National Ethics Advisory Committee
Kāhui Matatika o te Motu

Ethical Values for Planning for and Responding to a Pandemic in New Zealand

A Statement for Discussion

July 2006

Citation: National Ethics Advisory Committee. 2006. *Ethical Values for Planning for and Responding to a Pandemic in New Zealand*: *A Statement for Discussion*. Wellington: Ministry of Health

Published in July 2006 for the
National Ethics Advisory Committee
by the Ministry of Health
PO Box 5013, Wellington, New Zealand

ISBN: 0-478-30015-8 (Book)
ISBN: 0-478-30016-6 (Internet)
HP 4282

This document is available on the National Ethics Advisory Committee website:
http://www.newhealth.govt.nz/neac

Foreword

If a pandemic came, we would get through it. We know this because we have done it before. But it would be difficult. The better prepared we were, the better we would cope. To prepare ourselves, one thing we should do is to think through our values – the basic things that matter to us. This would give us a shared basis for making decisions. Many of us, in many different situations, would still have to make hard choices. But if we act on shared values with goodwill and reasonable judgement, then in general, we can expect that society would support us. Identifying our shared values now might also help us to act quickly and adapt well later, when there may be less time.

According to work done in the Canadian report *Stand on Guard for Thee* by the Joint Center for Bioethics following the outbreak of SARS (Severe Acute Respiratory Syndrome), if ethical values had been more widely used to guide decision-making, there would have been greater trust and solidarity within and between health care organisations and communities. Having ethics clearly built in to pandemic planning, and having buy-in from multiple sectors of society, may lead to greater acceptance of the plans, and more trust in decision-makers; the plans may carry greater authority and legitimacy. This may enhance cooperation with the plans, and people may be more likely to accept difficult decisions made by public leaders for the common good.

What values do we share that can help pandemic decision-making? The National Ethics Advisory Committee (NEAC) has made a first attempt to answer this question. The resulting "values statement" is included as an appendix in the current New Zealand Influenza Pandemic Action Plan (NZIPAP). With a few refinements, this NEAC statement is also included below (see section 1). NEAC invites your help to make this a better statement of the shared values of New Zealanders that are relevant to pandemic decision-making.

We have tried to state values that would be useful in many settings. To make their potential use vivid, we have included two hypothetical cases: a community response to a pandemic and a hospital based case (see section 2). The community response case is based on the actual response of New Zealanders to the 1918 pandemic. We thank Geoffrey Rice for his advice on this. Both these hypothetical cases involve major pandemic outbreaks. With good planning and response – keeping it out at the border and stamping out any clusters that get through – our aim is, of course, to prevent any major outbreak from ever occurring. Even so, we should think about how we would get through even this most difficult situation.

We have also tried to state values that can apply at all pandemic stages, from planning right through to recovery (see especially section 3). As part of this, more development and recognition of Māori values may be desirable in the statement, and we would appreciate comments in this area. Māori have been disproportionately affected by past pandemics, and we must ensure this does not happen again. Finally, we have tried to state values that New Zealanders share for *how* to make decisions as well as for *what* decisions to make. NEAC welcomes any suggestions you have for improving this work.

NEAC is an independent statutory advisor to the Minister of Health on ethical issues. Its values statement is only one part of the current NZIPAP. If your comments on our work would also help the pandemic work that others are doing, we would like to pass your ideas on to them.

Andrew Moore
Chair
National Ethics Advisory Committee

How to Respond

Ethical Values for Planning for and Responding to a Pandemic in New Zealand: A statement for discussion

The National Ethics Advisory Committee (NEAC) is seeking your feedback on this discussion document to help make its statement of Ethical Values for Planning for and Responding to a Pandemic in New Zealand as useful as possible. Questions we would like you to think about are raised throughout this discussion document, and there is a set of questions at the end you might like to use to help organise and present your feedback. Please feel free to make additional comments.

There are three ways you can respond to this document:

1. Write your details on the tear-out form provided at the back of this document and post your feedback to NEAC at the address below.
2. Complete the questions as an electronic Word document and either email it or print it out and send it by post to NEAC at the addresses below.
3. Write your comments as an email or as a letter that you can send to NEAC.

This document is available on the NEAC website, http://www.newhealth.govt.nz/neac

Please respond by Wednesday 16 August 2006.

Contact details

Postal address: NEAC
PO Box 5013
WELLINGTON

Email: neac@moh.govt.nz (Please put "Pandemic" in the subject line)

Contents

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 limit these negative impacts where 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 (NEAC) has prepared a statement of Ethical Values for Planning for and Responding to a Pandemic in New Zealand (statement of ethical values), and this has been included as an appendix in the Ministry of Health's New Zealand Influenza Pandemic Action Plan (NZIPAP) (version 15). The purpose of this discussion document is to seek feedback to make NEAC's statement of ethical values as reflective of shared values, and as useful, as possible. NEAC also hopes that this discussion document will help to raise issues and to facilitate public discussion. We anticipate that a future supporting document will also be produced that will provide further context to the statement of ethical values, based on material and feedback from this discussion document.

NEAC's statement of ethical values identifies a range of shared values on which to base the process and content of our decisions as we plan for, and potentially respond to, a pandemic. The statement aims to focus our attention on how to enable one another to act as best we can on the basis of those shared values. Cases described in section 2 illustrate how these values might be applied.

This discussion document is informed by other work on ethics and decision-making, and this work is acknowledged in the references. The discussion document has been designed to reflect the New Zealand context and to elicit feedback from anyone who might be affected by a pandemic in New Zealand. Questions are provided in boxes throughout this document, and a final set of questions is included in section 4 to help you organise and present your feedback.

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 community based and one hospital based, to show how the statement of ethical values could be used to plan for, and potentially respond to, a pandemic.

Section 3 describes why we think the shared values identified in the statement of ethical values are important.

Section 4 asks for your feedback.

Information about NEAC is included in **Appendix One**.

Information on the background to this work is included in **Appendix Two**.

1. Statement of Ethical Values

1.1 Ethical values for planning for and responding to a pandemic

Preamble

This statement identifies widely shared ethical values for planning for and responding to a pandemic. These values can be applied in a wide range of situations. Some govern *how* to make decisions. Others govern *what* decisions to make. Values recognised in Māori tikanga or kawa (right or correct ways of acting) are identified alongside other values.

The best way to act on our values depends on each particular situation. This may range from developing public policy for a future pandemic right through 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.

Ethical values informing how to make decisions

In good decision-making processes, we are:

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

Ethical values informing what decisions to make

Good decisions are those we base on:

Minimising harm	• not harming others • protecting one another from harm • accepting restrictions on our freedom where needed to protect others
Respect	• recognising that every person matters • supporting others to make their own decisions wherever possible • supporting those best placed to make decisions for people who can't make their own decisions • restricting freedom as little as possible, and as fairly as possible, if freedom must be restricted for public good
Fairness	• ensuring that everyone gets a fair go • prioritising fairly when there are not enough resources for all to get the services they seek • supporting others to get what they are entitled to • minimising inequalities
Neighbourliness/ whanaungatanga	• helping and caring for our neighbours and relations • working together where there is need to be met
Reciprocity	• helping one another • acting in accordance with any special responsibilities or social standing 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 seeing this through together • showing our commitment to strengthening individuals and communities

Notes

This statement of ethical values for planning for and responding to a pandemic in New Zealand aims to identify widely shared ethical values. If it achieves this aim, we can then focus on enabling one another to act on these shared values as best we can.

The statement has been developed by the National Ethics Advisory Committee (NEAC), Kāhui Matatika o te Motu. NEAC is an independent statutory advisor to the Minister of Health on ethical issues of national significance concerning health and disability.

1.2 Using the statement of ethical values

Key question A

Is the scope of the statement appropriate? Why, why not?

For example, could it be useful to communities responding to a pandemic as well as to policy makers in pandemic planning?

Aim

Our aim is to identify widely shared ethical values and to give people a tool to enable one another 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, and sometimes there may appear to be conflict between these values. This statement of ethical values and accompanying discussion aim to assist planning for and responding to a pandemic in a way that is as consistent as possible with each of these shared values.

Who could use this statement of ethical values?

The statement has been written in an inclusive, straightforward format to make it as accessible as possible. We hope 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.

When should this statement of ethical values be used?

Ideally, this statement of ethical values should be used before or during the decision-making process. It might also be useful in retrospect, when we review how well our decision-making measured up to our values. In practice, this may mean having an understanding of the relevant ethical values and processes in advance, and then referring to the statement during decision-making where needed. Ethical issues may arise at all five stages of pandemic planning in New Zealand (see table below), and this statement aims to be useful during each of these stages. The statement may also be useful in analysing, from an ethical perspective, our own decisions and those of others.

Five stages of pandemic planning in New Zealand

Planning	**"Plan for it"**
Border management	**"Keep it out"**
Cluster control	**"Stamp it out"**
Pandemic management	**"Manage it"**
Recovery	**"Recover from it"**

Source: Ministry of Health 2006

The New Zealand Influenza Pandemic Action Plan (NZIPAP)

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

The statement of ethical values has been included as an appendix to version 15 of 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 discussion document on ethical values for planning for and responding to a pandemic.

