure the best outcomes in the circumstances (Lo and Katz, 2005).

Promoting unity/kotahitanga through good communication

Good communication is crucial to planning for and managing a pandemic with maximum public trust and consent.

How communication occurs may affect unity in different ways. If we communicate with people according to the idea that people should and would help others in a pandemic, and that they will be supported in this, we are more likely to foster such 'helping behaviour'. By identifying widely shared values, and communicating with these values in mind, we can enable one another to act as best we can on the basis of those shared values.

While many measures to protect the public from harm during a pandemic would be implemented by healthcare workers or government authorities, all members of the public could do a lot to help themselves and others. For example, good hand and respiratory hygiene, social distancing and stocking up on household emergency supplies can all help people to be and feel more prepared. It is, therefore, very important to communicate with people in a way that maximises their trust and consent, so they are prepared to help each other.

The importance of good communication is also reflected in the Code, which states that people have a right to effective communication.

Diversity and communication

New Zealand is culturally diverse and includes several large ethnic populations, such as the Māori, Pacific and Asian populations. Good communication needs to consider all groups. This means communication must occur in a culturally appropriate manner that all groups can understand. Extra effort may be required to reach some groups, such as people who do not speak English as their first language.

Communication that recognises diversity is particularly important when effectively managing a pandemic. For example, if border management measures require new arrivals to comply with restrictive measures, compliance is improved with clear and culturally appropriate communication, especially because the population at the border is likely to be culturally and linguistically diverse. Good communication could also be important in ensuring that people arriving in the country during a pandemic had a good understanding and awareness of symptoms indicating possible infection.
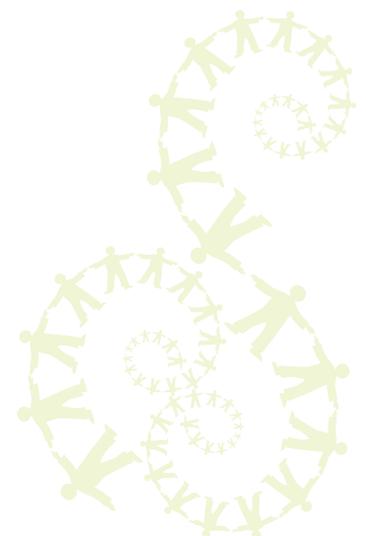
Inclusiveness may require particular attention to involving groups for whom communication in English may be more difficult, such as some migrant groups. Clear communication and inclusive decision-making can help to promote the legitimacy of the decisions made and may be important ways of promoting unity in a diverse society.

Avoiding isolation

Certain groups may pose particular communication challenges. For example, isolation is particularly common among older people, who may also lack access to modern forms of communication such as mobile phones and email. This means communicating effectively with older people during a pandemic requires particular attention.

Those living in rural areas are also more prone to isolation. Communication with people living in these areas, and with healthcare workers practising in these areas, may be particularly challenging during pandemic planning and response. ■

Appendices

Appendix A: Summary of guidance from the National Ethics Advisory Committee

This appendix draws together the guidance in this document from the National Ethics Advisory Committee – Kāhui Matatika o te Motu (NEAC) on important ethical issues likely to be faced in pandemic planning and response. These issues are discussed in the body of the document.

The NEAC guidance summarised here focuses mainly on the health sector. Some of this guidance is also useful in a wider range of settings.

NEAC guidance on restrictive measures and respect/manaakitanga

- When possible and appropriate, restrictions should be voluntary rather than compulsory. Measures that promote voluntary compliance will reduce the need for compulsory restrictions.

- Restrictive measures should restrict only those rights it is necessary to restrict. 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.

- Reciprocal support may be appropriate for people who, in order to protect others, are subject to restrictive measures.

- Restrictive measures can only be justified when all of the narrowly defined circumstances set out in human rights law, known as the Siracusa Principles, are met:

  – the restriction is provided for and carried out in accordance with the law

  – the restriction is in the interest of a legitimate objective of general interest

  – the restriction is strictly necessary in a democratic society to achieve the objective

  – there are no less intrusive and restrictive means available to reach the same objective

  – the restriction is not drafted or imposed arbitrarily, that is, in an unreasonable or otherwise discriminatory manner.

