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

____

Health and Disability Commissioner
Te Toihau Hauora, Hauātanga

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.

Which of these services do you engage with the most? (Please select all that apply)

☐ Health services ☐ Disability services ☐ Mental Health services

☐ Addiction services ☐ Aged Care Services ☐ Kaupapa Māori services

☐ Other services (please specify) ________________________________

What is your gender?

☐ Female ☐ Male

☐ Another gender (please specify) ____________________________________

☐ I don't want to answer this question

How old are you?

☐ Under 15 ☐ 15 - 17 ☐ 18 - 24 ☐ 25 - 34 ☐ 35 – 49

☐ 50 - 64 ☐ 65+ ☐ I don't want to answer this question

What is your ethnicity? (Please choose all that apply)

☐ NZ European ☐ Māori ☐ Samoan ☐ Cook Island Māori

☐ Tongan ☐ Niuean ☐ Chinese ☐ Indian

☐ I don't know my ethnicity ☐ I don't want to state my ethnicity

☐ Other/s (please state):____

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?

[redacted]

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:__[redacted]____

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'?

[redacted]. We have outlined our concerns in the below sections. Our replies are informed by the experiences of the birth trauma community's use of maternity care as well as HDC's complaints process following birth trauma (physical or psychological), including harm relating to baby/babies.

Regarding the Code of health and Disability Services Consumers' Rights – many within our community feel this is "just words" as their rights are repeatedly broken or ignored.
Rights 1 through 10 are often not met for the birth trauma community, resulting in significant trauma, psychological distress and physical injury to the birthing parent, their support people, and, sometimes baby. These impacts 'ripple out' in to the wider whānau and have many, lasting impacts on the birthing parent, the baby and other family members.

Our community feels there is a strong onus on the consumer to come to a resolution with health care providers before they take their complaint to the HDC. This is not reasonable or appropriate in the case of birth trauma – it is retraumatising to go back to the person/place where one has experienced trauma, to try and resolve concerns. Asking consumers to go back to the person/place that caused their trauma means they simply do not, thereby opportunities for resolution, accountability of health care staff and positive solutions to health sector failures do not occur.

Members of the birth trauma community find the complaints process convoluted, time-consuming, without timely resolution, lacking accountability of practitioners, and retraumatising as a process. Our community often feels ‘kept in the dark’ regarding the progress of their complaint.

Members of our community believe there is too heavy a reliance on written notes within the complaints process and would prefer interviews as part of the complaints process – many believe their notes have been falsified or not completed fully.

Our community is one where trauma has occurred – many members of our community have birth-related post-traumatic stress disorder. There is little to no support for members of our community as they work through the complaints process. Again, the process can be harrowing as merely retelling one’s story can be hugely traumatic.

Topic 1: Supporting better and equitable complaint resolution

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

* The suggested changes – regarding more focus on outcomes for people - is positive.

* The birth trauma community finds that, at present, the complaints process takes too long - one woman reported her process taking 5years from submission to resolution. Further, the process does not facilitate outcomes where health practitioners are accountable for their actions.
Our community often feels there is no “solid” outcome from the process.

* Our community also finds the process retraumatising – the length of time the process takes is part of this retraumatisation.
Our community report not knowing what point in the process their complaint is ‘up to’ and receiving no timeframe for the complaint to progress.

* Members of our community report waiting weeks and months for any update on how their complaint is progressing. This leaves complainants with little trust or faith in the process. It can also leave them feeling retraumatised as often (at least part of) their trauma comes ‘not being listened to or heard’.

* Further, having re-tell their experience (during the 'back and forth' process of reporting their experience and reviewing statements from various providers) is retraumatising.

* Holding the health consumer – who in this case is often also the victim of an abuse of their rights – at the centre of legislation and processes is essential. Specifying this consumer focus, by including the concept of mana, is highly appropriate.
In saying that, if we are to extend the Act/Code to include concepts such as mana, the Commission must be willing, and able, to make these concepts a reality in the way health consumers experience the complaints process and in the outcomes that may come from it.
We also need to continue to ensure processes are "fair, simple, speedy, and efficient'.

* Ideally, everyone who utilises the complaints service should have an independent advocate assigned to them (with the option to change advocates if the consumer wishes). This advocate would support the consumer throughout the entire process.
There also needs to be improved promotion of the current Advocacy Service – many people do not know this exists or what their functions include.

* The suggested language changes would be positive. More importantly, however, is the fact that members of our community are not being encouraged to use the complaints process at all because other birth trauma community members report it as re-traumatising, lengthy and without sufficient outcomes that hold practitioners accountable, meaning they feel the harrowing process "was for nothing". Until these 'core issues' are resolved, these minor changes suggested will be only that.