In what settings could the statement of ethical values be used?

Every sector of society would be affected in the event of 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. It should also be relevant to those making decisions in other government sectors (national and local), at the corporate/business level and at a community level.

We all know people who will have a role to play in making decisions that will have the potential to reduce the impact of any pandemic in New Zealand. For example, doctors may be confronted with prioritising patients for limited medical resources; officials may have to decide whether to close our borders, schools, 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, in the event of a pandemic?

Individually, we may also have difficult decisions to make, regarding our family, friends and neighbours. How would we check on our neighbours to see if 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?

The best way to act on our values would depend on each particular situation, and this statement of ethical values aims to be useful in a range of settings.

For further examples of how the statement could be used in different settings see the hypothetical cases in section 2.

Other questions – scope

Is the statement of ethical values aimed at the appropriate users? Why, why not?

Could the statement be used at all stages of planning for and responding to a pandemic? Why, why not?

How could the statement be made more useful for a wide range of situations?

2. Hypothetical cases

Preamble

These hypothetical cases are intended to illustrate and test the use of the ethical values identified in this document. They are also intended to generate discussion of the issues that particular cases can raise. As the cases are hypothetical, they could be quite different from an actual situation in a future pandemic. The scenarios may also differ in some ways from actual pandemic planning being undertaken, though we have tried to minimise any inconsistencies with current work. However, the aim here is to identify shared values and to raise issues for discussion that are important whatever the details of the specific events might be.

The ethical values in this document are intended to be applicable across all the pandemic phases and settings. The cases below cover two important settings: a community setting and a hospital setting. Both cases focus on the pandemic management phase. Many important decisions would already have been made during the phases of planning, border management and cluster control. Work during these earlier phases aims to avoid the need to manage a widespread pandemic. Even so, we should still think about how we would get through this most difficult situation of all.

2.1 Case one: using the statement of ethical values in a community setting

This first hypothetical case aims to show how the statement of ethical values might be used in pandemic decision-making in a community setting. The specific case described here aims to show the variety of decisions that might be faced by a volunteer community care team and the ethical problems that might confront those involved.

Parts of this scenario are based on the actual 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 believes that in situations of pandemic response, society would generally be supportive of people who act 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 normally need to do.

The situation

Imagine New Zealand is in the midst of a severe pandemic of influenza. Infection control measures are in place, the borders have been closed and appropriate protective equipment has been issued to doctors and nurses and other personnel in essential services such as ambulance, fire and police. Despite this, absentee levels are rising rapidly. Large numbers of people are falling ill and are staying away from work. Shopping malls, schools and early childhood centres have been closed to reduce the spread of infection. Parents have to stay at home to look after their children, whether ill or not. Many businesses, offices and factories have closed or are operating on reduced

hours. Police resources are stretched because, along with their normal duties, they now also have to guard banks, supermarkets and petrol stations against the possibility of looting.

Hospitals have been overwhelmed with cases of severe pneumonia following influenza, and intensive care units have to prioritise the most serious cases. Hospital and ambulance switchboards have been swamped with calls from people seeking assistance. In some cities, temporary hospitals are being set up, perhaps in public buildings that have toilet and cooking facilities.

Community assessment centres, staffed by primary care practitioners, have been set up, but most influenza sufferers are too ill to attend a centre. Some centres are sending doctors and nurses to visit patients in their own homes, to assess whether or not they need intensive care, but the sudden rise in numbers of cases and the shortage of beds have stretched workloads to capacity, and some doctors and nurses are collapsing from exhaustion.

An appeal has been made over radio and TV stations for all able-bodied volunteers to come forward to help locate people who may be too ill to summon help for themselves. As well as helping sick people, volunteers are needed to staff telephones, to keep records and to dispense equipment – stockpiles of equipment, such as face masks, surgical gloves, antiseptic hand wash, paracetamol and stretchers, are being distributed to community care teams for the volunteers to use.

Authorities have defined the areas surrounding each centre and have issued photocopied maps showing their boundaries. The leader then subdivides the area into smaller blocks, depending on the number of volunteers available to make up teams, and assigns one team per block.

Radio stations broadcast the phone numbers of community assessment centres for people to call if they need help. Many calls from householders for medical services are diverted to the community assessment centre for a visit by a community care team to assess the urgency of the case, if there are no doctors or nurses available for a home visit.

Volunteers with vehicles, especially station wagons or people-carriers able to accommodate a stretcher, are rostered for day and night ready-response to transport urgent cases to the public hospital or the 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 have been requisitioned as temporary morgues.

Detailed scenario

Volunteers at the centre have been ringing houses in its inner-city suburb area. This scenario follows a team as it visits those houses where phone contact could not be made, because of no answer or no phone.

The team might comprise four people. Ideally, its members would have training for this role and would also reflect the community in terms of gender and ethnicity. They would be identified in a clear way, perhaps by reflective jackets or raincoats and bright plastic hard hats, and plastic ID cards. Their equipment might include:

- mobile phones, to contact the centre and other relevant bodies
- digital thermometers
- personal protective equipment (face masks, gloves, etc)
- supplies of paracetamol, hand wash, etc
- a notebook for recording details from each visit.

These items would be carried in small backpacks. Rather than carry heavy bottles of fluids, they might carry sachets of essential salts to be mixed with water for dehydrated flu patients.

At each house, the team leader shows their ID card and explains that the team is there to offer immediate help and on-going support. The leader asks for the householder's consent to take a note of the name, age, sex and current health status of all occupants, including any with disability, chronic health problems, current medications and so on and reassures the householder that this information will remain confidential to the centre and any doctor or nurse called to attend the household.

Each team keeps a record of the decisions that are made and who makes them.

First house: Solo mother with two pre-school children. No flu symptoms as yet, but the mother is worried about her parents on the other side of town as they are not answering her phone calls. Team leader reports the parents' address to centre and requests that a team in that area visit the parents.

Second house: Elderly couple, husband very ill, wife unable to cope after several sleepless nights. Team reports to centre. No ambulance or doctor available. Team members administer an inhaler to assist breathing, also 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 ill, daughter coping well, administering fluids and paracetamol. She tells the team that the neighbour in the previous house is an elderly man living alone. She has not seen lights or movement lately but has been preoccupied looking after her parents.

Team leader reports this to the centre. Police assistance is sought to enter previous house but no help is available. Two volunteers break in and control starving dog. They find the male occupant dead in bed. No doctor is available to certify death, so the team decides to leave the body where it is for the time being.

Problem: Who looks after the dog?

Police arrive later, identify the victim and call the city council to send a van to remove body. They also secure the premises and attempt to contact next of kin. Dog-ranger collects the dog.

Fifth house: Family of recently arrived refugees, very little English, no reserves of food or medical supplies. Two children have mild flu. Wife very ill, but husband refuses to let her be examined in bed, for religious reasons. Team leader contacts the centre to try to locate an interpreter. A female team member finally persuades the husband to let her administer fluids and paracetamol to his wife, who really 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 flu cases in two bedrooms. No reserves of food or medical supplies. Parents and teenagers are feeling unwell and are not coping. They are also concerned about a family member who is away visiting Samoa at present but do not have contact details. Team members administer fluids and paracetamol and give instructions about nursing care but are unsure how much is understood by the parents, despite smiles and nods. House has no telephone so the family is advised to contact neighbours if those with flu deteriorate. Parents indicate that they don't know any neighbours as they have only recently rented the house. Team leader contacts the centre to arrange for food and medical supplies to be delivered.

Seventh house: Professional couple, no children, no flu, refuse to open door and converse with team through the catflap. They insist they are fine, with ample stocks of food, water, paracetamol etc 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 don't know them, don't want to catch the flu and it's not their problem.

Problem: How to encourage people to help their neighbours, even when this might put them at some risk?

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. Leader writes the phone number of the centre on a card and puts it through the cat flap, in case the couple later needs help. Team leader also suggests they could volunteer to help at the centre, but there is no reply.

Eighth house: Woman who uses a wheelchair, lives alone, fiercely independent, refuses to open door for fear of infection. She admits to being short of some food items. Team leader contacts the centre and requests delivery of food and medical supplies. A female team member persuades the woman to contact the centre or relatives if she begins to feel unwell.

Ninth house: Family with three school-age children with flu. The mother has just died and the husband is agitated and distraught. Team leader calls centre to arrange removal of the body, but the husband objects and insists the body remain where it is while he contacts relatives to arrange a tangi. 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 asks the centre to arrange delivery of food and medical

supplies and 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 flu. They are fearful of going to hospital or being separated. Running low on their current medication. Their GP is on the other side of town. Team members dispense fluids and paracetamol, give nursing advice and suggest support from centre, but the couple are reluctant. One is running a high fever. Team leader therefore insists that a doctor or nurse visit them, and contacts centre.

