Health and Disability Commissioner
Te Toihau Hauora, Hauātanga

Act and Code Review consultation questions | Ngā pātai matapakinga

This document contains all the questions we are asking as part of the Act and Code Review consultation. Aside from the required questions, you can answer as many or as few as you'd like. When completed, please either email it to review@hdc.org.nz or post it to us at PO Box 1791, Auckland, 1140.

Please visit https://review.hdc.org.nz to answer these questions online.

Your details (required)

It's important for us to know a bit about you so that we understand whose views are being represented in submissions. It helps us to make sure that any changes we recommend will work well for everyone and have an equitable impact.

1. What is your name? [redacted]

2. What is your email address? [redacted]

3. Are you submitting as an individual, or on behalf of an organisation or group?

☐ I am submitting as an individual
☐ I am submitting on behalf of an organisation or group

4. How did you hear about this consultation? (please select)

☐ HDC website
☐ Through my job
☐ News media
☐ Word of mouth
☐ Social media
☐ Other (please specify below)
☐ Internet

____

Please answer the following questions **if you are submitting as an individual**. If you are submitting on behalf of an organisation or group, please go to page 3.

[redacted]

☐ Other/s (please state):___Various______________________________________

Do you identify as having a disability?

☐ Yes ☐ No

If you are submitting on behalf of an organisation or group:

What is the name of your organisation or group?

Maternity Services Consumer Council

What type of organisation/group is it?

☐ Consumer organisation/group (please specify below)
☐ Iwi/ Māori organisation/group (please specify below)
☐ Health and/or disability services provider (please specify below)
☐ Central Government
☐ Local Government
☐ University/Academic
☐ Other (please specify below)

Please feel free to provide any further detail:____________________________

____

____

Share ‘one big thing’

This survey contains structured questions that ask for your feedback on each chapter in our consultation document. If you would prefer to give us your feedback as a whole, by telling us ‘one big thing’ – you can do so below.

If this is all you want to provide by way of your submission, that’s fine by us. We will consider all the submissions we receive.

What is your ‘one big thing’?

Topic 1: Supporting better and equitable complaint resolution

1.1: Did we cover the main issues about **supporting better and equitable complaints resolution**?

The main issue that has been brought to the attention of MSCC is timeliness. Consumers and providers alike, have spoken about the distress caused by the protracted time it has taken to first of all hear whether or not HDC is going to undertake further investigation and, if this has been decided, the amount of time it takes for the process to be concluded. Both complainant/s and careproviders have reported distress caused by this uncertainty and how the complaint impacts every aspect of their lives till the HDC ruling is released.

MSCC supports any moves that will:-

- streamline the complaints process
- more efficiently triage complaints and the introduction of a range of different processes to resolve complaints.
- require HDC to describe each of the steps in their process to every complainant and provider and to put a timeframe on each of these steps so that all parties know what to expect. In our experience, the primary motivation of a health care consumer when making a complaint is altruistic, to prevent another consumer from having to experience the harm they experienced. If there is no resolution for months or more than a year, complainants feel a sense of hopelessness, that they have wasted their time.
- We support the introduction of an appeal process
- We also recommend that both complainants and providers be routinely asked to provide feedback about their experience and outcome.

1.2: What do you think of our suggestions for **supporting better and equitable complaints resolution**, and what impacts could they have?

MSCC is not convinced that introducing clinical navigators is a better solution than allocating additional financial and personnel resources to the existing Patient Advocacy service. The discussion does not provide job descriptions for either role and there is no explanation about how these two services would work together to improve patients experience with the complaints process.

We note that the Consultation Documnt repeatedly states that “it’s best to resolve complaints directly with the provider” and that HDC promotes self advocacy processes. There seems to be no acknowledgement that dealing directly with the provider is the most challenging option for most consumers unless they are very well prepared and supported throughout the process.

