Te Kāwanatanga o Aotearoa
New Zealand Government

National Ethics Advisory Committee
Kāhui Matatika o te Motu

Summary of Submissions

Consultation on the Ethical Guidance for a Pandemic

June 2023

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Introduction

The **National Ethics Advisory Committee – Kāhui Matatika o te Motu** (NEAC) is an independent advisor to the Minister of Health. NEAC developed an update to its 2007 publication '**Getting Through Together: Ethical Principles for a Pandemic**'. The updated draft publication is called 'Ethical Guidance for a Pandemic: Whakapuāwaitia e tatou kia puāwai tātou' (EGAP) which provides ethical guidance for future pandemics in Aotearoa New Zealand, as well as the ongoing COVID-19 pandemic.

The draft publication is separated into six chapters:

- **Chapter 1** outlines a shared foundational approach to responding to a pandemic
- **Chapter 2** introduces a set of six ethical principles and a framework for decision-making in a pandemic
- **Chapter 3** explores how these ethical principles might operate before a pandemic (readiness and reduction of risk)
- **Chapter 4** explores how these ethical principles might operate during a pandemic (response)
- **Chapter 5** explores how these ethical principles might operate after a pandemic (recovery)
- **Chapter 6** provides insight into what these ethical principles mean for New Zealanders with disabilities.

The public consultation began on 26 July 2022 with the launch of an online survey. The survey closed on 1 November 2022 and received 428 submissions. In addition, NEAC also received 21 written submissions and held three online focus groups with stakeholders. The submissions were analysed by the NEAC Secretariat (the 'Secretariat') at the Ministry of Health.

The purpose of the consultation was to assess if the ideas contained within the draft publication are shared ideas based on shared values. Contributions were sought from individuals, communities, and organisations. The submissions have been analysed and summarised in this report and will be reviewed by NEAC. The feedback received may be used to make changes to the draft publication before it is published.

If you have any questions about the report, please email them to the Secretariat at: **neac@health.govt.nz**

Summary of submissions

Overarching themes

There were five themes that occurred across the survey responses:

- more information about using the frameworks in practice and the inclusion of examples or scenarios
- desire for an independent inquiry
- role of public and community involvement
- using mandatory interventions
- concern about data use and digital inclusion.

Survey responses

Section	Summary
Foundational elements	'Upholding human rights' was strongly supported and concerns were expressed about 'Build back better'. There was moderate support for the other foundational elements.
Ethical principles	'Liberty' was strongly supported as an ethical principle. 'Health and wellbeing' was moderately supported, however, it was also noted that health and wellbeing is not an ethical principle.
Elements for complex public health decisions	There was both support (50%) and objection (31%) to the elements for complex public health decisions. The comments highlighted that the biggest concerns were about the level of transparency in decision making and the role of the public in decision making. Communities and community organisations were particularly noted as being able to input, and much greater engagement with the disability community required in future pandemics.
Preparing our health and disability system	Respondents were supportive of a fair and equitable health system and that more support should be offered to these communities facing health inequities, particularly disabled communities. The key role that community organisations can play in addressing health inequalities was noted and that they should be supported to do this.
Health investment	Increased investment in the health and disability system was strongly supported with preventative health interventions, hospitals and frontline staff and pandemic preparedness of frontline staff highlighted as areas for investment.

Section	Summary
	This was also a key theme from the focus groups who supported increased health investment and expressed concern for the wellbeing of frontline staff during a pandemic. It was also noted that the health and disability system should support particular groups to reduce health inequalities, highlighting disabled people, older people, Māori, and people with mental health challenges.
Digital inclusion	Some respondents were supportive of everyone having access to digital resources, poor coverage in rural areas was noted and that this should be remedied. However, there were concerns expressed about requiring people to be digitally literate or not using other communication formats that are appropriate for these audiences, and communications via community groups or organisations should also be used.
Community readiness	It was noted that community readiness was not defined and what the concept of community readiness means for future pandemics. There was strong support for community organisations in a pandemic and the importance of using existing community organisations or meeting points as part of a pandemic response.
Reduction of risk	The comments focused on environmental risk and mostly the potential role of gain of function research in pandemics and the connection between climate change and health. It was noted that although climate change was raised as a risk for health, the report did not discuss potential actions fully, with a single action related to legislative change described. The responses asked for greater detail and a more considered section in the report.
Justification for interventions	There was strong support that restrictions should be agreed rather than imposed. There was moderate support that imposed restrictive measures should aim to minimise any restrictions on liberty and carefully describe the justification for that limitation There were mixed responses to the following: • reciprocal support may be appropriate for people who, to protect others, have restrictions imposed upon them • restrictive measures can be justified only when all the narrowly defined circumstances set out in human rights law, known as the Siracusa Principles.
Siracusa principles	The Siracusa Principles were not the focus of the comments received. The comments mainly expressed concerns about interventions that restricted choice and whether they should be possible in response to future pandemics. Some comments also suggested the introduction of a requirement for decision-makers to show how the principles were applied.
Intervention examples	'Protecting those who are more at risk of being affected by the pandemic due to pre-existing inequities' was strongly supported. There was moderate support for 'ensuring the intervention is widely utilised and its benefits obtained' and 'preventing the need for more restrictive measures later'.

Section	Summary
Effects of interventions	The following were noted by a few comments: • the consequences of closing the border and that additional mechanisms may be needed, e.g. support for those unable to return • fair rules and systems need to be developed for selecting and allocating opportunities to cross the border • there were positive consequences of the pandemic interventions and that these should be acknowledged as well. • the impact on health services and that consideration of how to keep services running where possible.
Communications and engagement	There was significant concern expressed about communications during the COVID-19 pandemic, with some noting the quantity of messaging to the public, the 'one source of truth' approach and suggesting more opportunities for open debate would have been useful. It was also noted that a response to future pandemics should make sure communications are provided through a wide range of channels and be provided in different formats so that it is accessible to all audiences. Disabled people were highlighted as a group this was particularly important for.
Data, privacy and digital technologies	The comments mostly raised concerns about health data and are raised outside a pandemic but may be more acute during one, for example: • individual privacy and how it is protected • caution about private sectors organisations accessing health data • appropriate consent by individuals for the use of their health data • data being deleted once it is no longer required • high security to prevent data breaches. Similar to the responses in digital inclusion, a few comments noted that accessibility should be supported for those who wish to access digital resources and that there are a wide range of community organisations and groups that could support people to gain access.
Ethical statements on vaccine development and use	The following statements were strongly supported: • 'Ideally, vaccination should be voluntary rather than non-voluntary' • 'If a vaccine certificate is required to access essential goods and services, vaccines are no longer truly voluntary' • 'People who cannot safely receive the vaccine for medical reasons should be given an exemption to vaccine certificate requirements'. This statement was moderately supported: 'The use of vaccine certificates must be based on scientific evidence that they are effective at achieving their stated outcome'. There were mixed responses to the following statements: • 'Priority access to vaccines should be given to the most vulnerable people in a pandemic' • 'Global cooperation is required to ensure fair and equitable access to vaccines in low-to-middle-income countries'.
Reopening	The comments on reopening mainly address lockdowns rather than reopening, with a few comments stating that lockdowns should rarely or never be used.

Section	Summary
	Clear criteria for reopening and that mental health services should be increased after a reopening were noted in a few comments.
Ongoing impacts	There were three ongoing impacts that were noted by a few comments: • there should be support services for those with long COVID and other post-viral conditions and a framework be developed for future pandemics to address conditions that arise from the pandemic • the vulnerability of those in shared accommodation should be addressed in the Report • annual sick leave allowances should be addressed in the Report as they may need to be increased to accommodate those with ongoing illness from the pandemic or those who care for them.
Disabled people	There were three questions asking about how well covered the ethical issues in the readiness and reduction, response and recovery section were for disabled people. On a scale of very well covered to very poorly covered most respondents chose neutral for all three questions. The comments across the three questions were not specific to the different phases of preparedness, response and recovery. They did note the following ways in which the disabled community may need a different response to other groups: • that further consultation with disabled people should be conducted • the lack of care and support available to disabled people, particularly those in care homes or facilities, who were isolated to a greater extent during the COVID-19 pandemic and that future pandemics would result in a similar lack of support as there were no scenarios addressing this • that a one size fits all approach does not necessarily provide support for those who are living with disability and that more clear detail be given for how a pandemic would be managed across differently abled people through the different phases of the pandemic.

Submission analysis

The Secretariat completed the analysis of the 428 survey submissions, 21 written submissions and three online focus groups. The Secretariat's was not able to analyse all the qualitative data.

