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16 January 2023

s 9(2)(a)

By email: s 9(2)(a)
Ref: H2022017383

Tēnā koe s 9(2)(a)

Response to your request for official information

Thank you for your request under the Official Information Act 1982 (the Act) to Manatū Hauora (the Ministry of Health) on 22 November 2022 for information regarding Focus Group meetings for the National Ethics Advisor Committee (NEAC). Each part of your request is responded to below:

How many of the roughly 440 submissions from the public were in respect to your consultation on "Ethical Guidance for a Pandemic" and how many provided input or responded to your Ethical Guidance for a Pandemic survey.

The submissions in question can be broken down into 428 survey submissions, and approximately 14 written submissions that were mailed to NEAC. Please note this number is an approximate as it is unclear whether some of these written submissions are in regard to the consultation on "Ethical Guidance for a Pandemic". Two focus group meetings were also held, which bring the approximate number of submissions up to 444. More information on this topic will be available in February 2023 on the Ministry website (www.health.govt.nz) once the submission analysis has progressed. This part of your request was provided to you on the 23 November 2022 via email response. Please note this information may have changed since.

1. Please provide the date of meeting, agenda, working papers, and meeting notes; minutes, outcomes, of the Focus Group meetings?

Professor John McMillan, the Chair of NEAC, met with stakeholders on 2 November 2022. Hansa Patel, NEAC member, was also present, as well as a member of the NEAC Secretariat. Shannon Hanrahan, Deputy Chair of NEAC, met with stakeholders on 3 November 2022. Penny Haworth, NEAC member, was also present, as well as two members of the NEAC Secretariat. Shannon Hanrahan also met with another group of stakeholders on 1 December 2022, with two members of the NEAC Secretariat present.

The Focus Group Run Sheet, which NEAC members and the Secretariat used to run these meetings, is provided in Appendix B of the Consultation and Communications Plan (Document 1 in Appendix 1). Please also find attached, a PowerPoint presentation which was displayed on screen during the meetings (Document 2 in Appendix 1). The only meeting paper for the focus group meetings was the draft EGAP (Ethical Guidelines for a Pandemic) publication, which is publicly available here: <https://consult.health.govt.nz/ethics/egap/>.

The meeting notes, minutes and outcomes are withheld under section 9(2)(g)(i) of the Act to maintain the effective conduct of public affairs through the free and frank expression of opinions by or between or to Ministers and officers and employees of any public service agency. NEAC will release a summary of submissions once this has been completed this year.

2. Please provide the names and titles of participants in the Focus Group meetings (where privacy is an issue I do not require the names of members of the general public who participated), and who led these meetings?

The names and organisations of the focus group participants have been withheld under section 9(2)(g)(ii) to maintain the effective conduct of public affairs through the protection of Ministers, members of organisations, officers, and employees from improper pressure or harassment. Please see above for who led these meetings. Where information is withheld under section 9 of the Act, I have considered the countervailing public interest in release in making this decision and consider that it does not outweigh the need to withhold at this time.

3. Please provide the background information that led to the initiation of the Focus Group meetings.

3a) Please provide all memos and briefings;

Please find attached a briefing to Hon Andrew Little, Minister of Health (Document 3 in Appendix 1), which outlines different options for consultation. This briefing was accompanied to the Minister's Office by a letter from the Chair of NEAC (also attached in Document 3).

3b) Please provide all materials in respect to Focus Group meetings developed prior to or post event, including; other formats; videos, zoom meeting files, proposed or published advertisements for focus group meeting participants etc.;

Please find attached copies of the emails sent to NEAC's organizational stakeholder list, inviting stakeholders to participate in online focus groups (Document 4 in Appendix 1). Please also refer to the EPAP Consultation Communication Plan (Document 1) mentioned above, which includes a section on focus groups on pages 4-5.

3c) Please provide all materials provided to the Focus Group meetings and any outcomes, documents, video or more formats;

Please refer to response to question 1 above.

3d) Please provide all information about or from any meetings, huis or other gatherings, in person or online related to the Focus Group Meetings conducted prior to or post the event;

The minutes of the following NEAC in person meetings refer specifically to focus groups held on the 26 May 2022 and 22 September 2022. These minutes are publicly available on the NEAC website at: <https://neac.health.govt.nz/meetings/2022-meetings/>.

Please see attached cover papers from working group meetings held on 9 August 2022 and 21 October 2022 which show the development of the focus group approach (Document 5 in Appendix 1). Please note, the focus group run sheet, contained in the appendixes of these papers, is not the final version. The Consultation Communications Plan (Document 1) shows the final version, which was finalised following the 21 October working group meeting.

I trust this information fulfils your request. Under section 28(3) of the Act, you have the right to ask the Ombudsman to review any decisions made under this request. The Ombudsman may be contacted by email at: info@ombudsman.parliament.nz or by calling 0800 802 602.

Please note that this response, with your personal details removed, may be published on the Manatū Hauora website at: www.health.govt.nz/about-ministry/information-releases/responses-official-information-act-requests.

Nāku noa, nā



Ruihua Gu
Acting Group Manager, Quality Assurance and Safety
Regulatory Services | Te Pou Whakariterite Ratonga

Appendix 1: List of documents for release

#	Date	Document details	Decision on release
1	N/A	EGAP Consultation Communications Plan	Released in full.
2	N/A	EGAP Focus Group Power Point Slides	Released in full.
3	6 December 2021	Briefing – Proposal to Consult-National Ethics Advisory Committee and accompanying letter from NEAC Chair.	Some information withheld under section 9(2)(a) of the Act to protect the privacy of natural persons.
4	16 September 2022	Copies of the email sent to NEAC's organizational stakeholder list	<p>Some information withheld under the following sections of the Act:</p> <ul style="list-style-type: none"> • Section 9(2)(a); and • Section 9(2)(g)(ii) to maintain the effective conduct of public affairs through the protection of Ministers, members of organisations, officers, and employees from improper pressure or harassment. <p>Some information deemed out of scope of your request.</p>
5	9 August 2022 and 25 November 2022	Cover papers from Working Group meetings held on 09 August 2022 and 21 October 2022	<p>Some information withheld under the following sections of the Act:</p> <ul style="list-style-type: none"> • Section 9(2)(a); and • Section 9(2)(f)(iv) to maintain the constitutional conventions that protect the confidentiality of advice tendered by Ministers and officials.

NATIONAL ETHICS PANDEMIC PLAN

OVERVIEW OF COMMUNICATIONS AND ENGAGEMENT

Background

The National Ethics Advisory Committee (NEAC) is a committee set up under New Zealand legislation to advise the Minister of Health on ethical issues in health services and research, and determine national ethical standards for the health sector.

NEAC acts as an independent advisor to the Minister of Health. The Ministry of Health (the Ministry) provides policy staff and other resources to support NEAC, but the Committee remains independent of the Ministry and its work.

The Committee was set up in 2001. Its full name is the National Advisory Committee on Health and Disability Support Services Ethics, and it is also known by its Māori name; Kāhui Matatika o te Motu, which translates as 'National Ethics Group'.

In 2007, NEAC published *Getting Through Together: Ethical Values for a Pandemic*. This publication considered the ethical issues which may arise during any pandemic, with the emphasis on using shared values so people can care for themselves, their whānau and their neighbours, and make decisions in such an event. It was designed to be used by a wide range of people, including health professionals, planners, policy makers and members of the public and business community, to plan for and think about their potential response to a pandemic.

The publication was provided in three sections:

- Section one introduced the ethical values, their purpose and application.
- Section two outlined two cases (an urban community and a hospital), to explore the possible challenges when planning for, and responding to, a pandemic.
- Section three identified shared ethical values and why they are important in how and what decisions we make.

A planned update to *Getting Through Together* in 2020 was delayed following the outbreak of a pandemic in New Zealand. Drafting began in 2021, and the update will be published in 2022 (referred to as 'Ethical Guidance for a Pandemic' or EGAP).

NEAC has agreed with the Minister of Health that the draft publication will be published for public consultation.

Context

NEAC agreed that EGAP should:

- Provide a small number of high-level ethical principles that guide our national response in future pandemics. In doing so, it will be designed for a range of audiences.
- Provide elaboration on the agreed principles throughout sections designed to align with the four 'R's of New Zealand's emergency management approach (reduction, readiness, response and recovery). This would help embed the publication in the wider central and local government, business, and community ecosystem of responding to a pandemic.
- Include a stand-alone section on disability.
- Weave te ao Māori throughout the document.
- Create a relatively timeless document, while reflecting overarching insights gleaned from the COVID-19 experience.
- Provide this information in a clear and easy to read manner, at an accessible reading level.

Purpose of this document

The purpose of this document is to provide an overview of the proposed approach to engagement communications for EGAP.

The engagement approach should be in line with the principles set out in the publication. This means there should be a clear opportunity for public participation.

Values for consultation

- Fair and equitable opportunity to have a say – contributors will be provided with the draft document to allow them to give informed feedback throughout the consultation period.
- Māori and Pacific participation – there will be equitable opportunities for Māori and Pacific peoples to be involved.
- Honouring the experiences of others – contributing to this topic could be an emotional or troubling experience. We are still battling a pandemic, affecting loved ones. We will treat contributions with dignity. We will be open and responsive to feedback to ensure that submissions are meaningfully considered and used to strengthen the document.
- Supporting disability and accessibility – we act on the intent of The Accessibility Charter to ensure stakeholders can interact with our content in a way that meets their individual needs and promotes their independence and dignity. More details about how this will be implemented can be found in the section on accessibility.
- Future-focussed – this document is designed to lead us into the future: not disenfranchise the decisions of individuals or leaders made without complete knowledge in the current pandemic.
- Independence – the independence of NEAC, given the potential political nature of the topic, should be emphasised.

IAP2 Spectrum

To help clarify the role of our stakeholders in this decision-making opportunity, we will use the International Association for Public Participation (IAP2) Spectrum model – and will apply the ‘consult’ standard within the IAP2 spectrum.

Public participation goal: to obtain public feedback on analysis, alternatives and/or decisions.

Objectives

- Provide equitable opportunities for consultation, with particular consideration given to disabled peoples, Pasific Peoples, and Māori.
- Use clear, concise ‘Plain English’ communication to support stakeholders through a seamless submission process.
- Find opportunities to engage in promotional support, with NEAC members personally encouraging feedback through networks.
- Create safe, non-confrontational spaces for stakeholders to share their views freely.
- Ensure the survey questions are asked and submission analysis undertaken in a fair and impartial manner, so as to avoid confirmation bias.
- Ensure focus group moderators stimulate and support discussions, rather than leading or directing participants. Impartiality is very important.
- Understand the shared public values surrounding getting through a pandemic, so that the document can be strengthened, if necessary, to reflect these understandings.

Public consultation approach

The Minister of Health was provided with a copy of the draft national ethics publication in December 2021. It was copied to the Office of Minister Hipkins, as Minister for COVID-19 Response, and Associate Ministers Henare and Verrall.

In February 2022, the Minister confirmed that NEAC could proceed with online public consultation.