  (The Siracusa Principles are summarised in World Health Organization, 2002a)

NEAC guidance on neighbourliness/whānaungatanga

- We all have obligations of neighbourliness/whānaungatanga to others.

- The extent of our neighbourliness/whānaungatanga could make an important difference to how well we get through a pandemic together.

- Pandemic planning should consider how best to foster self-care and neighbourliness/whānaungatanga.

- Communities may also wish to consider how best to foster self-care and neighbourliness/whānaungatanga. One question to address might be 'who is my neighbour?'.

NEAC guidance on health professionals' responsibilities

- NEAC supports the lead of health professional organisations that are providing guidance to their members on their responsibilities in a pandemic.

- Health professionals have obligations to provide care if a pandemic occurs, including when there is increased risk to themselves and their families.

- Community expectations of health professionals should be reasonable. For instance, we should not expect health professionals to provide care when personal risks outweigh patient benefits. Planning should aim to create conditions that enable health professionals to care for their patients and themselves.

- Extra support is appropriate for health professionals and other workers in recognition of their extra responsibilities. This includes facilitating their voluntary participation in pandemic response, minimising risk and, whenever possible, avoiding situations of unreasonable risk to health professionals. It also includes personal and public recognition of their contributions.

NEAC questions for health service prioritisation in situations of overwhelming demand

In an influenza pandemic, it is likely demand would be very high for limited healthcare resources. NEAC considers that the following questions may useful in guiding the prioritisation of resources, such as treatment in an intensive care unit, in such situations.

1. Would this patient meet the clinical criteria for this treatment during normal times (that is, when there is not overwhelming demand for the resource)?

2. Is this treatment the most beneficial form of treatment for this patient?

3. Does this patient require this treatment immediately (that is, it is not possible for this patient's treatment to be safely deferred)?

4. Could capacity to deliver this service be expanded to treat this patient, with only minimal disadvantage to others?

5. Is it impossible to mitigate the negative effects for this patient of missing out on this treatment?

6. Can this patient be ranked highly enough based on benefit from this treatment?

7. Can this patient be ranked highly enough based on order of presentation?

8. Can this patient be ranked highly enough based on random selection?

Source: NEAC's questions draw on Ardagh, 2006.

Appendix B: Respondents to discussion document

Name	Organisation
John Channon	Wairarapa District Health Board
Robert Logan	Hutt Valley District Health Board
Diana Spratt-Casas	Elder Care New Zealand
Teresa Wall	Māori Health Directorate, Ministry of Health
Tony Taylor	School of Psychology, Victoria University of Wellington
Wayne Knox	Waitakere City Council
David Bowler	CSL (Pharmaceuticals) NZ Ltd
Lucille Curtis	New Zealand Medical Association
Ron Paterson	Health and Disability Commissioner
Jill Briggs	Office for Disability Issues
Felicity Wood	Health Research Council Ethics Committee
Brian Sutcliffe	Registration Boards Secretariat
Dr Sally Roberts	Member, Pandemic Influenza Technical Advisory Group; Chair, Northern Region District Health Board Infectious Diseases and Infection Control Technical Advisory Group for Pandemic Planning
Angela Baldwin	Royal New Zealand Plunket Society
Dr Audrey Jarvis	Interchurch Bioethics Council
Margot McLean	Regional Public Health, Hutt Valley District Health Board
Sebastian Morgan-Lynch	Office of the Privacy Commissioner
Heather Ann Moodie	Australian and New Zealand College of Anaesthetists and Joint Faculty of Intensive Care Medicine
Adrian Brown	Taranaki District Health Board
Angie Perry	Pandemic Planning Group, Ministry of Health
Adrienne Steele	New Zealand Rural General Practice Network
Jim Turner	Royal New Zealand College of General Practitioners
Dr Pim Allen	Waikato District Health Board
Dr Joy Bickley Asher	New Zealand Nurses Organisation
Gabrielle McDonald	Public Health South
Chris Clarke	Hawke's Bay District Health Board
Louise Collins	Age Concern
Dr Karen Smith	Clinical Ethics Advisory Group, Auckland District Health Board
Lynda Sutherland	National Council of Women of New Zealand
Lesley Yule	Lakes District Health Board
Ngaire Mune	New Zealand Dental Therapists' Association
Warren Lindberg	Human Rights Commission
Patrick Dawes	New Zealand Society of Otolaryngology, Head and Neck Surgery