As the survey was about a pandemic response a considerable number of respondents provided information in the qualitative survey questions that were not related to the consultation. These responses were not included in the analysis for the qualitative questions. Additionally, some of the qualitative responses did not provide enough detail to be able to be analysed as changes to the draft report.

Survey and written responses

There were 428 responses received through the online survey and 22 written submissions submitted directly to the Secretariat. For each multichoice question the numbers of responses was compared to the number of respondents who answered that question. For the qualitative questions, each response was reviewed and coded and then the grouped responses were analysed for themes which were summarised for each qualitative question. A detailed description of the coding process can be found in the **Appendix.** Survey or written submissions that were verbally abusive or targeted individuals were excluded from the analysis and repeat submissions from one individual or group were only counted once.

When analysing the responses, the following thresholds were used, although due to the number of responses received, none of the quantitative analysis was statistically significant at a ±5% threshold.

Descriptor	Threshold
Few	<20%
Some	20-60%
Many	60-80%
Most	>80%

Focus groups

The NEAC subgroup chose key groups/organisations to invite to focus group meetings. They were asked if there was anyone else if there were any other key stakeholders that they would like to invite into their focus group. Focus group participants were sent the draft publication in advance of the meeting and were prompted with sections and pages highlighted by the members of the Secretariat conducting the meeting.

Demographics of respondents

Respondents were asked about three diversity characteristics – gender, age, and ethnicity. Although data was not collected on disability, a few respondents chose to identify as disabled. However, there was not sufficient data provided to report on disability. Data categories were combined where there were multiple ethnicities selected or insufficient respondents to create anonymised data.

The demographic data for the individual survey respondents when compared to the 2018 Census data shows there were:

- fewer male respondents than anticipated based on the composition of the Aotearoa New Zealand population
- more respondents in the 45-64-year-old bracket than anticipated, although this group are more likely to be aware of and respond to consultations
- more respondents identifying as European and less respondents identifying as Asian or Pacific peoples compared to the Aotearoa New Zealand population.

Overall, the survey respondents are reflective of most of the Aotearoa New Zealand population, however, additional sampling would be required of Asian, Pacific and young people to ensure the responses were reflective of all of the Aotearoa New Zealand population.

Organisational responses

Responses were received from 19 organisations, including:

- Age Concern New Zealand
- Asian Caucus of PHA
- Asian Family Services
- Associated New Zealand Society for ME/CFS
- Auckland Women's Health Council
- Hāpai Te Hauora
- IHC
- InterChurch Bioethics Council, Aotearoa New Zealand
- MECFS Canterbury
- NZ College of Public Health Medicine
- Office for Disability Issues, Whaikaha | Ministry of Disabled People
- Physicians and Scientists for Global Responsibility Charitable Trust
- Royal Australasian College of Surgeons
- Te Hapori Disability Trust

Table 1: Responses to the gender question

Response category	No of responses	Percentage	NZ population[1]
Female	203	56%	50%
Male	122	33%	50%
I identify in another way	2	1%	
Prefer not to say	38	10%	
TOTAL	**365**	**100%**	**100%**

Figure 1: Graph of gender responses to consultation

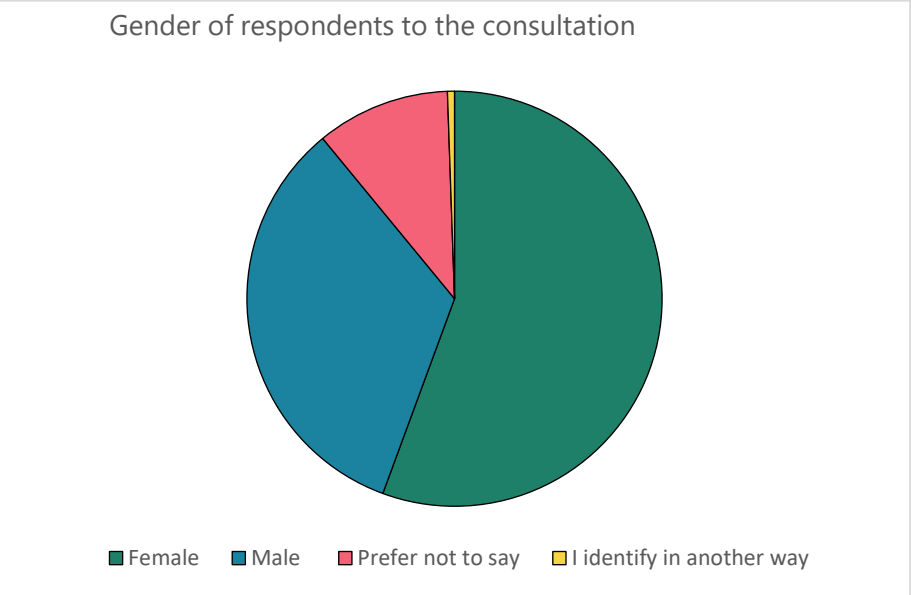
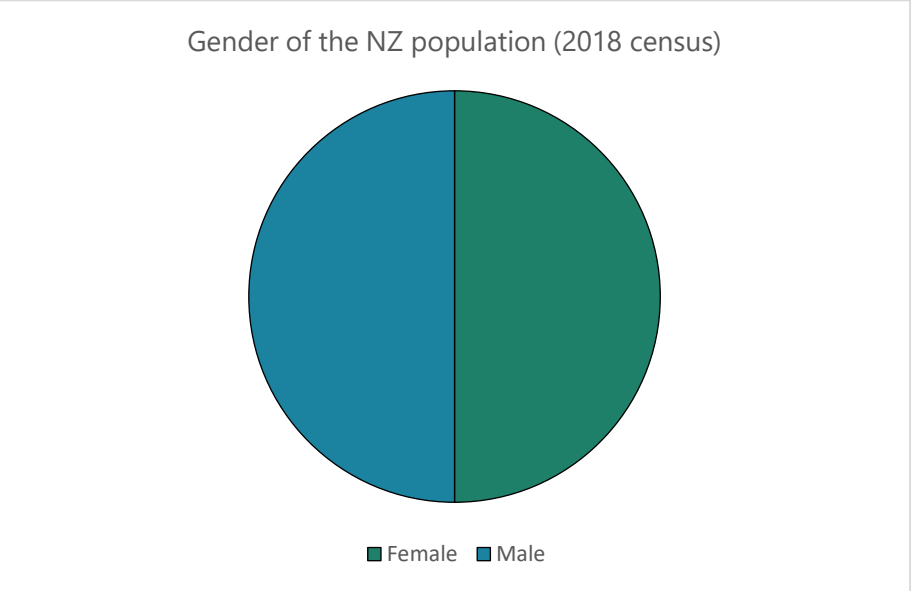


Figure 2: Gender of the NZ population (2018 census)



[1] 2018 Census data - **https://www.stats.govt.nz/tools/2018-census-place-summaries/new-zealand**

Table 2: Responses to the age question

Response category	No of responses	Percentage	NZ population[2]
<24 years	3	1%	33%
25-44 years	63	17%	27%
45-64 years	192	53%	25%
65+ years	64	18%	15%
Prefer not to say	39	11%	
TOTAL	**361**	**100%**	**100%**