Eleventh and twelfth houses: Four cases of flu between the two houses. These two families, already good friends, have prepared well, with stocks of food, paracetamol, face masks, surgical gloves and hand wash. They keep in close touch by phone each day. They ask the team if they should isolate their flu cases in one house and visit them there, with the remaining healthy individuals living in the other house, to avoid further cross-infection. Team leader agrees. However, closer examination by team members taking temperatures finds one man running a high fever with signs of distress and difficulty breathing. Team leader decides he needs hospital care but the centre advises that there is no ambulance available.

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

Thirteenth house: Distraught mother with two small children. Husband is delirious and violent, with high fever, refusing any assistance and no longer recognising his wife or children. Team leader calls the centre and requests urgent police assistance to restrain the husband, who has to be strapped to the bed. 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 centre to ask what to do.

Fourteenth house: Student flat. Usually five occupants, but no-one is sure where fifth flatmate is – perhaps staying with his girlfriend, but they do not have her number. Two in the flat appear to have flu, neither severe at present. One is an international student, recently arrived in New Zealand, and is very anxious as he has found it hard to understand all the advice in the media. Team leader contacts the centre to arrange for someone to call later who can talk with him in his own language. The other sick student is convinced she does not have pandemic flu, but team leader emphasises it is still important to take all precautions as though it were pandemic flu. 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/sneeze hygiene and distancing, and encourage them to help each other.

Fifteenth house: Retired couple trying to cope with their divorced daughter who has caught the flu while visiting from Australia. The daughter is anxious about her teenage sons in Brisbane, who are not responding to phone calls. Team leader sends contact details for the family in Australia to the centre and asks them to make e-mail enquiries.

Problem: How should the centre prioritise such enquiries against its many other roles?

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. Team leader agrees but suggests the parents contact other members of their church to arrange care for the children.

Seventeenth house: No flu cases. Father, a teacher, is already working as a volunteer at the centre. Good stocks of food, medicines, and so on. Mother is coping well.

Eighteenth house: Family of four with two flu cases, seem to be over the worst, convalescing comfortably and coping well but too busy to check on neighbours.

Nineteenth house: No reply to doorbell or knocking but the door is not locked. Team enters and there is a terrible smell. Woman found dead in bed, and an infant in a cot is comatose and dehydrated, with a soiled nappy. One team member goes back to house seventeen to ask if they could care for the infant while other arrangements are made.

They refuse but provide a contact phone number for the infant's father, who lives in another city. No reply when the father is called. Team leader calls centre for urgent assistance, but no reply.

Problem: How should the infant be cared for?

Twentieth house: No reply to doorbell or knocking. No signs of life. Team leader breaks in, and the house is empty.

Twenty-first house: No flu cases, but family is anxious and fearful. They say the neighbours at the previous house have gone off to their bach at the beach to isolate themselves for the duration.

By this time, the team members are exhausted and in need of a hot meal. They return to centre to find that the centre co-ordinator has collapsed from exhaustion and the deputy 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.

Discussion

This is just one scenario of what might happen in a pandemic and is towards the severe end of the range of possibilities. Through good planning and response at earlier phases, we would aim to prevent any such situation from ever arising. Still, it is important to think about how we would get through even the most difficult sort of situation that could possibly confront us.

If a pandemic occurred in New Zealand, the actual situation might be significantly different from the one described above. Identifying in advance shared values that might 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 used in a pandemic scenario, and to generate

issues for discussion. Some of the ethical values that have been used are identified in bold text below.

Many of the decision process values identified in this document were important considerations for the community care team described in this scenario. For instance, the team introduced themselves at each household, and explained who they were, which displayed **openness** and transparency. However, values important in the decision-making process would have been even more critical during the earlier pandemic planning phase. For instance, good decision-making processes would have been important in determining whether such teams should be used, how they would operate and who would be part of them. Ideally, the planning needed to underpin the community response imagined in this case would have been **inclusive**, **open**, **reasonable**, **responsive** and **responsible**. There are also important capabilities, including flexibility and decisiveness that those responding to a pandemic would have to exercise constantly.

The ethical values informing the content of decisions as identified in this document are also relevant to the events in this scenario. For example, the team showed **respect** by allowing people in households to make their own decisions and by respecting their privacy wherever possible; those who were most vulnerable, such as those with pre-existing medical conditions, were offered additional support where possible. In all cases, **minimising harm** was an important aim of the team. **Fairness** would have been important when deciding on the criteria for who should be visited by a doctor. Making personal protective equipment available to team members demonstrated the value of **reciprocity**. And the efforts made by this volunteer team, and by those community members who were helping each other, reflected the values of **neighbourliness/whanaungatanga** and **unity/kotahitanga**.

Other questions – community case

This case aims to illustrate how ethical values informing the process of decision-making and the content of decisions may be used in planning for and responding to a pandemic. How could this case be made more useful?

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

This second hypothetical case aims to show how the statement of ethical values might be used in pandemic decision-making in a hospital setting.

The case: prioritisation of access to an intensive care unit

> Imagine New Zealand is in the midst of an influenza pandemic. Despite measures to contain and control the pandemic, large numbers of people are becoming ill.
>
> Some of these people are sick enough to be considered for treatment in an intensive care unit (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 imagined case considers the questions that might be raised during this decision process and how this statement of ethical values relates to how decisions could be made. Where appropriate, examples of relevant values have been listed in bold text.

Prioritising pandemic patients who need an intensive care unit bed

The example is a patient with influenza who has severe breathing problems. Access to ventilation in an ICU may help. However, there are many other patients needing similar care and 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 even be harmed by ventilation. Even at times when demand is not overwhelming, access to ICU treatment will not always be granted, either because it may not benefit the patient, or because it may harm them.

The first question in terms of this patient therefore, is: **Does the patient meet the clinical criteria for ICU treatment during normal times (that is, when there is not overwhelming demand for the resource)?**

If the answer is **no** (for example, because they are not sick enough to need it, or they have a terminal illness and ultimately will not benefit, or they have other diseases such as asthma and ventilation may harm them) then the patient is not offered ICU treatment. If the answer is **yes**, then admission to ICU remains an option.

If access to ICU is denied as a result of this first question, then the reasons for this are communicated to patients openly, clearly and sensitively (**open**). Where appropriate, cultural support services and interpreters are provided to assist in this communication, to ensure that patients and families understand and have an opportunity to have any concerns heard and addressed (**responsive**, **inclusive**). Awareness that access to ICU is not in the patient's best interests and denial is not because of the limited resource allows energies to be re-focused towards accessing more useful interventions. Good communication is a sign of respect for patients (**respect**).

Assuming our patient does meet the criteria for access to ICU treatment during normal times and there are others who warrant access too, but there are too few ICU beds,

then the next question to consider is: **Would this patient (or some of the other patients) receive equal benefit from other treatment options?**

Some of these patients are able to 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 ICU is limited due to decreased staffing levels due to illness. 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 on patient outcomes and staff experiences (**responsive**). 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 of the patients competing for ICU treatment are likely to benefit just as well from an alternative service, and so competition is reduced. However, there are still too many patients for the ICU to accommodate. The next question to consider is: **Could this patient, or other patients, have their treatment safely deferred?**

During pandemic planning, the decision had been made that, where possible during a pandemic, major surgery would be deferred in cases where patients were likely to need to be admitted to the ICU after their operations. 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, due to effects on staffing levels and other difficulties in maintaining the usual quality of care during a pandemic.

These decisions were made in advance by hospital management in consultation with clinicians involved. During the pandemic, decisions for each individual patient are made by clinicians involved with their care, with continued liaison with hospital management. Processes are put in place to accept and address patient and family complaints, where patients felt they could be disadvantaged by having their surgery deferred, and in some cases rules are adjusted on the basis of this feedback (**responsive**). 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 assist staff in coping with the demands of a pandemic, and this team facilitates discussions of staff experiences and provides staff feedback to management where appropriate (**responsive, reciprocity, unity/kotahitanga**).

As a consequence of deferring care of some patients, demand for ICU treatment is reduced. However, the patients with severe respiratory compromise from influenza, who do not meet the criteria for the non-invasive ventilation alternative, cannot have their treatment deferred. There are still too many of these for ICU to accommodate.

The next question to entertain is: **Could ICU capacity be expanded without much disadvantage to others?**

During pandemic planning, a decision was made to invest in expanding ICU capacity in anticipation of the increased demands during a possible 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 attempted to ensure that the increased investment in ICU capacity outweighed the opportunity cost of using the funds elsewhere (**reasonable**). Discussions were held between the pandemic planning team, the ICU team and staff from the services that would be losing resources to help explain the justification for the redistribution and to address concerns. It was considered that following this process would help to promote trust and unity within the organisation (**unity/kotahitanga**).

Alternatively, 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.

However, after considering the questions of providing 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.