MSCC supports the kanohi ki te kanohi approach, as long as the complainant is well supported and prepared. Our experience has been that consumers making complaints are disempowered and often retraumatised by processes that are not made clear at the outset, that appear to have no timeline attached and no formal conclusion unless the complainant either goes through a formal process with HDC or is able to instigate a legal process. We therefore recommend that all institutional and organisational service providers must be required to notify complainants of the step-by-step process for responding to complaints and to define a timeline for its implementation and resolution. In addition we recommend that the service provider be required to report to HDC showing evidence that they have followed their process and to document the outcome and this must be signed off by the complainant as being an accurate description of the process and the agreed outcomes.
as being an accurate description of the process and the agreed outcomes.

We totally agree that all health care consumers “are the experts of their experience and are supported to decide what resolution looks like for them.”
We also recommend that consumers of all ethnicities be supported “to seek peace in the experience within a culturally safe and appropriate environment.” It is our experience that

particularly institutional providers usually dictate where any "direct" processes will take place and it is usually in a space within the institution where the perceived breach of rights occurred and often presents barriers for consumers in terms of accessibility and costs for transport, parking etc.

MSCC supports moves to introduce culturally acceptable processes defined and designed by tangata whenua, i.e. Hui a- whānau and houhou te rongo for complaint resolution. We also recommend that complainants of all cultures are offered complaints resolution processes, and are given the opportunity to decide which is the most acceptable and accessible to them at the beginning of any HDC complaints investigation and resolution process.

MSCC recommends that the advocacy service provide access to suitable neutral spaces for direct/ kanohi ki te kanohi resolutions processes. Such spaces must be accessible to complainants – in terms of access (especially for tangata whaikaha), parking (costs) etc and be able to comfortably accommodate whatever whānau supporters the complainant has chosen.

a. Amend the purpose statement of the Act

MSCC supports moves to recognise that the processes employed to reach outcomes are as impactful (positively or negatively) for complainants as the actual outcomes and to ensure that the entire process upholds the mana of individual consumers.

b. Clarify cultural responsiveness

MSCC supports the proposed wording change in Right 1(3).

c. Clarify the role of whānau

MSCC strongly supports the intentions expressed in this paragraph.
"The Code provides rights for individuals to have support people and whānau involved in their care at the consumer's discretion, including explicitly providing consumers with the right to support (Right 8). Other rights in the Code also support including whānau where appropriate, eg, it is often an expected standard of care (Right 4(1)), it can be culturally appropriate (Right 1(3)), and it can be essential for effective communication (Right 5)."
Individual consumers should absolutely have the right to involve whānau if that is their choice and service providers should be obliged to accommodate this involvement but service providers must also be required to ascertain whether or not any individual consumer wants to have whānau involvement in their care and HDC must include a process to ascertain whether or not an individual consumer supports whānau involvement in the complaint process or supports whānau making of a complaint on their behalf/about the services they received.

d. Ensure gender-inclusive language

MSCC has no objection to gender inclusive language in the wording of the Code.

e. Protect against retaliation

MSCC supports any move to protect consumers against retaliation but wonders how this can be monitored? Fear of retaliation is frequently cited as the reason consumers do not complain. Consumers who are afraid of retaliation may be more willing to make complaints if the provider is required to respond within a "prescriptive" timeframe and if a process for follow-up to ensure non-retaliation in terms of access to services, quality of service provision and interpersonal interactions, is put in place.

f. Clarify provider complaint processes

MSCC totally supports that clear/prescriptive timeframes that make it clear to all parties be defined/retained in response to complaints. We support direct resolution between complainant and service provider only when the complainant is able to access advocacy services throughout this process and when the providers "internal" complaints resolution processes are clearly defined, including timeframes for resolution. We agree that most healthcare consumers feel more confident and supported to make a complaint through a third party process like that provided by HDC. It is important to remind providers that although they may feel that complaints would have been better resolved directly, that the HDC Act and Code is about protecting the rights and needs of consumers NOT providers.