Figure 3: Graph of responses to age question

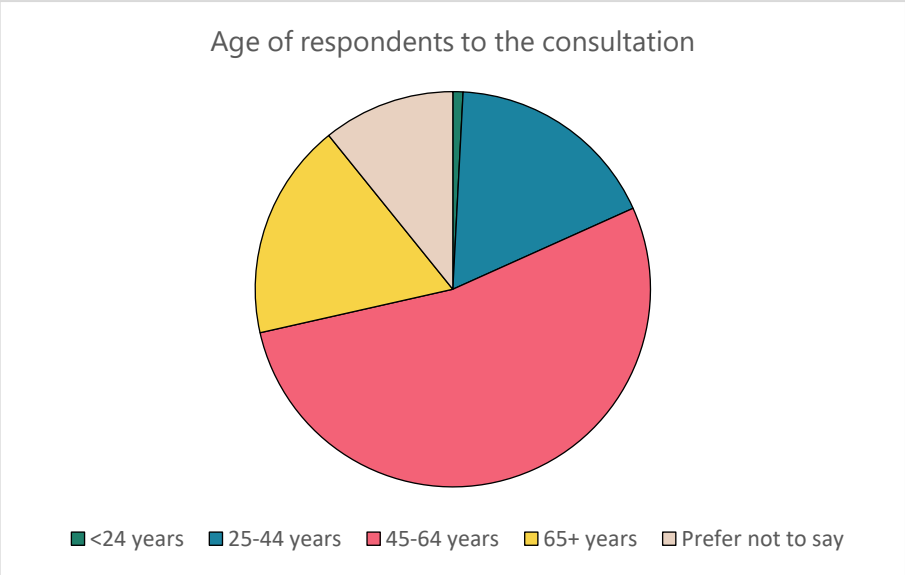
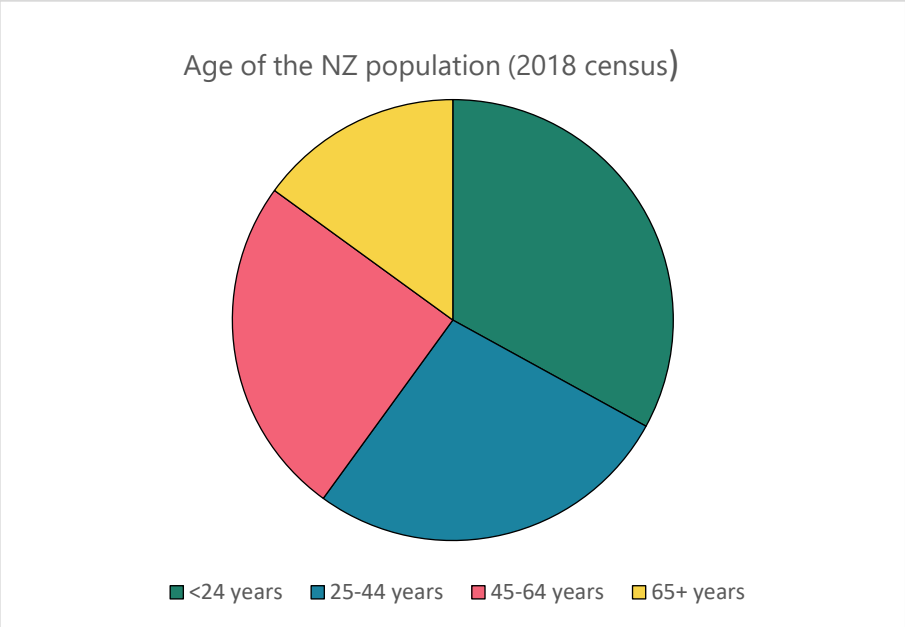


Figure 4: Graph of NZ population (2018) census



[2] Ibid

Table 3: Responses to the ethnicity question

Response category	No of responses	Percentage	NZ population[3]
Asian	3	1%	15%
Māori	47	13%	17%
European/Pākehā	186	52%	70%
Pacific Peoples	2	1%	8%
Other	43	12%	3%
Prefer not to say	76	21%	
TOTAL	**357**	**100%**	**113%[4]**

Figure 5: Graph of responses to the ethnicity question

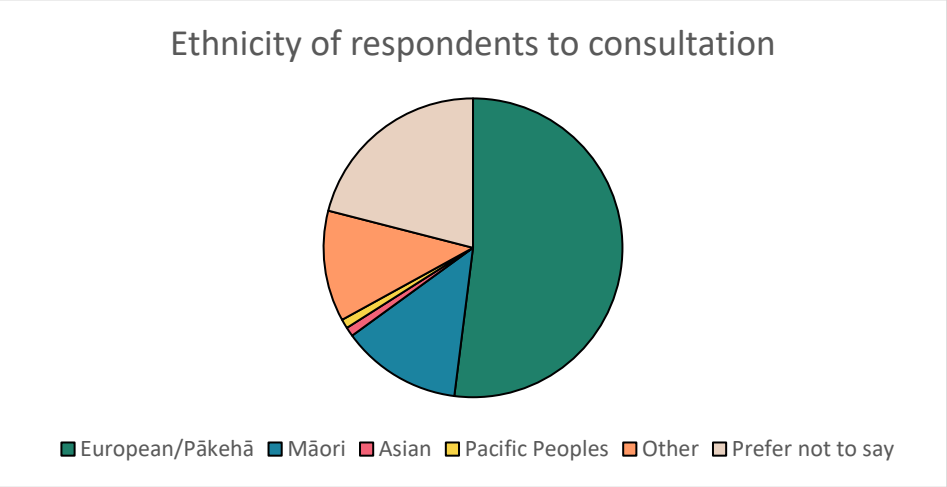
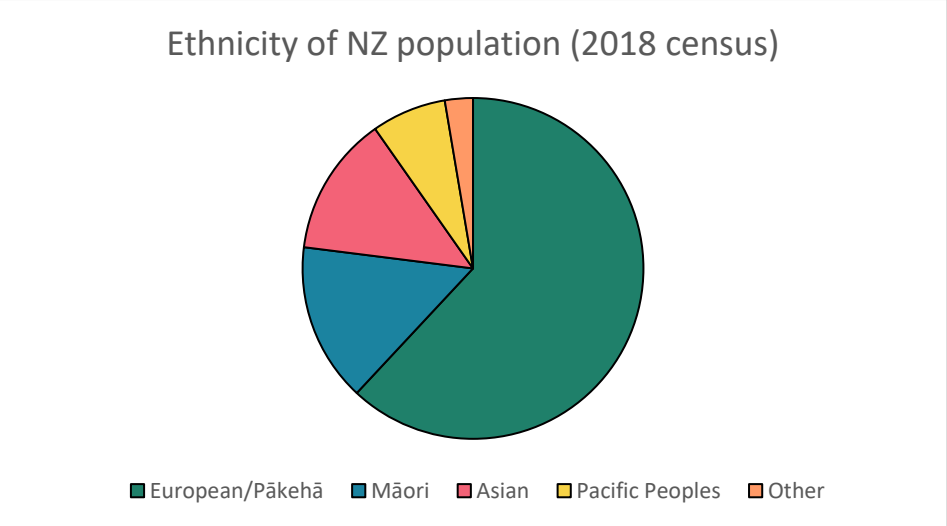


Figure 6: Graph of ethnicity of the NZ population (2018 census)



[3] 2018 Census data - **https://www.stats.govt.nz/news/ethnic-group-summaries-reveal-new-zealands-multicultural-make-up/**

[4] For the 2018 Census data where a person reported more than one ethnic group, they were counted in each applicable group meaning that the total was greater than 100%.

Survey question responses

The survey was launched on 26 July 2022 and closed on 1 November 2022. The Secretariat received 428 survey submissions and 21 written submissions. The survey was a mix of 22 open-ended and multiple-choice questions. The survey results have been analysed by question. In advance of this detailed analysis the recurring themes across all of the questions.

Recurring themes

Using the frameworks in the reports

It was noted often that greater clarity about how to use the report could be used. The following changes were suggested:

- examples were needed of how to use the three different frameworks in practice
- the foundational elements should be reflected in the latter parts of the document to illustrate their utility for decision-making and demonstrate what they mean in the context of preparation, response and recovery in a pandemic
- include an introduction setting out the document's purpose and who it is for, e.g., NEAC Ethics and Equity: Resource Allocation
- be clear about the relationship between the ethical principles and other ethical guidance e.g., professional codes of conduct
- consider different outputs for different audiences.

Independent inquiry

Many of the respondents noted a desire for an independent review of the COVID-19 pandemic response and for lessons to be taken from this. Hopefully the **Royal Commission of Inquiry into COVID-19 Lessons** will meet this desire.

Public and community involvement

Throughout the questions, the role of community groups and organisation in supporting pandemic measures, communicating with their communities, and providing on the ground intelligence was noted and greater acknowledgment in the draft EGAP Report was requested.

Public and community engagement was also frequently mentioned, noting that this should be built into future pandemic responses and be an integral part of

preparedness, response and recovery, particularly for vulnerable groups – disabled people were mention frequently as a group for consultation.

Mandatory interventions

Concerns were expressed about the use of mandatory interventions, particularly mandates and lockdowns and that greater transparency was required about what evidence is used to make these decisions.

Concern about data use and digital inclusion

The use of data and digital methods was noted frequently, particularly ensuring that privacy of data was maintained and that a wide range of communication who are unable or do not wish to be digitally connected. It was also noted that data should only be kept as long as absolutely necessary, and there was concern about the that the role of private companies in the developing digital products and processing health data.

Question 1a. Which of the proposed seven foundational elements to Aotearoa New Zealand's pandemic response do you agree with?

