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]

[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 on behalf of an organisation or group

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

☑ Through my job

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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:

Public and Private Healthcare provider for fertility treatment in 6 locations in NZ

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’?

The exponential growth in the number of complaints since 2021 and complexity of the HDC complaints process for providers is causing major issues and is not an effective process for patients.

There is insufficient prevetting of complaints by the HDC combined with the fact that patients have a lack of understanding of the timeframe and the process. Providers have little visibility of the status of complaints. Patients are not sufficiently encouraged, supported or required to seek resolution via their provider first and / or use the advocacy service as a first option for resolution.

The HDC should focus their attention on making the process simpler, timely, effective and accountable as their first and most important priority.

Topic 1: Supporting better and equitable complaint resolution

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

- We don't agree that for [redacted] there are barriers to using the complaint process. In general, we consider that patients are not sufficiently encouraged to seek support by using the free advocacy services.

- We agree the HDC should improve how they meet the principles of a simple and speedy and efficient process, and we absolutely agree with the statement they are not being met as well as they could be – for example:

  - Of our HDC complaints from 2023, 83 % remain open

  - Each HDC complaint requires a minimum of 40+ hours resource to complete which is a heavy burden on healthcare providers resources especially if they are a small to medium size provider. This cost ultimately is passed on to patients via private medical costs.

  - Complaints are duplicated between multiple regulatory bodies requiring providers to respond to both parties e.g., Medical Council, Medical Science Council and ACC. There is also the right of the complainant to take the matter to the HRRT which is another duplication of effort.

  - Complaints do not focus on the key issues but are often a download of many minor issues making responding to complaints difficult and time consuming. Better use of the advocacy service in complaint preparation should enable focus on the top 3-5 areas of concern.

The amount of information requested by the HDC is also large including all policies and procedures, timelines, full patient records. An interim step for the provider to respond at a high level so the HDC can ascertain if there is substance to the complaint before the next more detailed stage, would be useful and could streamline the application of resources.

- Limited consideration is taken of the impact of a drawn-out complaint on a medical practitioner and the provider. For example, one complaint raised in October 2023 which has already been dealt with by the Medical Council (where no conduct issues were found), is still in progress with the HDC and despite many follow-up requests, there is still no clear date for closure. Resolution was impacted by HDC staff changes and reassigned. However, it is unacceptable that a respected senior staff member who has no prior history is unable to fully clear his name and has to live with the stress of unsubstantiated allegations and an extended investigation process, with no clear timeframe for resolution. This ongoing long period of stress is a health and safety hazard for our staff and also we have received comments from doctors that they may not work in this area of medicine, due to the increase and related risk to them of HDC complaints. As an organisation, if we move forward with changes to our processes based on advice from the Medical Council, we may have to amend those changes once the HDC provide their response. Therefore, continuous improvement changes may be delayed to prevent rework. It is unacceptable and unjust that there is no mechanism for providers to raise a complaint about the HDC's internal processes which would enable us to get an approximate timeframe for resolution.

    - Obligations for culturally responsible practice is a good goal – however, small providers are given no or very little support or practical resources to enable us to achieve this. Large government Healthcare organisations have teams and resources dedicated to this, but this is not practical or cost effective for smaller providers.

- There is limited visibility of the status of a complaint or what escalation path it is on. HDC processes for the provider are not transparent.

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

a. Amend the purpose of the Act. Disagree - adding upholding mana is subjective and not an appropriate role of the HDC in our viewpoint.
b. Clarify cultural responsiveness – we do not consider this is a priority area for change as there is sufficient cultural requirements in the Health and Disability Standards to outline what is required.
c. Clarify the role of whanau – Agree whanau are an asset to enable better outcomes and should be encouraged in the complaint process.
d. Ensure gender-inclusive language – Agree
e. Protect against retaliation – Disagree - for private healthcare a provider should be free to manage their business risk and choose whether they wish to continue the treatment journey
f. Clarify the provider complaint processes – We agree this could use rework – given the growth in the level and complexity of complaints post Covid in the healthcare sector, and the risk to the provider if the complaint escalates to the HDC, the 10-day period to respond is not adequate to formulate a full and comprehensive response in the majority of cases. With over 89 complaints in 2023, that is a minimum of 178 individual patient letters, and grows to 267+ letters taking into account the monthly update requirement, an average of 5 letters per week. A more manageable timeframe would be 10 days to acknowledge the complaint, 30 days to respond initially and 2 monthly updates. The current timeframes do not take into account that some of the services like [redacted] are complex, treatment occurs over a long period and treatment is multi faceted.
g. Strengthen the Advocacy Service – Agree, this is a valuable and under utilised service. They should provide free independent cultural and/or interpreter support for both parties and facilitate restorative sessions were relevant. It should be much clearer to patients that the Advocacy Service and the HDC process does not include obtaining financial compensation / refunds and can take a long time for resolution.

h. Language in the Act – disagree there are higher priorities above.