The next question is: **Could the disadvantage of missing out on this treatment be mitigated?**

Some patients would have benefited significantly more from ICU treatment than ward care. However, for some, the disadvantage of being cared for on a ward can be mitigated in part by providing increased levels of care, for example, by providing intensive nursing care, increased monitoring of vital signs and physiotherapy. For other patients, with different clinical characteristics, the disadvantage of being treated on the ward cannot be mitigated as effectively. The extent to which negative impacts could be mitigated is taken into account in prioritising patients for ICU treatment. After considering alternative care, deferring care, expanding the ICU resource and how the disadvantage of missing out on ICU might be mitigated, there are still not enough ICU beds for the patients who need them.

Now we need to ask: **Can patients be ranked according to their benefit from this service?**

If the competing patients can be ranked according to benefit, then those whose "net benefit" ranks higher should access the resource before those whose "net benefit" ranks lower.

Ranking decisions are made by senior clinicians working together, and the views of patients and their families are taken into account in making these decisions (**inclusive**, **reasonable**). In a small number of cases, patients prefer not to receive life support in ICU, and the autonomy of these patients is respected, while ensuring that such decisions were well informed (**respect**). In prioritising patients, the decisions that are made, and who made them, are clearly documented (**responsible**). This is considered important for reasons of 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 (**open**). 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 (**inclusive**, **responsible**). Other hospitals were consulted in order to learn from their experiences and to help 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 some 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 had indicated that there was support from stakeholders and the public for including whether someone was a health care worker as one criterion when making 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 that the family are adequately supported and to express appreciation of the risk the charge nurse took on while providing valuable care to those with influenza (**reciprocity**). Due to a combination of an expectation that she would benefit significantly from ICU care and the fact that she is a charge nurse who was infected while caring for others, she 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.

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 determine access for many patients. However, there are still some patients that the clinicians cannot differentiate 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. Where even this was not enough to decide which patients should receive ICU treatment, it had been decided that the fairest way to allocate ICU treatment would be by a random selection process. The pandemic planning team had selected these criteria because it thought they were fair reasons for prioritisation. The consulted stakeholders supported the criteria, and the criteria were published prior to the pandemic (**open**, **inclusive**, **reasonable**, **fairness**).

This case gives 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. The decisions made by the hospital in this imagined case are not necessarily ideal decisions that would always be appropriate in other hospitals or other settings. However, many of the processes that this hospital followed in making its decisions, and the values on which its decisions were based, may be relevant in other similar situations.

Other questions – hospital case

This case aims to illustrate how ethical values informing the process of decision-making and the content of decisions may be used in planning for and responding to a pandemic. How could this case be made more useful?

3. Values

Key question B

Are the ethical values identified in the statement the ones that you feel are most important? Why, why not?

3.1 Ethical values informing how to make decisions

The ethical values for the decision-making process outlined on the next page form the first part of the statement of ethical values, which can be found on pages 2–3. These values came from thinking about the situations that people have faced in past pandemics and outbreaks, and might face in the future.

Why are ethical values important in how decisions are made?

It is important that pandemic planning decisions are not only ethical but are perceived as ethical.

If decision-making is perceived as being ethical, this may foster trust and goodwill towards institutions such as hospitals, leading to greater acceptance and satisfaction and fewer complaints.[1]

It has also been suggested that "due process requirements are inherently important because fair hearings affirm the dignity of the person."[2] Good decision-making processes may be necessary in order to show respect for people.

When ethical issues are considered, there is sometimes a lack of consensus on which values and principles are most important. This is a further reason why acceptable, fair processes need to be developed.[3]

This statement of ethical values identifies five key characteristics of ethical processes for decision-making. We think good decision-making processes should be inclusive, open, reasonable, responsive and responsible. Are these the ethical values for decision-making processes that you think are most important? (Key question B).

Other considerations

Further considerations, which are not ethical values as such, may also be important in pandemic decision-making. For example, it is important that decisions be timely, especially during the management stages of pandemic response. These practical considerations, as well as ethical considerations, inform decision-making. Other important considerations in decision-making for health interventions in New Zealand have been identified in a report by the National Health Committee.[4] However, they do

[1] Bell et al 2004.
[2] Gostin 2004: 571.
[3] Daniels and Sabin 2002.
[4] National Health Committee 2005.

not remove the need for ethical processes to be followed. For instance, many of the processes identified in the statement of ethical values can still be followed when the decision-making process is rapid. Those processes that are limited due to time constraints may still be addressed in part through responsiveness after decisions have been made.

In good decision-making processes, we are:

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

3.1.1 Inclusive

Inclusive decision-making means:

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

Why are inclusive decision-making processes important?

Should a pandemic occur we would 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 that decisions are based on shared values.

Inclusive processes may:

- help participants to feel engaged and help them to understand the decision-making process
- provide an opportunity to explain and refine the rationale behind proposed decisions
- make decisions seem fair to all people who have had an opportunity to participate and also to people who feel that their interests were represented by those who participated in the decision-making process.

We would also need to acknowledge time constraints in decision-making during a pandemic. It is likely that 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 acknowledged and any potential improvements to decisions retrospectively identified and implemented.

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

Finally, those involved in pandemic planning should understand, respect and make due allowance for diversity within affected populations. This wider point is expressed also by the Code of Health and Disability Services Consumers' Rights, in Right 1(3), which states: "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".[5]

3.1.2 Open

Open decision-making means:

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

Why are open decision-making processes important?

Using 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 showing respect for people. Related points are expressed in the Code of Health and Disability Services Consumers' Rights,[6] under which people have a right to be fully informed and to be communicated with effectively in health care decisions.

3.1.3 Reasonable

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 our decisions on shared values, and on the best evidence available.*

[5] Health and Disability Commissioner (Code of Health and Disability Services Consumers' Rights) Regulations 1996.
[6] Health and Disability Commissioner (Code of Health and Disability Services Consumers' Rights) Regulations 1996.

Why are reasonable decision-making processes important?

For decision-making to be perceived as reasonable, it is important that the rationale behind decisions is made clear. Explicit reasons for decisions help to avoid perceptions that decisions have been based on the decision-makers' own views and opinions. Those with differing views may well challenge decisions, and making reasons explicit may provide assurance that each decision has a valid basis. Good reasons on which to base decisions often involve consideration of available evidence. Values and principles are also important to consider. For example, having harsh penalties for lack of compliance with quarantine requirements might increase compliance but might not be acceptable to the public.

There is often a range of potential responses to a given problem. Decision-making may be seen as more reasonable if the alternative courses of action that were considered are also identified and reasons are given for the course of action that was chosen.

3.1.4 Responsive

Responsive decision-making means:

- *being willing to make changes and be innovative*
- *changing when relevant information or context changes*
- *enabling others to contribute wherever we can*
- *enabling others to challenge our decisions and actions.*

Why are responsive decision-making processes important?

Even with the best decision-making processes, decisions are never perfect. The information available, and the context in which we first make a decision, is 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 with the best intentions may later need to be revisited. For instance, during the SARS outbreak, some hospitals implemented absolute bans on visitors to suspected SARS patients, but concerns were subsequently expressed that this rule should have been revisited in the light of subsequent information.[7]

Since rapid decision-making may not fully cover all of the ethical processes for decision-making suggested here, it is particularly important to respond to any feedback on decisions after they have been made. For instance, some groups may not have been fully 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 that 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 of Health and

[7] Ovadia et al 2005.

Disability Services Consumers' Rights, which states that patients have the right to complain.[8] It has also been suggested that, if a clinician believes that an exception to a restrictive rule is justified for a patient, the clinician should advocate on the patient's behalf on this point.[9]

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.

3.1.5 Responsible

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 are responsible decision-making processes important?

It is important to have mechanisms in place to ensure that 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 providing an account of whether responsible decision-making is occurring.

Decision-making may occur at multiple levels, which means that 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. So, responsible decision-making also involves being aware of the decisions of others, and how this affects the outcome of decisions that have been made.

Where decision-makers act responsibly, and are seen to be responsible, people may be more likely to trust them. They may also be more likely to act responsibly themselves. In contrast, if people think that decision-makers are acting on the basis of self-interest, trust may be diminished. Decision-makers have a special responsibility to make decisions that are in the best interests of those they represent.

Expectations are an important influence on whether people act responsibly. Where people expect each other to act responsibly, people may be more likely to act accordingly. For instance, where decisions are made in a responsible way, and reflect an expectation that people will act responsibly in a pandemic, this may influence people's expectations and lead to people acting more responsibly. Where we each expect one another to meet our responsibilities, this helps us all to do so. It might even enable us to achieve things we could not otherwise have achieved.

[8] Health and Disability Commissioner (Code of Health and Disability Services Consumers' Rights) Regulations 1996.
[9] Lo and Katz 2005.

Other questions – ethical values informing how to make decisions

Do you agree that these are the most important ethical values informing the process of decision-making in planning for and responding to a pandemic? Why, why not?

What other ethical values for the decision-making process do you think are important and why?

3.2 Ethical values informing what decisions to make

The ethical values informing what decisions to make outlined below form the second part of the statement, which can be found on pages 2–3.

Why are ethical values important to what decisions to make?