g. Strengthen the Advocacy Service

MSCC supports strengthening and resourcing the Advocacy Service to ensure that it can safely and effectively support direct resolution processes in all cases where the consumer agrees that kanohi ki te kanohi is the most acceptable and effective process. Consumers/complainants must be confident that they are able to access advocacy services throughout any direct process.

h. Improve the language of complaint pathways in the Act

MSCC does not agree that 'no investigative action' more or less disempowering than 'no further action'. We would hope that an explanation would follows either of these decisions that clearly states why no further action/investigative action is going to be taken, i.e. why, based on the information provided and perhaps investigations to date, the HDC has reached the conclusion that consumer rights have not been breached or any other reason why further investigation/action is not considered necessary/practicable. We would also expect that such a determination would be followed with information about further actions that the consumer could take including the right of appeal.

MSCC supports the the terminology "facilitated resolution" and hope that this will be backed up by options that allow individual consumers to choose the resolution process that will best fit their needs.

1.3: What other changes, both legislative and non-legislative, should we consider for **supporting better and equitable complaints resolution**?

As above:

MSCC recommends that processes with timelines are clearly defined for complainants.

That providers are required to respond and/or meet within a clearly defined and not too protracted timeline.

That support and advocacy is available that meets the needs of individual complainants and that this includes the option of in person facilitation and support at any kanohi ki te kanohi meetings between complainant and service provider.

That there is a requirement that comfortable and accessible neutral spaces be made available for kanohi ki te kanohi meetings. Complainants should not be required to meet with the service provider in the service provider's facility/rooms etc as is often the case at present.

That service providers are required to report on outcomes to HDC (again within a weeks of any meeting/correspondence etc with complainant) and HDC surveys all complainants to find out whether these outcomes satisfied/met their needs/expectations.

That an appeal process is clearly defined and available.

Topic 2: Making the Act and Code more effective for, and responsive to, the needs of Māori

2.1: Did we cover the main issues about **making the Act and the Code more effective for, and responsive to, the needs of, Māori**?

MSCC supports all moves to facilitate input from Māori that will make HDC processes and the Code more acceptable, effective for and responsive to the needs of Māori.

We fully support the hui-a-whanau process and recommend that something similar is made available to complainants from other cultures.

a. Incorporate tikanga into the Code

It is MSCC's view that the HDC Act and Bill are about upholding human rights and it is our opinion that these are universal. It is our belief that concepts like Mana (Right 1 — Respect), Manaakitanga (Right 2 — Fair treatment), and Tū rangatira motuhake (Right 3 — Dignity and independence) are universally desirable and enhance and protect the safety, wellbeing and mana of all health and disability services consumers. We are not sure about either the efficacy or practicality of putting in place legislative protections, education, and guidance. MSCC fully supports that this legislation recognises Maori as tangata whenua and incorporates a Maori world view wherever this is practicable but also focuses on the commonality of human needs and rights when accessing/receiving health and disability services.

b. Give practical effect to te Tiriti o Waitangi | the Treaty of Waitangi in the Act

MSCC supports the need to give practical effect to the Te Tiriti o Waitangi in this and all other legislation. We do not have the expertise to comment on how this should/is able to be achieved.

2.2: What do you think about our suggestions for **making the Act and the Code more effective for, and responsive to, the needs of Māori**, and what impacts could they have?

2.3: What other changes, both legislative and non-legislative, should we consider for **making the Act and the Code more effective for, and responsive to, the needs of Māori**?

Topic 3: Making the Act and the Code work better for tāngata whaikaha | disabled people

3.1: Did we cover the main issues about **making the Act and the Code work better for tāngata whaikaha | disabled people**?