Online submissions

Survey

From **X June 2022** the draft document will be available on <https://consult.health.govt.nz/> for comments and suggestions in a survey.

This will facilitate generating responses through an already established government consultation site, while also ensuring a degree of separation for NEAC from the Ministry, as the site establishes it is for both Ministry and Ministerial committee-based consultations.

A series of questions will be asked to help focus the feedback from the public. Draft questions are provided in Appendix A. Following consideration and approval from the NEAC sub-group there may be changes made to refine the questions as the Ministry’s Publications team set ups the online questionnaire, regarding their experience with survey design.

The online survey clearly notes that any general questions about the consultation may be sent to the Secretariat at: neac@health.govt.nz. Following receipt of questions (where there is not a pre-agreed

response¹), the Secretariat will work with the NEAC sub-group to draft a response, and the Chair will agree the response.

Accessibility

The Secretariat will work with the Publications team at the Ministry of Health to facilitate the document meets accessibility approaches proposed by the Digital Public Service team at the Department of Internal Affairs. These include:

- Making sure we include alt text with images
- Providing long descriptions for tables, graphs and diagrams if the alt text isn't long enough to describe the complexity.
- Checking to make sure the webpage will provide enough colour contrast between text and background (there are online tools that will do this for us) – as it will be on the Health Citizen Space site rather than NEAC's website
- Making sure the survey webpages can be accessed and used with only a keyboard
- And making sure areas that need survey participants to type to answer the question are easily visible.

Overarching submissions

The Secretariat will also seek and accept written submissions from organisations and individuals.

Online focus groups

Focus groups allow for more open discussion and dialogue between NEAC and participants to gain a deeper insight into the views of these participants. Ideally, NEAC would be able to consult with all interested members of the public in a focus-group setting. However, due to the emotive and political nature of the consultation topic, there are security considerations which limit the feasibility of this approach. By approaching specialised organisations/subject matter experts, NEAC can better ensure the safety of its participants, its members and its Secretariat when hosting participants in online focus groups, as the participants' professional reputation is linked to their interactions.

The NEAC subgroup will choose key groups/organisations to invite to focus group meetings. They will be asked if there is anyone else if there are any other key stakeholders that they would like to invite into their focus group.

Focus group participants will be sent the draft publication in advance of meeting and will be prompted with sections and pages we would particularly like them to look at. They will also be invited to participate in the online survey if they like and share the survey with others they think may be interested.

The meetings will be supported by:

- At least one NEAC member facilitator, who will open and close the meeting and help with the flow of the conversation by responding to the participant's answers in a sensitive and appropriate way
- One Secretariat moderator, who will ask the questions and help with the flow of the meeting
- One Secretariat notetaker who will minute key discussion points for thematic summary.

¹ An example of a pre-agreed response could be the date the consultation closes, or a definition of a commonly used term in the document. Transactional emails like these will be dealt with directly by the Secretariat. A more rigorous approach is proposed for other emails, as these responses represent the position of NEAC.

If agreed in advance by the participants, the meeting will be recorded to assist with minute-taking and later deleted. The meetings will last between 45 and 90 minutes.

The focus group questions will provide a guide, but the conversation may take its own direction. The aim is to ask wide rather than prescriptive questions, that will enable discussion to flow.

Participants will be thanked with supermarket vouchers as a koha.

Please see Appendix B for a Focus Group Run-Sheet.

Supporting engagement with Pacific Peoples

A longer document from the Ministry for Pacific Peoples will be used by the Secretariat to further shape the engagement, but key points are outlined below:

- Take time to understand topical issues through Talanoa (or storytelling). Don't make assumptions. Engaging through Talanoa can be as simple as:
 - If you are addressing a group, let them know about you as well as attempting to learn about them by sharing your own story first and any of your experiences with Pacific communities, culture and issues
 - In a small group setting, ask people to introduce themselves and share their name, family and role. It helps to start building the relationship and creating the va. It allows people to make connections to one another and build a sense of belonging and safety
 - The use of fun and laughter creates an enjoyable experience where people are more likely to participate more fully. So being open, relaxed, smiling contributes to a relaxed and engaging atmosphere even if you are unable to speak the first language of participants
 - Use Pacific visuals in presentations but ensure they are used correctly. Respect and understand the origins of Pacific art and symbols you use
 - If you're going to start the Talanoa – then make sure you continue it or complete it by 'closing the loop'. Go back to participants about what you're doing with the information, regardless of outcomes
- Remember that politeness of participants is not necessarily an indication of acceptance or of their agreement
- Food is a symbol of thanks, hospitality and used to build relationships. It has a spiritual significance, recognising generosity, hospitality and sharing – so for an online focus group use a koha of a supermarket voucher as the most appropriate option rather than the traditional book voucher
- Appropriate dress is seen as a visible representation of the respect you hold for others, particularly in formal or professional settings, so we need to ensure those attending the meeting from the Secretariat and NEAC are well-presented.

Supporting engagement with Māori

Te Arawhiti (The Office for Māori Crown Relations) has offered guidance on engaging in a collaborative manner with Māori, including:

- Making time for whakawhanaungatanga
- Taking time to learn the history of the kaupapa before engaging with participants
- Learning about and respect each other's tikanga
- Understanding that relationships are mana-enhancing, and that the engagement should be mana-enhancing for participants
- Working to build trust -
 - Being clear about what we will do, and in a timely manner

- Communicating openly and clearly, particularly in agreeing what success looks like and what limitations to implementing their concerns could be
- Being transparent about responsibilities and what level the responsibility is exercised at.

This consultation is a national-level, as the issues it relates to affect all Māori in Aotearoa. Te Arawhiti provides [Te Kāhui Māngai](#) (the Directory of Iwi and Māori Organisations) as a useful resource to assist in the establishment of contacts for engagement.

Supporting engagement with disabled peoples

An overarching guide to engaging with disabled peoples has been adapted from the UN Disability Inclusive Communication Guidelines and through consultation with Gordon Jackman. This will be used by the Secretariat to shape the focus engagements, however, key elements are outlined below:

- Small actions can help to make virtual meetings much more inclusive -
 - Send materials out beforehand and ensure they're accessible. Participants, including persons with disabilities, can familiarize themselves with the content of the meeting in advance.
 - Before the meeting or webinar takes place, ask participants about any accessibility requirements. Prepare in advance for common accessibility needs or questions.
 - Consider whether services such as Communication Access Realtime Translation (CART) or New Zealand Sign Language (NZSL) interpreters would be beneficial to participants. Be sure to send captioners or interpreters the meeting materials beforehand so that they can become familiar with the topic. A note that complex or long meetings may require more than one captioner or NZSL interpreter.
- facilitating an inclusive online consultation through -
 - Making time at the beginning of the meeting to make sure everybody is familiar with the available accessibility features and "housekeeping rules" (i.e., asking that everyone have their camera on).
 - Seeking participants' approval ahead of time to record the meeting, and ensure confidentiality is respected. Tell the participants when the recording has started and stopped.
 - Using disability-inclusive language (e.g., person-first language) and avoid negative, ableist or stigmatizing language.
 - Using gender-inclusive language and materials and avoid gender stereotypes.
 - Avoiding jargon and technical language to be inclusive of all attendees.
 - (If there are hard of hearing or deaf participants) speaking clearly but not shouting or raising your voice. This makes it harder to understand and lip reading difficult.
 - Asking people to state their name each time they speak.
 - Allowing participants to finish their thoughts. For example, peoples with speech impairments have the same right to have their say and do not need their sentences finished for them.
 - Providing different options to participants to communicate any issues faced during the meeting, e.g., through chat, email, or speaking. However, use the chat feature with caution, as it can be distracting for some people. If chat comments are allowed, read the comments aloud as part of the meeting.
 - Sharing materials such as presentations in advance and always describe what is on the screen.
 - Muting participants who are not speaking to reduce background noise
 - Being clear that the end of the focus group does not mean the end of the discussion – state that written feedback or further thoughts are welcome.

Key messages/information

- NEAC wants to know the extent to which the ideas contained within the document are shared ideas based on shared values.
- NEAC recognises the devastating impact the Covid-19 pandemic has had on people's lives. Contributing on this topic could therefore be an emotional or troubling experience for some. Contributions will be treated with dignity.
- NEAC wants the document to be useful in providing guidance in future pandemics, rather than just the current pandemic. Therefore, the consultation should be viewed not as an opportunity to critique the current pandemic response but, rather, as an opportunity to share feedback that will help the guidance to be useful across multiple different pandemic scenarios.
- As well as providing overarching principles for a pandemic, EGAP provides specific guidance on different areas such as digital inclusion and responding to misinformation. This consultation seeks to glean insights and improvements on these specialist sections, particularly from experts within these fields.
- Due to the ever-changing nature of the current pandemic, some of the references contained in the document may no longer be accurate. This consultation welcomes this feedback so that we can update the document accordingly.
- Contributions from all voices, individuals, communities and organisations are welcomed and encouraged. It is important that NEAC hears from a diverse, representative spread of New Zealanders in this consultation.
- Abusive or otherwise vitriolic submissions will not be tolerated. This is for the safety of the Secretariat.
- NEAC is an independent advisor to the Minister of Health. NEAC acts independently to the Ministry of Health.

Timeframe

The online survey will run for eight weeks, finishing **X August 2022**. During this time organisations and specialised bodies will have a chance to 'have their say' in online focus groups. Following the end of the survey-based consultation there will be an additional space to engage further with specialist bodies and organisations if the public consultation has indicated a gap of information in the document (that requires further expert discussions), or consultation with a particular segment of society is missing. This will bring consultation to an end in **September 2022**.

Critical success factors and measures

- Feedback is received from a diverse range of New Zealanders. This will be reflected through the (optional) collection of demographic information in the online survey and the selection of focus groups.
- Useful, accurate insights can be gleaned from the feedback and can be used to strengthen the document.
- Submitters find it easy to make an online submission and to understand the questions being asked of them. This is reflected in a lack of follow-up questions from submitters regarding how to submit, or verifying what a question means.

- We may receive positive feedback from submitters and focus groups regarding the value and/or importance of the topic/discussion, and their ability to contribute. This should be considered an indication of successful engagement.

Channels

Taking into consideration our key communication and engagement principles, Māori and Pacific engagement aspirations, the Accessibility Charter, and our ambition to remove as many barriers to participation as possible, our communication and engagement channels will involve a multi-faceted approach. This includes all, or a combination of, the following channels:

- NEAC-based
 - Press release (NEAC branded sent from Chair to media organisations)
 - Member networks
- External organisations
 - Govt.nz consultation listings
 - Other relevant stakeholder bodies, including potentially those who have participated in focus groups and are interested in letting their members know about the consultation. Directories like Te Kāhui Māngai and [disabled people's organisations](#) will be used to identify participants.
- Ministry-based
 - Pae Ora Newsletter
 - Related COVID-19 stakeholder groups.
 - Stakeholder email list from previous NEAC consultations
 - Twitter

Submission Analysis

The Secretariat will transfer data from the online submission form into an excel spreadsheet. Data collected in the free text sections will be themed by members of the Secretariat. The Secretariat will review the proposed themes and where discrepancies arise, these will be resolved in discussion together. Multiple themes might be extracted from each response. A summary of the themes will be provided to the NEAC sub-group, and members may wish to attend the session where the themes are reviewed.