Pandemic planning involves making a wide range of advance decisions about pandemics. At the same time, many decisions will not be able to be made until the nature of a pandemic is known. It would be 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 that these values are widely shared among all those who are potentially affected. This may then help lead to decisions being made 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.

Good decisions are those we base on:

Minimising harm	• not harming others • protecting one another from harm • accepting restrictions on our freedom where needed to protect others
Respect	• recognising that every person matters • supporting others to make their own decisions wherever possible • supporting those best placed to make decisions for people who can't make their own decisions • restricting freedom as little as possible, and as fairly as possible, if freedom must be restricted for public good
Fairness	• ensuring that everyone gets a fair go • prioritising fairly when there are not enough resources for all to get the services they seek • supporting others to get what they are entitled to • minimising inequalities
Neighbourliness/ whanaungatanga	• helping and caring for our neighbours and relations • working together where there is need to be met
Reciprocity	• helping one another • acting in accordance with any special responsibilities or social standing 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 seeing this through together • showing our commitment to strengthening individuals and communities

3.2.1 Minimising harm

Minimising harm means:

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

Why is minimising harm important?

During a pandemic, it would be desirable for society to continue to function as normally as possible under the circumstances. In many ways, protection of the public is the primary goal of pandemic planning and response. This would involve reducing the amount of illness and death caused by a pandemic. It would also involve taking into account broader pandemic management strategies that are not directly related to health.

Some strategies for pandemic management could 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.[10] It is important to consider any potential harm arising from pandemic control strategies.

Another example would be the potential use of quarantine during the border management pandemic phase. For instance, if there were four people with 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 freedom, but those passengers who were currently not infected could be put at higher risk of infection, depending on the quarantine procedures used. Thus, in some cases, quarantine might increase 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, there is a need to make the public aware of the risks of a pandemic, and what they can do about it, and yet also avoid overemphasising the risk, which could lead to initial anxiety and a subsequent lack of urgency if a pandemic does not arrive immediately.

Clinicians often aim to put the patient first. However, in a public health emergency, a clinician's role may shift. The 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.[11]

[10] Kotalik 2005.
[11] Lo and Katz 2005.

Minimising harm in a pandemic would require action from a number of different people. Those involved in pandemic planning have a role to play, since good pandemic planning could limit harm if a pandemic occurred. Health care workers would 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 health care workers accepting these responsibilities. But all community members may potentially 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 health care workers, including family, friends and neighbours. Measures that enable all of these people to maintain this "helping behaviour" must be an important part of pandemic planning, and an important way to minimise harm from any pandemic.

3.2.2 Respect

Respect means:

- *recognising that every person matters*
- *supporting others to make their own decisions wherever possible*
- *supporting those best placed to make decisions for people who can't make their own decisions*
- *restricting freedom as little as possible, and as fairly as possible, if freedom must be restricted for public good.*

Why is respect important, and how can we foster respect?

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.[12] Respect also involves protecting people with impaired or diminished autonomy and respecting privacy. These three aspects of respect are discussed below.

A) 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 sorts of measures limit people's freedom. Taking away people's choice of whether to undergo treatment also restricts their freedom. This means there is a potential conflict between the need to respect individual freedom and the need to protect the public by taking such restrictive measures.

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

[12] Council for International Organizations of Medical Sciences (CIOMS) 2002.

be currently required to comply with restrictive measures that aim to prevent the disease from spreading to others.[13] Nevertheless, additional restrictive measures may be necessary in an influenza pandemic, and it is necessary to plan for these in advance.

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.[14] The Siracusa Principles are another source of guidance in international human rights law on the 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 to the restriction of individual freedoms in the public interest during a pandemic. The Siracusa Principles have been summarised as follows:

- 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.[15]

Using the least restrictive measures possible

Where 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, fair and cater for divergent needs. Supportive measures may help alleviate the negative effects of such restrictions. For instance, ensuring that those affected have good access to safe means of communication with family and friends, for example, by telephone, could be a useful way to provide support. Identifying ways to mitigate the impacts of restrictive measures on patients may be a way in which clinicians can help fulfil their responsibilities to act in the interest of their patients.[16]

[13] Tuberculosis Act 1948.
[14] Gostin 2003.
[15] The Siracusa principles on the limitation and derogation provisions in the international covenant on civil and political rights. Summarised in: World Health Organization 2002b.
[16] Lo and Katz 2005.

Informed consent

A further way to respect individual autonomy is to ensure that people are adequately informed. In research, informed consent helps to protect the individual's freedom of choice and respects the individual's autonomy.[17] Although some pandemic measures such as quarantine may be compulsory and thus not require consent, ensuring that affected individuals are well informed can still protect autonomy.

Even in cases where freedom was restricted by infection control measures, clinicians could continue to act in the best interests of the patients to the greatest extent possible. Addressing the patient's needs and concerns may help patients cope in such a situation,[18] and is consistent with respecting people.

Good decision-making processes

Whether restrictive measures are perceived to be fair and ethical 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.

Encouraging voluntary measures

In some cases, 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, since enforcing compulsory mass vaccination might well be impossible.[19]

Proportionality

As suggested by the Siracusa Principles, there may be some situations where the restriction of human rights may be 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, where the risk to the public is small, highly restrictive measures might not be appropriate. 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 also 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 health care workers were required to travel directly between work and home without stopping at other destinations, and the quarantine of an entire housing complex.[20]

[17] CIOMS 2002.
[18] Lo and Katz 2005.
[19] Gray 2006.
[20] Ries 2004.

- Is quarantine voluntary or mandatory? For instance, during the SARS outbreak, Canada relied primarily on voluntary compliance.[21]

- What is the penalty for non-compliance? While Canada relied mainly on voluntary compliance, it has been reported that some citizens of China faced penalties of imprisonment or execution for breach of quarantine.[22]

In some 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 clear that this is possible. The converse – 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 New Zealand law and ethical implications

In New Zealand, the Health Act 1956 already provides the legal authority for some restrictive measures, such as quarantine or compulsory examination. Some of these provisions in existing legislation may need to be reviewed or updated to ensure that legislation adequately provides for reasonable measures needed for pandemic control. This would also be in line with the Siracusa Principles, which require that measures employed 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 freedom of association and freedom of peaceful assembly. However, if limiting social gatherings were necessary to reduce the spread of infection, and there were no other less restrictive means of reducing the spread of infection, then it might be ethically acceptable to use such restrictions. Even so, it would not be acceptable to restrict gatherings only for certain groups, such as certain ethnic groups, as this would be arbitrary and discriminatory.

Under the Code of Health and Disability Services Consumers' Rights, Right 1(1) states that: "every consumer has the right to be treated with respect".[23] Thus, the importance of respect for people is also reflected in New Zealand legislation.

B) Protection of people with impaired or diminished autonomy

Respect for people also includes the protection of people with impaired or diminished autonomy. This requires that people who are dependent or vulnerable (vulnerable populations) are protected against harm.[24]

Vulnerable persons have been defined as

> 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.[25]

[21] Ries 2004.
[22] Mitka 2003.
[23] Health and Disability Commissioner (Code of Health and Disability Services Consumers' Rights) Regulations 1996.
[24] CIOMS 2002.

Societal factors such as relative disadvantage or disablement may also create vulnerability for some people.

For instance, people who depend upon additional support would be vulnerable to the removal of that support in a pandemic. This may include people with disability, older people and children. People with chronic illnesses may also be vulnerable where they have limited mobility, require extra care and support, or are taking medications to maintain their health. Other vulnerable populations may include people with psychiatric or behavioural disorders, refugees and prisoners.

Pregnant women and foetuses may require special consideration for reasons such as the safety of protective measures such as antiviral medication and vaccines. Breast-feeding mothers and children may also warrant special consideration on this basis.

Other 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 the general population.[26] This indicates that, from a health perspective, Māori are a vulnerable population, and that working with Māori for the protection of the Māori population in the event of a pandemic would require particular attention. In New Zealand, other populations with poorer health status, who may thus be vulnerable, include Pacific peoples and people with low socioeconomic status.

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 were 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.

C) Privacy

The protection of individuals' privacy may come under threat in a pandemic. Examples of privacy issues arose from 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 that they could be vigilant about symptoms and seek treatment early if they became unwell. However, informing these passengers might not require the individual to be named. The principle of proportionality requires that the least intrusive means possible be used.[27]

As a further example, the woman who carried SARS from China to Canada was named, with the family's consent, as it was felt that this would provide a public health benefit. However, the linking of SARS with someone who had travelled from China subsequently led to people avoiding Chinese businesses.[28] When releasing personal

[25] CIOMS 2002. Guideline 13: Research involving vulnerable persons
[26] Bramley et al 2004.
[27] Singer et al 2003.
[28] Singer et al 2003.

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 Privacy Act 1993 sets out conditions under which personal information may be disclosed, including:

> An agency that holds personal information shall not disclose the information to a person or body or agency unless the agency believes, on reasonable grounds,—
>
> (f) That 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[29]

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

3.2.3 Fairness

Fairness means:

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

Why is fairness important?