MSCC finds the wording, "Traditionally, HDC ***has had*** a Deputy Commissioner Disability with a particular responsibility for ensuring that HDC is accessible and responsive to tāngata whaikaha | disabled people…". The use of "has had" (at tense usually used to talk about past events which are already over but have influence on the present) makes it seem that as though this may be going to change. MSCC strongly recommends that the role of Deputy Commissioner Disability with a particular responsibility for ensuring that HDC is accessible and responsive to tāngata whaikaha | disabled people is retained.

3.2: What do you think of our suggestions for **making the Act and the Code work better for tāngata whaikaha | disabled people**, and what impacts could they have?

a. Strengthen disability functions within the Act

MSCC supports introducing a requirement that HDC be required to report to the Minister for Disability Issues as well as the Minister of Health.

b. Update definitions relating to disability

MSCC does not have the expertise or experience to make comment or add suggestions to how the Act's definitions relating to disability could be changed to strength-based language.

c. Strengthen references to accessibility

MSCC supports the removal of the clause 'and reasonably practicable' in Right 5 in relation to the right to a competent interpreter as it is effectively meaningless. Providers must be required to access interpreters where these are required to facilitate health or disability consumers access to care that supports their rights.

d. Strengthen and clarify the right to support to make decisions

MSCC supports all the proposed changes in this section especially the change from competence and incompetence to "decision-making capacity" and "affected decision-making capacity" and the change from "views" to "will".

e. Progress consideration of HDC's draft recommendations relating to unconsented research

MSCC has concerns about "best interests". It seems to us that in this case, best interests, will almost certainly be decided upon by someone other than the individual consumer concerned. We recommend that this be strengthened by using words like, "has been shown will likely provide/confer benefit to…"

We are not sure who the, "Suitable persons interested in the welfare of the person…" – again, suitable seems very subjective and likely to be determined by someone other than the consumer – we wonder if this should be strengthened to require the individual who has legal responsibility (e.g. medical power of attorney) for the consumer to consent to or veto participation in research of someone who has affected decision-making capacity.

MSCC supports the concerns that Tāngata whaikaha | disabled people and whānau have expressed about any proposed increase in the threshold for unconsented research and of the ability of specialist ethics committees to consider disability interests adequately. We support a requirement that any ethics committee considering any research involving Tāngata whaikaha must include a representation of people with lived experience of disability on such committees.

3.3: What other changes should we consider (legislative and non-legislative) for **making the Act and the Code work better for tāngata whaikaha | disabled people**?

Topic 4: Considering options for a right of appeal of HDC decisions

4.1: Did we cover the main issues about **considering options for a right of appeal of HDC decisions**?

MSCC strongly supports the right of health and disability service consumers to appeal any decision made by the HDC and therefore the need for processes and information to be designed and communicated to facilitate this.

a. Introduce a statutory requirement for review of HDC decisions

MSCC supports that there is a statutory requirement for HDC to review decisions if requested by a complainant and that such a review requires a second opinion from a different decision-maker and peer involvement in the process.

In order to prevent an endless cycle of appeals, there needs to be clear criteria/grounds described that must be met for appeal Advocacy services need to be available to consumers throughout the appeal process.

MSCC would like to suggest that complainants be asked when they submit their original complaint what outcomes they would like. All decision-making by HDC needs to include reference to these outcomes, including in instances where the HDC has reached the conclusion that consumer rights have not been breached or any other reason why further investigation/action is not considered necessary. Health and disability service consumers who make a complaint are often not seeking punishment as much as wanting to ensure that service provision and service providers acknowledge their experience and consider that other consumers may also have the same experience (even if they don’t complain) and are open to at least considering the need for introducing changes that will make the service more acceptable to and better able to meet the needs of the consumers whose needs it is designed to meet. We believe that if there was more focus on and process related to, the outcomes consumers would like to see, that this would help avoid the need for appeals.

b. Lower the threshold for access to the HRRT

MSCC does not have the expertise to make a recommendation on this section. In general we would prefer complaints made about the HDC Code to be resolved by the HDC and that HDC be resourced to meet e.g. the additional workload that may arise from a statutory requirement for HDC to review decisions if requested, in a timely manner. However, we would expect HDC to inform consumers whose complaint involves a breach of their fundamental human rights of the option and processes required for having such a complaint referred to the HRRT.