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

* We believe it's important to not rely on, or expect, the consumer to use complaints processes 'directly with providers' – in the case of birth trauma this is incredibly unrealistic and would be unfair, and irresponsible, to expect consumers to raise issue with the individual/organisation/institution where their rights were neglected or abused. If this were to be encouraged, it would be essential to have safe, trauma-informed, services that were very easily accessible and which incur no extra cost (financial, emotional, etc.) to the consumer.

* Many members of the birth trauma community specifically do not wish to lay a complaint directly with the provider where their trauma (physical or psychological) occurred. The HDC complaints process is vital as it is removed from the individual, organisation or institution involved in the events relating to the birth-related harm.
Therefore, HDC complaints processes need to be available to consumers who do not wish to pursue a complaint to the provider and, thus, HDC processes need to be timely, consumer-centric and outcomes-focused where accountability on the part of the health practitioner occurs.

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

* We recommend utilising interviews as part of the complaints process, as well as written notes.

* We highly recommend ensuring legislative changes, and complaints processes, are trauma-informed. We also recommend trauma-informed training for HDC complaints staff.

* We recommend ensuring a complaints process takes no longer than 1 year to completion.

* We highly recommend trauma-informed emotional supports are available for complainants, should they need them through the process. This is to ensure those who are retraumatisd by the complaints process are well supported.

* Making the complaints process appealing to whānau Māori will be essential. Ensuring Te Tiriti is put in to action will be a way to do this; wide promotion of the complaints service is another way to centre Te Tiriti.

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**?

* It is positive that there are new roles within HDC, that centre the needs of Māori.
Changes to the Act and Code need to be done following engagement with various Māori stakeholders, including rangatahi.

* Centring Te Tiriti within HDC mahi is essential, as is altering processes to include tikanga Māori – these changes must be Māori-led.

* Targeted promotion of Health and Disability rights, and the complaints process, towards whānau Māori is needed to better inform these whānau of their rights and resolutions processes. This must follow engagement with various Māori stakeholders as to the best promotional methods.

* Clarifying the role of whānau is positive (Rights 3, 8, 10), as is ensuring gender-inclusive language.

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?

* The suggested changes are positive. Enacting these changes must be done following wide engagement with Māori.

* HDC will need to ensure that there is adequate resourcing available to enact the changes made to centre Te Tiriti, for example, incorporating tikanaga in to processes.

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**?

* Effective and sincere engagement with Māori must take place, prior to, during, and after (as a means of assessment and monitoring) changes to the Code and Act.

* The centering of Te Tiriti in the Act and Code is essential. HDC needs to ensure that processes utilised by whānau Māori are safe for whānau Māori.

* Kaupapa Māori promotion of Health and Disability Rights, and the

Complaints process, is required in order to improve knowledge among whānau Māori of consumer's rights, and to ensure the complaints process is safe for, and trusted by, whānau Māori.

* Ensuring that Māori needs are being met by continuous feedback processes with Māori will be essential.

* It will also be essential to ensure that data collection, reporting and changes to come from these have an equity focus.

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**?

* The suggestions for making the Act & Code work better for tangata whaikaha are positive.

* Effective and sincere engagement with tangata whaikaha must take place, prior to, during, and after (as a means of assessment and monitoring) changes to the Code and Act.

* Ensuring that disabled people's needs are being met by continuous feedback processes with disabled people will be essential.

* HDC must ensure that processes are safe for tangata whaikaha.

* It is essential to ensure accessibility for tangata whaikaha, of the supports that ensure their rights are upheld when using health/disability services, as well as when considering, and using, HDC complaints processes – accessibility is vital.

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?

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**?

* Many members of the birth trauma community believe they do not have a satisfactory final outcome – there is no accountability of health practitioners. Many members of the birth trauma community would like an appeal process however, by this stage it is often years after the event and they are exhausted by the complaints process. They just "give up".

* If an appeals process was to be utilised, there needs to be psychological supports available to complainants as they navigate the process.

* Accountability of practitioners needs to be a focus of processes.

* We recommend that the Act be amended so appeals are undertaken by an entirely independent appeals group – this group needs to include consumer perspectives/members.

* If an appeals process is included in the changes, the same suggestions as above (for example, psychological support services for those utilising the service; equity focus) need to be included as part of the appeals process also.

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?

* Similar to the suggestions above, appeals need to be consumer-centred; trauma-informed, uphold Te Tiriti and be equitable.

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?

* These suggestions are positive.

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

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

* We are concerned about the possibility of these technologies replacing human interaction and consideration.

* There needs to be assurance that technological advances do not replace humanity in Health and Disability service use, and complaints processes.

* Again, consumers – their rights, needs and wishes - must be held central to any decisions regarding technological advances. We must ask ourselves: “is this technological advancement going to better serve consumers and uphold their rights, needs and wishes?” before accepting those technological advances.

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

Publishing and data protection

Health and Disability Commissioner
Te Toihau Hauora, Hauātanga

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

Health and Disability Commissioner
Te Toihau Hauora, Hauātanga

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

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.