Appendix C: Background information

Introduction

Getting Through Together: Ethical values for a pandemic has been greatly informed by *Stand on Guard for Thee* (Joint Centre for Bioethics Pandemic Influenza Working Group, 2005). Many of the values and processes suggested in the statement of ethical values in section 1 are similar to those suggested in *Stand on Guard for Thee*. We wish to acknowledge the work of the authors of that report.

Many other papers and publications have also informed the statement of ethical values. These are referenced throughout and are listed in the bibliography.

Value of a New Zealand statement of ethical values for a pandemic

The World Health Organization (WHO) lists the consideration of ethical issues as part of its checklist for countries involved in pandemic preparedness planning. This statement of ethical values helps to satisfy the WHO recommendation for New Zealand pandemic planning. The WHO is also working on addressing ethical issues in pandemic influenza planning (World Health Organization, 2006), a process to which the National Ethics Advisory Committee – Kāhui Matatika o te Motu (NEAC) has contributed.

Stand on Guard for Thee suggests that the lesson learned from the severe acute respiratory syndrome (SARS) outbreak was 'to establish the ethical framework in advance, and to do it in a transparent manner' and that 'SARS taught the world that if ethical frameworks had been more widely used to guide decision-making, this would have increased trust and solidarity within and between healthcare organizations' (Joint Centre for Bioethics Pandemic Influenza Working Group, 2005: 4). It also suggests that having ethics clearly built in to pandemic planning and having buy-in from multiple sectors and stakeholders may lead to greater acceptance of the plans and more trust in decision-makers. The plans may carry greater authority and legitimacy (Joint Centre for Bioethics Pandemic Influenza Working Group, 2005: 3). This may enhance co-operation with the plans, and people may be more likely to accept difficult decisions made by public leaders for the common good.

The development of a specific statement of ethical values for New Zealand carries several further advantages. For example, it:

- allows consideration of issues specific to New Zealand; for instance, the importance of 'improving health outcomes for Māori' and enabling Māori 'to contribute to decision-making on, and to participate in the delivery of, health and disability services' (New Zealand Public Health and Disability Act 2000, section 4)
- allows consideration of equity for population groups in New Zealand that are disadvantaged by health inequalities and may be further disadvantaged in a pandemic
- enables feedback to be incorporated from the people, organisations and sectors involved in, and affected by, pandemic planning in New Zealand

- promotes consistency with other ethical guidelines used in New Zealand
- allows, when necessary, ethical values to be reframed or differently emphasised to be more appropriate for the New Zealand context
- allows the consideration of issues raised during more recent discussion and debate.

Incorporating ethics appropriately in pandemic planning in New Zealand may help to lead to pandemic planning that:

- is reasonable, ethically sound and likely to be effective at minimising harm from a pandemic
- that people, including stakeholders and the public, perceive as being reasonable, ethically sound and likely to be effective at minimising harm from a pandemic.

Furthermore, in some areas, attempts to minimise harm from a pandemic will depend on the ethical behaviour of communities and professions. For example, during a pandemic:

- the provision of care and the maintenance of other essential services will depend on carers and workers accepting a degree of personal risk in the course of helping others
- much illness is likely to be managed in communities; individuals and families who are ill are likely to depend on assistance from neighbours and others in the community, which may carry some degree of personal risk for those community members.

How pandemic planning and communication are carried out may play an important role in enabling such ethical behaviour. ■

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