4.2: What do you think about our suggestions for **considering options for a right of appeal of HDC decisions**, and what impacts could they have?

4.3: What other **options for a right of appeal of HDC decisions**, both legislative and non-legislative, should we consider?

Topic 5: Minor and technical improvements

5.1: What do you think about the issues and suggestions for **minor and technical improvements**, and what impacts could they have?

a. Revise the requirements for reviews of the Act and the Code

MSCC agrees that the requirement to review the Act at least every five years, and the Code at least every three years is too intensive an unnecessary 30 years after the passimg of this legislation.

MSCC considers that because the Code Rights are fundamental and therefore, that it should not be necessary, nor is it desirable for these to be regularly amended or revised. We agree that any review of Code Rights needs to be clear that it is not the Rights themselves that are being reviewed (unless there is a need to articulate and add futher Rights), but the language that enshrines these. Given this, we agree that the Code does not need review every 3 years. We also agree the whatever timeframe is considered optimal that reviews of the Act and the Code need to be aligned. We are unsure about the timeframe for these reviews. Given the rapid changes in the Health and Disability sector in terms of service provision, technologies and medications etc we are not convincerd that a 10 yearly review, as suggested by previous commissioners, is frequent enough for review of the Act.

b. Increase the maximum fine for an offence under the Act from $3,000 to $10,000

MSCC supports increasing the maximum fine to at least $10,000.

c. Give the Director of Proceedings the power to require information

MSCC supports giving the Director of Proceeding the power to require information from providers and complainants or third parties to inform their decision-making.

d. Introduce a definition for ‘aggrieved person’

MSCC supports the addition of this definition.

e. Allow for substituted service

Modern technology makes it increasingly difficult for individuals not to be able to be contacted although we agree that contact via “postal services” is becoming obsolete. We support the introduction of alternative services for notifying/contacting consumers and providers. We do however recommend that regular contact is made with both consumers and providers during the couse of whatever level of investigation is being undertaken and that these individuals are asked what their preferred means of contact is and that this is checked/updated at every contact.

f. Provide HDC with grounds to withhold information where appropriate

MSCC supports the amendment to provide HDC with grounds to withhold information during the course of an investigation in alignment with the powers in this respect of the Privacy Commissioners office.

g. Expand the requirement for written consent for sedation that is equivalent to anaesthetic

MSCC supports expanding the requirement for written consent for sedation whose effects are equivalent to general anaesthetic.

h. Clarify that written consent is required when there is a significant risk of serious adverse effects

MSCC is unsure about adding “serious” as a qualifier unless or until there is a nationally accepted definition of what constitutes serious adverse effects in thje health and disability services sector. We are concerned that unless the words “significant” and “serious” are clearly defined, and that these are explained to the consumer, they offer no support or protection to consumers and are at best ambiguous and at worst open to interpretation by the provider. Providers, whose daily work involves the management of conditions akin to adverse effects can easily become inured to the impact of pain, suffering, anxiety or loss of function etc when these are unexpectedly experienced by someone who is was not expecting these side effects. Health care consumers are too often told that their symptoms are mild, or expected to be mild, when their personal experience of them is anything but. We believe that the word “significant” is particularly problematic. If a medication or procedure carries with it the risk for serious side effects – this is significant. Rather than seeing the requirement for consumers to provide written consent as burdensome, we see this as ensuring that consumers are able to make fully informed choices. We do not support reducing the requirement for written consent on the basis that providers have already interpreted this as only being necessary if they believe that there is a probability of serious adverse effects. We believe that providers need to put in place processes that easily allow health and disability consumers to give written consent, now that so many services are nearly paperless, and that the situations that require written consent are very clearly defined.

i. Clarify the Code’s definitions of teaching, and of research

MSCC does not have the experience of expertise to offer clarification of the definitions of teaching and research but we support the need for clearly defining these terms. Unless all the terms in the Code are clearly defined they do not protect health and disability consumers.

j. Respond to advancing technology

5.3: What are your main concerns about **advancing technology** and its impact on the rights of people accessing health and disability services?