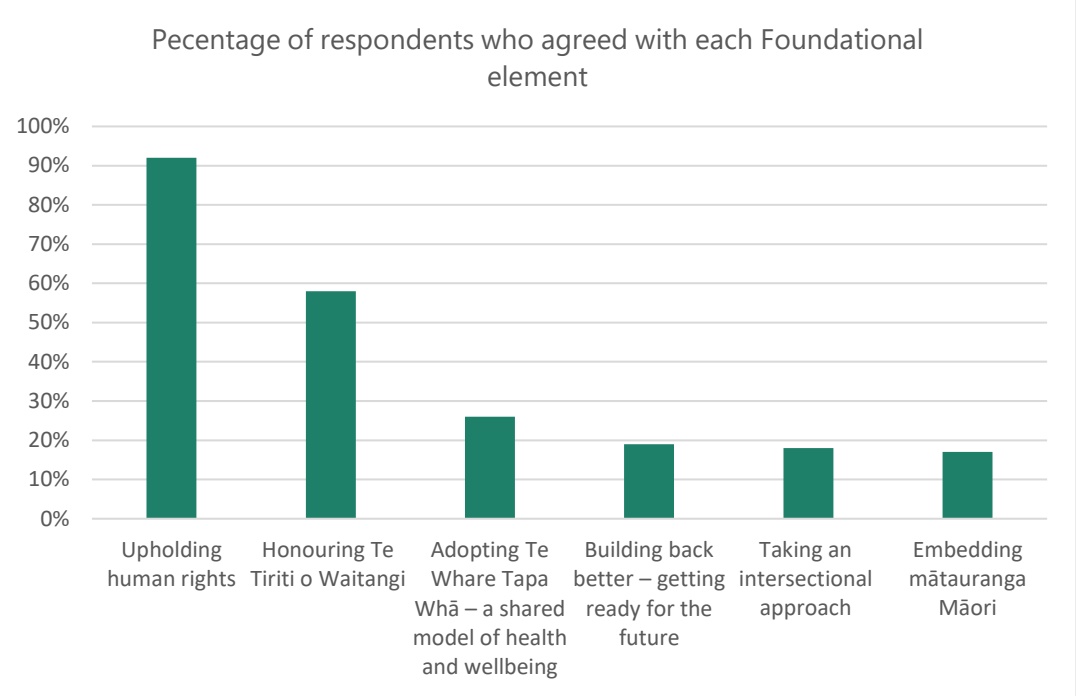
- Honouring Te Tiriti o Waitangi
- Developing a strong and well-functioning health system
- Building back better – getting ready for the future
- Adopting Te Whare Tapa Whā – a shared model of health and wellbeing
- Embedding mātauranga Māori
- Taking an intersectional approach
- Upholding human rights

There was a total of 1019 responses and 392 respondents that provided answers to this question. The number of responses is greater than the number of respondents as respondents were able to choose all of the principles that they agreed with among the seven foundational principles.

Table 4: Responses to Foundation Elements

Foundational element	No of respondents that agreed	Percentage
Upholding human rights	361	92%
Honouring Te Tiriti o Waitangi	226	58%
Adopting Te Whare Tapa Whā – a shared model of health and wellbeing	103	26%
Building back better – getting ready for the future	76	19%
Taking an intersectional approach	69	18%
Embedding mātauranga Māori	67	17%

Figure 7: Graph of Responses to Foundational Elements



Most respondents agreed that 'Upholding human rights' should be at the core of Aotearoa New Zealand's pandemic response with 92% of those who chose to respond agreeing with this foundational element.

There were some respondents who agreed that 'Honouring Te Tiriti o Waitangi', 'Developing a strong and well-functioning health system' and 'Adopting Te Whare Tapa Whā – a shared model of health and wellbeing' should be foundational elements.

There were a few respondents that agreed that 'Building back better – getting ready for the future', 'Taking and intersectional approach' and 'Embedding mātauranga Māori' should be foundational elements.

Question 1b. Do you have any comments about the seven foundational elements? Are there any foundational elements you want added, removed, or significantly changed?

There were 172 comments analysed in response to this question. The comments covered a wide range of topics, with the most comments received on the 'Building Back Better' foundational element and rights.

Overall

A few respondents commented on the foundational elements as a whole and noted that the relationship between the foundational elements and existing legislative and ethical guidance could be explicitly addressed.

Building Back Better

A few individuals were concerned about 'Building back better' as a foundational element and suggested it be removed. Although few respondents outlined why they wanted 'Building Back Better' removed, their responses indicated that their concerns were around the role of international organisations, like the World Economic Forum and the United Nations, and whether the 'Building Back Better' framework was appropriate for Aotearoa New Zealand.

Rights

Some of the suggestions for additions and removals focused on specific human rights and the protections of rights generally. Some respondents supporting the inclusion of 'Upholding human rights' as a foundational element.

Many of the responses on human rights supported the addition of language to strengthen rights against coercive measures, with particular concern about mandates and lockdowns. A few responses also noted the need to consider different communities (e.g., minority communities, disabled communities, domestic violence victims) although it was not clear whether this was an additional foundational element or within the foundational elements outlined in the consultation.

Question 2a. Which of the six ethical principles proposed for Aotearoa New Zealand to apply during a pandemic do you agree with?

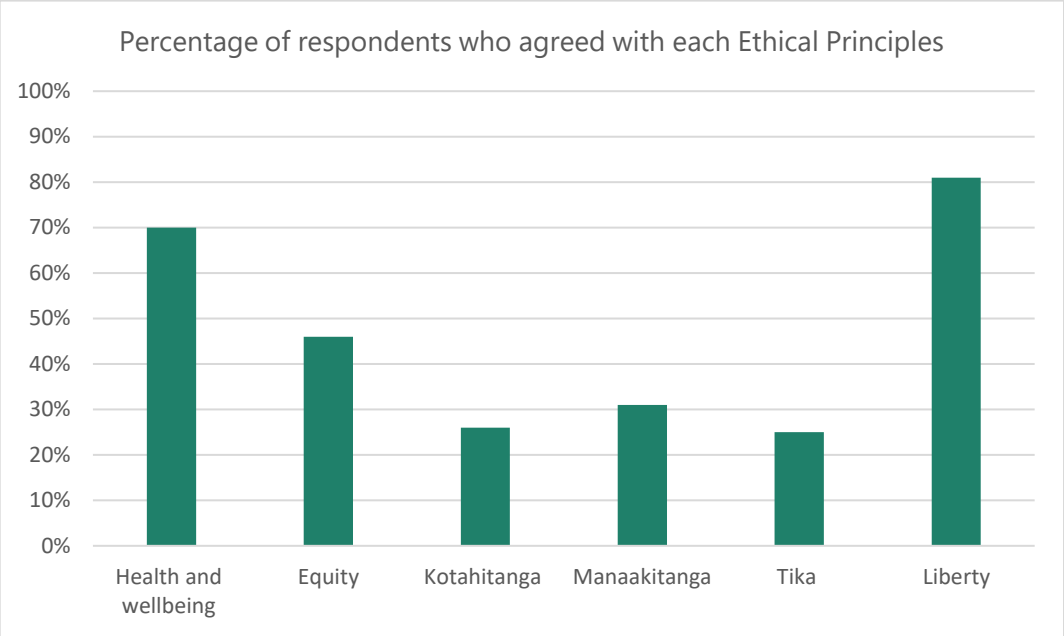
- Health and wellbeing
- Equity
- Kotahitanga
- Manaakitanga
- Tika
- Liberty

There was a total of 1043 responses and 374 respondents that responded to this question. The number of responses is greater than the number of respondents as respondents were able to choose all of the principles that they agreed with among the six ethical principles.

Table 5: Responses on the Ethical Principles

Ethical principles	No of respondents that agreed	Percentage
Health and wellbeing	262	70%
Equity	171	46%
Kotahitanga	99	26%
Manaakitanga	115	31%
Tika	92	25%
Liberty	304	81%

Figure 8: Graph of responses to the Ethical Principles question



Most respondents agreed with 'Liberty' as an ethical principle to guide decisions in a pandemic and many respondents agreed with 'Health and wellbeing'. Some respondents supported the four other ethical principles 'Equity', 'Kotahitanga', 'Manaakitanga' and 'Tika'.

Question 2b. Do you have any comments about the six ethical principles? Are there any ethical principles you want added, removed, or significantly changed?

There were 183 comments analysed in response to this question. The comments covered a wide range of topics with most comments received on two ethical principles – liberty and equity.

Overall

Additional ethical principles were suggested by a few respondents, including community involvement (especially of those impacted by decisions), environmental protection, international responsibilities, and an ethical principle that looks towards the future. A few respondents noted that health and wellbeing was not an ethical principle.

