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? Vikki Challies

2. What is your email address? [redacted]

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

4. How did you hear about this consultation? Through my job

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

☐ Health services ☐ Mental Health services

What is your gender? [redacted]

How old are you? [redacted]

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What is your ethnicity? [redacted]

Do you identify as having a disability? [redacted]

What is your 'one big thing'?

You need to find a way to address the significant and entrenched delays in your processes which is damaging your credibility and social licence to operate and puts at risk the engagement of both consumers and providers with the purpose of the Act and the Code.

Topic 1: Supporting better and equitable complaint resolution.

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

On Page 8 of the consultation document you provide a definition of "complaint". I have never been able to find a definition in the Act or the Code of "complaint." I have always thought this was deliberate when the Act and Code were first drafted, as legislators did not want to limit what might be able to be considered as a complaint. However, over time it has led to variation in how providers interpret "complaint." Many providers refer to "informal" and 'formal" complaints or categorise comments as "feedback" or "suggestion" when another lens might actually see the consumers comments as dissatisfaction with the standard of services i.e. complaint. There is also a view that a complaint is only a complaint if it in writing (despite Right 10(1)) because this is how the provider interprets a 'formal" complaint requiring action under Right 10.

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

a. *Amend purpose statement.*

Agree including "fair, simple, speedy and efficient resolution of complaints" is repetitive of Right 10 and is process focused rather than an aspirational statement on the overarching purpose of the Act. If the right to complain and have that complaint responded to, is already a right under the Code then does the purpose of the Act need to include reference to complaints any more than any of the other rights in the Code. Is the purpose of the Act more about maintaining safe, high-quality health services for consumers?

e.g.

"Promote and protect health consumers and disability services consumers entitlement to receive services to a standard consistent with the Code of Rights and facilitate mana-

enhancing and restorative processes to address consumer concerns when their rights have not been upheld.

b. *clarify cultural responsiveness.*

Support change to Right 1 (3) to be inclusive and acknowledging of te ao Māori.

c. *clarify the role of whānau.*

Supported, providing degree of involvement is still subject to consumer's consent. An individual's right to privacy must take precedence- there are numerous scenarios where a complaint proceeding only on the basis of whanau raising the matter would result in a breach of the consumer's trust and confidence and could potentially damage a therapeutic relationship or place the consumers safety at risk. There are some people who just do not want their family/whanau to have access to details of their health care, for a variety of reason, some of which may not be recognised, understood or valued by the consumers whānau. An example of this is when a person is undergoing gender reassignment. People often choose not to have information shared with whanau due to the attitudes they have encountered in their whanau around their identity. Iin physical health such as cancer treatment, whānau views on whether the care provided is appropriate can differ from the consumer e.g. where a consumer chooses not to undergo a particular treatment and does not share this decision with whanau who can then be left with the impression "not everything was done to cure our loved one". There is also the scenario of the 'nosey/well intentioned/malicious" person who represents themselves as the consumers advocate but are not actually closely connected to them e.g. a neighbour, who makes a complaint on behalf of the person without having any accurate understanding of the true situation.

d. *ensure gender inclusive language.*

Appropriate.

e. *protect against retaliation.*

"**threaten** (to treat less favourably)" is very subjective. In the case of an allegation how would this be assessed and resolved? There is potential for unjust accusations to be made against clinicians, particularly when the therapeutic relationship has broken down. Many things happen in a person's health journey e.g. being declined to be placed on a waiting list, which a consumer may be inclined to view through a lens of being treated "less favourably" and attribute to having at some point in the past made a complaint. People can carry the trauma from the event which lead to the complaint for a very long time. Sometimes this can cause them to see everything which happens after this as being related to the event. For example they have a different, unrelated procedure some years after, a known complication occurs and they form the view the adverse outcome from the recent procedure is some type of "payback" for having made a complaint years ago. To some extent it can become a self-fulfilling prophecy.