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

Fairness in pandemic planning and response

Certain groups would be at higher risk during a pandemic, such as those identified as vulnerable populations (see section 3.2.2), and people such as health care workers would be at higher risk of infection due to contact with infected patients. As these populations are at higher risk, fair treatment requires that they receive additional protective measures.

[29] Privacy Act 1993. Section 6. Information privacy principles.

Reducing inequalities is a goal of the New Zealand Health Strategy.[30] Groups currently disadvantaged by health inequalities, including Māori, Pacific and low-income populations, are at risk of being further disadvantaged in the event of a pandemic. Equity considerations mean that pandemic planning should strive to ensure that any pandemic does not further increase health inequalities.

Fairness may also require equitable communication. There are specific cultural groups for whom communication in English may be more difficult, and who might also be at higher risk during a pandemic, and special attention may need to be paid to communicating in such situations.

Using fair processes may also contribute to ethical decision-making. If fair processes are used, even if people do not completely agree on the decisions reached, they may feel that they have been fairly treated as their views have been heard. Inclusive processes may help avoid a situation where certain groups feel unfairly treated due to exclusion from the decision-making process. Even where good decisions are made, people may feel unjustly treated if they believe that the decision-making processes used were not appropriate.

As pandemics spread from one country to another, they may provide fertile ground for stigmatisation and discrimination. Many health care workers from SARS-affected hospitals felt stigmatised due to their occupation.[31] Stigmatisation also occurred for people from countries that the community associated with SARS outbreaks.[32] 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 non-Māori.[33] 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.

In common with many other indigenous populations, Māori have poorer health status than the general population.[34] Reducing such inequalities in health status is one of the goals of the New Zealand Health Strategy[35] and He Korowai Oranga: Māori Health Strategy.[36] The existence of these health inequalities is also an indication that, from a health perspective, Māori are a vulnerable population. This suggests that protection of the Māori population in the event of a pandemic will require particular attention.

[30] Minister of Health 2000.
[31] Nickell et al 2004.
[32] Singer et al 2003.
[33] Pool 1973 and Rice 1983.
[34] Bramley et al 2004.
[35] Minister of Health 2000.
[36] Minister of Health and Associate Minister of Health 2002.

The importance of health gain for Māori is stated also 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".[37] Accordingly, pandemic decision processes should involve Māori at all stages and levels of pandemic planning and response. In addition, Māori involvement is essential in order to ensure that 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 that resources be used in the best way possible. This means that 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, supply would be likely to decrease. For instance, if a large proportion of the population were unwell with influenza, the supply of health 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 in order 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.[38]

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 that 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 due to illness in the health sector and other sectors. Considerations such as these are raised in the NZIPAP.[39]

Prioritising fairly

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

[37] New Zealand Public Health and Disability Act 2000, section 4.
[38] Kotalik 2005.
[39] Ministry of Health 2006.

For instance, stocks of antiviral medication are limited. Decisions must be made about whether to use these stocks for prophylaxis (preventing people becoming sick) or just for treating those who are already sick; using stocks for prophylaxis may prevent disease in some people but would also result in stocks being used up more quickly. If stocks are too low to offer treatment to all, decisions must be made about who will be offered antiviral treatment first and who may not be offered antiviral 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 made clear to others). In general, explicit criteria are preferable. Using explicit criteria makes 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 also promotes transparency and may enable those who are potentially affected to give feedback on the criteria, and to challenge criteria where necessary.

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

Support for those implementing prioritisation decisions

Prioritisation decisions must not only be made well but also implemented well. Prioritisation measures may create conflicting demands for clinicians and others involved in their implementation. It is necessary to provide appropriate support for those implementing these measures and to monitor the situation to ensure that decisions are being properly implemented.[40]

3.2.4 Neighbourliness/whanaungatanga

Neighbourliness/whanaungatanga means:

- *helping and caring for our neighbours and relations*
- *working together where there is need to be met*

Why is neighbourliness/whanaungatanga important?

Encouraging people to act in a neighbourly way towards each other during a pandemic would perhaps be one of the most effective tools we have to manage the effects of a pandemic. Hospitals and doctors are likely to be overwhelmed quickly in the event of a pandemic, which would make the way we act in our own homes and communities even more important. A major lesson learned from the 1918 pandemic was the importance of neighbourhood and community cohesion in times of crisis.[41]

[40] Lo and Katz 2005.
[41] Rice 2005.

According to the value of whanaungatanga, individuals may expect support from both near and distant relatives, and the collective group may also expect the support and help of its members. Whanaungatanga may also include relationships with people who are not relatives.[42]

Helping and caring for our family/whānau, friends and neighbours could be as simple as ensuring that those affected have good access to 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?

We can all be "carers"

An effective pandemic response would require health care workers to be available to help people who are sick. However, many other community members are 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 health care workers, for society to continue to function.

In a severe pandemic, many people who are sick would need to be cared for by people other than health care workers. This would see an important role being taken on by family members and potentially neighbours and other members of the community. 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 that any of us could give, such as making sure that a sick person has enough to drink.

So, the best outcome from a pandemic would be likely to occur if community members were to help others who were sick, especially if there were shortages of medical care. This means that approaches that support and enable such "helping behaviour" may be important ways to ensure the best outcome from any pandemic. For instance, those who accepted extra responsibilities (and, potentially, extra risks) through helping other community members during a pandemic would need to be supported in what they do. 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.

[42] Mead 2003.

3.2.5 Reciprocity

Reciprocity means:

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

Why is reciprocity important?

People helping one another is an expression of reciprocity and would be crucial to minimising harm from a major pandemic. People may be more likely to help one another where there is an atmosphere of trust. Trust may also invite reciprocal trust, a process that has been called "virtuous spirals".[43] So, reciprocity is an important part of people trusting and helping one another.

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 health care workers, other workers and those caring for and helping others) and those who are affected by restrictive measures designed to limit pandemic spread.

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

Increased burdens and responsibilities for health care workers

During a pandemic, large numbers of people would become ill. Many of these people would require medical treatment and the demand for health care workers would increase. However, treating patients with influenza may pose a risk to health care workers. During the SARS outbreak, some staff refused to work because of the risk they perceived to themselves and their families. There was a real risk, and health care workers were among those who died during the SARS outbreak.[44] However, if health care workers refuse to work, staff shortages could increase. The health care system would not function in a pandemic if staff refused to go to work.

[43] O'Neill 2002.
[44] Singer et al 2003.

This means that there may be a conflict between the desire of health care workers to provide care to patients (and the need of patients to receive this care) and the understandable desire of health care workers to protect themselves and their families from harm, potentially by choosing not to work with infectious patients.

One important way to manage this potential conflict is to reduce the risk to health care workers. Extra support can also be provided to health care workers with extra responsibilities.

Providing reciprocal support for health care workers

Reciprocity, in the case of health care workers, can mean providing additional support to acknowledge the extra responsibilities these people take on. This may be an important way to manage the conflict experienced by health care workers providing care despite the increased risk to themselves. Ways of providing support could involve either reducing the extra risk that health care workers face or providing extra support for health care workers in other ways.

One form of additional support could include publicly acknowledging and demonstrating appreciation of this risk, providing aid with coping with stressful situations and offering financial support for families of health care workers affected by illness.[45] Other measures that have been suggested include taking all reasonable precautions to prevent illness among health care workers and their families, and (in the USA) reducing or eliminating malpractice threats for those working in high-risk emergency situations.[46] However, the New Zealand environment is much less litigious. In New Zealand, discussion of "provider compliance" in the Code of Health and Disability Services Consumers' Rights requires "reasonable actions in the circumstances",[47] and it has been suggested that it is unlikely that "discipline would be invoked to judge medical practice during a pandemic".[48] Good training on pandemic patient care, the use of personal protective equipment and the potential risks for transmission may also help protect and support health workers.[49]

Adverse effects on health workers may extend beyond the risk of infection. During the Canadian SARS outbreak, hospital staff felt stigmatised because of their position and avoided public spaces and interaction with family and friends.[50] Measures to support hospital staff and others affected by a pandemic should also consider such indirect adverse effects.

[45] Singer et al 2003.
[46] Huber and Wynia 2004.
[47] Health and Disability Commissioner (Code of Health and Disability Services Consumers' Rights) Regulations 1996, reg 2.
[48] Paterson 2005: 15.
[49] Loutfy et al 2004.
[50] Nickell et al 2004.

Employer responsibilities

Employers have a responsibility to provide safe working conditions. While health care 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.[51] 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 that reciprocity is a shared public value.[52]

Employers' responsibilities are also reflected in the Health and Safety in Employment Act 1992, which states that:

> 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:
>
> - provide and maintain for employees a safe working environment
> - provide and maintain for employees while they are at work facilities for their safety and health[53]

What extra responsibilities might health care workers reasonably take on?

The extent to which health care 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",[54] while others suggest that there are limits on the risks that health care 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.[55] At the very least, it seems reasonable that health care workers should accept *some* degree of risk, where this risk cannot be prevented through reasonable measures.