Equity

A few responses noted that access is part of ensuring equity and wanted this explicitly included, and that groups experiencing health inequities should be involved in designing solutions that are appropriate for them.

Liberty

Some responses specifically addressed liberty although there was divergence within the responses. Many of the comments on liberty agreed with it as an ethical principle to protect autonomy and resist coercive measures. Whereas some of the comments on liberty noted the tension between individual and collective responsibilities and that

liberty may have limits as an ethical principle. This was with particular reference to vulnerable groups who may rely on the actions of others to stay safe.

Question 3a. Do you agree that elements for making complex public health decisions combine to create a useful process for decision-makers to use in a pandemic?

Elements for making ethically complex public health decisions:

- Transparency
- Consistency
- Justification
- Participation
- Managing conflicts of interest
- Openness for revision
- Regulation

There was a total of 412 respondents that completed this question.

Response	No of responses	Percentage
Strongly agree	71	17%
Agree	134	33%
Neutral	78	19%
Disagree	39	9%
Strongly disagree	90	22%
TOTAL	**412**	**100%**

Of those that responded to the question, 50% agreed (agree or strongly agree), 19% were neutral and 31% disagreed (disagree or strongly disagree).

Question 3b. Do you have any comments about the elements for making ethically complex public health decisions? Do you have any other suggestions about how we can ethically make complex public health decisions?

There were 162 comments analysed in response to this question. The comments covered a wide range of topics with the transparency and participation elements receiving the most comments.

Overall

There was little comment on the elements collectively and a few responses supporting the elements were concerned about how they would be applied in practice. A few responses also noted the connections between health and other sectors that may have

an impact on how prepared or how long recovery takes e.g., building regulations and how these elements would be connected to those sectors.

Transparency

Most of the comments on transparency were supportive of greater transparency for decision making during a pandemic, particularly disclosure of the principles and evidence used in decision making. A few comments supported additional transparency mechanisms e.g., an independent commissioner, or ensuring support across government parties.

Participation

There were a few comments on participation but most of the comments expressed the need for greater participation and wanted this strengthened, particularly highlighting that non-urgent decisions should involve public participation and that possibly partnership would be a better name for this element. There were also a few comments that noted the need to involve highly impacted communities, e.g., disabled communities, minority ethnic communities, especially as there is poor health data on these communities to base decisions on.

Question 4. Do you have any comments about the section on preparing our health and disability system? Is there information you want added, removed, or substantially changed in this section?

There were 110 comments analysed in response to this question. The 'Preparing our health and disability system' section focused on two areas – indigenous health and equity. The comments received on this section focused on equity, there were no comments on indigenous health directly.

Equity

A few comments addressed equity and were supportive of a fair and equitable health system, and many of these comments highlighted groups facing health inequalities and that more support should be offered to these communities, particularly disabled communities.

A few comments also noted the key role that community organisations can play in addressing health inequalities and that their role should be acknowledged and supported as part of the health and disability system.

Question 5. Do you have any comments about the section on health investment? Is there information you want added, removed, or substantially changed in this section?

There were 110 comments analysed in response to this question. The 'Health investment' section focused on three areas – the economics of readiness, building back better and the social determinants of health. The comments received on this section focused on health investment rather than addressing the three individual areas.

Health investment

Some of the comments focused on health investment, of these, most strongly supported increased investment in the health and disability system. Preventative health interventions, hospitals and frontline staff (e.g., nurses, GPs, midwives) were highlighted as areas for investment and activities to ensure healthcare workers were prepared for any future pandemic. Some of these responses also noted that the health and disability system should support particular groups to reduce health inequalities, highlighting disabled people, older people, Māori, and people with mental health challenges.

A few comments also noted the need to balance providing urgent services to address a pandemic but also allowing the continuation of non-pandemic related services. This was highlighted as being especially necessary where things will progress regardless of the pandemic e.g., pregnancies, cancer detection and treatment.

Question 6. Do you have any comments about the section on digital inclusion? Is there information you want added, removed, or substantially changed in this section?

There were 153 comments analysed in response to this question.

A few comments noted that the digital inclusion section was shorter and did not include the same level of analysis as other sections of the report.

Some of the comments were supportive of everyone having access to digital resources, poor coverage in rural areas was noted and that this should be remedied. However, there were concerns expressed about requiring people to be digitally literate or not using other communication formats that are appropriate for these audiences. It was also noted that communications during a pandemic should not be limited to digital resources, that free to air media, newspapers, pamphlets, letters and communications via community groups or organisations should also be used.

A few comments also noted the role of community organisations in developing digital literacy e.g., libraries and Citizens' Advice Bureau and that there are resource and budgetary pressures for these organisations.

A few comments noted the importance of providing any communications in a pandemic in different languages to ensure inclusion regardless of the format of the communication.

A few comments expressed that centralised up-to-date and evidence-based information was useful, but there was also concern express about the 'one source of truth' approach as well as the role of disinformation/misinformation.

A few comments also noted the need for considering the safe use of digital technologies in their use and development to ensure appropriate protections a built in and that vulnerable groups are kept safe (e.g., those experiencing family violence).

Question 7. Do you have any comments about the section on community readiness? Is there information you want added, removed, or substantially changed in this section?

There were 94 comments analysed in response to this question. The 'Community readiness' section focused on two areas – businesses and collectives (LGBTQ+, refugees and migrants, iwi, individuals and families). Most of the comments received in response to this question focused on community groups, their role in a pandemic and how they could be better supported and utilised in future pandemics. There were less than ten comments on the role of businesses.

Overall

There were a few comments that noted that community readiness was not defined, and what it would mean for a community to be ready was not outlined or what the concept of community readiness means for pandemic readiness planning.

Businesses

A few comments noted the role of businesses in a pandemic to provide for communities and as employers, although a few of these expressed concerns about when businesses were required to enforce pandemic rules, inconsistency in application of pandemic rules by businesses and the impact of pandemic rules on small businesses. There was also concern about how businesses could be encouraged to implement readiness measures for a pandemic when these could be costly and of unknown utility e.g., ventilation systems.

Collectives

Many of the comments received were about the role of community organisations in a pandemic, and within this, some comments noted the importance of using existing community organisations or meeting points as part of a pandemic response.

Some comments also noted that community organisations could have a more impactful role in future pandemics, especially as they have trusted relationships with their communities. This could be through activities like community engagement, offering support and providing up-to-date assessments 'on the ground', although this may also require additional resourcing for these organisations, partnerships models of working and devolving some decisions to the community level.

Some of the comments noted that there are a broad range of community organisations, and that this diversity should be reflected in the report, for example, churches, organisations that work with those in poverty, victims of family or sexual violence, and community activity groups.

Question 8. Do you have any comments about the section on reduction of risk? Is there information you want added, removed, or significantly changed? For example, are there any other risk reduction factors that should be taken into account?

There were 48 comments analysed in response to this question. The 'Reduction of risk' section focused on two areas – environmental risks and international cooperation.

Environmental risks

A few comments were received on environmental risk, and they focused on the potential role of gain of function research in pandemics and the connection between climate change and health.

It was noted that although climate change was raised as a risk for health that the report did not discuss potential actions fully, with a single action related to legislative change described. The responses asked for greater detail and a more considered section in the report.

International cooperation

A few comments addressed Aotearoa New Zealand's contribution to the reduction of global pandemic risk, as a national response alone is unlikely to prevent a future pandemic and sought further detail as to what actions could be taken.

A few comments were received on the role of international organisations and concerns raised about how appropriate international initiatives are for an Aotearoa New Zealand context, and to prioritise pandemics against other international health issues that also require urgent attention.

Question 9. The section on justification for interventions outlines that interventions designed to slow or eliminate the spread of a pandemic should align with the national ethical principles, and they must reflect four further considerations.

Do you agree with these considerations (stated below)?

a. When possible and appropriate, restrictions should be agreed rather than imposed.

Response	No of responses	Percentage
Strongly agree	228	57%
Agree	72	18%
Neutral	32	8%
Disagree	23	6%
Strongly disagree	43	11%
TOTAL	**398**	**100%**

Of those that responded to the question, many respondents agreed (75% agree or strongly agree), a few were neutral (8%) and a few disagreed (17% disagree or strongly disagree).

b. Imposed restrictive measures should aim to minimise any restrictions on liberty and carefully describe the justification for that limitation. Special attention may be needed for people who are subject to restrictions (for example, to their freedom of movement) to ensure their other rights are protected.