Data to be collected from each question:

- frequency of response,
- demographic data of respondents (if deemed appropriate), and
- analysis of key themes seen in responses.

The online submissions are likely to suggest changes to the document. However, survey questions can be quite difficult to build a nuanced understanding of concerns or suggestions. The answers supplied in the focus groups are therefore an opportunity to both hear directly from experts and potentially build a more nuanced understanding of concepts raised in the online survey.

This means that data collected from the focus groups will be reviewed in partnership with the survey submissions analysis. The focus group submissions will be managed through thematic analysis in Microsoft Word, with ideally the themes coded identically to the analysis of the survey submissions. This may mean the submissions need to be reviewed by the same individuals.

Based on the thematic analysis, Members of NEAC will need to consider what should be changed, and what should remain the same. This will be decided by the NEAC sub-group with the overall changes reviewed by the whole Committee.

The range of feedback NEAC could receive may be broad, and NEAC will have roughly three choices for responding to the suggestions from the public:

- to make a change based on feedback (for example, the weight of public feedback suggests that an additional ethical principle is required to cover a key perspective)
- not to make a change based on public feedback (for example if responders expressed concern with the inclusion of New Zealand sign language, NEAC may wish to still include because it signals an openness to deaf New Zealanders – that they are part of this conversation)
- to make a change that responds to, but is different from the public feedback (for example survey responders may express concern with te reo Māori terms they don't know being used, rather than removing, NEAC members may choose to include a glossary of terms, including but not limited to terms in te reo Māori).

A consultation summary has been traditionally published by NEAC after consultations, to encourage transparency. This means that the justifications for the choices NEAC make will need to be clear.

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Appendix A – website text

The following information is designed to show the online survey that members of the public will access to complete the consultation. Some differences in layout and form are expected, reflecting the differences between online browsers and Microsoft Word products. Nevertheless, a degree of representation is provided.

RELEASED UNDER THE OFFICIAL INFORMATION ACT 1982

Ethical Guidance for a Pandemic

Overview

The [National Ethics Advisory Committee – Kāhui Matatika o te Motu](#) (NEAC) is an independent advisor to the Minister of Health. NEAC has developed an update to its 2007 publication '[Getting Through Together: Ethical Principles for a Pandemic](#)'. The updated publication is called '[Ethical Guidance for a Pandemic: Whakapuāwaitia e tatou kia puāwai tātou](#)'. This online survey is seeking your feedback on the draft publication.

Closes X August 2022

Contact

neac@health.govt.nz

NEAC wants to know if the ideas contained within the publication are shared ideas based on shared values. Contributions from all voices, individuals, communities and organisations are welcomed and encouraged. This consultation provides an opportunity to inform the ethical guidance for future pandemics in Aotearoa New Zealand, as well as the ongoing Covid-19 pandemic. You can submit on your own behalf or on behalf of an organisation. Your submissions will be taken into consideration by NEAC and may be used to make improvements to the draft publication before it is published.

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 survey matches these six chapters, with a final set of overarching and demographic questions. Clicking the links in the survey will take you to the relevant sections of the draft publication. You can answer all of the survey questions or just a few – it is up to you. There are a combination of tickbox and open-comment questions. The survey could take you 10 minutes or it could take you longer if you have more that you would like to share. You can save your progress at any point and complete the survey later. If you prefer, you can submit a written submission here:

Dialogue box

With demographic and privacy questions at the end.

NEAC recognises the devastating impact that the Covid-19 pandemic has had on people's lives. Contributing on this topic could therefore be an emotional or troubling experience for some. Contributions will be treated with dignity.

The submissions will be analysed by the NEAC Secretariat in the Ethics team at the Ministry of Health. By participating in this survey you are consenting for the NEAC Secretariat to share your submission with NEAC. Please note that survey or written submissions that are verbally abusive or target individuals may not be

Ethical Guidance for a Pandemic

reviewed, and repeat submissions from one individual or group will only be counted once. You do not have to share any of your identifiable information.

The draft publication is available to download in Word or PDF at the bottom of this page. A hard copy of the draft publication can be made available on request.

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


Please make your submission using the following link by the closing date, X August 2022.

Give us your views

Online Survey

Related

 [Ethical Guidance for a Pandemic: Whakapuāwaitia e tatou kia puāwai tātoui](#) (Word)

 [Ethical Guidance for a Pandemic: Whakapuāwaitia e tatou kia puāwai tātoui](#) (PDF)

The draft *Ethical Guidance for a Pandemic* publication is separated into six chapters.

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Closes X August 2022

Chapter One proposes [seven foundational elements](#) (pg#) to Aotearoa New Zealand's pandemic response:

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

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

- ☒ 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

Question 1b. Do you have any comments about the seven foundational elements? Are there any foundational elements you want added, removed or significantly changed? Please explain. (1000-character limit)

- ☒ No comment

Ethical Guidance for a Pandemic

The draft *Ethical Guidance for a Pandemic* publication is separated into six chapters.

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Closes X August 2022

Chapter two sets out [six ethical principles](#) (pg#) for Aotearoa New Zealand to apply during a pandemic.

These are designed to be shared principles that offer a shared basis for decision-making. The principles are interconnected and relate strongly to each other.

The six principles are:

- [Health and wellbeing](#) (pg #)
- [Equity](#) (pg #)
- [Kotahitanga](#) (pg #)
- [Manaakitanga](#) (pg #)
- [Tika](#) (pg #)
- [Liberty](#) (pg #).

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

- | | |
|--|--|
| <input checked="" type="checkbox"/> Health and wellbeing | <input checked="" type="checkbox"/> Equity |
| <input checked="" type="checkbox"/> Kotahitanga | <input checked="" type="checkbox"/> Manaakitanga |
| <input checked="" type="checkbox"/> Tika | <input checked="" type="checkbox"/> Liberty |

Question 2b. Do you have any comments about the six ethical principles? Are there any ethical principles you want added, removed or significantly changed? (1000-character limit)

- ☒ No comment

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Chapter two also outlines a [framework](#) (pg #) for making ethically complex public health decisions in a pandemic. Public health focuses on groups of people rather than individuals and could involve decisions about a wide range of situations or services that impact the [Te Whare Tapa Whā](#) model of health. The seven elements of the framework are identified as:

- [Transparency](#) (pg #)
- [Consistency](#) (pg #)
- [Justification](#) (pg #)
- [Participation](#) (pg #)
- [Managing conflicts of interest](#) (pg #)
- [Openness for revision](#) (pg #)
- [Regulation](#) (pg #).

Question 3a. Do you agree that these elements combine to create a useful process for decision-makers to use in a pandemic?

Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Question 3b. Do you have any comments about these elements? Do you have any other suggestions about how we can ethically make complex public health decisions? (1000-character limit)

☒ No comment

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The draft *Ethical Guidance for a Pandemic* publication is separated into six chapters.

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Chapter three outlines the ethical importance of Aotearoa New Zealand being ready for the next pandemic, emphasising:

- [The readiness of our health system](#) (pg#)
- [Digital inclusion](#) (pg#); and
- [Community readiness](#) (pg #).

Question 4. Do you have any comments about the section on health system readiness? Is there information you want added, removed or substantially changed in this section? (limit 500 characters)

☒ No comment

Question 5. Do you have any comments about the section on digital inclusion? Is there information you want added, removed or substantially changed in this section? (limit 500 characters)

☒ No comment

Question 6. Do you have any comments about the section on community readiness? Is there information you want added, removed or substantially changed in this section? (limit 500 characters)

☒ No comment

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Chapter three also outlines '[reduction of risk](#)' (pg#) or steps that Aotearoa New Zealand can take to reduce the likelihood of a pandemic beginning here or overseas. This section emphasises environmental risks and global cooperation.

Question 7. 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? (limit 1000 characters)

☒ No comment

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Chapter four outlines ethical issues in responding to a pandemic. This Chapter is divided into an ethical review of:

- [interventions to improve a pandemic situation](#)(pg#)
- [communications and engagement during a pandemic](#) (pg#)
- [data, privacy, and digital technologies in a pandemic](#) (pg#).

Question 8. The section on interventions to improve a pandemic 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.

Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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.

Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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

Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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.

Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Question 9. How appropriate are the [Siracusa Principles](#) for Aotearoa? Are there other more appropriate principles that could guide intervention? (500 character limit)

☒ No comment

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The section on interventions discusses [examples](#) where restricting or removing choice in a pandemic might be justified.

Question 10a. Which of these examples do you agree with? Tick all that apply.

- ☒ 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

Question 10b. Do you have any comments on these examples? Are there other examples that you think we should discuss? (500 character limit)

☒ No comment

Question 11. Do you have any comments about the [effects of interventions](#) section? Are there any other effects of interventions that we haven't listed that are likely to be relevant in future pandemics? (1000 character limit)

☒ No comment

Question 12. Do you have any comments on the [communications and engagement section](#)? Is there information you want added, removed or substantially changed in this section? (1000 character limit)

☒ No comment

Question 13. 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? (1000 character limit)

☒ No comment

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Chapter five outlines the path of recovery emphasising relevant ethical considerations, including:

- [vaccine development and use](#) (pg#),
- [reopening](#) (pg#), and
- [ongoing impacts](#) (pg#)

Question 14. 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 45).

Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

b. Ideally, vaccination should be voluntary rather than non-voluntary ([Levels of coerciveness](#), page 45).

Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

c. The use of vaccine certificates must be based on scientific evidence that they are effective at achieving their stated outcome (e.g. preventing spread of the pandemic) ([Efficacy](#), page 45).

Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

d. If a vaccine certificate is required to access essential goods and services, vaccines are no longer truly voluntary. ([Supplementary effects](#), page 46).

Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

e. People who cannot safely receive the vaccine for medical reasons should be given an exemption to vaccine certificate requirements ([Equity](#), page 46).

Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

f. Global cooperation is required to ensure fair and equitable access to vaccines in low-to-middle-income countries ([Global cooperation](#), page 46).

Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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Question 15. Do you have any comments on the [reopening section](#) (pg#)? Is there information you want added, removed or substantially changed in this section? (1000 character limit)

☒ No comment

Question 16. Do you have any comments on the [ongoing impacts section](#) (pg#)? Is there information you want added, removed or substantially changed in this section? (1000 character limit)

☒ No comment

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[Chapter six](#) (pg#) focuses on the ethical considerations of and for disabled people in a pandemic. The Chapter is similarly structured to reflect '[readiness](#)' (pg#), '[response](#)' (pg#), and '[recovery](#)' (pg#).