Professional codes

Health care workers may come from several different professions, and are expected to act professionally. Professionalism includes practising skills of special value and maintaining relationships of trust with clients. Professionals also have a special status

[51] Loutfy et al 2004.
[52] Public draws line at flu doses for politicians. *The New Zealand Herald*. Retrieved 4 Jan 2006 from URL: http://www.nzherald.co.nz/topic/story.cfm?c_id=255&ObjectID=10362366
[53] Section 6, Health and Safety in Employment Act 1992.
[54] Ovadia et al 2005: 78.
[55] Huber and Wynia 2004: W9.

within society.[56] This means that there are special expectations and responsibilities for professionals compared with the general population.

Some health professionals, such as doctors, have a duty to help others that is set out in their professional codes. The Medical Council of New Zealand (the Medical Council) currently provides some 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.[57]

However, the Medical Council also recognises that there are some situations where doctors can, may or should not attend an emergency, for example:

> if attending the emergency places the personal safety of the doctor at risk[58]

This means that there is still some uncertainty, even in medical codes of practice, about the extent of risk that should be accepted in the provision of care.

Thus, in the case of doctors and some other professions, there is a professional duty to help, as set down in professional codes. For some others there is no such professional code, but their contributions will still be needed. This means that professional duties cannot be solely relied upon to ensure that people help others where needed, whether in the context of health care or the wider community. Given this, it is also important to consider what can be done to enable this "helping behaviour", both for health care workers and for other community members.

3.2.6 Unity/kotahitanga

Unity/kotahitanga means:

- *being committed to seeing this through together*
- *showing our commitment to strengthening individuals and communities.*

Why is unity/kotahitanga important?

During a pandemic, factors such as scarcity of resources, overload of health systems and a possible atmosphere of anxiety and fear could have a divisive effect. Unity between community members, patients, health care workers, organisations, different levels of government and governments in different countries could be affected. "Kotahitanga" may be interpreted as working together, being holistic in nature and employing unified approaches.[59]

[56] Freidson 1994.
[57] Medical Council of New Zealand 2002.
[58] Medical Council of New Zealand 2002.
[59] Ministry of Health 2003.

Paradoxically, unity/kotahitanga may be particularly important during this time. Health care 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 who are 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 health care 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 also be strained during a pandemic. However, during a pandemic, trust 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.[60] For instance, good communication and transparency in decision-making may enhance public trust in decision-makers. Where members of the public trust decision-makers, they may be more likely to accept difficult decisions, such as restrictive measures.

The amount of public trust in those who are in decision-making roles, or in positions of power or responsibility, may be fostered where people in these positions display integrity in their commitments and actions. Related concepts include good governance and stewardship.[61] 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 best interests of the public.

Inclusion in decision-making processes may also be an important way to promote feelings of unity between the public and authorities. For instance, inclusive decision-making may help improve public understanding of restrictive measures, and lead to increased compliance. Compliance with quarantine, for instance, could be affected by an appreciation of 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 some situations, such as where clinicians have to inform patients that, due to prioritisation or infection control measures, the patient's wishes cannot be fully 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

[60] Kotalik 2005.
[61] Joint Center for Bioethics Pandemic Influenza Working Group 2005.

to quarantine measures, they would probably agree that it is important to recognise the risk that others would face if they were not to comply.[62]

Where restrictive public health measures such as quarantine or prioritisation measures were implemented, clinicians could be faced with a conflict between their duty to the patient and the need to protect the interests of the public. 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 best interests of the patient to the greatest extent possible within the limits of restrictive public health measures.[63] Strategies such as these may help maintain the clinician-patient relationship while continuing to protect the public interest.

Promoting unity/kotahitanga through good communication

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

The way in which communication is carried out may affect unity in a number of 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 may be 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 health workers or government authorities, there is also a lot that all members of the public could do to help themselves and others. For example, good hand and respiratory hygiene, social distancing when necessary 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 that they feel comfortable with helping each other and are prepared to help each other.

The importance of good communication is also reflected in the Code of Health and Disability Services Consumers' Rights,[64] which states that people have a right to effective communication.

Diversity and communication

New Zealand is culturally diverse and includes several large subgroups, such as Māori, Pacific and Asian populations. Good communication needs to consider all groups. This means that communication needs to occur in a culturally appropriate manner and needs to be easy for all groups to understand. Extra effort may be required to reach some groups, such as those who speak English as a second language.

---

[62] Lo and Katz 2005.
[63] Lo and Katz 2005.
[64] Health and Disability Commissioner (Code of Health and Disability Services Consumers' Rights) Regulations 1996.

In some cases, communication that caters for diversity would be particularly important in effectively managing a pandemic. For example, if border management measures required new arrivals to comply with restrictive measures, compliance could be improved by clear and culturally appropriate communication, given that the population at borders is particularly 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 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.

Communication and clinicians

It has been suggested that clinicians and other frontline staff do not just want good decision-making, they want their experiences to be heard. Even where they agree with the decisions that have been made, and understand the rationale for the decisions, they still want to be listened to and to have their experience of implementing these decisions heard.[65] This shared understanding is another potential benefit of good communication and emphasises that communication is a two-way process. Clinicians, in turn, may be able to use their listening skills to aid patients in coping.[66]

Other questions – ethical values informing what decisions to make

Do you agree that these are the most important ethical values on which to base the content of our decisions? Why, why not?

What other ethical values do you think are important and why?

Are there any other Māori values that would be appropriate to include?

(Utu was considered for inclusion with "reciprocity", but as it can mean "revenge" for some people in common usage, it was not included.)

[65] Bell et al 2004.
[66] Lo and Katz 2005.

4. Questions for Feedback

Feedback for statement on:

Ethical values for planning for and responding to a pandemic in New Zealand

The National Ethics Advisory Committee (NEAC) seeks your feedback on a proposed statement of ethical values for planning for and responding to a pandemic in New Zealand. The proposed statement is set out on pages 2–3 of this document.

NEAC is interested in your comments on any aspect of the discussion document and statement of ethical values and is particularly interested in your thoughts on the following questions:

- Is the scope of the statement of ethical values appropriate?
- Do the ethical values described in the statement correspond to those you feel are important in planning for and responding to a pandemic?
- Can the statement of ethical values be made more usable?

The questions in this feedback form follow the content of the proposed statement of ethical values. There are also general questions and issues you may want to comment on.

The feedback received will be used to produce a final statement of ethical values for inclusion in the New Zealand Influenza Pandemic Action Plan (NZIPAP). However, due to the nature of pandemic planning, it is possible that NEAC might need to provide a revised statement at short notice, before the consultation period has elapsed. If this were the case, NEAC would incorporate feedback received to date. NEAC anticipates that a supporting document will also be produced that will be available to provide further context to the statement of ethical values. Feedback on this discussion document will also inform such a future supporting document.

Further, if NEAC receives feedback beyond the scope of this work, it will be passed on to those who are leading the wider work on the NZIPAP.

Returning feedback

Please return a copy of your feedback no later than **Wednesday 16 August 2006** to:

NEAC
Ministry of Health
PO Box 5013
Wellington
Email: neac@moh.govt.nz

This response was completed by:

Name: _____

Address: _____

_____

_____

Email: _____

Organisation (if applicable): _____

Position (if applicable): _____

Details of your response may be requested under the Official Information Act 1982. If this happens, your response will be released to the person who requested it. However, if you are an individual rather an organisation, you can choose to have your personal details removed from your response by ticking the following box:

☐ I do not give permission for my personal details to be released to persons under the Official Information Act 1982.

Thank you for your feedback.

QUESTIONS

Key question A

Is the scope of the statement of ethical values appropriate? Why, why not?

For example, could the statement be of use to communities responding to a pandemic as well as to policy makers in pandemic planning?

Key question B

Are the ethical values and processes identified in the statement the ones that you feel are most important? Why, why not?

Key question C

Could the statement of ethical values be made more useful? How?

Further questions

i. Scope

- Is the statement of ethical values aimed at the appropriate audience? Why, why not?
- Could the statement be used at all stages of pandemic planning? Why, why not?
- How could the statement be made more useful for a wide range of settings?

ii. Ethical values informing how to make decisions

- Do you agree that these are the most important values for the decision-making process in planning for and responding to a pandemic? Why, why not?
- What other values for the decision-making process do you think are important and why?

iii. Ethical values informing what decisions to make

- Do you agree that these are the most important values informing what decisions we should make? Why, why not?
- What other values informing what decisions to make do you think are important and why?
- Are there any other Māori values that would be appropriate to include? (Note: "utu" was considered for inclusion with "reciprocity", but as it can mean "revenge" for some people in common usage, it was not included.)

iv. Community case

- How could this case be made more useful in demonstrating the processes and values used in planning for and responding to a pandemic?

v. Hospital case

- How could this case be made more useful in demonstrating the processes and values used in planning for and responding to a pandemic?