Response	No of responses	Percentage
Strongly agree	208	55%
Agree	69	18%
Neutral	28	7%
Disagree	15	4%
Strongly disagree	61	16%
TOTAL	**381**	**100%**

Of those that responded to the question, many respondents agreed (73% agree or strongly agree), a few were neutral (7%) and some disagreed (20% disagree or strongly disagree).

c. Reciprocal support may be appropriate for people who, to protect others, have restrictions imposed upon them.

Response	No of responses	Percentage
Strongly agree	110	30%
Agree	66	18%
Neutral	70	19%
Disagree	19	5%
Strongly disagree	100	28%
TOTAL	365	100%

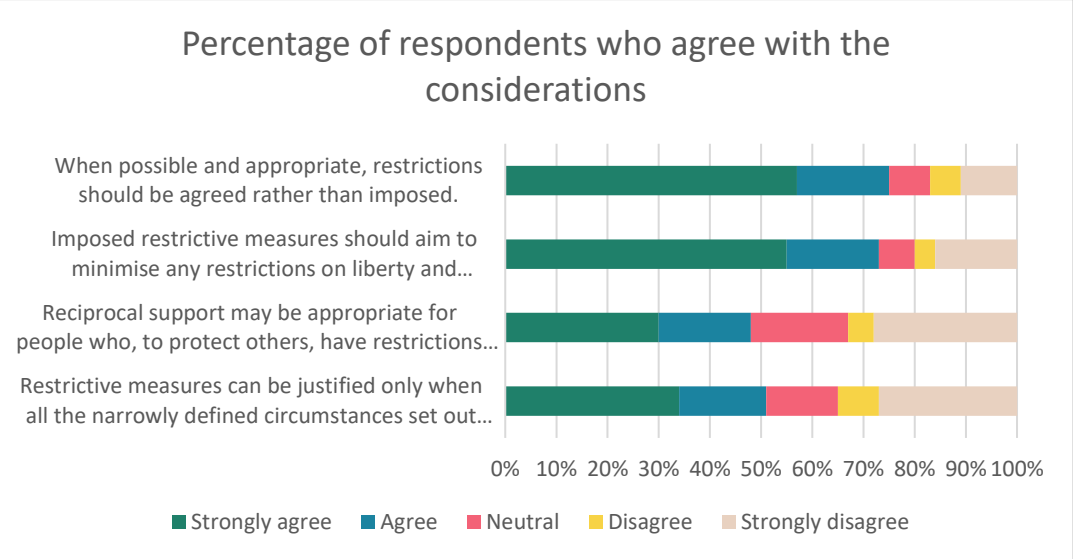
Of those that responded to the question, some respondents agreed (48% agree or strongly agree), a few respondents were neutral (19%) and some respondents disagreed (33% disagree or strongly disagree).

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

Response	No of responses	Percentage
Strongly agree	126	34%
Agree	62	17%
Neutral	52	14%
Disagree	29	8%
Strongly disagree	98	27%
TOTAL	**367**	**100%**

Of those that responded to the question, some agreed (51% agree or strongly agree), a few were neutral (14%) and some disagreed (35% disagree or strongly disagree).

Figure 9: Graph of responses on the considerations



Question 10. How appropriate are the Siracusa Principles, for Aotearoa New Zealand? Are there other more appropriate principles that could guide intervention?

There were 208 comments analysed in response to this question. Although the question asked about the Siracusa Principles, comments were received on content across the 'Justification for interventions' section.

A few comments noted that the Siracusa Principles did not take into consideration an Aotearoa New Zealand context and that reviewing them in this light would be appropriate.

Question 11a. Which of these examples do you agree with?

- Ensuring the intervention is widely utilised and its benefits obtained
- Preventing the need for more restrictive measures later
- Protecting those who are more at risk of being affected by the pandemic due to pre-existing inequities

There was a total of 300 responses and 177 respondents that answered this question. The number of responses is greater than the number of respondents as respondents were able to choose all of the examples that they agreed with among the three examples.

Table 6: Responses that agreed with the examples

Example	No of respondents that agreed	Percentage
Ensuring the intervention is widely utilised and its benefits obtained	67	38%
Preventing the need for more restrictive measures later	80	45%
Protecting those who are more at risk of being affected by the pandemic due to pre-existing inequities	153	86%

Most respondents agreed with protecting those who are more at risk of being affected by the pandemic due to pre-existing inequities. Some respondents agreed with ensuring the intervention is widely utilised and its benefits obtained and preventing the need for more restrictive measures later.

Question 11b. Do you have any comments on these examples? Are there other examples that you think we should discuss?

There were 158 comments analysed in response to this question. As with Question 10, many of the comments expressed concerns about interventions that restricted choice and whether they should be possible in response to future pandemics.

A few comments also noted the tension between individual and collective responsibilities and that vulnerable groups may rely on the actions of others to stay safe.

Question 12. Do you have any comments about the section on effects of interventions? Are there any other effects of interventions that we have not listed that are likely to be relevant in future pandemics?

There were 45 comments analysed in response to this question. The 'Effects of interventions' section focused on borders and immigration, refugees, incarcerated populations and treatment and elective surgeries.

A few comments noted the consequences of closing the border and that additional mechanisms may needed, e.g., support for those unable to return It was also noted that fair rules and systems need to be developed for selecting and allocating opportunities to cross the border.

A few comments noted that there were positive consequences of the pandemic interventions and that these should be acknowledged as well.

A few comments were concerned about the impact on health services and wanted consideration of how to keep services running where possible even when restrictions are required.

A few comments were concerned about the impact on mental health and wanted this explicitly considered if interventions are considered for future pandemics.

A few comments also noted the need to evaluate interventions and the role that communities could play in this.

Question 13. Do you have any comments on the communications and engagement section? Is there information you want added, removed, or substantially changed in this section?

There were 122 comments analysed in response to this question. The 'Communications and engagement' section focused on the need for timely accurate information in a pandemic and the roles of Government, media, community groups and iwi and individuals and families.

Many of the comments expressed concern about communications during the COVID-19 pandemic, with some noting the quantity of messaging to the public, the 'one source of truth' approach and suggesting more opportunities for open debate would have been useful. A few comments were supportive of communications during the COVID-19 pandemic.

A few of the comments also noted a response to future pandemics should make sure communications are provided through a wide range of channels e.g., TV, radio, letters and national and local newspapers. It was also noted in a few responses that information should be provided in different formats so that it is accessible to all audiences, disabled people were highlighted as a group this was particularly important for.

A few comments were supportive of the role that communities and community organisations could play in disseminating information and that a wide range of community organisations should be included in supporting their communities.

A few comments expressed concerns about misinformation and disinformation, with a few respondents noting that accurate information is important but also noting that public debate should not be stifled by measures to reduce dis/mis-information.

Question 14. Do you have any comments on the data, privacy and digital technologies section? Is there information you want added, removed, or substantially changed in this section?

There were 91 comments analysed in response to this question. The 'Data, privacy, and digital technologies in a pandemic' section focused on privacy, access to medical data, digital inclusion, contract tracing, Māori data and 'further considerations'. The 'further considerations' section included the limits of data as a tool, consent for data use and the role of private-sector technology companies.

Many of the comments raised concerns that relate to health data and its use generally, for example:

- individual privacy and how it is protected
- caution about private sectors organisations accessing health data
- appropriate consent by individuals for the use of their health data
- data being deleted once it is no longer required
- high security to prevent data breaches.

Like the responses to Question 7, a few comments noted that accessibility should be supported for those who wish to access digital resources and that there are a wide range of community organisations and groups that could support people to gain access.

Question 15. The section on vaccine development and use considers many ethical issues. How much do you agree with these ethical statements?

a. Priority access to vaccines should be given to the most vulnerable people in a pandemic (Equity, page 46).

Response	No of responses	Percentage
Strongly agree	108	29%
Agree	100	26%
Neutral	73	19%
Disagree	10	3%
Strongly disagree	87	23%
TOTAL	**378**	**100%**

Of those that responded to the question, many agreed (55% agree or strongly agree), a few were neutral (19%) and some disagreed (26% disagree or strongly disagree).

b. Ideally, vaccination should be voluntary rather than non-voluntary (Levels of coerciveness).

Response	No of responses	Percentage
Strongly agree	324	82%
Agree	36	9%
Neutral	13	3%
Disagree	12	3%
Strongly disagree	12	3%
TOTAL	**397**	**100%**

Of those that responded to the question, most agreed (91% agree or strongly agree), a few were neutral (3%) and a few disagreed (6% disagree or strongly disagree).

c. The use of vaccine certificates must be based on scientific evidence that they are effective at achieving their stated outcome (eg, preventing spread of the pandemic) (Vaccine Certificates – Efficacy).