Question 17a. How well does the section on readiness capture the relevant ethical issues for disabled people? *(Noting the Likert scale will be structured differently to match the question.)*

Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Question 17b. Do you have any comments on this section? Is there information you want added, removed or substantially changed in this section? (1000-character limit)

☒ No comment

Question 18a. How well does the section on response capture the relevant ethical issues for disabled people? *(Noting the Likert scale will be structured differently to match the question.)*

Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Question 18b. Do you have any comments on this section? Is there information you want added, removed or substantially changed in this section? (1000-character limit)

☒ No comment

Question 19a. How well does the section on response capture the relevant ethical issues for disabled people? *(Noting the Likert scale will be structured differently to match the question.)*

Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Question 19b. Do you have any comments on this section? Is there information you want added, removed or substantially changed in this section? (1000-character limit)

☒ No comment

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Overarching questions

Question 20. Do you have any comments on the structure of the publication? (500 character limit)

Question 21. Do you have any further comments on the publication? (500-character limit)

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The following **optional** questions are asked in order to understand how different communities in New Zealand respond to this document. The demographic data is collected to assist in the analysis of results. If you choose to provide contact information, this may also be used to request follow up information about your submission.

If you are completing this survey in your own behalf, please answer questions A to G below.

If you are completing this survey on behalf of an organisation, please skip to question H below.

A. What is your name?

☒ Prefer not to say

B. What is your email address?

☒ Prefer not to say

C. What is your postal address?

☒ Prefer not to say

D. What is your interest in this topic (e.g. health professional, member of public, business owner, disabled person, etc.)? List as many as you identify with.

☒ Prefer not to say

E. Are you:

☒ Male

☒ Female

☒ I identify in another way

☒ Prefer not to say

F. Which age group do you belong to?

☐ under 18 years

Ethical Guidance for a Pandemic

- ☐ 18-24 years
- ☐ 25-44 years
- ☐ 45-64 years
- ☐ 65+ years
- ☐ Prefer not to say

G. Which ethnic group(s) do you belong to? (tick as many as apply)

- ☒ Māori
- ☒ Pacific Peoples
- ☒ Asian
- ☒ NZ European/Pākehā
- ☒ Middle Eastern
- ☒ Latin American
- ☒ African
- ☒ Other: _____
- ☒ Prefer not to say

If you are completing this survey on behalf of an organisation, please answer questions H to J below.

H. Please provide the name of your organisation.

I. Please provide a brief description of that organisation

- ☒ Prefer not to say

Privacy

We may publish all submissions, or a summary of submissions on the Ministry of Health's website.

If you are submitting as an individual, we will automatically remove your personal details and any identifiable information. Your identifiable information will also be withheld if your submission is requested under the Official Information Act 1982.

Ethical Guidance for a Pandemic

If you do not want your submission published on the Ministry's website, please tick this box:

☒ Do not publish this submission.

Submit

Thank you for taking the time to complete this survey. The National Ethics Advisory Committee greatly appreciates your contribution and will treat this submission with dignity and respect.

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Appendix B – focus group run sheet

NATIONAL ETHICS PANDEMIC PLAN

FOCUS GROUPS FOR CONSULTATION

Introduction

The Chair will open with a karakia.

Tūtawa mai i runga	Come forth from above,
Tūtawa mai i raro	below, within,
Tūtawa mai i roto	and from
Tūtawa mai i waho	the environment
Kia tau ai	Vitality
Te mauri tū	and wellbeing, for all
Te mauri ora	Strengthened in unity.
Ki te katoa	
Haumi e	
Hui e	
Tāiki e!	

Whakawhanaungatanga

The Chair will then lead a round of introductions and introduce the *Ethical Guidance for a Pandemic* publication and explain why NEAC have asked this group to meet. This is an opportunity to ask about the **participants' experience of the COVID-19 pandemic**, as a way to frame the rest of the discussion. This could involve a discussion of the participants' views on the strengths or weaknesses of Aotearoa's pandemic response.

Discussion

The discussion will continue by NEAC members asking the participants what they think **does or does not work** about the EGAP document, and whether they think there is **anything that is missing** or that **could be improved**. The intention is to **create an open dialogue** about the draft publication. If the participants wish to discuss a particular section of the publication, this can be shared on screen by the Secretariat if necessary.

Further questions (time-permitting)

Depending on how much time is remaining, and if the discussion has not already covered these topics, the Secretariat will share slides on the screen relating to the follow sections of the publication:

- Seven foundational elements of a pandemic response
- Six ethical principles to guide Aotearoa New Zealand through a pandemic
- Decision-making framework for making ethically complex public health decisions
- Situations where restricting choice might be justified in a pandemic.

The below are **examples** of questions that could be asked about these sections of the document. These questions will **not** be shown on screen.

Seven foundational elements of a pandemic response

1. How useful are these foundational elements?

2. Are there any elements that you see as more or less important than the others?
3. Are there any elements you would add or remove or substantially alter?

Six ethical principles to guide Aotearoa New Zealand through a pandemic

1. Do you believe these principles are widely shared across Aotearoa?
2. Do you think these are the ethical principles that New Zealanders need to get through a pandemic?
3. Are there any principles that you see as more or less important than the others?
4. Are there any principles you would add or remove or substantially alter?

Decision-making framework for making ethically complex public health decisions

1. How useful do you think the framework will be for making ethically complex public health decisions in a pandemic in Aotearoa New Zealand?

Situations where restricting choice might be justified in a pandemic.

1. Do you support the view that there are contexts in which restricting choice is preferable to voluntary measures?
2. If not, why not?
3. If so, do you agree with the contexts/examples provided?
4. Are there other contexts or examples that you would like to see discussed?

Conclusion

The Chair will thank the participants for meeting and then close with a karakia.

Tūtawa mai i runga
Tūtawa mai i raro
Tūtawa mai i roto
Tūtawa mai i waho
Kia tau ai
Te mauri tū
Te mauri ora
Ki te katoa
Haumi e
Hui e
Tāiki e!

Appendix C – Risk register

Risks and issues register

#	Risk/Issue description	Impact/effect	Strength of risk	Mitigation(s)
1	Low volume of submissions	<p>We do not get enough information to understand public opinion of the document; and we lose a potential opportunity to show that the document is publicly validated.</p> <p>We do not get the added value of submissions, e.g., problems identified, and additional information provided.</p>	Medium risk	<p>Using available channels:</p> <ul style="list-style-type: none"> - Member networks - Media - NEAC website - relevant Ministry networks <p>Additionally, the impact of pandemics is currently clear to all New Zealanders, increasing the likelihood of submissions.</p> <p>The questionnaire has been structured to allow people to submit without completing all the questions.</p> <p>Citizen Space is easy to use, document and survey are easy to navigate.</p> <p>Six weeks is given for people to submit.</p>
2	Inequitable reach	<p>Low volume of submissions from Māori, Pacific, and disabled communities.</p> <p>Submissions do not reflect diverse views of society. We miss out on the valuable contributions that these groups have to offer.</p> <p>We fail to uphold our te Tiriti o Waitangi obligations.</p> <p>Reputational damage, criticism from stakeholders who feel that they have not had sufficient opportunity to engage.</p> <p>Inaccessibility of consultation due to limited digital capability or access, especially among disabled, older, and lower socioeconomic communities.</p>	Medium risk	<p>Utilise key networks/channels to encourage engagement with this consultation.</p> <p>Use focus groups as an opportunity to speak directly to these groups.</p> <p>(Regarding inaccessibility) Contact with the National Library to increase awareness in Libraries and with Librarians (as libraries are key source of computer access).</p> <p>Emphasise that the online approach has been chosen in part due to COVID-19.</p> <p>Engage with immigrant and refugee organisations who may be able to comment on behalf of clients who could struggle to engage with the reading-level required in the document.</p>

		Inaccessibility of consultation due to language barriers, especially for those for whom English is not their primary language.		
3	Comments focus on COVID-19	<p>Abusive, inappropriate, or vitriolic responses mean Secretariat staff and/or NEAC members feel attacked and intimidated.</p> <p>Public comments focus on what has happened, rather than focussing on preparing for the future, limiting the relevance of comments.</p> <p>As one of the only government-related sites for feedback on COVID-19 there may be a high volume of responses and Secretariat capacity to perform a meaningful submission analysis rapidly is overwhelmed.</p>	High risk	<p>Advise submitters that verbally abusive submissions may not be reviewed, for the safety of staff.</p> <p>Disseminating the document through the appropriate channels.</p> <p>Limiting the frequency of open-answered question boxes where people can type text. Putting a character limit on open-text boxes.</p> <p>Document emphasises that this is for any pandemic, not covid-specific.</p> <p>Monitoring of repeat submissions, and/or a statement that multiple submissions from one individual/group will only be counted twice.</p> <p>Flexible timings on analysis allowing Secretariat staff greater time to process and review the submissions.</p>
4	Reputational damage	<p>The document provides high-level guidance to a wide range of New Zealanders but is not specifically designed for any scenario, profession, or pandemic. This may mean the document faces criticism as for not providing specific guidance in a pandemic.</p> <p>The ever-changing COVID-19 situation may mean that some references could be proven scientifically inaccurate during consultation.</p>	Low risk	<p>Focus groups can provide input on specific sections of the document, e.g., data experts providing feedback specifically on data section.</p> <p>Information and caveats can be added during the consultation.</p>

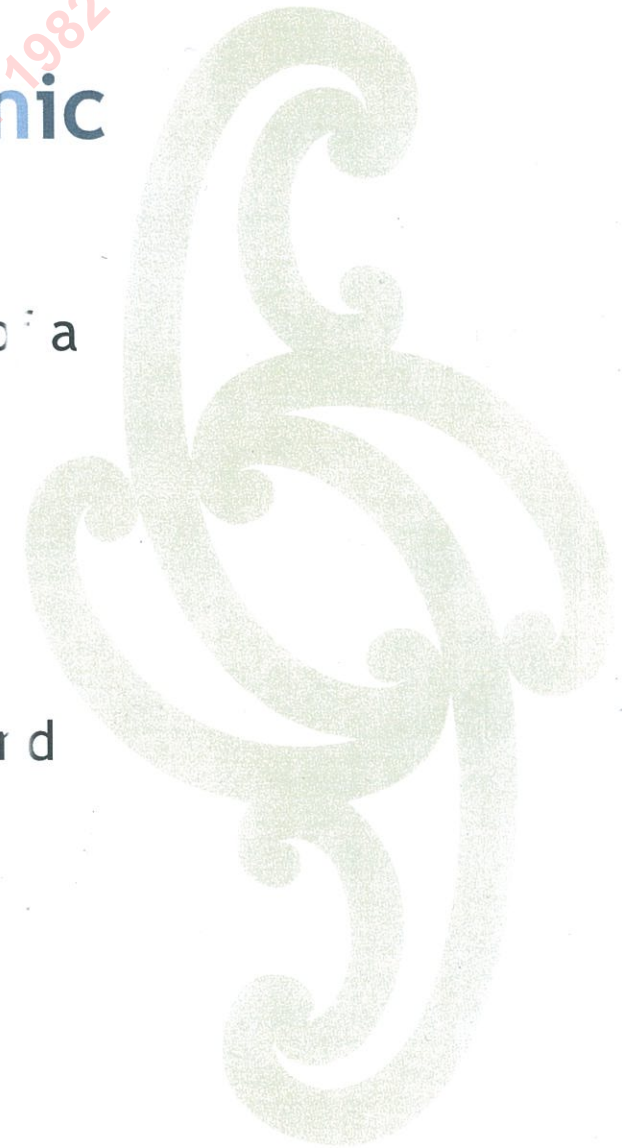
Ethical Guidance for a Pandemic: Whakapuāwaitia e tatou kia puāwai tātou

NATIONAL ETHICS ADVISORY COMMITTEE
AOTEAROA NEW ZEALAND

Foundational elements of a pandemic response

The publication proposes seven elements as the foundation of a pandemic response:

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



Ethical Principles for a Pandemic



Health and wellbeing

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



Equity

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



Kotahitanga

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



Tika

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



Manaakitanga

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



Liberty

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



Framework for making ethically complex public health decisions

Marckmann et al

- 1) Transparency
- 2) Consistency
- 3) Justification
- 4) Participation
- 5) Managing conflicts of interest
- 6) Openness for revision
- 7) Regulation

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Restricting choice

The section on ‘interventions to improve a pandemic situation’ discusses some examples in which restricting or removing choice in a pandemic might be justified.