Appendices

Appendix One: The National Ethics Advisory Committee and committee membership

About the National Ethics Advisory Committee

The National Ethics Advisory Committee (NEAC), Kāhui Matatika o te Motu, is an independent advisor to the Minister of Health on ethical issues of national significance concerning health and disability matters.

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

Dr Andrew Moore – Chair
Dr Allison Kirkman – Deputy Chair
Professor Michael Ardagh
Barbara Beckford
Dr Dale Bramley
Elisabeth Harding
Dr John Hinchcliff
Dr Te Kani Kingi
Associate Professor Joanna Manning
Professor Charlotte Paul
Dr Martin Sullivan

Secretariat

Barbara Burt – Senior Analyst
Dr Jamie Hosking – Public Health Medicine Registrar
Dr Fiona Imlach – Public Health Medicine Registrar
Vanessa Roberts – Analyst

Appendix Two: Further background information

This statement has been greatly informed by the publication *Stand on Guard for Thee* (Joint Center for Bioethics Pandemic Influenza Working Group 2005). Many of the values and processes suggested in this statement of ethical values are similar to those suggested in that report. We wish to acknowledge the work of the authors of that report.

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

The value of a New Zealand ethical statement for pandemic planning

The World Health Organization (WHO) lists 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.

Stand on Guard for Thee suggests that the lesson learned from the SARS (Severe Acute Respiratory Syndrome) outbreak was "to establish the ethical statement 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 health care organizations".[67] 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.[68] 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 ethical statement 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 of 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 equity considerations for population groups in New Zealand that are disadvantaged by health inequalities and may be further disadvantaged in the event of 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 guidance used in New Zealand;

[67] Joint Center for Bioethics Pandemic Influenza Working Group. 2005: 4.
[68] Joint Center for Bioethics Pandemic Influenza Working Group. 2005: 3.

- allows, where necessary, ethical values to be reframed or differently emphasised, in order 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 lead to:

- pandemic planning that is reasonable, ethical and likely to be effective at minimising harm from a pandemic;

- pandemic planning being perceived by others, including stakeholders and the public, as being reasonable, ethical and likely to be effective at minimising harm from a pandemic.

Furthermore, in some areas, attempts to minimise harm from a pandemic will depend upon 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 upon carers and workers accepting a degree of personal risk in the course of helping others;

- during a pandemic, 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;

- the way in which pandemic planning and communication is carried out may play an important role in enabling such ethical behaviour.

Bibliography

Bell JA, Hyland S, DePellegrin T, et al. 2004. SARS and hospital priority setting: a qualitative case study and evaluation. *British Medical Council Health Services Research* 4(1): 36.

Bramley D, Hebert P, Jackson R, Chassin M. 2004. Indigenous disparities in disease-specific mortality, a cross-country comparison: New Zealand, Australia, Canada, and the United States. *New Zealand Medical Journal* 117 (1207): 1215.

Council for International Organizations of Medical Sciences (CIOMS). 2002. International Ethical Guidelines for Biomedical Research Involving Human Subjects. Geneva: The Council for International Organizations of Medical Sciences. Retrieved 1 Mar 2006 from URL: http://www.cioms.ch/frame_guidelines_nov_2002.htm

Daniels N, Sabin JE. 2002. *Setting Limits Fairly. Can We Learn to Share Medical Resources?* New York: Oxford University Press.

Day M. 2005. How the media caught Tamiflu. *British Medical Journal* 331: 1277.

Freidson E. 1994. *Professionalism Reborn: Theory, prophecy, and policy.* Cambridge: Polity Press.

Gostin LO. 2003. When terrorism threatens health: how far are limitations on human rights justified. *Journal of Law, Medicine and Ethics* 31: 524–8.

Gostin LO. 2004. Pandemic influenza: public health preparedness for the next global health emergency. *Journal of Law, Medicine and Ethics* 32(4): 565–73.

Gray B. 2006. *Coercive Emergency Health Powers in New Zealand and Proposed Legislative Reform.* (Dissertation). Dunedin: University of Otago.

Health Act 1956.

Health and Safety in Employment Act 1992.

Health and Disability Commissioner (Code of Health and Disability Services Consumers' Rights) Regulations 1996.

Health and Safety in Employment Act 1992.

Huber SJ, Wynia MK. 2004. When pestilence prevails ... physician responsibilities in epidemics. *American Journal of Bioethics* 4(1): W5–11.

Joint Center for Bioethics Pandemic Influenza Working Group. 2005. *Stand on Guard for Thee. Ethical issues in preparedness planning for pandemic influenza*. Toronto: University of Toronto.

Kotalik J. 2005. Preparing for an influenza pandemic: ethical issues. *Bioethics* 19(4): 422–31.

Lo B, Katz MH. 2005. Clinical decision making during public health emergencies: ethical considerations. *Annals of Internal Medicine* 143(7): 493–8.

Loutfy MR, Wallington T, Rutledge T, et al. 2004. Hospital preparedness and SARS. *Emerging Infectious Diseases* 10(5): 771–6.

Mead HM. 2003. *Tikanga Māori: Living by Māori values*. Wellington: Huia Press.

Medical Council of New Zealand. 2002. *A Doctor's Duty to Help in an Emergency*. Wellington: Medical Council of New Zealand.

Minister of Health. 2000. *The New Zealand Health Strategy*. Ministry of Health: Wellington.

Minister of Health and Associate Minister of Health. 2002. *He Korowai Oranga Māori Health Strategy.* Wellington: Ministry of Health.

Ministry of Health. 2003. *Māori Public Health Action Plan 2003–2004.* Wellington: Ministry of Health, 2003.

Ministry of Health. 2006. *New Zealand Influenza Pandemic Action Plan v15. NHEP: ID, Appendix III. Draft for Discussion*. May. Wellington: Ministry of Health.

Mitka M. 2003. SARS thrusts quarantine into the limelight. *The Journal of the American Medical Association* 290(13): 1696–8.

National Ethics Advisory Committee. 2006. *Ethical Guidelines for Observational Studies: Observational research and audits and related activities*. (Draft). Wellington: Ministry of Health.

National Health Committee. 2005. *Decision-making about New Health Interventions. A report to the New Zealand Minister of Health*. Wellington: National Advisory Committee on Health and Disability (National Health Committee).

New Zealand Bill of Rights Act 1990.

New Zealand Herald, The. Public draws line at flu doses for politicians. Retrieved 4 Jan 2006 from URL: http://www.nzherald.co.nz/topic/story.cfm?c_id=255&ObjectID=10362366

New Zealand Public Health and Disability Act 2000

Nickell LA, Crighton EJ, Tracy CS, et al. 2004. Psychosocial effects of SARS on hospital staff: survey of a large tertiary care institution. *Canadian Medical Association Journal* 170(5): 793–8.

Olick RS. 2004. Ethics, epidemics, and the duty to treat. *Journal of Public Health Management and Practice* 10(4): 366–7.

O'Neill O. 2002. A question of trust. (Lecture 2). *Trust and Terror*. BBC. Retrieved on 7 Jun 2006 from URL: http://www.bbc.co.uk/radio4/reith2002/lecture2.shtml

Ovadia KL, Gazit I, Silner D, Kagan I. 2005. Better late than never: a re-examination of ethical dilemmas in coping with severe acute respiratory syndrome. *Journal of Hospital Infection* 61(1): 75–9.

Paterson R. 2005. Pandemic disciplinary fears addressed. (Letter). *New Zealand Doctor* 30 November: 15.

Pool DI. 1973. The effects of the 1918 pandemic of influenza on the Māori population of New Zealand. *Bulletin of the History of Medicine* 47 (3): 273–81.

Privacy Act 1993.

Rice G. 2005. *Black November: The 1918 influenza pandemic in New Zealand*. (2nd edition) Christchurch: Canterbury University Press.

Rice G. 1983. Māori mortality in the 1918 influenza epidemic. *New Zealand Population Review* 9(1): 44–61.

Ries NM. 2004. Public health law and ethics: lessons from SARS and quarantine. *Health Law Review* 13(1): 3–6.

Royal Commission on Social Policy. 1988. *The April Report: Report of the Royal Commission on Social Policy.* Wellington: The Royal Commission on Social Policy.

Selgelid MJ. 2005. Ethics and infectious disease. *Bioethics* 19(3): 272–89.

Sibbald B. 2003. Right to refuse work becomes another SARS issue. *Canadian Medical Association Journal* 169(2): 141.

Singer PA, Benatar SR, Bernstein M, et al. 2003. Ethics and SARS: lessons from Toronto. *British Medical Journal* 327(7427): 1342–4.

Siracusa Principles on the Limitation and Derogation of Provisions in the International Covenant on Civil and Political Rights, Annex, UN Doc E/CN.4/1984/4 (1984).

Tuberculosis Act 1948.

World Health Organization. 2002a. *WHO Checklist for Influenza Pandemic Preparedness Planning.* Geneva: World Health Organization.

World Health Organization. 2002b. *25 Questions and Answers on Health and Human Rights.* Geneva: World Health Organization.