MSCC’s major concern about advancing technology is loss of privacy. Our second biggest concern is loss of individualised care.

- 5.4: What changes, both legislative and non-legislative, should we consider to respond to **advancing technology**?

MSCC believes that the local health and disability service providers using AI and robots etc should be legally required to ensure that consumer rights under the Code are upheld. Local service providers must also be required to be legally answerable to consumer complaints when they have recommended or accessed these new technologies when providing services.

Legal accountability at this level will go some way towards ensuring that novel technologies are not employed simply because they are cheaper, readily available, labour saving, interesting etc.

E koekoe te tūī, e ketekete te kākā, e kūkū te kererū[1]

The tui chatters, the kākā cackles, the kererū coos

MSCC believes that the whakataukī you have used to acknowledge submissions and submitters is equally apt when thinking about the impact of new technologies on the health and wellbeing and of health and disability service consumers. Technology is no substitute for the health giving effects of individualised health care that is provided with empathy and respect.

5.2: What other **minor and technical improvements**, both legislative and non-legislative, should we consider?

---

[1] Edwards, S., *Titiro Whakamuri Kia Marama Ai Te Wao Nei: Whakapapa Epistemologies and Maniapoto Māori Cultural Identities.* Massey University Research Repository; 2009: http://hdl.handle.net/10179/1252.

5.3: What are your main concerns about **advancing technology** in relation to the rights of people accessing health and disability services?

5.4: What changes, both legislative and non-legislative, should we consider to respond to **advancing technology**?

Publishing and data protection

This section provides important information about the release of your information. **Please read it carefully.**

You can find more information in the Privacy Policy at hdc.org.nz.

Being open about our evidence and insights is important to us. This means there are several ways that we may share the responses we receive through this consultation. These may include:

- **Publishing all, part or a summary of a response** (including the names of respondents and their organisations)
- Releasing information **when we are required to do so by law** (including under the Official Information Act 1982

Publishing permission

May we publish your submission? (Required)

☐ Yes, you may publish any part of my submission

☐ Yes, but please remove my name/my organisation/group's name

☐ No, you may not release my submission, unless required to do by law

Please note any parts of your submission you do not want published:

Reasons to withhold parts of your submission

HDC is subject to the Official Information Act 1982 (The OIA). This means that when responding to a request made under the OIA, we may be required to disclose information you have provided to us in this consultation.

Please let us know if you think there are any reasons we should not release information you have provided, including personal health information, and in particular:

- which part(s) you think should be withheld, and
- the reason(s) why you think it should be withheld.

We will use this information when preparing our responses to requests for copies of and information on responses to this document under the OIA.

Please note: When preparing OIA responses, we will consider any reasons you have provided here. However, **this does not guarantee that your**

submission will be withheld. Valid reasons for withholding official information are specified in the Official Information Act.

☐ Yes, I would like HDC to consider withholding parts of my submission from responses to OIA requests. I think these parts of my submission should be withheld, for these reasons:

Follow up contact

If needed, can we contact you to follow up for more detail on your submission? (required)

☐ Yes, you can contact me

☐ No, do not contact me

Further updates

Would you like to receive updates about the review?

☐ I'd like to receive updates about the review

☐ I'd like to receive updates from HDC about this and other mahi

Health and Disability Commissioner
Te Toihau Hauora, Hauātanga

Thank you

We really appreciate you taking the time to share your thoughts with us. If you have provided your details, we'll keep you updated on progress. If not, feel free to check our consultation website https://review.hdc.org.nz for updates or to contact us if you have any questions. We can be reached at review@hdc.org.nz.