These are:

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

Briefing

Proposal to consult - National Ethics Advisory Committee

Date due to MO: 6 December 2021 **Action required by:** 10 January 2022

Security level: IN CONFIDENCE **Health Report number:** 20212559

To: Hon Andrew Little, Minister of Health

Copy to: Hon Chris Hipkins, Minister for COVID-19 Response; Hon Dr Ayesha Verrall, Associate Minister of Health; and Hon Peeni Henare, Associate Minister of Health

Contact for telephone discussion

Name	Position	Telephone
Clare Perry	Deputy Director-General, Health System Improvement and Innovation	s 9(2)(a)
Emma Prestidge	Group Manager, Quality Assurance and Safety, Health System Improvement and Innovation	s 9(2)(a)

Minister's office to complete:

- | | | |
|---|------------------------------------|--|
| <input type="checkbox"/> Approved | <input type="checkbox"/> Decline | <input type="checkbox"/> Noted |
| <input type="checkbox"/> Needs change | <input type="checkbox"/> Seen | <input type="checkbox"/> Overtaken by events |
| <input type="checkbox"/> See Minister's Notes | <input type="checkbox"/> Withdrawn | |

Comment:

Proposal to consult - National Ethics Advisory Committee

Security level: IN CONFIDENCE **Date:** 6 December 2021

To: Hon Andrew Little, Minister of Health

Purpose of report

1. This briefing provides an overview of the *Getting Through Together: Ethical Principles for a Pandemic* publication from the National Ethics Advisory Committee and seeks your confirmation on a preferred approach to public consultation.
2. This report discloses all relevant information and implications.

Summary

3. The National Ethics Advisory Committee has drafted an update to their *Getting Through Together* publication, last published in 2007.
4. This update focusses on providing more practical guidance, emphasising equity and an ao Māori approach to pandemics, as well assessing ethical issues which can arise at all stages of a pandemic response.
5. Following your agreement, the draft publication will be published to seek feedback from New Zealanders on the proposed shared ethical principles for a pandemic, high-level decision-making framework, and the ethical issues before, during and after a pandemic.
6. Three approaches to public engagement are provided for your consideration, including high-level costings and benefits and risks. The Ministry is recommending an option allowing for online public engagement.
7. The title of the publication will be changed by members of the committee before the public consultation is launched, due to its similarity with the name of a mental health campaign from the Mental Health Foundation.

Recommendations

We recommend you:

- a) **note** the title of the publication will change prior to public consultation, and the Ministry will inform your office of the new name

- b) **agree** to public consultation of the publication

Yes/No

- c) **indicate** your preferred engagement option:

Option one (recommended) – online only engagement, beginning February 2022

Yes/No

Option two – focus groups and online engagement, beginning March 2022

Yes/No

Option three – public and online engagement, with a report back to your office in April 2022

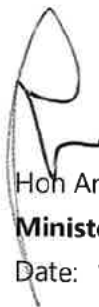
Yes/No

- d) **note** that the Ministry will contact your office in January 2022 about the potential for your involvement in the public consultation.

- e) **note** that the publication will return to you for sign-out before it is published as formal advice from the National Ethics Advisory Committee.



Clare Perry
Deputy Director-General
Health System Improvement and Innovation



Hon Andrew Little
Minister of Health
Date: 11/2/22

Proposal to consult - National Ethics Advisory Committee

Background

1. The National Ethics Advisory Committee – Kāhui Matatika o te Motu (NEAC) is an independent advisor to you, as the Minister of Health, on ethical issues of national significance, and it sets ethical standards for the health and disability sector. The Ministry of Health (the Ministry) provides Secretariat staff and other resources to support NEAC but the Committee remains independent of the Ministry and its work.
2. In 2019 it was agreed with the previous Associate Minister of Health (Hon Jenny Salesa) that NEAC would update its 2007 publication *Getting Through Together: Ethical Values for a Pandemic* (or *Getting Through Together*). However, given the disruption of the COVID-19 pandemic in 2020, NEAC refocussed on providing more targeted advice to health professionals through the online publication *Ethics and Equity: Resource Allocation and COVID-19*.
3. The update of *Getting Through Together* remained on its work programme for 2021 and has now been drafted. This update differs markedly from the 2007 edition, reflecting both the recent experience of the COVID-19 pandemic and the limitations of the earlier edition around practicality and applicability.

Context

4. The arrival of the coronavirus disease or SARS-CoV-2 virus (COVID-19) to New Zealand's shores in 2020 indicated how disruptive and impactful a pandemic is to our families, communities and social and economic lives.
5. While the update of *Getting Through Together* is designed to build on the lessons of COVID-19, it is not designed to be a critique or an explicit roadmap for the ongoing COVID-19 response. Instead, it is focussed on providing ethical guidance in responding and preparing for many types of pandemics, with shared ethical principles, a high-level decision-making framework, and an elaboration of ethical issues relating to the four 'R's'¹ of New Zealand's wider emergency management approach.
6. The *Getting Through Together* document remains in draft, as NEAC will look to finalise the publication after public consultation. This consultation is proposed in the first half of 2022, and this briefing seeks to confirm your preferred approach to the level of consultation undertaken.
7. The publication shares a title with the Mental Health Foundation's 2019 campaign, which is also called 'Getting Through Together'. The Chair of NEAC has agreed the title of this publication will change before the public consultation is launched. The Ministry will provide

¹ New Zealand's integrated approach to civil defence emergency management is described by the four areas of activity: reduction, readiness, response and recovery (these are known as the four 'R's'). These are used as a model for discussion of ethical issues in the *Getting Through Together* update.

an update to your office with the new name. The publication will also be sent to an Editor prior to public consultation.

Overview of document

8. The draft of Getting Through Together is provided alongside this briefing, and is structured in six sections:
 - a. Section 1 outlines six elements NEAC has identified as foundational to New Zealand's pandemic response.
 - b. Section 2 introduces shared ethical principles for a pandemic and a high-level framework for decision-making. The identified principles share similarities with the principles from the 2021 Pae Ora Bill, particularly around opportunities for iwi and hapū to exercise decision-making authority, and the success of resourcing kaupapa Māori and whānau-centred services.
 - c. Sections 3 to 5 provide insight into ethical issues and how these principles operate before, during and after pandemics. These sections are structured using the four 'R's.
 - d. Section 6 explores the ethical values in the context of New Zealanders with disabilities. Because disabled individuals are a diverse group that have unique needs in a pandemic, NEAC has chosen to provide a section solely focussed on the ethical considerations of and for disabled people in a pandemic. This section is designed to sit within Getting Through Together and potentially stand-alone.
9. NEAC has deliberately chosen to emphasise equity and te ao Māori throughout Getting Through Together. Honouring Te Tiriti o Waitangi, mātauranga Māori² and the Te Whare Tapa Whā model of health are identified in the first section as foundational elements.
10. The publication is designed to be used by a wide range of people, including health professionals, planners and policy makers and members of the public and business community, to plan for and think about ethical responses in a pandemic.

Public consultation

11. We are seeking your agreement on the public consultation approach, due to both the sensitivity of engaging with the public around pandemics at this time, and NEAC's role as a Ministerial advisory committee to you as Minister of Health.
12. NEAC is anticipating beginning public engagement in the first half of 2022 for a six-to eight-week period. Members are proposing a delayed start to the consultation to ensure that New Zealanders do not miss out on having their say over the traditional summer holiday period. Following this engagement, NEAC anticipates updating the content in response, commissioning any new design elements, and providing the finalised publication for your consideration and agreement to publish. Following your agreement, the document would be published on the NEAC website <https://neac.health.govt.nz/>.
13. The Ministry is seeking your preference of three consultation options: online-only, online and in-person, and online and wider public engagement.

² Or Māori knowledge and wisdom, encompassing skills, understanding, awareness and practices.

14. The Ministry will also be in contact with your office in January 2022 about potential options for your involvement in the launch of the public consultation. This will offer you a chance to be directly involved in the public consultation, for example through a media release or (depending on your preferred consultation approach) a launch event.

Option 1 – online only (recommended)

15. In this option NEAC would publish the draft of *Getting Through Together* online, with survey questions, so members of the public could give direct feedback on the publication. A wide variety of networks would be contacted, to let individuals become aware of the publication and the intended principles. This could include Te Rōpū Whakakaupapa Urutā, Health and Disability Advocacy Service, and Ministry of Health networks.
16. Feedback could be sent to, and collated by, the Secretariat for consideration by the Committee and inclusion in the final publication.
17. This approach would be supplemented by invitations to key contributors to participate in online focus groups on the topic. Because of the sensitivity and interest in pandemic management, the Ministry is not suggesting open hui, as it is likely that there would be disruptive contributors focussed on vaccine mandates, who could overtake proceedings and stop other voices from being heard. This approach would also allow NEAC members to facilitate these meetings directly, as they would be less likely to be exposed to threats and aggressive online behaviours.
18. The Ministry would provide koha to participants of the online focus groups. This would be koha between \$10 and \$20 in supermarket or petrol vouchers.
19. NEAC members could choose to use their social media accounts to drive interest in the document and highlight questions, such as: "Manaakitanga – extending support and compassion to others - should this be a principle that guides our pandemic response?". Some members may choose not to do so, given this may encourage personal or disruptive comments on their account.
20. The benefit of this approach is that it allows New Zealanders to have their say on a national ethical response to pandemics, in a cost-effective and safe way for participants. It is the only engagement approach that would allow non-vaccinated individuals to take part in focus group discussions under the highest level of the COVID-19 Protection Framework.
21. It is also the only option that remains within the original consultation budget (below \$10,000). This is the Ministry's recommended option.
22. However, with this option there are downsides:
 - a. This approach only provides one method (online) for suggesting alternatives to the ethical principles, which are designed to be collective principles for all New Zealand that underpin our future pandemic responses.
 - b. It relies on focus group contributors having online access and strong internet connections to participate in video calls. However, having diverse voices heard through representative groups who can speak on behalf of others, goes some way to remedying the limits of smaller online engagements.
23. There may be some criticism of this approach due to its limited engagement beyond the survey if the principles are not felt to be shared widely by New Zealanders. Ultimately, if the principles are not accepted, it could impact the value and use of the publication.