Response	No of responses	Percentage
Strongly agree	163	46%
Agree	57	16%
Neutral	55	15%
Disagree	9	3%
Strongly disagree	72	20%
TOTAL	**356**	**100%**

Of those that responded to the question, some agreed (62% agree or strongly agree), a few were neutral (15%) and a few disagreed (23% disagree or strongly disagree).

d. If a vaccine certificate is required to access essential goods and services, vaccines are no longer truly voluntary. (Vaccine Certificates – Supplementary effects).

Response	No of responses	Percentage
Strongly agree	300	77%
Agree	46	12%
Neutral	17	4%
Disagree	8	2%
Strongly disagree	19	5%
TOTAL	**390**	**100%**

Of those that responded to the question, most agreed (89% agree or strongly agree), a few were neutral (4%) and a few disagreed (7% disagree or strongly disagree).

e. People who cannot safely receive the vaccine for medical reasons should be given an exemption to vaccine certificate requirements (Vaccine Certificates – Equity).

Response	No of responses	Percentage
Strongly agree	291	78%
Agree	43	12%
Neutral	20	5%
Disagree	4	1%
Strongly disagree	13	4%
TOTAL	**372**	**100%**

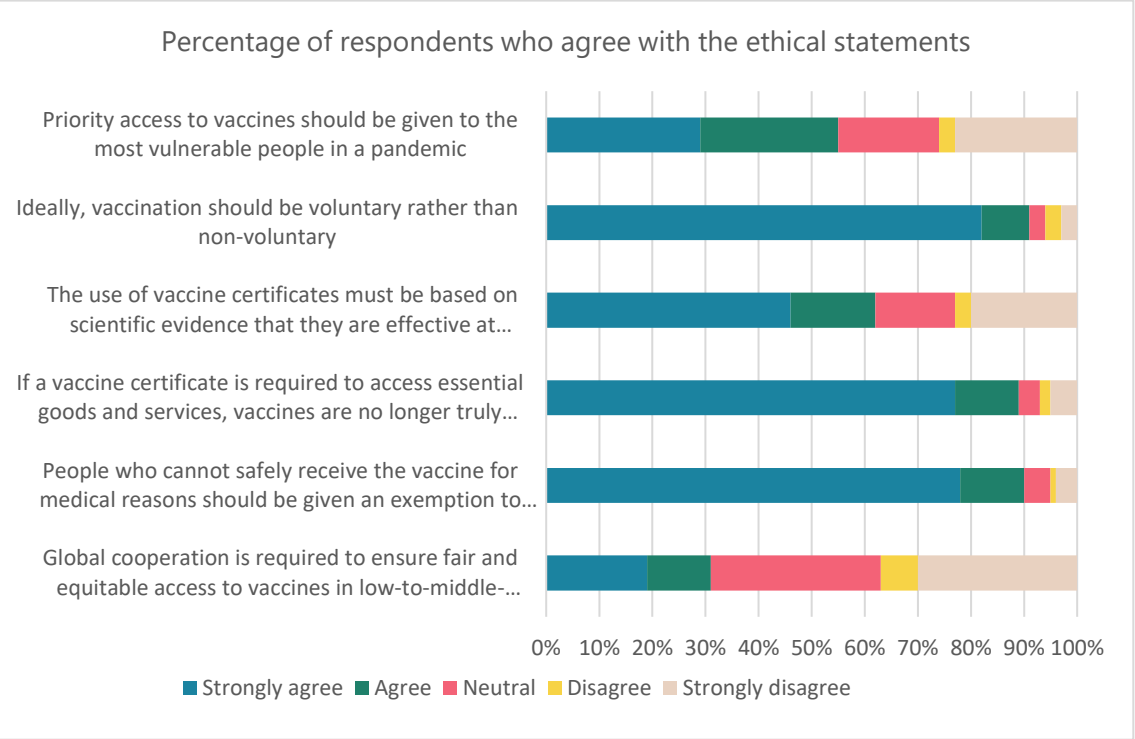
Of those that responded to the question, most agreed (90% agree or strongly agree), a few were neutral (5%) and a few disagreed (5% disagree or strongly disagree).

f. Global cooperation is required to ensure fair and equitable access to vaccines in low-to-middle-income countries (Global cooperation).

Response	No of responses	Percentage
Strongly agree	73	19%
Agree	45	12%
Neutral	123	32%
Disagree	25	7%
Strongly disagree	113	30%
TOTAL	**379**	**100%**

Of those that responded to the question, some respondents agreed (31% agree or strongly agree), some were neutral (32%) and some disagreed (37% disagree or strongly disagree).

Figure 10: Graph of responses to the ethical statements



Question 16. Do you have any comments on the section on reopening? Is there information you want added, removed or substantially changed in this section?

There were 65 comments analysed in response to this question. The 'Reopening' section focused on mental health, returning to work and education, and redefining the 'new normal'.

Many of the comments in response to Questions 16 focused on lockdowns rather than reopening, a few stating that lockdowns should rarely or never be used.

A few comments suggested that there should be clear criteria for reopening and a few comments noted that after a reopening that mental health services should be increased.

Question 17. Do you have any comments on the section on ongoing impacts? Is there information you want added, removed, or substantially changed in this section?

There were 65 comments analysed in response to this question. The 'Ongoing impacts' section focused on long COVID.

There were a few comments supporting services for those with long COVID and other post-viral conditions and suggested a framework be developed for future pandemics to address conditions that arise from the pandemic.

There were a few comments that noted the vulnerability of those in shared accommodation and that this should be covered in the report.

There were a few comments on annual sick leave allowances and that they should be increased to accommodate those with ongoing illness from COVID-19 or those who care for them.

Question 18a. How well does the section on readiness and reduction of risk capture the relevant ethical issues for disabled people?

Response	No of responses	Percentage
Very well	15	4%
Well	40	12%
Neutral	181	54%
Poor	33	10%
Very poor	69	20%
TOTAL	**338**	**100%**

Of those that responded to the question, a few respondents considered that the ethical issues for disabled people are well covered (16% well or very well covered), some were neutral (54%), and some considered them poorly covered (30% poor or very poor).

Question 18b. Do you have any comments on this section? Is there information you want added, removed, or substantially changed in this section?

There were 32 comments analysed in response to this question. Most of the comments were concerning the theme of disability. Some responses addressed the safety, harm, and validity of vaccines, and a few were related to health investment. There was also a strong prevalence of sentiment indicating that further consultation with disabled people should be conducted.

Question 19a. How well does the section on response capture the relevant ethical issues for disabled people?

Table 7: Responses on how well the responses section captures ethical issues for disabled people

Response	No of responses	Percentage
Very well	14	4%
Well	39	12%
Neutral	168	52%
Poor	30	9%
Very poor	74	23%
TOTAL	**325**	**100%**

Of those that responded to the question, a few respondents considered that the 'Response' section captured the relevant ethical issues for disabled people well (16% well or very well captured), some were neutral (52%), and some considered them poorly captured (32% poor or very poor).

Question 19b. Do you have any comments on this section? Is there information you want added, removed, or substantially changed in this section?

There were 19 comments analysed in response to this question. The comments showed a few of the respondents were concerned with disability and the impacts of the vaccine mandates and lockdowns, which in almost all cases were identified as secondary themes.

Overall

Almost all the comments provided in this section in some capacity addressed the lack of care and support available to disabled people, particularly those in care homes or facilities, who were isolated to a greater extent during the COVID-19 pandemic. The respondents were concerned that future pandemics would result in a similar lack of support as there were no scenarios addressing this in the section. A few respondents noted that there should be more consultation with disabled people around this section of the paper as it appeared to take a narrow view of disability in a pandemic.

Vaccine mandates and lockdowns

A few of the respondents noted that there was lack of consideration for the actual impact of the lockdowns and vaccine mandates on the disabled community. Access to information and the accessibility of this document were raised as issues within this, as in a few responses it was made clear that intellectual disabilities were impacted at a higher rate specifically in relation to the requirements placed upon people regarding lockdowns.

Question 20a. How well does the section on recovery capture the relevant ethical issues for disabled people?

Table 8: Responses on how well the recovery sections captures ethical issues for disabled people

Response	No of responses	Percentage
Very well	13	4%
Well	42	13%
Neutral	168	52%
Poor	32	10%
Very poor	70	21%
TOTAL	325	100%

Of those that responded to the question, a few respondents considered that the 'Recovery' section captured the relevant ethical issues for disabled people well (17% well or very well captured), some were neutral (52%), and some considered them poorly captured (31% poor or very poor).

