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
X 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 X Word of mouth ☐ Other (please specify below)

____

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?

Ovarian Cancer Foundation New Zealand

What type of organisation/group is it?

X 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: We provide support and advocate on behalf of and alongside women and people affected by ovarian cancer. We also fund research to improve survival, and raise awareness of ovarian cancer symptoms and risk factors to improve diagnosis.

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'?

While we agree that the HDC is a fundamental part of the health system, we feel it has not been as good at recognising the role of systemic gender bias, particularly in relation to ovarian cancer.

We note the pervasiveness of the thread in HDC decisions that ovarian cancer is difficult to diagnose, used as justification for not testing people presenting with symptoms consistent with ovarian cancer. There is also a trend to complaints being upheld when the presenting symptom is abnormal bleeding (which is a less common ovarian cancer symptom) but not for more common symptoms such as bloating and bowel changes.

BACKGROUND

The broader context is that almost half of all women with ovarian cancer experience an emergency diagnosis in New Zealand, ranking us as the worst among comparable health systems in the International Cancer Benchmarking Partnership. Women in NZ with ovarian cancer are significantly less likely to be tested for ovarian cancer on their first or second doctor's visit compared to women in Australia. Additionally, there are significant regional variations in CA-125 testing, which is a very easy and accessible test, with some regions reporting rates of two or less per 1000 population, and others 10 or more. In other words, in some areas of New Zealand, ovarian cancer is significantly under-tested.

This is overlaid on a background of pervasive gender bias within healthcare in NZ, as outlined in the Ministry of Health Women's Health Strategy.

When considering the medical community's response to delays in diagnosis, it is important to note that it was only in 2000 that someone decided to research the enduring myth that ovarian cancer was silent, and showed what women had been saying to deaf ears for decades; that there were characteristic symptoms and an opportunity to diagnose people earlier. This article discusses some of the issues https://journals.lww.com/greenjournal/citation/2022/02000/ovarian_cancer_is_not_so_silent.1.aspx. However, this knowledge has been slow to be adopted into mainstream practice.As of our last check several years ago, Otago University Medical School still had text books stating incorrectly that ovarian cancer is largely silent.

Another disadvantage for ovarian cancer complainants is the difficulty of demonstrating that outcomes are worsened by delays. This is because delays to diagnosis affect the ability to fully resect ovarian cancer surgically but less often result in a stage shift. Even today, reflecting the lack of research, there is debate in the medical community as to whether a prompt diagnosis improves survival.

Part of the issue is that ovarian cancer is disproportionately under-researched. Relative to lethality, ovarian cancer receives 18 times less funding than prostate cancer. Consequently, five-year survival rates for advanced ovarian cancer are three to four times lower than those of advanced breast and prostate cancer. The lack of effective treatments means survival differences for diagnosis delays are less marked.

Research from the ICBP in 2022 showed that emergency diagnosis in New Zealand doubles the risk of death from ovarian cancer within the first year of diagnosis, from 17% to 42%.

Judgments need to reflect both the psychological trauma of misdiagnosis and the impact of delays on survival rates as indicated by the ICBP research.

While we recognise the need to uphold individual GPs and other medical specialists to the minimum standards of their peers in NZ, we are concerned that this risks perpetuating bias within the health system.

We see an issue where the level of ‘minimum acceptable care’ for ovarian cancer diagnosis in New Zealand deviates from what would be considered acceptable in Australia.

We believe there should be scope within the HDC to consider whether the minimum acceptable standard that practitioners are held against is indeed sufficient, and make directions to other bodies such as the NZ Medical Council, Royal GP College, Te Aho o Te Kahu, Te Whatu Ora, and the Ministry of Health to investigate further systemic changes as appropriate.

BARRIERS FOR COMPLAINANTS

We note that some members of our community have been deterred from making a complaint about misdiagnosis due to how previous complaints have been treated. It is difficult for women and their families to see complaints where people have had characteristic symptoms of ovarian cancer, gone to extreme lengths, yet had concerns dismissed repeatedly without tests being ordered, despite CA-125 being cheap, readily available, and indicated by Health Pathways, and for the HDC to find that the right to services of an appropriate standard has not been breached. This hugely disincentives people from making complaints.

In addition, there are difficulties relating to the proof of diagnosis, due to the ‘he said/ she said’ nature of the complaints process, with significant emphasis placed on medical notes. These notes can be biased, as many practitioners only record what they consider significant at the time, discounting some or all ovarian cancer symptoms. Gender bias can also contribute to the dismissal of women’s complaints. This is made harder when the woman in question is no longer here to answer questions and defend herself, further exacerbating the power imbalance between practitioner and patient.

Additionally, there is an obvious barrier that people who are misdiagnosed with ovarian cancer are usually very unwell and having to come to terms with a poor life expectancy. With almost half of all women in NZ experiencing an emergency diagnosis, and 42% of those dying within the first year, there often isn’t time for women to go through a complaints process. If not already in place, there should be a fast-track option for people with poor life expectancy,recognising the significant time and effort required to first attempt to resolve concerns directly and then prepare an application to the HDC.

Topic 1: Supporting better and equitable complaint resolution

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

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

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?

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**?

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**?

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?

We agree with the principle of a right of appeal. This needs to be conducted in a timely manner.

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?

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?

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)

X 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)

X 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

X 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.