Option 2 – online and in-person engagement

24. In this option NEAC would again publish the draft so members of the public could give direct feedback on the publication. NEAC members could also use their personal social media accounts to engage directly with the public, where they feel comfortable doing so.
25. Alongside the online survey, in-person focus groups would be undertaken by a third party provider, with NEAC members and Secretariat members in attendance. The proposal to use a third-party provider as the facilitator of these focus groups, reflects not only the specialist skills required for in-person consultation, but also the importance of maintaining Ministry independence from NEAC's draft. It could be falsely assumed that Ministry officials are leading the development of these ethical principles as a formal component of our COVID-19 response. NEAC members could also choose to host their own in-person focus groups within their communities, where they felt comfortable to do so.
26. The Ministry would provide koha of between \$10 and \$20 in vouchers to all in-person participants.
27. Focus groups would be made up of established networks (for example members of Te Rōpū Whakakaupapa Urutā) and small groups of New Zealanders. A number of NEAC members are based in rural hubs (for example Ōpōtiki and Thames), which would allow for a diverse representation of participants. It would also decrease the associated costs through reduced travel for members and make use of their community links to help advertise the consultation and identify useful connections.
28. This approach is anticipated to cost between \$14,000 and \$25,000 – depending on the number of focus groups and the cost of the selected third-party provider. This funding would need to be redirected from a number of other items in the Secretariat's work programme but could be accommodated.
29. The in-person focus groups would only be available to vaccinated New Zealanders, so they could be undertaken at all levels of the COVID-19 Protection Framework.
30. The benefit of this approach is that it allows for a greater say from diverse New Zealanders on the proposed collective principles for a pandemic. This option provides strong avenues for both experts and diverse New Zealanders to have their say.
31. Compared to Option 3 there are also reduced security costs, as the focus groups are likely to be highly-targeted for a diverse range of individuals and not widely publicly advertised.

Option 3 – online and public engagement

32. In this option, NEAC would work directly with the community during the engagement process through public workshops to discuss the publication in depth and seek feedback. This is NEAC's preferred option, although the safety and security risks associated with this approach have not been discussed by members.
33. The Ministry is aware of the heightening security environment relating to COVID-19, including increasing threats of violence against workers in MIQ facilities and increasing security provisions for Ministers following COVID-related death threats. The Ministry is aware that as a Ministerial advisory committee proposing collective ethics for a pandemic, members of NEAC may be exposed to such threats and concerns. Therefore, this approach would come with increased security costs and considerations.

34. As in previous options, NEAC would still propose to publish the draft. However, the major focus would be on public workshops, with Committee members, Secretariat and the third-party facilitators engaging directly with interested members of the public. These public workshops could be undertaken both online and in person. Koha would not be provided. Care would need to be taken to ensure the more vocal contributors did not limit the engagement of others, nor impact their safety.
35. This option would be the most expensive. Recent public consultations by the Ministry have included costs of \$5,000 to \$7,500 for each in-person hui, and if a similar approach was followed, the engagement could cost between \$35,000 to \$150,000, with additional security costs. This approach is not preferred by the Ministry, as it would require considerable reallocation of funds.

Equity

36. NEAC members have deliberately sought to amplify the call for an ao Māori and strengths-based approach to pandemic planning. Equity is one of the proposed collective ethical principles, and the approach rests on the foundation of honouring Te Tiriti o Waitangi and mātauranga Māori.
37. Committee members are looking at engaging with Māori deliberately and proactively over all options of engagement, including through a wide variety of networks.
38. NEAC is committed to ensuring that participants selected for the focus groups are diverse and can represent a wide variety of backgrounds.

Next steps

39. If you agree for online consultation to proceed on the *Getting Through Together* draft publication, NEAC hopes to begin this work in late February 2022.
40. If you select Option 3 as your preferred method of engagement (public workshops), the Ministry will report back to you about the development of this approach.
41. The Ministry will be in further contact with your office in January 2022 about potential options for your involvement in the launching of the public consultation.
42. Following the public consultation, NEAC will seek to finalise the content and provide a finalised product for your consideration. Following your agreement, it would likely be published in May 2022 on NEAC's website <https://neac.health.govt.nz/>.

ENDS.



6 December 2021

Hon Andrew Little
Minister of Health
andrew.little@ministers.govt.nz

Tēnā koe Honourable Mr Little

Re: Getting Through Together: Ethical Principles for a Pandemic

I write on behalf of the National Ethics Advisory Committee (NEAC).

A key focus of NEAC's role is to provide advice to you, in your capacity as the Minister of Health, on ethical issues of national significance relating to health and disability matters.

Regarding this aspect of our role, we wanted to provide you with a publication for your review and consideration, ahead of the proposed public consultation. This publication is an update to the 2007 NEAC publication on national ethics in a pandemic and is called *Getting Through Together: Ethical Principles for a Pandemic*.

Summary of document

The Committee have designed this publication to be of practical value in both the current pandemic, and potential future pandemics. This means that while the experiences of COVID-19 have informed our selection of ethical considerations relevant in a pandemic, the document is not wholly focused on our present circumstances.

We have structured the publication into six parts:

- Section 1 outlines the basis of any pandemic response in New Zealand – emphasising elements such as mātauranga Māori, investment in our healthcare system, and the strength of our communities
- Section 2 introduces the foundational ethical principles and framework for decision-making in a pandemic
- Sections 3 to 5 provide insight into how these principles operate before, during and after a pandemic
- Section 6 explores the ethical principles in the context of New Zealanders with disabilities.

The Committee has chosen to weave te ao Māori and equity throughout the document.

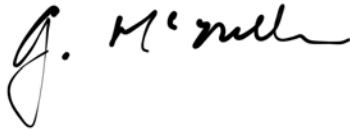
Next steps

With your agreement we are proposing to begin public consultation on this document in the new year, after the holiday period, to encourage the involvement of a wide-range of New Zealanders in the engagement.

We hold the diversity of this engagement to be particularly important, as we are proposing ethical principles for *all* New Zealanders to uphold in a pandemic.

I understand the Ministry of Health-based Secretariat will contact your office in the new year to gauge your interest and availability in supporting this consultation through a media release or attending an event. But for now, let me note that I hope you find the proposed publication an insightful and valuable read, and I look forward to discussing it with New Zealanders in the new year.

Yours sincerely,

A handwritten signature in black ink, appearing to read 'J. McMillan', with a stylized, cursive script.

Professor John McMillan
Chair, National Ethics Advisory Committee

RELEASED UNDER THE OFFICIAL INFORMATION ACT 1982

s 9(2)(g)(ii)

From: s 9(2)(g)(ii) on behalf of NEAC <NEAC@health.govt.nz>
Sent: Friday, 16 September 2022 12:06 pm
Subject: Ethical Guidance for a Pandemic consultation: seeking expressions of interest for focus groups and update to online survey

Dear colleague,

This email is to update you on the [National Ethics Advisory Committee's](#) (NEAC's) current [consultation on its draft publication](#) 'Ethical Guidance for a Pandemic: Whakapuāwaitia e tatou kia puāwai tātou' (EGAP).

Firstly, NEAC is extending the submission period for our online survey by 4 weeks.

The new closing date for the online survey is 18 October 2022. This is in response to requests for more time to develop feedback.

Secondly, based on feedback, NEAC will accept written submissions from organisations.

This is for instances where it is not possible to submit your organisation's response into the online survey, for example, if this cannot receive sign-out through your organisation. However, NEAC still strongly encourages organisations to respond to the survey where possible, and written submissions are encouraged to respond to the questions raised in the survey, as this will be very helpful for submission analysis.

Lastly, NEAC is seeking expressions of interest in hosting a series of online focus groups to discuss the ideas contained within the draft publication.

The intention of holding focus groups is to allow for more open discussion and dialogue between NEAC and your organisation, to gain a deeper insight beyond what is captured in the online survey.

We envision that each focus group would run via Zoom for up to 1.5 hours, and would comprise of a max. of 5-6 participants, as well as 1-2 NEAC Committee members and 1-2 members of NEAC's Secretariat. We will let you know in advance if there any particular areas of the publication we are likely to ask your view on. The focus group would begin with a whakawhanaungatanga session so that we can get to know each other a bit better for our discussion of pandemic ethics, which may be a sensitive or distressing topic for some. It is our intention that the sessions would be recorded, for the sole purpose of helping the Secretariat to take accurate minutes. The recording would be kept confidential within NEAC's Secretariat at the Ministry of Health and would be deleted once the minutes are completed.

NEAC would like to shape the composition of these focus groups around your preferences and interests. You might prefer for the focus group to contain only members of your own organisation, or maybe you would be open to a focus group across different organisations, perhaps woven together by a common interest or area of expertise. Please let us know, and we will do our best to facilitate a focus group session for you that will be a respectful, inclusive space to discuss with NEAC the areas of the publication that are of interest to you.

Please let us know if you are interested in a focus group, your preferences around this, and if you have any questions about this consultation.

Nāku noa, nā

s 9(2)(g)

Secretariat Lead – National Ethics Advisory Committee (NEAC)
Advisor
Ethics
Regulatory Services
Manatū Hauora, 133 Molesworth Street Thorndon, Wellington 6011

s 9(2)(g)(ii)

From: s 9(2)(g)(ii) on behalf of NEAC <NEAC@health.govt.nz>
Sent: Friday, 16 September 2022 2:17 pm
To: s 9(2)(a)
Subject: Ethical Guidance for a Pandemic consultation: seeking expressions of interest for focus groups and update to online survey

Dear colleague,

This email is to update you on the [National Ethics Advisory Committee's](#) (NEAC's) current [consultation on its draft publication](#) 'Ethical Guidance for a Pandemic: Whakapuāwaitia e tatou kia puāwai tātou' (EGAP).

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Please let us know if you are interested in a focus group, your preferences around this, and if you have any questions about this consultation.

Nāku noa, nā

s 9(2)(g)(ii)

Secretariat Lead – National Ethics Advisory Committee (NEAC)
Advisor
Ethics
Regulatory Services
Manatū Hauora, 133 Molesworth Street Thorndon, Wellington 6011

s 9(2)(g)(ii)

From: s 9(2)(g)(ii) on behalf of NEAC <NEAC@health.govt.nz>
Sent: Friday, 16 September 2022 12:12 pm
To: s 9(2)(a)
Subject: Ethical Guidance for a Pandemic consultation: seeking expressions of interest for focus groups and update to online survey

Dear colleague,

This email is to update you on the [National Ethics Advisory Committee's](#) (NEAC's) current [consultation on its draft publication](#) 'Ethical Guidance for a Pandemic: Whakapuāwaitia e tatou kia puāwai tātou' (EGAP).