It is not clear what benefit this amendment would offer over existing provisions in the Code. Every instance of services not being provided in accordance with COR can be progressed as a complaint. As noted in the consultation document, if a person feels they have been treated less favourably this can be considered as a new complaint and assessed against relevant rights including Right 2 (freedom from discrimination and harassment) Right 3 (dignity) and Right 4 (1) and (2) (reasonable care and skill; comply with relevant standards), all of which offer the opportunity to consider if the issues in the complaint have arisen due to retaliation from a previous complaint.

This also needs to be considered in the context of existing legislation offering protection against retaliation in specific circumstances being rarely used in HDC complaints. In more than 20 years of managing responses to HDC complaints I have only seen two complaints utilising the Protected Disclosures Act. While fully appreciating the PD Act has a high benchmark to be accessed, it is still worth considering if there are routine conversations with consumers to help them to understand they can ask for protection of their identity if the qualifying criteria is met.

f. *clarify provider complaint processes.*

Support removal of "10 day" clause- this is confusing and poorly understood. Focusing only on the 20-day timeframe means timeliness of response is consistent with other legislation requiring a response within 20 working days e.g. complaints under Privacy Act.

Suggest the update after 20 days should also be required to be made "in a form and manner that takes into account the consumers needs", the same as wording of 5(a). If it is important to ensure acknowledgement of a complaint is made in a way which can be understood by the consumer, then the same consideration should apply to updating progress on resolving their concern and also for advising outcome of the complaint.

How would the proposal for providers "promoting the right to complain" add to and/or differ from existing obligations under the current Right (6)(b) where providers ***"must"*** have a complaint system that ensures the consumer is informed of any "relevant… internal …complaints procedure". What would the new expectation look like in reality? Would it be as specific as the requirement for consumers to be told of the availability of the HDC ((6)(b)(ii)). Has there been a pragmatic consideration of how providers could demonstrate they have fulfilled this to avoid being found in breach?

g. *strengthen the Advocacy Service*

There is a huge potential for the Advocacy Service to have a leadership role in facilitating a restorative approach to complaints in healthcare, similar to the community based restorative justice network in the justice setting.

Obviously, there are resourcing consideration which, in current environment, makes an expansion of the Advocacy function unlikely.

h. *improve the language of complaint pathways in the Act.*

Disagree re "No further Action." This is an outcome, not a description of process. At some point in time a matter has to be concluded, even if it not to the liking of all parties. My experience of reviewing HDC communications to complainants and providers is there is always a considered and detailed description of the review which has taken place before setting out a rationale for reaching a decision (outcome), one possible one being that the matter raised has not been established to a level of seriousness/serious harm/public interest which warrants additional time, resource or analysis to be invested- in a nutshell "no further action". It is difficult to see how this conclusion could be expressed as anything other than "no further action." Using words such as "not justified" or "not proven" is likely to be just as poorly received and from the provider side could add to a perception the process is orientated to finding fault (already an issue) rather than reflecting a "no blame" learning focus.

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

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**?

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?

a. *incorporate tikanga into the Code.*

Supported

b. give practical effect to te Tiriti in the Act

Supported

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**?

Yes- choice and control for disabled people is critical. Anything impacting on this must be enabling, not disabling.

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?

Support all of below.

a. *Strengthen disability functions in the Act*
b. *Update definitions relating to disability*
c. *Strengthen references to accessibility*
d. *Strengthen and clarify the right to support to make decisions*
e. *Progress consideration of HDC's draft recommendations relating to unconsented research*

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**?

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?

a. *Introduce a statutory requirement for review of HDC decisions.*

Not supported. This would increase the compounded harm from the HDC process experienced by providers and consumers. There is risk it would be used by complainants who seek to extend vexatious and minor harm matters, particularly when HDC review has determined no further action is warranted. Providers will also utilise the appeal option when found in breach which will add to the distress complainants experience from the complaints process and the issue(s) which caused the complaint.