Question 20b. Do you have any comments on this section? Is there information you want added, removed, or substantially changed in this section?

There were 12 comments analysed in response to this question. The comments covered primarily the topic of disability as would be expected considering the question. There were also a few comments regarding health investment and communication.

Disability

Some respondents commented on the fact that a one size fits all approach does not necessarily provide support for those who are living with disability. The respondents requested that more clear detail be given for how recovery will be managed across differently abled people through the different phases of the pandemic.

Health Investment

It was stated by some that there was concern within what is perceived as an already stretched healthcare system that the needs of people without disabilities were not being met and that this would only increase the inequities experienced by the disabled community in a pandemic. The response noted that there were not enough carers or workers supporting disabled people that could aid in recovery.

Communication

A few respondents noted that there were some accessibility issues inherent in both communications provided by government sources during the pandemic as well as in this document that needed to be addressed. Multiple sensory loss was raised by a few as an issue not considered in the document.

Focus group responses

The focus groups identified key issues and changes that they wished to be made to the way the guidance document was presented and discussed at length what were later identified as key themes for this consultation. The participants in these groups were primarily concerned with the themes of education, health investment, health and wellbeing and community. Additionally, there was support for the EGAP report being more able to support action if it was tailored to several different audiences and provided guidance on how the ethical principles in the EGAP report should be utilised in real life situations.

Education

Thematic analysis of the conversation that took place showed that there were key issues faced across the education system, but particularly the tertiary education of nurses and other frontline health workers. The groups noted that the disruption of a pandemic on the provision of workers was further impacted by the removal of student nurses, midwives etc. from the workplace that was found to be unnecessary in the case of COVID-19 and could be addressed within the response section of this document. The groups wanted assurance that the pandemic guidance document would be made suitable for these students to implement as well as suitably addressing any issues that may be faced in the use of this document in a practical setting. They further requested the case studies be included in the guidance to aid in training for these situations.

Health investment

One of the key aspects raised by all focus groups was the lack of investment in the health sector prior to the COVID-19 pandemic which created more inequities of treatment and resourcing issues that would need to be addressed prior to any future pandemics. The groups noted that this particularly should extend to groups and support for peoples who are part of minority groups or are less able to care for themselves (such as people with disabilities and those in care homes).

Health and wellbeing

Generally, feedback from the focus groups centred on the health and wellbeing of frontline healthcare staff and the request for specific guidance for this group, who were faced with the impacts of enforcing restrictions in healthcare settings.

It was a consensus of the focus groups that the document should focus strongly on health and safety benefits to justify restrictions. To this effect they noted that proportionality of harms, over a long-term period, need to be considered. The focus groups also felt that while there were acknowledgments within the pandemic guidance

document of the social determinants of health, the document should also strive to highlight the responsibility to address and act upon them.

Community

The groups noted that there is a requirement for different forms of communication for different communities and that this should be something addressed in this document. A strong line of conversation addressed the ethics of choice and the right for certain communities to choose how best they may manage their interactions during a pandemic. An example of this was the lockdown of rest homes where many workers and residents did not have the ability to choose what would have been best for them and their communities.

Appendix

Ethical Guidance for a Pandemic – Submission Analysis Protocol

Excel spreadsheet set up

1. The excel spreadsheet with the raw data from the survey will be used as the basis for the analysis, with columns/rows added for the following data:
    a. Submission number
    b. Submission type
    c. Answer type
    d. Theme
    e. Quotes, references etc
    f. Secretariat comment
2. The raw data set will be cleaned, with abusive or repeat submissions archived and quantitative survey data hidden from view, as this does not require thematic analysis from the Secretariat.
3. Each analyst will be given a portion of the questions to code and analyse key themes.
4. Written submissions and documents with tracked changes can be directly correlated to the survey questions.

Themes and subthemes

Each answer can be coded by as many themes and subthemes as apply. Answers will be coded N/A where no answer has been provided.

Answer type:

- Additions (small changes)
- Removals (small changes)
- Substantial changes
- Positive
- Negative
- Neutral
- No response
- Out Of Scope (reason provided)

Themes

• Building Back Better - WEF	• Lockdowns
• Comms - Pandemic	• Manaakitanga
• Comms - Report	• Mental health
• Community	• Racism
• Disability	• Rights
• Economy	• Te Tiriti
• Education	• Te Whare Tapa Wha
• Equity	• Tika
• Health - Responsibility	• Transparency
• Health and Wellbeing	• Vaccine - Harm/Safety/Validity
• Health investment	• Vaccine - Mandates
• Kotahitanga	• Other/moderate
• Liberty	

Scope

Some responses were out of scope for the consultation, these are shown in the table below.

When a comment was in the **orange** category, that part of the answer was viewed as out of scope. This is on the basis that, for one or more of the reasons below, the answer is not useable or implementable by the Ministry of Health or NEAC to strengthen the EGAP publication. The rest of the respondent's answer and submission will still be analysed, and in-scope comments considered by NEAC.

When a submission contained any comments that fall within the **red** category, the entire submission was viewed as out of scope. This is based on safety and wellbeing concerns for the Secretariat members reading the submission or, in the case of repeat submissions, ensuring that everyone has an equal opportunity to have their feedback heard.

Participants were informed of this in the survey, which noted that submissions that are verbally abusive or target individuals may not be reviewed and repeat submissions from one individual or group will only be counted once.

Comment is not implementable	Comment is abusive, threatening, targets individuals, repeat submissions.
Not responding to EGAP or the survey questions, e.g. • Responding to the Government's COVID-19 response (without a link made to EGAP)1 • Commenting on a different section of the document than what is being asked. • Misinterpretation or misquote of what is stated in the document	Abusive language, e.g. • Profanities • Hate speech
Indirect threats, e.g. • "May you be granted mercy"	Direct threats, e.g. • "Public executions for all health officials"
Individuals outside of NEAC or the Ethics Team targeted	Individuals within (or close to) NEAC or the Ethics Team targeted
Does not honour Te Tiriti o Waitangi	Repeated submissions from one individual or group
Discrimination e.g., racism, ableism, transphobism etc.	
Meaning of feedback cannot be interpreted.	
Action: the relevant comment is invalidated. The rest of the respondent's answer and submission will be analysed.	Action: the entire submission is invalidated, and further analysis stopped.

A fair approach

It is important that the Secretariat uses a fair and objective approach when determining that a response is out of scope. This is to uphold the consultation objectives of ensuring that everyone has fair and equitable opportunity to have a say as well as honouring the experiences of others.

Sometimes, it may be difficult to decide whether a comment falls within one of these categories. For example, the distinction between discrimination and hate speech may not always clear. It will be up to the discretion of the Secretariat to determine how to code a response. The intent of the respondent should be considered in this process, including when interpreting spelling or grammatical mistakes. The moderation process described below will help to ensure that responses are fairly coded.

Data privacy

The submission data is held by the Ministry of Health within the Ethics team. Survey participants have already consented to the Ethics team sharing their data with NEAC. Written submissions sent to the NEAC inbox may also be shared with NEAC, as well as feedback received in focus group meetings held with NEAC members.

The excel spreadsheet has a column indicating whether participants are willing for their submission to published. Where respondents have indicated that they do not want their submission to be published, we will ensure these submissions are removed in the event that NEAC decides to publish the submissions. Direct quotes will not be used

from these participants in the submission analysis report. However, paraphrasing may be used.

Once the coding is complete, the spreadsheet will be locked to ensure that the data is not comprised.

Staff wellbeing

Members of the Secretariat who are reading the analyses should check in with each other and their manager on a regular basis with special attention paid to how they are feeling about the content of the submissions. Staff are encouraged to take breaks from reading the submissions. If, due to the distressing nature of submissions, a member needs to step away from the task, this must be accommodated for.

Moderation process

Before the coding commences in full, each analysts read a small sample of the same submissions as a test run of both the excel spreadsheet and the thematic coding. They will discuss and make any changes to the spreadsheet and the coding as required, before the analysis commences in full.

The code will have an option for 'moderation', for when the Secretariat is not sure how to code it. The analysts will meet to discuss these as they arise. Advice can be sought from members of the NEAC EGAP subgroup for final say where agreement cannot be reached.

Once the initial coding is complete, a sample will be selected at random for further moderation. If discrepancies are found, members of the Secretariat may be asked to review or reconsider the submissions that they coded.