Firstly, NEAC is extending the submission period for our online survey by 4 weeks.

The new closing date for the online survey is 18 October 2022. This is in response to requests for more time to develop feedback.

Secondly, based on feedback, NEAC will accept written submissions from organisations.

This is for instances where it is not possible to submit your organisation's response into the online survey, for example, if this cannot receive sign-out through your organisation. However, NEAC still strongly encourages organisations to respond to the survey where possible, and written submissions are encouraged to respond to the questions raised in the survey, as this will be very helpful for submission analysis.

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The intention of holding focus groups is to allow for more open discussion and dialogue between NEAC and your organisation, to gain a deeper insight beyond what is captured in the online survey.

We envision that each focus group would run via Zoom for up to 1.5 hours, and would comprise of a max. of 5-6 participants, as well as 1-2 NEAC Committee members and 1-2 members of NEAC's Secretariat. We will let you know in advance if there any particular areas of the publication we are likely to ask your view on. The focus group would begin with a whakawhanaungatanga session so that we can get to know each other a bit better for our discussion of pandemic ethics, which may be a sensitive or distressing topic for some. It is our intention that the sessions would be recorded, for the sole purpose of helping the Secretariat to take accurate minutes. The recording would be kept confidential within NEAC's Secretariat at the Ministry of Health and would be deleted once the minutes are completed.

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Please let us know if you are interested in a focus group, your preferences around this, and if you have any questions about this consultation.

Nāku noa, nā

s 9(2)(g)(ii)

Secretariat Lead – National Ethics Advisory Committee (NEAC)
Advisor
Ethics
Regulatory Services
Manatū Hauora, 133 Molesworth Street Thorndon, Wellington 6011

s 9(2)(g)(ii)

From: s 9(2)(g)(ii) on behalf of NEAC <NEAC@health.govt.nz>
Sent: Friday, 16 September 2022 4:14 pm
Subject: National Ethics Advisory Committee: Consultation on 'Ethical Guidance for a Pandemic' Draft Publication

Dear colleague,

The [National Ethics Advisory Committee](#) (NEAC) has prepared an online survey to canvas public feedback on its draft publication 'Ethical Guidance for a Pandemic: Whakapuāwaitia e tatou kia puāwai tātou' (attached). The consultation period began in July, and your organisation's contact details have since been added to our stakeholder list.

Background

NEAC is an independent advisor to the Minister of Health. NEAC is established under section 92 of the Pae Ora (Healthy Futures) Act 2022.

The National Ethics Advisory Committee's statutory functions are to:

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

NEAC is the author of a 2007 document 'Getting Through Together: Ethical Values for a Pandemic' (Getting Through Together). Getting Through Together considered the ethical issues which may arise during any pandemic. NEAC have drafted a publication 'Ethical Guidance for a Pandemic: Whakapuāwaitia e tatou kia puāwai tātou' (EGAP) to replace Getting Through Together. This update seeks to draw on the lessons and experiences of the COVID-19 pandemic in order to provide more detailed guidance around ethical issues not covered in the 2007 document, such as the use of digital technologies, public health interventions and the consideration of equity.

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.

How to have your say

You may give feedback on your own behalf or on behalf of an organisation. You can contribute your views by completing the **online survey** here: <https://consult.health.govt.nz/ethics/egap/>. The last day for submitting feedback via the online survey is 18 October 2022.

NEAC will accept **written submissions** via email if it is not possible for your organisation to submit via the online survey, for example, if this cannot receive sign-out through your organisation. However, NEAC still strongly encourages organisations to respond to the survey where possible, and written submissions are encouraged to respond to the questions raised in the survey, as this will be very helpful for submission analysis.

NEAC is also seeking expressions of interest in hosting a series of online focus groups to discuss the ideas contained within the draft publication.

The intention of holding focus groups is to allow for more open discussion and dialogue between NEAC and your organisation, to gain a deeper insight beyond what is captured in the online survey.

Document 4

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s 9(2)(g)(ii)

Secretariat Lead – National Ethics Advisory Committee (NEAC)

Advisor

Ethics

Regulatory Services

Manatū Hauora, 133 Molesworth Street Thorndon, Wellington 6011

s 9(2)(g)(ii)

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Sent: Friday, 16 September 2022 4:17 pm
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Please let us know if you are interested in a focus group, your preferences around this, and if you have any questions about this consultation.

Nāku noa, nā

s 9(2)(g)(ii)

Secretariat Lead – National Ethics Advisory Committee (NEAC)

Advisor

Ethics

Regulatory Services

Manatū Hauora, 133 Molesworth Street Thorndon, Wellington 6011

s 9(2)(g)(ii)

From: s 9(2)(g)(ii) on behalf of NEAC <NEAC@health.govt.nz>
Sent: Friday, 16 September 2022 3:52 pm
To: s 9(2)(a)
Subject: Re: Clarifying closing date for feedback on Ethical guidance for pandemic

Dear colleague,

This email is to update you on the [National Ethics Advisory Committee's](#) (NEAC's) current [consultation on its draft publication](#) 'Ethical Guidance for a Pandemic: Whakapuāwaitia e tatou kia puāwai tātou' (EGAP).

Firstly, NEAC is extending the submission period for our online survey by 4 weeks.

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Lastly, NEAC is seeking expressions of interest in hosting a series of online focus groups to discuss the ideas contained within the draft publication.

The intention of holding focus groups is to allow for more open discussion and dialogue between NEAC and your organisation, to gain a deeper insight beyond what is captured in the online survey.

We envision that each focus group would run via Zoom for up to 1.5 hours, and would comprise of a max. of 5-6 participants, as well as 1-2 NEAC Committee members and 1-2 members of NEAC's Secretariat. We will let you know in advance if there any particular areas of the publication we are likely to ask your view on. The focus group would begin with a whakawhanaungatanga session so that we can get to know each other a bit better for our discussion of pandemic ethics, which may be a sensitive or distressing topic for some. It is our intention that the sessions would be recorded, for the sole purpose of helping the Secretariat to take accurate minutes. The recording would be kept confidential within NEAC's Secretariat at the Ministry of Health and would be deleted once the minutes are completed.

NEAC would like to shape the composition of these focus groups around your preferences and interests. You might prefer for the focus group to contain only members of your own organisation, or maybe you would be open to a focus group across different organisations, perhaps woven together by a common interest or area of expertise. Please let us know, and we will do our best to facilitate a focus group session for you that will be a respectful, inclusive space to discuss with NEAC the areas of the publication that are of interest to you.

Please let us know if you are interested in a focus group, your preferences around this, and if you have any questions about this consultation.

Nāku noa, nā

s 9(2)(g)

Secretariat Lead – National Ethics Advisory Committee (NEAC)

Advisor

Ethics

Regulatory Services

Manatū Hauora, 133 Molesworth Street Thorndon, Wellington 6011

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Out of scope

RELEASED UNDER THE OFFICIAL INFORMATION ACT 1982

NEAC WORKING GROUP

Subject Ethical Guidance for a Pandemic (EGAP) – Consultation Focus Groups

Meeting Date 09 August 2022

Members Shannon Hanrahan, Rochelle Styles, Gordon Jackman

Secretariat s 9(2)(a) s 9(2)(a)

Purpose

1. The purpose of this working group meeting is to organise the next steps for the online focus groups as part of the EGAP public consultation.

Background

2. At the end of June, the EGAP consultation communications plan was agreed by the working group via email.
3. The consultation communications plan includes a section detailing the high-level approach to focus groups (appendix A) and the focus group run sheet (appendix B).

Next steps

4. Agree how many focus groups to hold.
5. Agree who to invite to the focus groups.
6. Agree which members will attend each focus group meeting.
7. Agree some potential dates for focus group meetings.

Appendix A – online focus groups overview

Focus groups allow for more open discussion and dialogue between NEAC and participants to gain a deeper insight into the views of these participants. Ideally, NEAC would be able to consult with all interested members of the public in a focus-group setting. However, due to the emotive and political nature of the consultation topic, there are security considerations which limit the feasibility of this approach. By selecting specialised organisations/subject matter experts, NEAC can better ensure the safety of its participants, its members and its Secretariat when hosting participants in online focus groups, as the participants' professional reputation is linked to their interactions.

The NEAC subgroup will choose key groups/organisations to invite to focus group meetings. They will be asked if there is anyone else if there are any other key stakeholders that they would like to invite into their focus group.

Focus group participants will be sent the draft publication in advance of meeting and will be prompted with sections and pages we would particularly like them to look at. They will also be invited to participate in the online survey if they like and share the survey with others they think may be interested.

The meetings will be supported by:

- At least one NEAC member facilitator, who will open and close the meeting and help with the flow of the conversation by responding to the participant's answers in a sensitive and appropriate way
- One Secretariat moderator, who will ask the questions and help with the flow of the meeting
- One Secretariat notetaker who will minute key discussion points for thematic summary.

If agreed in advance by the participants, the meeting will be recorded to assist with minute-taking and later deleted. The meetings will last between 45 and 90 minutes.

The Secretariat will develop some slides and will share screen in the meeting. These will display the questions/discussion points, and some graphics. **The focus group questions will provide a guide, but the conversation may take its own direction. The aim is to ask wide rather than prescriptive discussion, that will enable discussion to flow.**

Participants will be thanked with supermarket vouchers as a koha.

Appendix B – focus group run sheet

ETHICAL GUIDANCE FOR A PANDEMIC

FOCUS GROUPS FOR CONSULTATION

Introduction

We will begin with a karakia:

Tūtawa mai i	Come forth from above,
runga	below, within,
Tūtawa mai i	and from
raro	the environment
Tūtawa mai i	Vitality
roto	and well being, for all
Tūtawa mai i	Strengthened in unity.
waho	
Kia tau ai	
Te mauri tū	
Te mauri ora	
Ki te katoa	
Haumi e	
Hui e	
Tāiki e!	

We will then have a round of introductions and introduce the *Ethical Guidance for a Pandemic* publication and explain why we have asked this group to meet with us.

The Secretariat will then share a power point on the screen that shows discussion prompts/questions with some visual aids.

Questions

Before we discuss the publication in particular, we wanted to take the time to ask you about your community's/organisation's experience of the COVID-19 pandemic to help us frame the rest of the discussion.

1. In your experience, what were some the strengths or positives of the pandemic response? What were some of the negatives or weaknesses? (Whether that was within your whānau, community, the government, your organisation...)?

Keeping those experiences in mind, and also thinking towards the unique challenges that future pandemics may hold, we now want to move into looking at specific sections of the publication.

2. The publication proposes seven elements as the foundation of a pandemic response:
 - Honouring Te Tiriti o Waitangi
 - Developing a strong and well-functioning health system
 - Building back better – getting ready for the future
 - Adopting Te Whare Tapa Whā – a shared model of health and wellbeing
 - Embedding mātauranga Māori
 - Taking an intersectional approach
 - Upholding human rights.