As the consultation document highlights, there already exists options for complainants to seek a review of a complaint outcome. It is difficult to identify any additional benefit from adding a further pathway for review, when weighed against the harm the appeals process would cause.

b. Lower threshold for access to the HRRT

Not supported. The current process reserves HRRT for the "most serious of the serious" complaints and as such the decision to refer a provider to HRRT carries significant weight and mana. A lower threshold risks HRRT evolving into a second "HDC" with minor and vexatious matters.

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 requirement for reviews of the Act and the Code
b. Increase maximum fine for an offence under the Act
c. Give the Director of Proceedings the power to require information
d. Introduce a definition for "aggrieved person"
e. Allow for substituted service
f. Provide HDC with grounds to withhold information where appropriate
g. Expand requirement for written consent for sedation that is equivalent to anaesthetic

Supported, although has significant operational/interpretation implications.

Will this apply when the substance changing the person's level of consciousness/awareness/recall is in gas form which might not be recognised as a "medication" e.g. nitrous oxide?

Has there been work done to understand potential impacts of the change on the use of sedation in the acute (inpatient) mental health setting – would it be captured by the requirement to have written consent and if so, is that an intended or unintended outcome of the amendment?

h. Clarify requirement for written consent where there is a high risk of serious adverse consequences.

Definition of 'serious" would be needed, otherwise it is very open for the practitioner to decide what is 'serious" and must therefor be properly consented with the patient. There is already an entrenched and prevalent culture where 'complications' are regarded as an expected and acceptable outcome of a procedure, provided the overarching purpose of surgery is accomplished. Without a definition the application will be problematic, as there will be varying views between clinicians and consumers on what is actually a "serious" adverse effect. Some complications considered quite routine and minor by the practitioner will be "serious" to consumer due to the on-going detrimental effect it has on their quality of life. Having a stoma would be an example of this. While seen as a routine outcome of surgery, they are regarded with horror by many patients to the extent some people refuse to have a procedure if formation of a stoma required. If the clinical benchmark is set too high on what is a "serious" adverse consequence, this will contribute to people being inadequately informed of the risks of their procedure and not fully understanding what they are consenting to.

i. Clarify the Codes definition of teaching and research.

Agree definitions could be more explicitly stated. See also comments in 5.2.

j. Respond to advancing technology.

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

1. Teaching and Research

Why are "teaching" and "research' referred to together/ linked in Right 6 (1)(d) and Right 9? They are two distinctly separate activities and considerations for each are very different. "Teaching" impacts a much larger cohort of consumers in a range of settings and has less controls around it, compared to Research which generally goes through rigorous approval processes including ethics and consent. The average consumer is much more concerned about being treated by a "trainee" which they often equate with not being "competent" or "qualified" (especially when something doesn't go according to plan), than research which is something they agree to join.
Suggest consideration be given to having separate clauses in The Code for consumer rights specifically in relation to teaching and research rather than having the two bundled together.

2. Consent for sensitive examinations to be conducted by students.

Does there need to be a specific clause around medical students obtaining informed consent from consumers for them to be involved in a sensitive examination? There is a two-fold consideration in this scenario- the first is the Consumer consenting to being involved in teaching and secondly that their agreement extends to the student/trainee conducting a sensitive examination. While consumers may have a level of comfort around an experienced clinician conducting a sensitive exam, this reduces when it is a student, potentially conducting the exam for the first time. The Commissioner has previously expressed concerns on this aspect of informed consent and research suggests compliance with seeking informed consent is poor.

Should an explicit requirement be added to the Code for informed consent to be gained and documented for sensitive examinations conducted by a medical student/trainee, perhaps adding it to Clause (6) of Right 7?

3. Health & Disability Commissioner Act 41 (b)(ii)

Extend the current standard timeframe for submitting a response (currently 15 working days) to 20 working days – more realistic, allows time for provider to properly consider and consult on a response. Also consistent with other legislative timeframes.

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 permission

May we publish your submission? Yes, you may publish any part of my submission

Follow up contact.

If needed, can we contact you to follow up for more detail on your submission? Yes, you can contact me

Further updates

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Would you like to receive updates about the review? I'd like to receive updates about the review

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.