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

The focus of change should be on internal HDC processes to manage complaints in an efficient way and to be accountable to providers and patients for achieving set timeframes. The above ideas are not resolving the core root causes of the current non performance of their core duties by the HDC.

The survey idea for providers is a good idea – we have never received such a survey, so the process is clearly not embedded. The outcomes of these surveys should be reported publicly and measured against KPIs.

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?

Unsure: Comment from our Māori Doctors is the HDC should seek feedback from a Māori patient focus group for on an array of perspectives, not [redacted] doctors' perspectives which will be medically and clinically skewed and not with a specific cultural lens.

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?

Refer above.

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**?

Refer above

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**?

Yes.

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?

No comment as our service is not really impacted.

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**?

Rather than just changing the code to remove the reference to if reasonably practical in the right to a competent interpreter, the HDC could further support practically ensuring that adequate free access to interpreters is available so that this can be delivered when required.

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**?

Yes – of major concern to us as providers is the risk that adding further appeal processes increases the potential costs and delays what is already a drawn-out delayed process.

A factor to consider is by the time the HDC responds to complaints, and they get to appeal status, the employees involved the complaint or service delivery, or the investigation may have left the organisation and not be available making it difficult for handover to the new team now involved in any appeal process and any further new questions may be difficult to respond to.

What is not mentioned is the ongoing emotional stress for both patients and providers if the appeal processes are extended as well as the potential to delay implementation of changes, if the decision is under appeal.

The impact and validity of a decision is also at risk if too much time passes from the incident to a decision, and it becomes potentially less relevant.

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?

Disagree, a right of appeal only extends the process further and the HDC is not effectively dealing with the level of complaints it currently has without adding further appeal processes.

After a full and deep investigation, we consider it is best for both parties to accept the decision and move on allowing patients to get on with their lives and providers to make improvements where necessary.

We disagree with lowering the threshold for access to the HRRT. There is already adequate ability to seek redress under these regulatory bodies already and multi regulator claims should be discouraged to reduce duplication. Complaints should choose their path of complaint but not be able to lodge mutli regulator complaints as this just makes the whole process more complex, expensive and time consuming.

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

None – there are adequate ways under the current approach.

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?

- Revise the requirements for review of the code – Agree - it should change to 10 years from 3 years.
- Increase the maximum fine from $3k to $10k – Agree
- Power to require information – Disagree – third parties should not be required to disclose information if they choose not to unless required by a Court of law.
- Definition of aggrieved person – Disagree - continue to let the High Court determine this – the views of relatives may be quite different to the views of the deceased and the rights should not automatically transfer.
- Allow for substituted service – Agree - this is also an issue for providers so any developments in acceptable methods of contact to accept more modern technology is welcomed as industry standard.
- HDC to withhold information – Disagree - there should not be the ability to withhold information as all parties should equally be subject to the laws of NZ, as are providers.
- Expand the requirement for written consent to sedation that is equivalent to anaesthetic – Agree.
- Clarify that written consent is required when there is a significant risk of serious adverse effects – Agree
- Clarify the codes definitions of teaching and research - Agree

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

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

Risks to privacy
Enforcing rights when the service provider is not based in NZ
Bias, misleading predictions, adverse events
Ensuring informed consent for self-improving AI
Accountability for upholding consumer rights if care is provided by a non-human

We consider privacy aspects should be covered by the Privacy Commission rather than the HDC. If terms of use of AI or non-human service provision – this could lower costs and make treatment more available and also provide tools for enhanced analysis. These tools should be disclosed and consented to if they are part of treatment and limitations on consumer rights should be clearly disclosed. All process have underlying risks and full accountability could result in these tools not be adopted to the disadvantage of patients and providers. Disclosure is the key and informed decision to use by the patient.

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

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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

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.