- a. How useful are these foundational elements?
 - b. Are there any elements that you see as more or less important than the others?
 - c. Are there any elements you would add or remove or substantially alter?
3. The publication presents six ethical principles to guide Aotearoa New Zealand through a pandemic:
 - Health and wellbeing
 - Equity
 - Kotahitanga
 - Manaakitanga
 - Tika
 - Liberty
 - a. Do you believe these principles are widely *shared* across Aotearoa?
 - b. Do you think these are the ethical principles that New Zealanders *need* to get through a pandemic?
 - c. Are there any principles that you see as more or less important than the others?
 - d. Are there any principles you would add or remove or substantially alter?
4. The publication proposes a decision-making framework for making ethically complex public health decisions (decisions focused on groups of people rather than individuals). The seven elements of the framework are identified as:
 - Transparency
 - Consistency
 - Justification
 - Participation
 - Managing conflicts of interest
 - Openness for revision
 - Regulation
 - a. How useful do you think the framework will be for making ethically complex public health decisions in a pandemic in Aotearoa New Zealand?
5. The section on 'interventions to improve a pandemic situation' discusses some examples in which restricting or removing choice in a pandemic might be justified. These are:
 - Ensuring the intervention is widely utilised in order to obtain its benefits,
 - Preventing the need for more restrictive measures later, and
 - Protecting those who are more at risk of being affected by the pandemic due to pre-existing inequities.
 - a. Do you support the view that there are contexts in which restricting choice is preferable to voluntary measures?
 - b. If not, why not?
 - c. If so, do you agree with the contexts/examples provided?
 - d. Are there other contexts or examples that you would like to see discussed?
6. The document is structured around the four Rs of emergency management:
 - Reduction
 - Readiness
 - Response

- Recovery
 - a. How useful did you find this approach?
 - b. Is there another way you would suggest it is structured?

Follow-up questions

For example:

1. NEAC wanted to make this publication useful to a wide range of audiences, across both the current pandemic and in future pandemics.
 - a. How useful do you perceive this document to be, for use in a pandemic?
 - b. How could its usefulness be improved?
2. Is there anything we didn't touch on that you feel is important?
 - a. Do you have any suggestions about how or where this idea/information should be incorporated into the publication?
3. Do you have any other comments about the publication?
4. Do you have any questions you would like to ask us?

Conclusion

We will thank the participants for joining us and let them know the next steps.

We will then close with a karakia.

Tūtawa mai i runga

Tūtawa mai i raro

Tūtawa mai i roto

Tūtawa mai i waho

Kia tau ai

Te mauri tū

Te mauri ora

Ki te katoa

Haumi e

Hui e

Tāiki e!

NEAC WORKING GROUP

Subject	Ethical Guidance for a Pandemic (EGAP) – Consultation Focus Groups
Meeting Date	21 October 2022
Members	John McMillan, Shannon Hanrahan, Gordon Jackman, Penny Haworth, Hansa Patel
Secretariat	s 9(2)(a) s 9(2)(a)

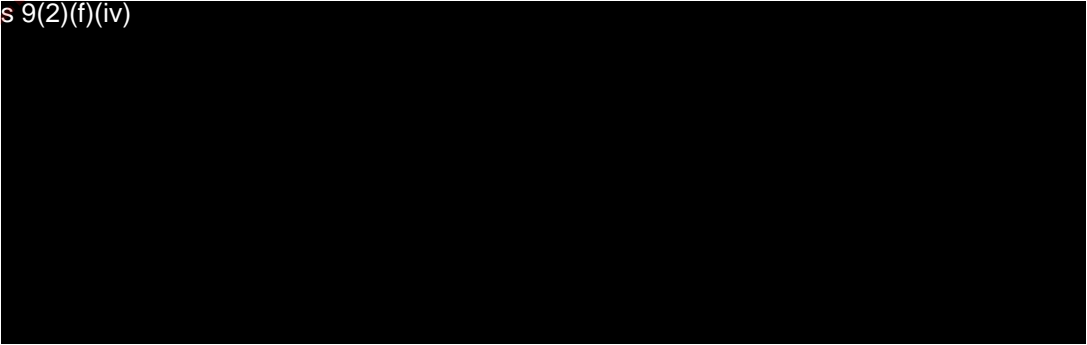
Purpose

1. The purpose of this working group meeting is to organise the next steps for the online focus groups as part of the EGAP public consultation.

Background

2. At the end of June, the EGAP consultation plan was agreed by the working group via email. This plan includes a section detailing the high-level approach to focus groups (appendix A) and a focus group run sheet (appendix B).
3. At the previous EGAP working group held on 9 August, it was noted that **we will not have time to ask all of the questions in the focus group run sheet**. Rather, one or two key questions should be asked. The importance of asking a question about disability was also noted.
4. At the previous working group, it was also agreed that rather than inviting a limited selection of stakeholder organisations to participate, NEAC should instead seek expressions of interest from the whole of its stakeholder list. This email was sent and NEAC have received expressions of interest from the following organisations, and have suggested the following assignment of NEAC members to meet with each of these groups:

s 9(2)(f)(iv)



Proposed approach

5. The Secretariat recommends that NEAC should begin each focus group meeting with a whakawhanaungatanga session that seeks to gain a better understanding of the participants' experience of the COVID-19 pandemic. Following this, a few key questions should be chosen for each group, for example, about:
 - a. The proposed foundational approach
 - b. The proposed ethical principles
 - c. Justifications for restricting choice
 - d. Protecting disabled people in a pandemic.
6. It is important that space and time is also given to **allow for the participants to discuss and ask questions about the issues of importance to them**. The focus group questions will provide a guide, but the conversation may take its own direction. **The aim is to ask wide rather than prescriptive questions, that will enable discussion to flow.**
7. Once the key questions have been decided, focus group participants will be informed of the sections of the document that they will be asked about (to help them prepare for the meeting).

Next steps

8. Agree assignment of NEAC members to focus groups.
9. Agree key questions to ask each focus group.
10. Agree potential meeting dates to propose to focus group participants.

Appendix A – online focus groups overview

Focus groups allow for more open discussion and dialogue between NEAC and participants to gain a deeper insight into the views of these participants. Ideally, NEAC would be able to consult with all interested members of the public in a focus-group setting. However, due to the emotive and political nature of the consultation topic, there are security considerations which limit the feasibility of this approach. By approaching specialised organisations/subject matter experts, NEAC can better ensure the safety of its participants, its members and its Secretariat when hosting participants in online focus groups, as the participants' professional reputation is linked to their interactions.

The NEAC subgroup will choose key groups/organisations to invite to focus group meetings. They will be asked if there is anyone else if there are any other key stakeholders that they would like to invite into their focus group.

Focus group participants will be sent the draft publication in advance of meeting and will be prompted with sections and pages we would particularly like them to look at. They will also be invited to participate in the online survey if they like and share the survey with others they think may be interested.

The meetings will be supported by:

- At least one NEAC member facilitator, who will open and close the meeting and help with the flow of the conversation by responding to the participant's answers in a sensitive and appropriate way
- One Secretariat moderator, who will ask the questions and help with the flow of the meeting
- One Secretariat notetaker who will minute key discussion points for thematic summary.

If agreed in advance by the participants, the meeting will be recorded to assist with minute-taking and later deleted. The meetings will last between 45 and 90 minutes.

The focus group questions will provide a guide, but the conversation may take its own direction. The aim is to ask wide rather than prescriptive questions, that will enable discussion to flow.

Participants will be thanked with supermarket vouchers as a koha.

Appendix B – focus group run sheet

ETHICAL GUIDANCE FOR A PANDEMIC

FOCUS GROUPS FOR CONSULTATION

Introduction

We will begin with a karakia:

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runga	below, within,
Tūtawa mai i	and from
raro	the environment
Tūtawa mai i	Vitality
roto	and well being, for all
Tūtawa mai i	Strengthened in unity.
waho	
Kia tau ai	
Te mauri tū	
Te mauri ora	
Ki te katoa	
Haumi e	
Hui e	
Tāiki e!	

Whakawhanaungatanga

We will then have a round of introductions and introduce the *Ethical Guidance for a Pandemic* publication and explain why we have asked this group to meet with us. Question 1 below can be viewed as part of this whakawhanaungatanga.

Questions

Before we discuss the publication in particular, we wanted to take the time to ask you about your community's/organisation's experience of the COVID-19 pandemic to help us frame the rest of the discussion.

1. In your experience, what were some the strengths or positives of the pandemic response? What were some of the negatives or weaknesses? (Whether that was within your whānau, community, the government, your organisation...)?

Keeping those experiences in mind, and also thinking towards the unique challenges that future pandemics may hold, we now want to move into looking at specific sections of the publication.

2. The publication proposes seven elements as the foundation of a pandemic response:
 - Honouring Te Tiriti o Waitangi
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 - 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.
 - a. How useful are these foundational elements?
 - b. Are there any elements that you see as more or less important than the others?
 - c. Are there any elements you would add or remove or substantially alter?
- 3. The publication presents six ethical principles to guide Aotearoa New Zealand through a pandemic:
 - Health and wellbeing
 - Equity
 - Kotahitanga
 - Manaakitanga
 - Tika
 - Liberty
 - a. Do you believe these principles are widely *shared* across Aotearoa?
 - b. Do you think these are the ethical principles that New Zealanders *need* to get through a pandemic?
 - c. Are there any principles that you see as more or less important than the others?
 - d. Are there any principles you would add or remove or substantially alter?
- 4. The publication proposes a decision-making framework for making ethically complex public health decisions (decisions focused on groups of people rather than individuals). The seven elements of the framework are identified as:
 - Transparency
 - Consistency
 - Justification
 - Participation
 - Managing conflicts of interest
 - Openness for revision
 - Regulation
 - a. How useful do you think the framework will be for making ethically complex public health decisions in a pandemic in Aotearoa New Zealand?
- 5. The section on 'interventions to improve a pandemic situation' discusses some examples in which restricting or removing choice in a pandemic might be justified. These are:
 - Ensuring the intervention is widely utilised in order to obtain its benefits,
 - Preventing the need for more restrictive measures later, and
 - Protecting those who are more at risk of being affected by the pandemic due to pre-existing inequities.
 - a. Do you support the view that there are contexts in which restricting choice is preferable to voluntary measures?
 - b. If not, why not?
 - c. If so, do you agree with the contexts/examples provided?
 - d. Are there other contexts or examples that you would like to see discussed?

Follow-up questions

For example:

1. NEAC wanted to make this publication useful to a wide range of audiences, across both the current pandemic and in future pandemics.
 - a. How useful do you perceive this document to be, for use in a pandemic?
 - b. How could its usefulness be improved?
2. Is there anything we didn't touch on that you feel is important?
 - a. Do you have any suggestions about how or where this idea/information should be incorporated into the publication?
3. Do you have any other comments about the publication?
4. Do you have any questions you would like to ask us?

Conclusion

We will thank the participants for joining us and let them know the next steps.

We will then close with a karakia.

Tūtawa mai i runga

Tūtawa mai i raro

Tūtawa mai i roto

Tūtawa mai i waho

Kia tau ai

Te mauri tū

Te mauri ora

Ki te katoa

Haumi e

Hui e

Tāiki e!

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